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Original Paper

# Impact of Mental Health Screening on Promoting Immediate Online Help-Seeking: Randomized Trial Comparing Normative Versus Humor-Driven Feedback

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## Abstract

**Background:** Given the widespread availability of mental health screening apps, providing personalized feedback may encourage people at high risk to seek help to manage their symptoms. While apps typically provide personal score feedback only, feedback types that are user-friendly and increase personal relevance may encourage further help-seeking.

**Objective:** The aim of this study was to compare the effects of providing normative and humor-driven feedback on immediate online help-seeking, defined as clicking on a link to an external resource, and to explore demographic predictors that encourage help-seeking.

**Methods:** An online sample of 549 adults were recruited using social media advertisements. Participants downloaded a smartphone app known as “Mindgauge” which allowed them to screen their mental wellbeing by completing standardized measures on Symptoms (Kessler 6-item Scale), Wellbeing (World Health Organization [Five] Wellbeing Index), and Resilience (Brief Resilience Scale). Participants were randomized to receive normative feedback that compared their scores to a reference group or humor-driven feedback that presented their scores in a relaxed manner. Those who scored in the moderate or poor ranges in any measure were encouraged to seek help by clicking on a link to an external online resource.

**Results:** A total of 318 participants scored poorly on one or more measures and were provided with an external link after being randomized to receive normative or humor-driven feedback. There was no significant difference of feedback type on clicking on the external link across all measures. A larger proportion of participants from the Wellbeing measure (170/274, 62.0%) clicked on the links than the Resilience (47/179, 26.3%) or Symptoms (26/75, 34.7%) measures ( $\chi^2=60.35$ ,  $P<.001$ ). There were no significant demographic factors associated with help-seeking for the Resilience or Wellbeing measures. Participants with a previous episode of poor mental health were less likely than those without such history to click on the external link in the Symptoms measure ( $P=.003$ , odds ratio [OR] 0.83, 95% CI 0.02-0.44), and younger adults were less likely to click on the link compared to older adults across all measures ( $P=.005$ , OR 0.44, 95% CI 0.25-0.78).

**Conclusions:** This pilot study found that there was no difference between normative and humor-driven feedback on promoting immediate clicks to an external resource, suggesting no impact on online help-seeking. Limitations included: lack of personal score control group, limited measures of predictors and potential confounders, and the fact that other forms of professional help-seeking were not assessed. Further investigation into other predictors and factors that impact on help-seeking is needed.

**Trial Registration:** Australian New Zealand Clinical Trials Registry ACTRN12616000707460; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=370187> (Archived by WebCite at <http://www.webcitation.org/6y8m8sVxr>)

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## KEYWORDS

online help-seeking; screening; feedback; randomized trial; mental health; resilience; depression

## Introduction

Mental health screening and feedback has been purported to improve recognition and encourage service use, despite minimal evidence supporting its benefits in the community [1]. Mental health screening websites and mobile apps are widely available, and many provide personal feedback related to mood, anxiety, and wellbeing [2,3]. While personal feedback is often incorporated in online and mobile interventions as an engagement strategy [4], few studies have examined whether providing such feedback encourages help-seeking in brief online screening tools. Online mental health screeners with personal feedback appear to engage participants, with a third of participants completing one or more follow-ups after initial screening and feedback [5]. There is some support from observational studies that providing personal feedback encourages help-seeking; for instance, 42% of university students who received positive screening results after using a self-help mental health screening website requested a referral to the university's mental health clinic [6]. Similarly, BinDimh et al [7] provided personal score feedback in a depression-screening app and recommended that users with scores above threshold seek help from a health care professional. Approximately 38% of users who did not have a previous self-reported depression diagnosis reported that they had consulted a health care professional after one month [7]. However, only one randomized controlled trial has been conducted to evaluate whether providing personal score feedback after online screening promotes help-seeking from professional sources [8]. A large online sample was randomized to receive feedback about their mental health and information about treatment services, or receive no feedback, after completing a lengthy mental health survey. Participants who received feedback were significantly less likely to complete the follow-up measures about help-seeking after three months [8]. Among those who responded, there was no effect of depression feedback, and social anxiety feedback appeared to have a small negative effect on help-seeking. However, the differential completion rates among those who received feedback or not indicate issues with attrition and potential nonresponse bias. Overall there is mixed evidence to support the effects of online screening, but all studies to date have only focused on seeking professional help. Given the provision of online screening and feedback, it remains unclear whether there is an impact on online help-seeking.

Furthermore, the reason for differences in rates of help-seeking may be related to how the personal feedback is presented. Providing user-friendly and easily comprehensible information may be more useful than simply providing score feedback, as it increases the personal relevance of messages and subsequently

increases the likelihood of deeper processing and strengthens motivation for behavior change [9]. There are many variations in which personalized feedback can be presented to enhance processing. Normative comparison of an individual's results to a reference group is one of the widely used strategies to increase salience of the message. Normative feedback is effective in reducing problematic drinking behaviors as it reveals discrepancies in individual behavior, along with perceived and actual group behavior [10]. Providing normative feedback for mental health may also improve help-seeking among those with high scores. Indeed, a qualitative study reported that the majority of undergraduate students with moderately severe to severe depressive symptoms found that receiving normative feedback increased their awareness about their own symptoms and motivated them to seek treatment [11]. Another potential way of engaging respondents is through the use of humor in the feedback messages. Self-stigma of mental illness is associated with low self-esteem [12] and deters help-seeking [13,14]. However, it has been found that people with mental illness who view their illness in a relaxed and humorous way have higher self-esteem [15]. Indeed, humor has been used as a successful strategy to engage Australian men in mental health issues [16] and to reduce mental health stigma among military personnel [17], and may be a useful feedback tool to reduce stigma and encourage help-seeking.

The current study describes the results of a pilot randomized trial that compared the impact of receiving personal normative versus humor-driven feedback on promoting immediate online help-seeking. This study attempted to address the gaps in existing literature by assessing online help-seeking rather than face-to-face help, and to examine immediate help-seeking to avoid loss to follow-up.

## Methods

### Participants and Procedure

Participants were recruited on social media websites between June-October 2016. A series of paid advertisements were placed on Facebook mobile with themes such as, "worried about your mental health?" "how tough is your mind," and, "are you on the path to happiness?" Partner organizations (beyondblue, the Black Dog Institute, and the Movember Foundation) also shared posts about the study on their Facebook and Twitter pages. Interested individuals were directed to the study website or the Google Play or Apple App Store to download the *Mindgauge* app for free, which featured measures on *Symptoms*, *Resilience*, and *Wellbeing*. Individuals were eligible to participate if they were 18 years or older, owned a smartphone, and were a resident in Australia, New Zealand, the United States, or the United Kingdom. Informed consent to take part in this study was obtained when participants used the app for the first time.

Participants first completed basic demographic questions on gender, age, and whether or not they had a self-reported period of poor mental health for more than one month in the past two years. Participants were then free to choose to complete any of the measures on *Symptoms*, *Resilience*, and *Wellbeing*. Users could complete the measures more than once (following a one-week gap), but for the purposes of this study only the first completion of each measure was analyzed because seeking help after subsequent completions of the measure may indicate heightened interest or concern in that measure rather than the impact of the feedback.

### Randomization

Upon completion of each measure, participants were randomly allocated to receive either (1) normative feedback comparing their scores to a relevant reference group, or (2) humor-driven feedback that presented their scores in a light-hearted manner (see [Figure 1](#) for an example). Randomization was independent for each measure (ie, a participant was randomized for the *Symptoms* measure and randomized again for the *Resilience* measure). The humor-driven feedback was pilot tested among the larger research team. The feedback messages were slightly different depending on the score range and the list of feedback for each measure is shown in [Multimedia Appendix 1](#).

Participants received feedback immediately after completing each measure. To assess the impact of the type of feedback on immediate online help-seeking, participants who scored within the moderate or poorer categories of any measure (as described

below) were additionally provided with a link to an appropriate external online resource and were included in the analyses. [Figure 2](#) shows the flow of participants.

### Measures

#### Primary Outcome

The study website automatically recorded whether participants clicked on the link to the online resource presented as part of their feedback, as a proxy of online help-seeking.

#### Self-Reported Measures

##### Symptoms

The Kessler 6-item Scale [18] is a measure of nonspecific psychological distress and is validated for use among the Australian population. Participants with scores ranging from 12-19 were considered to have moderate symptoms, and scores from 20-30 were high symptoms, based on standardized cut-points [19].

##### Wellbeing

The World Health Organization (Five) Well-Being Index [20] is a commonly used measure of subjective wellbeing. Five items produce a score ranging from 0 to 25, with higher scores indicating better quality of life. Using the population mean as the center, scores between 0-12 were considered as low wellbeing, and scores between 13-21 were considered moderate wellbeing.

**Figure 1.** Screenshot of the feedback for moderate resilience.

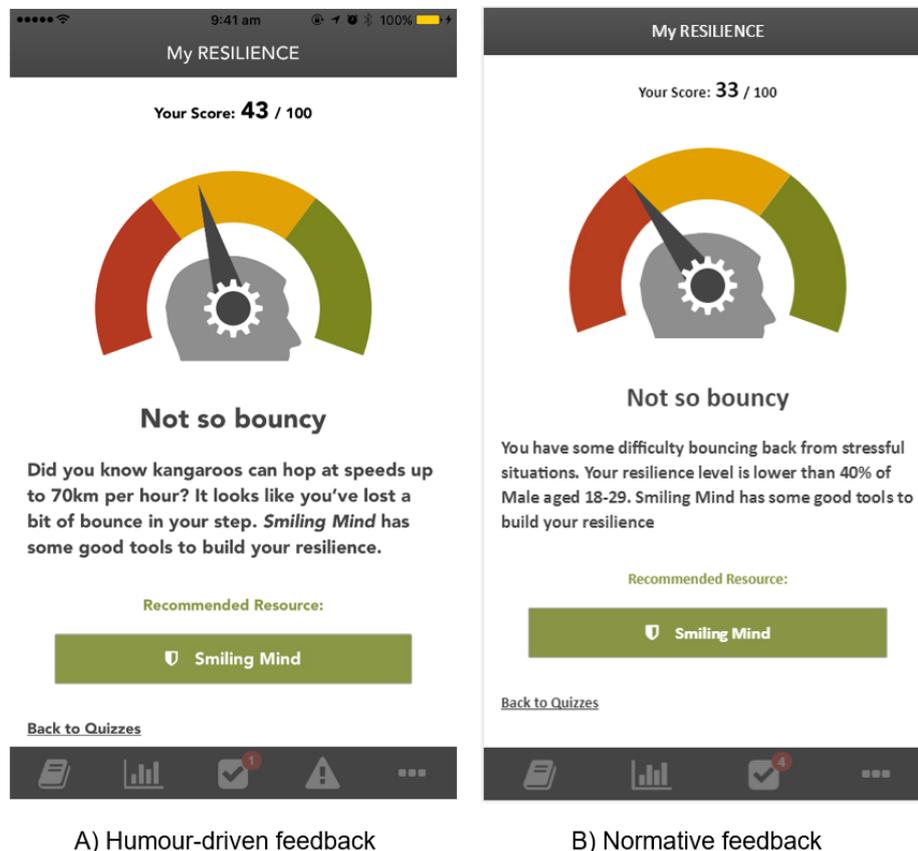
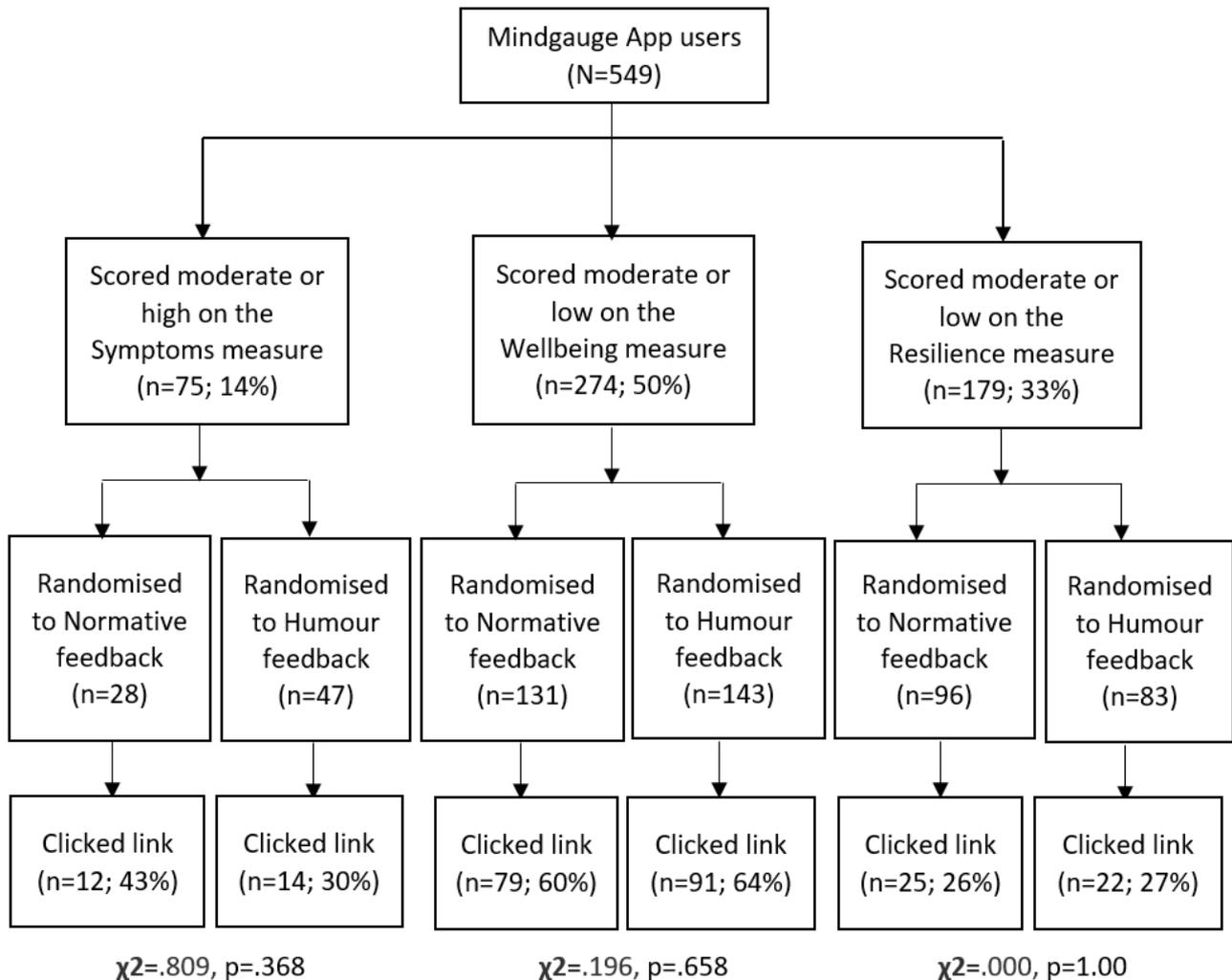


Figure 2. Participant flow in trial.



### Resilience

The Brief Resilience Scale [21] measures one's ability to bounce back from difficult times. Scores range from 6 to 30, with higher scores indicating better resilience. Similarly, using the population mean as the center, scores between 6-17 were considered as low resilience while scores between 18-24 were considered moderate resilience.

### Statistical Analysis

Results were analyzed using IBM SPSS 24 statistical software. Chi-square tests were used to compare the proportion of participants who clicked on a link between the normative and humor-driven feedback conditions for each measure, and to compare the difference in clicks among the measures. Logistic regression analyses were used to examine the association between clicks on the link and demographic factors for each measure independently and pooled.

### Ethical Approval

The study was approved by the Human Research Ethics Committee at the University of New South Wales (HC15584).

## Results

### Participant Characteristics

Of the 549 unique *Mindgauge* app users, 318 participants scored in the moderate or poorer ranges on one or more measures and were included in the analyses, with 161 participants (161/549, 29.3%) having scored undesirably on one measure, 104 (104/549, 18.9%) on two measures, and 53 (53/549, 9.7%) on all three measures. Over half of the included sample (197/318; 61.9%) was female, 118 (118/318, 37.1%) were male, and 3 (3/318, 0.9%) did not specify their gender. There were 93 participants (93/318, 29.2%) aged between 18-29 years, 79 (79/318, 24.8%) aged between 30-39 years, 98 (98/318, 30.8%) aged between 40-49 years, and 48 (48/318, 15.1%) aged 50 or above. More than two thirds of participants (228/318, 71.7%) reported that they had an episode of poor mental health in the past.

### Clicks on Links

There was no significant impact of feedback type on whether participants clicked on the external link for each of the measures (all  $P$  values  $>.05$ ; Figure 1). A significantly higher proportion of participants who scored below threshold on the *Wellbeing* measure (170/274, 62.0%) clicked on the links compared to

those who scored undesirably on the *Resilience* (47/179, 26.3%) or *Symptoms* (26/75, 34.7%) measures ( $\chi^2=60.35$ ,  $P<.001$ ).

### Factors Associated With Clicking on the Link

Logistic regression analyses found that participants with previous poor mental health were less likely than those without such history to click on the link in the *Symptoms* measure ( $B=-2.48$ ,  $Wald=8.54$ ,  $P=.003$ , odds ratio [OR] 0.83, 95% CI 0.02-0.44). There were no significant demographic factors associated with clicking on the link for the *Wellbeing* or *Resilience* measures. When all three measures were pooled, participants aged 18-29 were significantly less likely to click on the link compared to those above 50 years of age ( $B=-.82$ ,  $Wald=7.78$ ,  $P=.005$ , OR 0.44, 95% CI 0.25-0.78).

## Discussion

This pilot randomized trial showed no significant difference between normative and humor-driven feedback on the likelihood of an individual who has screened positive for a poor mental health outcome clicking through to online resources to seek further help. There was no evidence to suggest that the manner in which personal feedback was presented encouraged individuals to seek treatment, suggesting that there may be other factors influencing whether one seeks help after receiving personal feedback, which warrant further investigation. These factors could be related to personal characteristics or other external factors, such as stages of change, motivation, or the perceived credibility of feedback or helpfulness of an intervention. Web-based and smartphone app interventions are often perceived as low in credibility and helpfulness, which are key considerations for patients in choosing to engage with mental health treatment [22]. Given that there is support suggesting that providing simple information about the intervention improves attitudes towards Internet interventions and intention to use [23,24], it is possible that the rate of clicks to resources in this study may be improved if we provide further information about those resources in the feedback.

Nonetheless, the online help-seeking rate in our study ranged from 26% to 60% and was comparable to the rates of seeking face-to-face help following online screening, as previously reported [6-8]. Interestingly, the *Wellbeing* measure had more frequent clicks than the *Symptoms* or *Resilience* measures regardless of feedback type. It is possible that online resources aimed at improving “wellbeing” were seen as more attractive or achievable than improving “symptoms” or “resilience,” which may have a negative connotation related to poor mental health. It is also possible that receiving negative personal feedback on the *Symptoms* and *Resilience* measures may have been confronting and inadvertently exacerbated avoidance behaviors [8].

The finding that individuals with previous poor mental health were less likely to click on external resources on the *Symptoms* measure suggested that they may be using screening apps for symptom monitoring rather than treatment seeking. Conversely, this finding provides some support that such screening tools may be targeted to those who were distressed, but without a

history of mental health problems, to improve recognition and treatment seeking. However, this finding should be interpreted with caution given the small numbers in the *Symptoms* measure, and it was not significant when all measures were pooled. Younger people were also less likely to click on the link across all measures compared to the oldest age group. This result is in line with previous studies showing that there is a lack of evidence that online services facilitate mental health help-seeking in young people [25].

A strength of this study was that it measured clicks to an online resource as a proxy of immediate online help-seeking. The use of objective measures of help-seeking within the app overcame some of the limitations in previous studies, such as reliance on participant self-report and loss to follow-up [4,5], which may have led to nonresponse sampling bias. However, it is important to note that clicks to the online resource only suggest interest in seeking further help online, but do not indicate actual engagement in further online help-seeking. Participants may have also engaged in other forms of help-seeking using other online resources and treatments, or sought face-to-face help, but this was not assessed. Future studies could also explore reasons why participants did not seek further help and explore longer-term outcomes. Another limitation of the study was the lack of a personal score control group; as such, we were unable to determine if there were any added effects of normative and humor-driven feedback to simply providing personal scores. Furthermore, there were limited measures of predictors and we were unable to control for potential confounders, such as self-esteem and stigma. A limitation in the app build and design meant that scores were calculated within the app but were not recorded on the database; thus, we were unable to report the psychometric properties of the measures and conduct further analyses to explore whether severity of scores impacted on clicking on the link. Despite pilot testing the humor-driven feedback, humor perception is subjective and not necessarily transcultural, and thus may be misunderstood or even be seen as trivializing the matter of mental health. However, there is support that the use of humor as a communication tool in medical contexts has a small but positive effect on perceived credibility [26], and our results suggest that the humor-driven feedback used in this study did not appear to negatively impact help-seeking.

This is the first study to compare the impact of different types of feedback on seeking online mental health support. The nil findings suggest that the feedback type does not affect online help-seeking, and less frequent clicks on the *Resilience* and *Symptoms* measures echo previous studies that indicate that feedback on certain measures may be less conducive to help-seeking [8]. Nonetheless, the 60% click rate on the *Wellbeing* measure provides encouraging support that online screening tools can promote help-seeking. Given the widespread use of online and mobile screening tools, and the limited research on its efficacy, further research is needed to explore predictors and factors that improve help-seeking, such that developers and researchers can better tailor such tools to address the gaps in service use.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Normative and humor-driven feedback provided for scores on the measures.

[[PDF File \(Adobe PDF File\), 29KB - mental\\_v5i2e26\\_app1.pdf](#) ]

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## Abbreviations

**OR:** odds ratio

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## Case Study

# Ethical Issues in Addressing Social Media Posts About Suicidal Intentions During an Online Study Among Youth: Case Study

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## Abstract

Due to the popularity of social media, researchers are increasingly conducting studies that monitor and analyze people's health-related social media conversations. Because social media users can post about any topic at any time, no known best ethical practices exist as to whether and how to monitor participants' posts for safety-related issues that might be unrelated to the study, such as expressions of suicidal intentions. This is a case study during a social media-based study on sleep and activity among freshman undergraduate students, where we by chance noticed that a student was using social media to express suicidal intentions. Although we connected the student to student psychological services in order to receive treatment, we encountered a number of barriers that initially prevented this from occurring, such as institutional review board and regulatory practices related to lack of experience with these newer types of studies. We discuss the implications of this experience for future research.

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### KEYWORDS

suicide; social media; undergraduates

## Introduction

Severe depression and suicide are common public health concerns among college aged young adults. Approximately 15% of college undergraduates experience a depressive disorder, and suicide is a leading cause of death for university students in the United States [1-3]. The percentage of students with severe psychological issues seeking help at university centers increased from 16% in 2000 to 44% in 2010, with only 13% of suicides being from past clients of student counseling centers [4,5]. Identifying ways to monitor student psychological health, increase referral to psychological services, and reduce suicide is a top public health concern.

Over the past decade adolescents have been using social media at an increasing rate, with more than 94% of youth using some form of social media [6,7]. Recently, studies have shown that

social media can be used to monitor psychological issues, such as depression [8] and suicide [9]. These can be monitored on social media by screening for key words that social media users discuss online [10-12] and emotions expressed in their posts [13].

While conducting a study using social media to monitor the Twitter activity and general health and wellness among 197 freshmen undergraduates [14,15], we encountered an unexpected situation. Although our primary study aim was to examine the relationship between social media and general health such as sleep and activity, our method of social media tracking uncovered one student who was expressing suicidal thoughts on Twitter. Institutional Review Board (IRB) protocols and consent forms often have a predetermined process in place designed to reduce risk and address potential mentions of suicide that might occur among participants during the course of the

study. These suicide protocols are typically created based on collaboration between the IRB, which is experienced with these issues, and the study researchers, who are experienced with the type of research being conducted. However, due to the novelty and lack of studies using social media as a tool for monitoring health behavior, lack of suicide-related issues that have been documented in social media monitoring studies, and the (presumably) healthy student population we thought were studying, no suicide-related protocol was included in our study.

This case study describes the incident and the process we undertook to address the situation of encountering unexpected suicide-related posts from a student. We explore the implications of our experience and raise ethical questions to facilitate a conversation on how to address these concerns in the future.

## Methods

The study protocol was approved by the University of California, Los Angeles IRB. Participants (N=197, incoming freshman undergraduates) completed in-person consent to join a 3-month study to assess their stress, sleep, and social media patterns during their first quarter. We recruited students from Facebook advertisements posted on the freshman class of the 2019 page and in-person on campus. Recruitment occurred from mid-September through mid-October 2015. To qualify for the study, students had to be freshmen or first-year transfers, aged 18 to 21 years, in their first quarter, active Twitter users (>3 posts per week), and willing to allow us to follow them on Twitter.

Students completed an initial demographic survey; weekly surveys on stress, sleep, and emotions; and a final survey including the Patient Health Questionnaire. They received \$5 worth of online gift cards for completing each survey. Participants received an additional \$5 if they completed all 4 weekly surveys in a given month. Students who completed all weekly surveys could receive a total of \$75. We collected students' Twitter activity using the Twitter application program interface.

## Results

To analyze the Twitter data collected, we identified conversational tweets and created a list of the top 3 people most frequently written to by each student. During the data analysis, we identified 1 student who had tried numerous times to contact members of a popular teenage band rather than trying to tweet at other noncelebrity Twitter users as their peers did. We decided to further review the social media content of this student to determine differences between this student and others. During the course of this exploration, we discovered 6 tweets expressing suicidal ideation and severe depression.

These statements appeared to be credible and concerning. In consultation among our staff, including a licensed clinical social worker, along with the IRB, we determined that without a formal protocol on how to address this situation, we should immediately contact student psychological services to notify them of the incident and attempt to route the student to care with them. Upon contacting student psychological services, we discovered

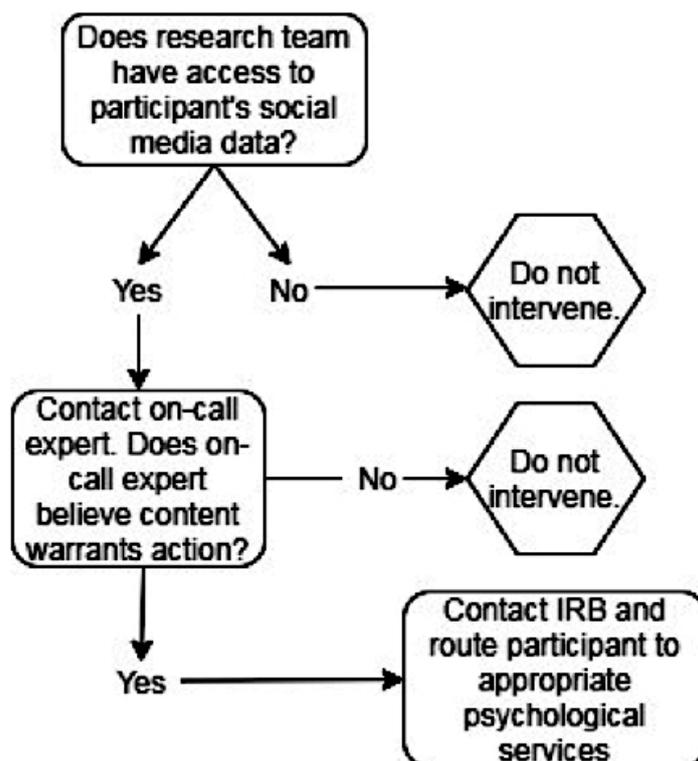
that they were unable to verify the student and veracity of the student's intentions because university policy prohibited their staff from viewing students' social media activity. Additionally, the student used a pseudonym on Twitter and in other forms filled out for the study. Due to this, staff members at psychological services were initially unable to identify the student in their database, causing delays in contacting the student. We later referenced the original consent sheet to discover the student's legal name.

## Discussion

To our knowledge, only 1 study has explored expressions of suicidal ideation among social media users, and it explored how to theoretically mine social media data for suicidal content [16]. As social media becomes a more widely used tool in research, we believe it is essential for researchers using social media for monitoring to craft a plan before beginning the study to address identification of clinical issues in social media such as suicidal intentions. Although the American Psychological Association and American Counseling Association have ethical guidelines for integrating telehealth technologies into clinical practice and for health communications, this case study suggests a greater need to develop specific guidelines on how to respond to clinical issues from social media posts as part of a research study.

It is important to note that our research was not designed to study suicide or to directly study clinical health of students but rather to study and monitor general health behaviors such as sleep. Future researchers using social media as a tool for monitoring or interventions may therefore encounter similar situations where participants post about suicide or clinical issues even if the primary goal of the study is focused on issues unrelated to clinical care. This study therefore raises ethical questions on considerations researchers and ethical review boards should have when reviewing studies related to social media and online posting. For example, should a consent form include information that researchers might intervene if they detect clinical emergencies? Should researchers be required to act on this information? Are researchers required to conduct periodic or routine monitoring just because they have access to these data? Should researchers take steps to remind study participants who are publicly expressing clinical issues that they are in a study and being monitored? More broadly, when monitoring publicly available information on social media, in what situations should information be reported to IRBs, clinical experts, or police? These are just some of the many questions arising from this growing area of research.

We learned 3 additional lessons from this experience. First, we were fortunate to have a clinical expert assisting with the study in order to gain clinical expertise on how to address the issue immediately. It may be advisable that studies on social media monitoring have a clinical expert available to address emergency situations if the IRB does not have the appropriate clinical staff. Second, we encountered delays because student psychological services was unable to view the student's social media profile to verify the student and assess the validity of their suicidal intentions.

**Figure 1.** Potential protocol for addressing suicidal intentions in social media studies.

Although it is understandable that psychological services should not view student social media posts in order to maintain confidentiality and privacy, a plan should be in place to address this issue.

As social media is often publicly available, viewing public social media posts would be similar to overhearing a student talking on the street. Additional discussion on this topic could help to identify how and when participants in social media-based research studies receive emergency clinical care. Finally, our results have led us to believe that at minimum, all research studies that seek to monitor social media content from individuals, whether or not the topic is related to mental health, should include a provision for how to address potential suicidal content that may arise.

While we do not have a finalized protocol in place to address study participants expressing suicidal intentions, we describe a working draft of a potential protocol for future studies of this nature below and outline the protocol in [Figure 1](#).

Researchers look at social media for various reasons including advertising for recruitment, monitoring, and intervention. If a person is actively enrolled in a study for monitoring or intervention and has gone through the consenting process, the study team should have a protocol in place to address suicidal thoughts or intentions expressed on social media.

If a person in the study is expressing suicidal thoughts or intentions on social media, it should be the responsibility of the research team to have a certified clinician on call to assess the social media posts and determine if action is warranted. If the

posts are deemed dangerous or indicative of severe mental distress, the clinician should contact the IRB and reach out to the participant if needed to provide a referral to appropriate services. It should be made clear in the consent form that participants are agreeing to being contacted by this clinician if they express suicidal thoughts or intentions during the duration of the study.

We suggest ways to integrate our findings into future social media-based research protocols. First, researchers should have a process in place for how to address the risk of participants posting suicidal and clinical information in social media-based studies. Second, studies on this topic should have a strict set of procedures about whom to contact and what information to share with outside agencies that deal with psychological concerns that may present themselves during the course of the study. Although this is standard in many ethical protocols, there is limited discussion on whether and how to do this in social media-based research. Third, during recruitment and consent, effort should be taken to gain accurate contact information for participants, should the need arise to contact them.

Social media has become an increasingly common tool in research. Because people commonly use social media to publicly communicate their thoughts and behaviors, including those of a clinical nature, participants in social media-based studies may disclose personal clinical risks, such as suicidal intentions. As these types of incidents increase in prevalence along with social media-based research, it is imperative that researchers identify the ethical questions and frameworks that can address these issues.

## Conflicts of Interest

None declared.

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## Abbreviations

**IRB:** institutional review board

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Original Paper

# Diurnal Variations of Depression-Related Health Information Seeking: Case Study in Finland Using Google Trends Data

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## Abstract

**Background:** Some of the temporal variations and clock-like rhythms that govern several different health-related behaviors can be traced in near real-time with the help of search engine data. This is especially useful when studying phenomena where little or no traditional data exist. One specific area where traditional data are incomplete is the study of diurnal mood variations, or daily changes in individuals' overall mood state in relation to depression-like symptoms.

**Objective:** The objective of this exploratory study was to analyze diurnal variations for interest in depression on the Web to discover hourly patterns of depression interest and help seeking.

**Methods:** Hourly query volume data for 6 depression-related queries in Finland were downloaded from Google Trends in March 2017. A continuous wavelet transform (CWT) was applied to the hourly data to focus on the diurnal variation. Longer term trends and noise were also eliminated from the data to extract the diurnal variation for each query term. An analysis of variance was conducted to determine the statistical differences between the distributions of each hour. Data were also trichotomized and analyzed in 3 time blocks to make comparisons between different time periods during the day.

**Results:** Search volumes for all depression-related query terms showed a unimodal regular pattern during the 24 hours of the day. All queries feature clear peaks during the nighttime hours around 11 PM to 4 AM and troughs between 5 AM and 10 PM. In the means of the CWT-reconstructed data, the differences in nighttime and daytime interest are evident, with a difference of 37.3 percentage points (pp) for the term "Depression," 33.5 pp for "Masennustesti," 30.6 pp for "Masennus," 12.8 pp for "Depression test," 12.0 pp for "Masennus testi," and 11.8 pp for "Masennus oireet." The trichotomization showed peaks in the first time block (00.00 AM-7.59 AM) for all 6 terms. The search volumes then decreased significantly during the second time block (8.00 AM-3.59 PM) for the terms "Masennus oireet" ( $P < .001$ ), "Masennus" ( $P = .001$ ), "Depression" ( $P = .005$ ), and "Depression test" ( $P = .004$ ). Higher search volumes for the terms "Masennus" ( $P = .14$ ), "Masennustesti" ( $P = .07$ ), and "Depression test" ( $P = .10$ ) were present between the second and third time blocks.

**Conclusions:** Help seeking for depression has clear diurnal patterns, with significant rise in depression-related query volumes toward the evening and night. Thus, search engine query data support the notion of the evening-worse pattern in diurnal mood variation. Information on the timely nature of depression-related interest on an hourly level could improve the chances for early intervention, which is beneficial for positive health outcomes.

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**KEYWORDS**

depression; consumer health information; information seeking behavior; infoveillance; infodemiology; mental health; search engine

## Introduction

### Background

Temporal variations and clock-like rhythms govern many different health-related behaviors and complications [1,2]. Partly because of the methodological barriers presented by traditional means of collecting data, research has mainly focused on longer temporal scale patterns, such as annual or seasonal variations, rather than shorter scale patterns such as weekly or hourly rhythms [2]. However, recent advances in information and communication technology are emerging to fill some of these methodological gaps in public health surveillance research [2]. Most health-related behaviors on the internet, such as health information seeking, leave digital footprints that can be traced with surprising accuracy. Having a broader understanding of these temporal variations can have great public health advantages. Internet health information seeking related to different health problems is common everyday behavior, and daily, millions of people seek help on the internet, ranging from identifying symptoms to finding diagnoses and treatments [3-5]. In Finland, internet use is ubiquitous, also in relation to health, as 66% of the Finnish population aged 16-89 years search for information related to health. For the younger demographic segment aged 25-34 years, the percentage is 82 [6]. More generally, it has been estimated that between 70% and 90% of health care is undertaken by individuals without the involvement of health care professionals [7,8]. This would suggest that before seeking treatment from health care professionals, people will first try to treat their problems themselves, with search engines as the most common approach [7-11]. The most popular search engine in the world, Google [12], had a market share of 96% in Finland in 2016 [13]. This kind of information behavior reveals the information seekers' thoughts and actions in relation to interests, causes, symptoms, advices, and cures that people who suffer from poor health or illness develop [1,14-16]. As said, it also leaves digital footprints, or user-generated online data, which are easily accessible in near real-time, and allows for identifying and proposing new hypothesis as well as open up unique opportunities to investigate health-related behaviors on a gigantic scale [17-19].

### Objective

Several studies, ranging from seasonal influenzas [20-23], viruses [24], and general diseases surveillance [25-30] to mental health problems [1,2,17,31,32], have demonstrated that valid trends and insights reflecting entire populations have been extracted from online data, particularly search engine data. Predicting the incidence of both communicable and noncommunicable diseases has been shown reliable [15,18,23,33]. This utilization of online data for health care research is especially useful when studying phenomena where little or no traditional data exist, and has even led to an emerging field of research called infodemiology, defined by Eysenbach [9] as the science of the distribution and determinants of information in an electronic medium, specifically the internet, or in a population, with the ultimate aim to inform public health and public policy [9,15,18,34]. One specific area where traditional data are incomplete is the study of diurnal variations of depression. In depression-related health information-seeking

behavior, seasonal variations have been identified with the help of search engine data [17,31]. Thus, one possible way of studying diurnal variations of mood is analyzing information-seeking behavior with the help of search engine data, which are available on an hourly level. To the authors' best knowledge, no study has investigated how search engine variables perform as predictors for interest in depression on an hourly level. Therefore, the aim of this exploratory study was to analyze diurnal variations for interest in depression on the Web to discover hourly patterns of depression interest and help seeking.

Depression is one of the most burdensome diseases in the world [35]. Each year about 7% of the global population suffers from major depression and 25% suffers from anxiety or milder forms of depression [35]. In Finland, at least 5% of the adult population suffers from depression every year [36]. One of the characteristics of depressive mood is diurnal mood variation (DMV). DMV refers to noticeable diurnal or daily changes in the overall mood state experienced by individuals suffering from depression as well as healthy individuals [37-39]. The occurrence of diurnal variations has been shown to be somewhat irregular, and the presence and direction of mood variations are decidedly inconclusive over time, with evidence for both morning-worse and evening-worse peaks in emotional distress [37,38,40]. There are very few studies recording DMV at distinct periods of time, partly due to the limitations of ways to monitor DMV [37]. As individuals suffering from mental health issues have been shown to be more likely to seek information about their problems on the internet, studying search engine data and health information-seeking behavior has the potential to provide new meaningful insights into DMVs [8,31,37,41].

## Methods

### Study Design

Search data generated in Google can be accessed via Google Trends, a public Web-based database that provides time series data of search trends. Data from Google Trends are provided as relative search volumes (RSVs), which, in contrast to raw or absolute search volumes, is corrected and adjusted over time due to changes in internet access or disposable time (for example, all searches may decline during Saturday) [1,42]. correct changes in search volume variations due to availability of internet access or disposable time [1,42]. Queries in Google Trends are monitored relative to all queries, in this case each hour, and reported as RSV, where RSV=100 is the hour with the highest search proportion for the day, and RSV=50 is 50% of that highest proportion. Queries from search activity on Google are disaggregated to geographical and temporal units, ranging from years to minutes, and deidentified from any identifying information to protect user privacy. In this study, the following 6 Finnish search queries related to depression were monitored "Masennus" (Eng. depression), "Masennus oireet" (Eng. depression symptoms), "Masennustesti" (Eng. depression test), "Masennus testi" (Eng. depression test), "Depression," and "Depression test" (the Swedish as well as the English term for depression and depression test). Query terms were not used in combination and not with quotes around

the search terms. Additional terms to the root term depression were added using Google Trends–related terms function, which identifies associated top search terms by either content or users' search behavior [42]. The query terms were chosen to represent an extensive sample of queries related to depression, in general, as well as symptoms and self-diagnosis, in Finnish and Swedish, the 2 official languages of Finland. The search queries were specified to Finland as a geographic area to avoid mixing with search queries originating elsewhere. Data were downloaded on a weekly basis from Google Trends throughout March 2017. March was chosen as the prevalence of depression in Finland has been shown to peak in spring [43]. Weekly downloads enabled obtaining hourly search volume data for each day in March, resulting in a RSV value for 744 hours for the 6 different search terms (n=4464), ranging from March 1 to 31, 2017. The analysis in this study are based on public meta-data that do provide neither information about the race, gender, age, or any other identifying information of the person entering a search term nor involve any intervention in the integrity of a person. Therefore, no institutional board review was required.

### Wavelet Power Spectrum Analysis

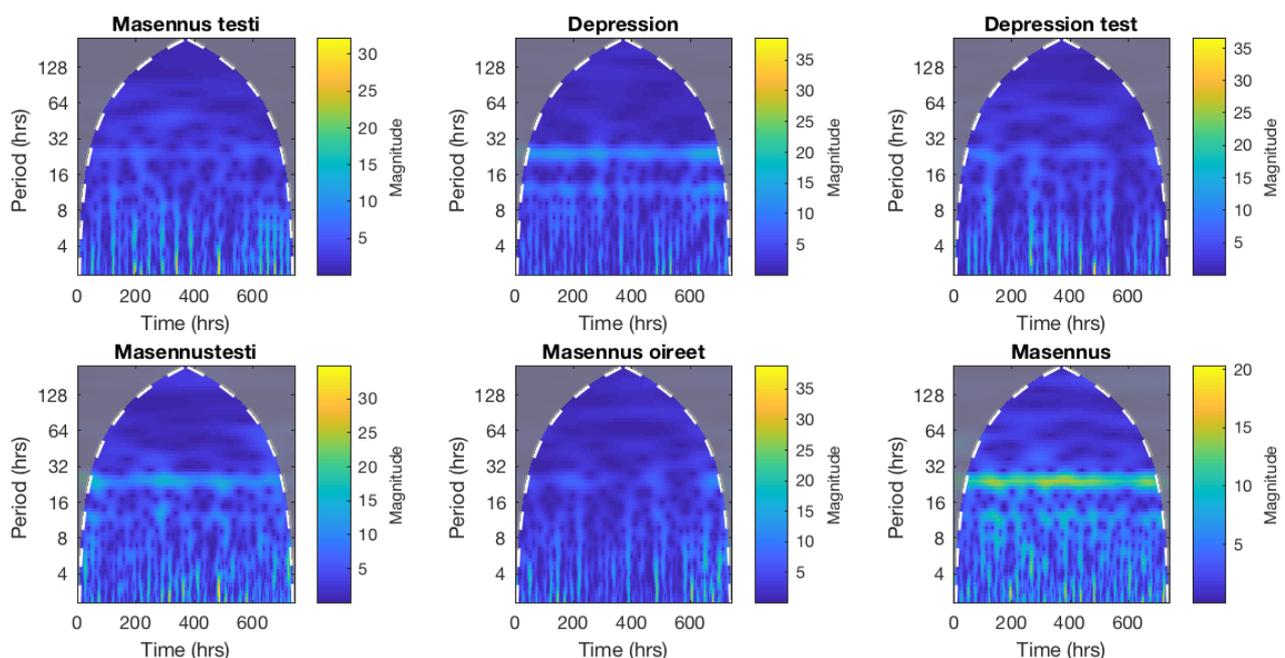
A continuous wavelet transform (CWT) was applied to the hourly data to focus on the diurnal variations. The CWT and subsequent analysis were conducted with MathWorks Matlab R2017b. The wavelet power spectra (WPS) for the RSVs of each query are shown in Figure 1. To extract the diurnal variation, longer term trends were removed by discarding components with a period of longer than 32 hours. Similarly,

components with a period of less than 4 hours were considered noise, and also eliminated. Calculating the inverse transform of the remaining part of the CWT thus provides a reconstruction of the signal without the trends and noise. The reconstructed data are presented in Figure 2, with all the days superimposed with their arithmetic mean, separately for each query. An analysis of variance was conducted to determine the statistical differences between the distributions of each hour, applying the Tukey-Kramer procedure for multiple comparisons. The results are summarized in Figure 3, where each marker represents a statistically significant ( $\alpha=.05$ ) difference between the interests of the corresponding hours.

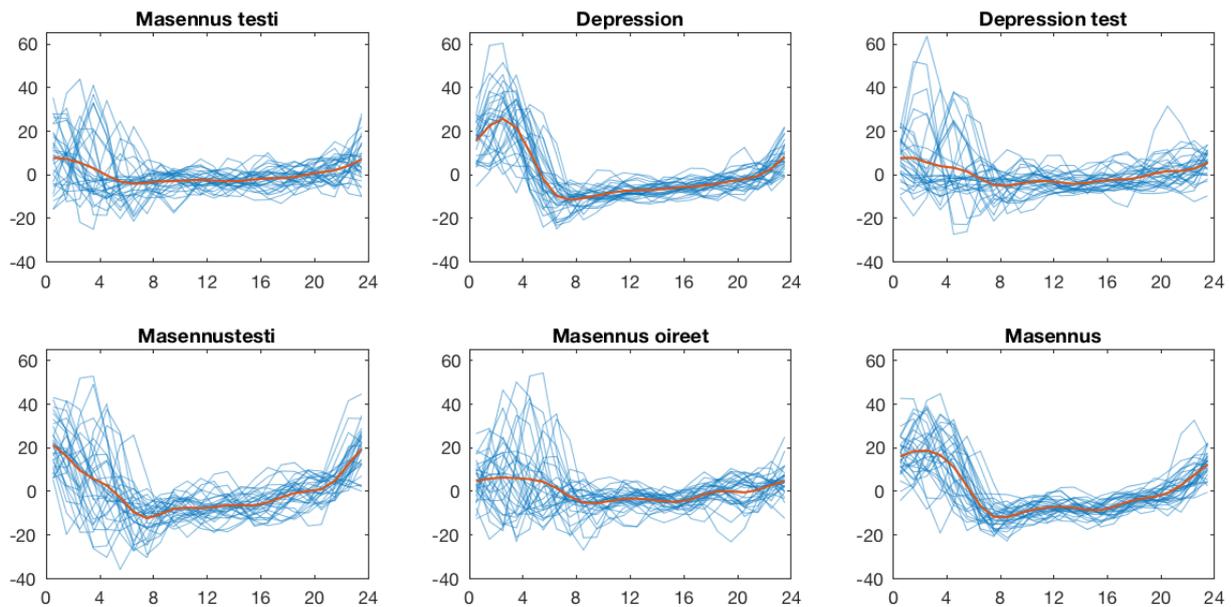
### Trichotomization

The hourly data were also trichotomized and analyzed in 3 time blocks: 8.00 AM to 3.59 PM, 4.00 PM to 11.59 PM, and 0.00 AM to 7.59 AM. The trichotomization of the 24 hours of a day makes it possible to distinguish and compare structured time (office hours), unstructured time (leisure time) as well as nighttime. All hourly RSV values between 0 and 100 for each search term were added to the set time blocks. Differences between search volumes in the 3 time blocks were then calculated. Analysis of variance was conducted to calculate statistical differences in the distributions between the different time blocks. In post hoc between-group (time blocks) comparisons, the Bonferroni correction was used.  $P \leq .05$  was considered statistically significant. The trichotomization analyses for were performed with SPSS (version 24.0; SPSS Inc., Chicago, Illinois, USA).

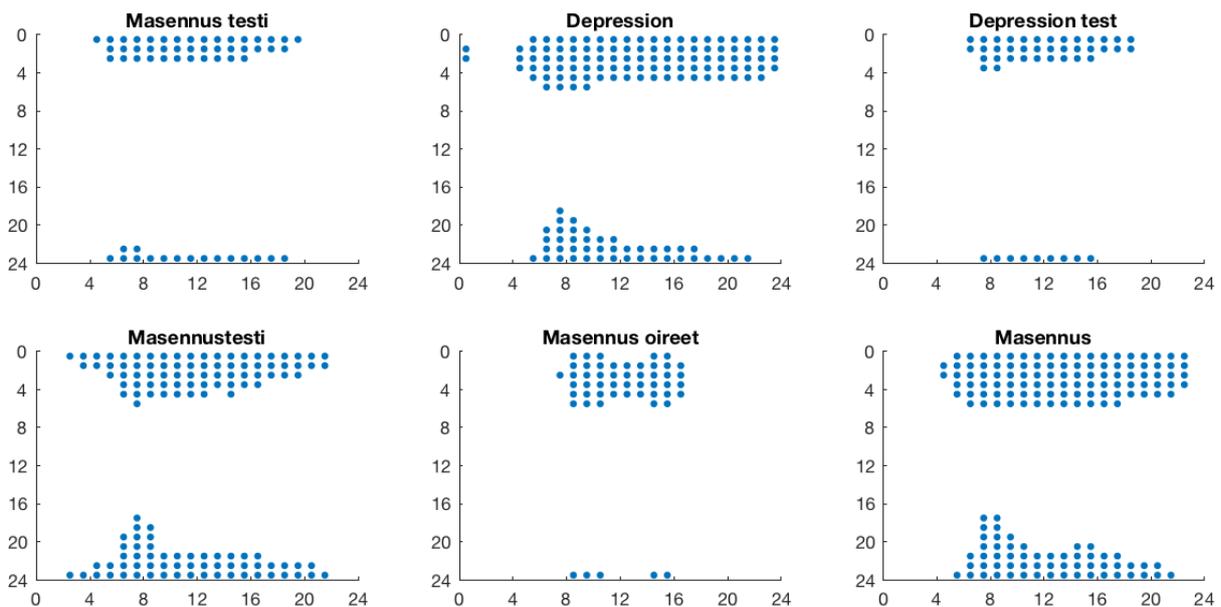
**Figure 1.** Wavelet power spectra for the relative search volumes (RSVs) of each query.



**Figure 2.** Each 24-hour period (in blue) of the reconstructed signal superimposed with its arithmetic mean (red), separately for each query.



**Figure 3.** Plots for each query indicating between which hours of day the differences are statistically significant. Each marked dot means that the interest for the hour on the y-axis is significantly greater than that for the hour on the x-axis.



## Results

### Wavelet Power Spectrum Analysis

The main results of this study are shown in [Figures 1-3](#) and [Multimedia Appendix 1](#). The daily variability is identifiable in each figure of the WPS ([Figure 1](#)) as a consistent signal with elevated power for components with a period around 24 hours, and is most distinctly observable in the case of “Masennus.”

As can be seen in [Figure 2](#), the search volumes for all depression-related query terms showed a unimodal regular pattern during the 24 hours of the day for the time period studied. All queries feature clear peaks during the nighttime hours around 11 PM to 4 AM and troughs between 5 AM and 10 PM.

The analysis of variance ([Figure 3](#)) reveals that search interest during nighttime hours 11 PM to 3 AM is greater than the interest during daytime hours 8 AM to 4 PM, with some variation for different queries.

In the means of the CWT-reconstructed data, the differences in nighttime and daytime interest are evident. As the original data were scaled to 100 for the maximum weekly RSV, the units here are in percentage points (pp) of that value. The largest difference between peaks and troughs is visible for the query term “Depression,” with a difference of 37.3 pp (max. at 2-3, min. at 7-8), followed by “Masennustesti,” with a difference of 33.5 pp (max. at 0-1, min. at 7-8), and “Masennus,” with a difference of 30.6 pp (max. at 2-3, min. at 8-9). “Depression test” (difference 12.8 pp, max. at 0-1, min. at 8-9), “Masennus

testi” (difference 12.0 pp, max. at 0-1, min. at 6-7), and “Masennus oireet” (difference 11.8 pp, max. at 2-3, min. at 9-10) showed smaller differences, with fewer statistically significant differences during the 24-hour period.

### Trichotomization

Analysis of mean search activity of the 3 time blocks showed peaks in the first time block (00.00 AM-7.59 AM) for all 6 terms. The mean search volumes then decreased significantly during the second time block (8.00 AM-3.59 PM) for the terms “Masennus oireet” ( $P<.001$ ), “Masennus” ( $P=.001$ ), “Depression” ( $P=.005$ ), and “Depression test” ( $P=.004$ ). Thereafter, the mean search volume between the second and the third time block (4.00 PM-11.59 PM) rose again for the term “Masennus oireet” ( $P=.04$ ). Furthermore, there was a tendency for higher mean search volumes for the terms “Masennus” ( $P=.14$ ), “Masennustesti” ( $P=.07$ ), and “Depression test” ( $P=.10$ ) between the second and third time blocks. [Multimedia Appendix 1](#) shows the search volumes and standard deviations for various search terms in the 3 time blocks.

## Discussion

### Principal Findings

This study provides novel, rapid, cost-effective, and efficient internet-based evidence for insights in to the diurnal variations of depression-related health information seeking. The results of this study suggest that help seeking for depression has clear diurnal patterns, with significant rise in depression-related query volumes toward the evening and night. Our findings support the notion of the previously identified evening-worse DMVs, which is thought to be associated with milder depressive symptoms [40]. The nighttime peaks in search volumes also support the notion of poor sleep quality in subjects with depression and the causal relationship between insomnia and depression noted by Tsuno et al [44]. One interpretation of this finding, supported by Rusting and Larsen [40], is that structured versus unstructured time may account for DMVs. Evening time, for most people, is less constrained by external demands and obligations, and the most likely time of day in which negative thinking may take place, compared with the more structured working hours during the day. According to Hasler [37], the specific patterns of these diurnal mood changes are assumed to characterize different subtypes of depression. DMV has been linked most closely to melancholic depression, characterized by a pattern of feeling worst in the morning, and to atypical depression, which is characterized by the evening-worse pattern [37]. Among both depressed and nondepressed individuals, the evening-worse pattern is thought to be associated with milder depressive symptoms, and may characterize chronic dysthymia with neurotic-type symptoms of depression, including responsiveness of mood, initial insomnia, self-pity, hypochondriasis, hopelessness, and anxiety [40,45,46]. On the basis of the results in this study, more Finnish people in need of help may require support during nighttime rather than during office hours. In addition, as the evening-worse pattern is associated with milder depressive symptoms, early intervention could be beneficial for positive health outcomes. Traditional epidemiological surveys on DMVs and depression suffer from

data-related issues, such as long-term data retrieval, collection, and processing. Earlier research on DMVs has been based on self-ratings of mood, using visual analogue scales and retrospective assessment [38], where patients have been asked to describe the pattern retroactively, either during a clinical interview or in response to an item in a questionnaire [37]. In this respect, infodemiology, and especially search engine data, which is a relatively new concept, presents a promising complementary approach to population and public health research. As stated by Nuti et al [33], Google Trends has potential to afford meaningful insights into population behavior and its link to health and health care. The advantages of monitoring and mining search engine data also lie in the cost-effective and near real-time analysis it enables. In this case, gathering data at hourly intervals using conventional techniques such as surveys would be expensive, time-consuming, and difficult. The strength of this type of big data analysis is that it allows to draw conclusions based on populations of information units rather than on an individual level [34].

### Limitations

It needs to be noted that the results of this study are based on query terms, and there is a challenge in interpreting the semantics of Google queries. It is not clear why a person is searching for the keyword in question, and individual search queries do not necessarily reflect the actual mood state of the user [17,34]. Therefore, it is important to note that the variables used in this paper present interest and not actual incidence. However, as earlier research using search query analysis has shown, it is reasonable to assume that the reason people seek health information about a specific symptom on the internet is because they, or people they know, may be experiencing the symptoms in question [17]. These diurnal trends of help seeking can also provide information that may be useful in further hypothesis testing. As already stated, the internet is by far the most popular vehicle for health information seeking, and changes in health status are often reflected in immediate changes in information and communication patterns on the internet [15,34]. Today, people are more inclined to self-diagnose and seek information to improve their understanding of their personal health using information that is available online [7-9,14]. Search query volumes do not offer demographic data, thus limiting our ability to draw conclusions about population behavior in general. However, as statistics in Finland show, almost all age-by-demographic population categories seek health information on the internet, suggesting that search engine trends may reflect trends in the health of populations. The use of search engine data has, moreover, been proposed to foster and encourage infodemiological research, not to replace or substitute the need for traditional epidemiological research. Therefore, this approach should be seen as complementary to traditional surveillance methods. There are also limitations in the Google Trends database, as there are insufficiencies in detailed information on the method by which Google Trends generates search data and the specific algorithms it employs to analyze it [33].

## Implications

The findings in this study could be utilized by public health officials to facilitate aid and optimize positive health outcomes by providing resources at the best time for intervention, that is, when the majority of people with information needs related to depression are engaged in the process of information seeking. This is a time when the subjects are focusing their attention on the health threat and direct their efforts to becoming more engaged and providing ways of managing depression-related contemplations. This could increase the chances of early intervention for people in need of help or those feeling depressed or worrying about depression-related issues. As the evening-worse pattern for DMV has been linked to milder symptoms in depressed as well as nondepressed individuals [37,40,45], optimal intervention time is very important to guide individuals to optimal sources before their symptoms get worse. In addition, DMV is believed to have clinical relevance as a predictor of treatment response [38]; therefore, it is essential to have an extensive understanding of this phenomenon to help health care professionals and others to plan optimal treatments. Thus, these findings should be concomitant with strategies to ensure that those in need of help have a Web-based pathway to

evidence-based information and aid, such as the Finnish mental health hub [47].

## Conclusions

This paper is a novel attempt at utilizing search engine data on an hourly level to monitor diurnal variation in interest in depression. These initial steps could be developed further in subsequent studies, with the aim to discover larger temporal variations and patterns of health contemplations on an hourly timescale. The method of studying hourly variations and trends in search engine query volumes could also be utilized in other health-related contexts, besides depression. The aim of this study was to draw attention to the possibility of gaining hourly insights into diurnal variations of depression-related information seeking by using search engine data. It is of vital importance to have a wide understanding of depression-related behavior to be able to provide the best possible treatments at the best possible time. Monitoring hourly search volume could serve as an efficient surveillance method for investigating the timely nature of depression-related help seeking. Despite its limitations, this preliminary analysis showed that monitoring hourly search volumes for depression is informative, and that the benefits of this kind of an approach are various.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Analysis of mean search activity of the 3 time blocks.

[[PNG File, 102KB - mental\\_v5i2e43\\_app1.png](#)]

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## Abbreviations

**CWT:** continuous wavelet transform

**DMV:** diurnal mood variation

**RSV:** relative search volume

**WPS:** wavelet power spectra

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Original Paper

# Mobile Phone Intervention to Reduce Youth Suicide in Rural Communities: Field Test

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## Abstract

**Background:** Suicide is a leading cause of death among 10- to 19-year-olds in the United States, with 5% to 8% attempting suicide each year. Suicide risk rises significantly during early adolescence and is higher in rural and underserved communities. School-based universal prevention programs offer a promising way of reducing suicide by providing strategies for emotion regulation and encouraging help-seeking behaviors and youth-adult connectedness. However, such programs frequently run into difficulties in trying to engage a broad range of students. Text messaging is a dominant medium of communication among youths, and studies show both efficacy and uptake in text messaging interventions aimed at adolescents. Text-based interventions may, thus, offer a means for school-based universal prevention programs to engage adolescents who would otherwise be difficult to reach.

**Objective:** We field tested Text4Strength, an automated, interactive text messaging intervention that seeks to reach a broad range of early adolescents in rural communities. Text4Strength extends Sources of Strength, a peer-led school suicide prevention program, by encouraging emotion regulation, help-seeking behaviors, and youth-adult connectedness in adolescents. The study tested the appeal and feasibility of Text4Strength and its potential to extend universal school-based suicide prevention.

**Methods:** We field tested Text4Strength with 42 ninth-grade students. Over 9 weeks, students received 28 interactive message sequences across 9 categories (Sources of Strength introduction, positive friend, mentors, family support, healthy activities, generosity, spirituality, medical access, and emotion regulation strategies). The message sequences included games, requests for advice, questions about students' own experiences, and peer testimonial videos. We measured baseline mental health characteristics, frequency of replies, completion of sequences and video viewing, appeal to students, and their perception of having benefited from the program.

**Results:** Of the 42 participating students, 38 (91%) responded to at least one sequence and 22 (52%) responded to more than a third of the sequences. The proportion of students who completed multistep sequences they had started ranged from 35% (6/17) to 100% (3/3 to 28/28), with responses dropping off when more than 4 replies were needed. With the exception of spirituality and generosity, each of the content areas generated at least a moderate number of student replies from both boys and girls. Students with higher and lower levels of risk and distress interacted with the sequences at similar rates. Contrary to expectations, few students watched videos. Students viewed the intervention as useful—even those who rarely responded to messages. More than 70% found the texts useful (3 items, n range 29-34) and 90% (36) agreed the program should be repeated.

**Conclusions:** Text4Strength offers a potentially engaging way to extend school-based interventions that promote protective factors for suicide. Text4Strength is ready to be revised, based on findings and student feedback from this field test, and rigorously tested for efficacy.

**KEYWORDS**

suicide prevention; school-based program; text messaging; school health services

## *Introduction*

### **Background**

Suicide is the third-leading cause of death among 10- to 19-year-olds in the United States, and 5% to 8% of adolescents attempt suicide each year [1]. The risk for suicide and associated disorders (eg, depression, anxiety, and distress) rises during early adolescence [2]. The risk is higher in rural and underserved communities [3] where mental health services are less accessible or acceptable [4,5]. School-based universal prevention programs that address protective and risk factors across a population of students in early childhood [6,7] and adolescence [8-11] are emerging as viable ways to reduce youth suicide. Help-seeking behaviors, youth-adult connectedness, and strategies for the regulation of emotion are promising targets [11-13]. However, in the context of schoolwide prevention programs, reaching a diverse array of early adolescent students can be challenging, especially for students who are less engaged with school.

This study sought to overcome this challenge through a program of automated, interactive text messages (short message service [SMS]) that targeted help-seeking attitudes and norms, social coping resources, and emotion regulation skills in order to reinforce and extend school-based universal suicide prevention. Automated SMS text messaging interventions have proliferated in recent years, and studies have shown efficacy and uptake in adolescent populations. Interventions delivered through text messaging to youth enrolled in health behavior programs, such as diabetes control [14], HIV management [15], cancer posttreatment care [16], and substance abuse [17] have shown positive results. A pilot test of an automated SMS text-based intervention for adolescents who screened positive for depression and past-year violence in an emergency department was well received by patients and promising in terms of symptom improvement [18,19]. Few SMS texting interventions aimed at youth in the general population (outside of clinical contexts) have been tested for efficacy. However, studies of population-oriented programs such as Text4baby, SEXINFO, Hookup, and Smokefree Teen have shown that adolescents are often willing to adopt and use texting programs in large numbers [20-25].

To our knowledge, SMS text messaging has not yet been used successfully to extend a universal school-based intervention, nor to engage internal and social protective factors for suicide prevention. However, prior work suggested that individuals are often more willing to engage in social-emotional communication in text-based media than in face-to-face communication [26], perhaps because electronic media provide a layer of privacy that frees the individual to explore feelings and topics with which they might otherwise be uncomfortable. Most interventions delivered through text messaging to youth in clinical populations have not harnessed the potential of the medium for interactive communication, instead using one-way messaging or reminders to reinforce behaviors and direct the

attention of participants toward core intervention concepts. One exception to this trend is the iDOVE program [18,19], which made limited use of interactivity, providing cognitive behavioral therapy coaching to adolescents with depressive symptoms who presented in a general emergency department. In response to automated daily prompts, participants could receive a single automated daily message or could initiate the receipt of a single additional support message if they were feeling sad, angry, or stressed.

In this paper, we report the results of field testing Text4Strength. Text4Strength was developed as a universal SMS text messaging intervention to strengthen protective factors for suicide prevention at the key transition point of high school entry [27]. This program extends Sources of Strength [11], an evidence-based peer network intervention in schools. Text4Strength seeks to promote healthy norms, attitudes, and behaviors by using a variety of novel interactive SMS text messaging sequences and by leveraging peer modeling and testimonials consistent with Sources of Strength.

### **Text4Strength for Ninth Grade: Text Messaging Extension of Sources of Strength**

#### *Text4Strength and Sources of Strength*

Sources of Strength is a program, certified by the US National Registry of Evidence-based Programs and Practices, that trains peer opinion leaders in messaging and social marketing activities that promote healthy social norms and communication with trusted adults, and help-seeking from adults for suicide concerns. In a randomized controlled trial (RCT) conducted in 18 schools, schoolwide help-seeking norms increased where Sources of Strength was implemented. Trained peer leaders were 4 times more likely to refer a suicidal friend to an adult [11]. An ongoing RCT [28] with 40 schools in rural and underserved communities is testing the impact of Sources of Strength on reducing self-reported suicide attempts. Text4Strength shares Sources of Strength's core strategy of leveraging peer leaders' creativity and positive modeling, and aims to extend both the reach and scope of Sources of Strength and other school-based interventions. Text messaging has the potential to reach students who are isolated, do not have close friendship ties, or are hesitant to participate in prevention activities in the school setting. In terms of scope, Text4Strength extends Sources of Strength concepts by teaching specific skills for the self-regulation of emotion in addition to reinforcing the core concepts of Sources of Strength.

#### *Developmental Context*

We field tested a version of Text4Strength that centers on the concerns of ninth graders in the United States as they transition to high school. As discussed below, research on early adolescence suggests that this period may be ideally suited for interventions focused on emotional skills, help-seeking skills, and supportive resources. High school provides opportunities

for meeting new friends and mentors, as well as for academic growth and engagement in new activities, but it also presents a host of new stressors [29]. Furthermore, starting high school coincides with the pronounced increase in emotional and behavioral problems that occurs between the ages of 14 and 15 years [2,30]. On entering high school, ninth graders have to take on a greater responsibility than before for seeking help, rather than relying on adults to initiate help. Despite generally feeling that they receive greater support from peers than from adults, ninth graders' perception of adult support is more strongly related than perceived peer support to their adjustment to the transition [31,32]. Incoming high schoolers also face greater academic pressures [30] and increased emphasis on dating relationships, as well as normal age-related developmental changes that result in mismatches between heightened emotional activation [31-33] and executive functions responsible for inhibitory control [34,35]. These mismatches contribute to adolescents' greater susceptibility to suicide-related modeling [36].

### ***Text4Strength Targets and Strategies***

Text4Strength targets are (1) norms and attitudes toward help seeking, (2) connections with trusted adults, (3) connections with other social resources (eg, Sources of Strength), and (4) strategies for emotion self-regulation during the transition to high school (Table 1). Our previous work showed that high school students with suicide ideation were more likely to seek adult help if they held positive views toward seeking such help (eg, belief that friends and family would want them to ask for help), if they perceived adults at school as available and capable of helping suicidal students, and if they believed that the social resources in their lives (family support, positive friends, mentors, healthy activities, generosity, spirituality, mental health, and medical access) would help them get through tough times [12]. Positive help-seeking attitudes are also associated with both a lower risk for suicidal behavior [37] and increased help-seeking behavior among suicidal youth [12]. Numerous studies have demonstrated the importance of youth-adult connections in adolescent health [38-40] and for suicidal youth in particular [41-45]. Having trusted adults at school, at home, and in the community was associated with fewer suicide attempts in a large nonclinical sample of adolescents from an underserved community [13]. Maladaptive emotion self-regulation processes have been linked to key risk factors for suicide: depression [46-48], anxiety [49,50], antisocial behavior [51,52], and drug use [53]. Difficulties in various aspects of emotion regulation, including lack of emotional awareness [54], restrictive emotionality [48], and strategies for responding to and recovering from emotional upset [13,54-56], have been linked directly with suicide risk and attempts. The association between suicide attempts and difficulties in emotion regulation is moderated by having trusted adults [13].

Text4Strength focuses on three core emotion self-regulation skills [57]: (1) monitoring one's own and others' emotions, (2) reducing escalation of emotions, and (3) building relationships that aid in maintaining control and regaining equilibrium. These

skills are critical in adolescent development, and the lack of such skills is associated with suicide risk [13].

### **Text4Strength Text Messaging Strategies**

Text4Strength introduces new strategies for engaging participants in order to ultimately promote positive health behavior changes. In addition to reinforcing concepts and norms related to help-seeking and making connections with trusted adults and other social resources, Text4Strength teaches emotion regulation strategies through interactions in a novel environment. This gives participants the opportunity for deeper personal reflection, particularly because of the option-rich nature of the intervention, which allows them to choose the extent to which they would like to interact with it.

Text4Strength targets the aforementioned constructs through a range of different interactive, automated SMS text message sequences. This approach is consistent with other qualitative research suggesting that adolescents prefer variety in text messaging [18]. Text messages included (1) brief videos and text-based testimonials generated by high school peer leaders and designed to draw participants in for further skill-building interactions, (2) direct questions inviting ninth-grade students to consider their own experiences and the support available for personal problems, (3) requests for advice for other students dealing with difficult situations, and (4) light-hearted games and activities such as Choose Your Own Adventure (students select among positive emotional strategies in response to a challenging social scenario) and Would You Rather (students choose from a series of alternatives that start off silly and humorous and become more serious, ie, different options for seeking adult help for a suicidal friend; Table 1). Positive peer modeling cuts across message types based on past research demonstrating the importance of peers in an array of prosocial and risky adolescent behavior [58,59], including suicidal behavior [36]. Almost all the Text4Strength messages offered participants choices in the content they would receive (eg, watching a video or answering a question), because individual risk, needs, and access to resources vary, necessitating universal interventions that are option-rich [13]. Peer leaders generated video- and text-based testimonials with the aid of an online coaching interface we developed previously called StoryPRIME. The program coached students through a step-by-step process of creating testimonials based on successful experiences of managing emotions and using coping resources. Our previous work showed that StoryPRIME produced relatable, relevant, and interesting text messages for ninth graders [60].

In this study, we examined the degree to which ninth-grade students (1) replied to text messages sent to them; (2) viewed peer-generated videos sent via links in SMS text messages; (3) judged the messages and videos as fun, appealing, and easy to use; and (4) judged the messages and videos as relevant and beneficial to them. We further explored how students with different levels of preexisting protective and risk factors interacted with and learned useful skills from text messages, and we examined the relationships between the degree of interaction with texts and students' perceptions about the usefulness of the program.

**Table 1.** Text4Strength text message concepts and skills, and presentation formats.

Concepts and skills, and format	Example of one outgoing message in a sequence <sup>a</sup>
<b>Norms and attitudes toward help seeking</b>	
Questions about individual experience and available support	“After a lot of stress, she took a risk and talked to her teacher, who became a mentor. Who could you go to at school if you were stressed?”
Requesting advice	“Adults want to help, but sometimes they don’t realize you want to share something. If a student wants to speak [with a] teacher, how could they get their attention?”
Games, challenges, and activities	“If a friend broke their leg in front of you but told you not to get help, would you... A) call 911 B) wait until they said it was OK to call C) order pizza” “What if your friend was really depressed but said not to get help? I’d... A) go [with] them to a counselor B) convince them it’s okay to get help C) say suck it up”
<b>Connections with trusted adults</b>	
Peer video and text testimonials	“Sometimes family can be supportive during tough times. Here’s a video from Karen {VIDEO LINK} Who in your family can cheer you up?”
Questions about individual experience and available support	“Sarah found adults in her life she could trust as mentors. Who is your most important mentor? (parent, family member, teacher, coach, neighbor, counselor, etc)”
Requesting advice	“We want your advice...let’s say your friend got in a fight with his mom, has three papers due tomorrow, and has a soccer game tonight. Would you tell your friend to A) write his papers before the game B) skip the game C) ask his teacher or coach for help D) talk to his mom E) not sure”
Games, challenges, and activities	“Hi, [high school] students say family, friends, and mentors can be there for you when you’re dealing with a tough time. Ready for a challenge? Tell someone in your family something you appreciate about them. Let us know how they responded.”
<b>Connections with other social resources</b>	
Peer video and text testimonials	“Hey! Here’s a video from John from {School} {VIDEO LINK} sharing how he made friends in [high school]. Text FRIEND after you’re done watching.”
Questions about individual experience and available support	“Have you felt like you were trying to find your place like John? Reply YES or NO”
Requesting advice	“It can be hard to figure out who to be friends with in high school. What advice would you give somebody who felt like they are trying to find their place?”
Games, challenges, and activities	“Generosity is a source of strength. Want a generosity challenge? Think of someone who might be a little down and how you could go out of your way to encourage/help them. See if you can do this every day this week! Good luck!”
<b>Strategies for emotion self-regulation</b>	
Peer video and text testimonials	“Want to hear from Simone about how she dealt with handling a lot of things in [high school]? {VIDEO LINK}”
Questions about individual experience and available support	“Hard feelings tell you many things. When they last a long time, it usually means you need other people involved. Could that be true here? YES NO or MAYBE”
Games, challenges, and activities	“When you’re confused about how you’re feeling, you can do a gut check. There are three steps you can take. Want to try? YES or NO”

<sup>a</sup>Some examples may address more than one concept or skill.

## Methods

### Participants

A total of 175 ninth-grade students in 2 rural high schools attended informational meetings organized by their schools. Research staff provided information and parent permission packets inviting participation to the students in attendance. Students were paid a total of US \$30 for their participation in surveys and feedback; payment was not contingent on reading or replying to messages. All study materials and recruitment procedures were approved by the University of Rochester Research Subjects Review Board, Rochester, NY, USA.

### Procedures

Participants completed baseline surveys before the intervention. They then received 28 interactive, automated text message sequences (16 with links to peer-leader videos) over 9 weeks (approximately twice per week). Each week was dedicated to 1 module: Sources of Strength introduction, positive friend, mentors, family support, healthy activities, generosity, spirituality, medical access, or emotion regulation strategies. The number of responses requested from students in a text message sequence ranged from 0 to 8. Student responses to texts, interactions with links, video views, and viewing times were logged automatically. Participants completed follow-up surveys within 2 weeks of completing the intervention. Baseline

and follow-up surveys were administered by study staff either in homeroom or a class and took about 15 minutes to complete.

### **Safety Protocols**

None of the messages in Text4Strength invited students to share about suicide-related thoughts or risk-related behaviors; however, precautions were taken to account for the possibility that students could spontaneously send a message that caused concern. At enrollment, students and parents were informed of the safety protocols for the field test, and the limits of confidentiality were explained. Texts were not monitored in real time but were reviewed within 72 hours. If students replied to automated texts with any unexpected words, the texting system replied with school-specific information about how to get help during and after school hours, along with a reminder that their replies were not monitored in real time. When texts were reviewed within the 72-hour period, any messages that caused concern would be brought to the principal investigator, and further action would be taken as needed. In addition, at the end of each assessment, students received an on-screen message and a paper handout detailing counseling resources they could access if they were experiencing any emotional distress.

### **Measures**

#### ***Baseline Characteristics and Risk Factors***

The baseline survey consisted of questions about demographics; frequency of mobile phone use; measures of depression, distress, anxiety, and coping and support and emotion regulation; expectations about ninth grade; and their social network, with questions meant to identify friends at school. For scales, we noted Cronbach alpha for this sample.

#### **Frequency of Cell Phone Use**

Students reported how often they used their mobile phones to send and receive texts, talk to people, post to social media, and play online games [61].

#### **Depression, Distress, and Anxiety**

To characterize our convenience sample, students completed a baseline measure of depression (Short Mood and Feelings Questionnaire [62,63],  $\alpha=.96$ ), psychological distress (Kessler Psychological Distress Scale [64,65],  $\alpha=.94$ ), and anxiety (Generalized Anxiety Disorder 7-item scale [66],  $\alpha=.95$ ).

#### **Coping and Support and Emotion Regulation**

To determine the status of students on target constructs at baseline and subsequently examine whether their status would be related to their degree of interaction or perceived usefulness, we measured the following at baseline: Sources of Strength coping [11,12] ( $\alpha=.87$ ), integration with peers [67] ( $\alpha=.94$ ), caring adults at school [68] ( $\alpha=.86$ ), adults to trust at school [13] ( $\alpha=.95$ ), and the Lack of Emotional Clarity and the Limited Access to Strategies for Emotion Regulation subscales of the Difficulties in Emotion Regulation Scale [69] ( $\alpha=.84$  and  $\alpha=.89$ , respectively).

#### **Social Network Out Nominations**

Students were asked to name up to 7 close friends from a list of ninth-grade students at their school.

### ***Interaction With Texts***

Text messages were sent and tracked using a Web app developed at the University of Rochester for this program of research. Students provided their phone numbers at the end of the baseline surveys. We then entered these phone numbers into the texting system and used them to track texts sent to and received by each student. We calculated the number of replies for students and proportions of students responding to individual messages, along with total number of sequences completed. Total responses within each module (eg, introduction, positive friends, generosity) were also calculated. Sequences were considered complete once no more responses were requested for that particular sequence.

### ***Interaction With Videos***

Peer-leader testimonial videos were hosted on wistia.com (Wistia Inc, Cambridge, MA, USA). Outgoing links from the text messages to wistia.com were tracked via link management site bit.ly (Bitly, Inc, New York, NY, USA) using unique URLs for each student. The video hosting platform tracked both the number of views and the percentage of each video watched by a given viewer.

### ***Appeal of Text4Strength***

We measured the appeal of Text4Strength using questions designed specifically for this study about the appeal of the text content, whether students shared the content with family or friends, and whether they felt comfortable texting (eg, "I read messages even when I didn't reply back;" "It was fun to reply to messages and see what responses I'd get. "). Students were also asked questions based on the System Usability Scale [70-72], examining the ease and appeal of using the texting system itself, as well as about problems they encountered in receiving texts and viewing videos. Those who had seen at least one video were asked about having time to watch videos, the appeal of videos, and whether they were useful (eg, "I could relate to the peer leaders' stories;" "I preferred videos made by peer leaders who go to our school. "). All questions were rated on a 5-point scale ranging from 1 ("strongly disagree") to 5 ("strongly agree").

### ***Perceived Benefit***

We asked students whether the texts were relevant or helpful to ninth graders and whether the students recommended that ninth graders should receive these messages in the following school year (eg, "The texts helped me in my transition to high school;" "Next year the 9th graders at my school should get these texts. ").

### ***Student Feedback***

Students responded to 6 open-ended items inviting them to state what they found most useful and to give their ideas for improving the program. The items were "What was most useful to you as a 9th grader?," "What would make the program more useful for 9th graders?," "What would make the texts more fun or enjoyable?," "The video I remember most is...," and "What would make the video more interesting and useful?"

## Analyses

We examined engagement with texts by coding valid responses to all delivered text messages and creating variables for total number of responses to each sequence and overall number of responses. By examining response patterns, we determined whether each participant had completed each sequence and created a sum of sequences completed. Similarly, we were able to determine the number of views for all videos and the amount of video that had been viewed. For both types of engagement, we examined whether the proportions of students replying differed by sex and school using independent-samples *t* test and, for text engagement, by depression, distress, anxiety, and coping and support and emotion regulation using correlations.

We examined the relationship between baseline characteristics (depression, distress, and anxiety; coping and support and emotion regulation) and survey responses to items on appeal and usefulness of the text messages using correlations for continuous variables and *t* tests or analysis of variance for grouped variables (ie, sex, depression cutoff, and psychological distress groups). We also examined free responses to the students' suggestions. All statistical analyses were conducted in IBM SPSS v22 (IBM Corporation).

## Results

### Baseline Characteristics and Risk Factors

Of the 175 ninth-grade students who attended the information meetings, 58 (33.1%) returned completed parental permission packets and 53 (30.3%) participated in the initial survey held a few weeks later. Of these, 42 (79%, 30 female, 12 male) had mobile phones and could participate in receiving text messages and interacting with them; 2 students did not complete the follow-up survey. A total of 39 students (93%) identified as white, 1 as American Indian, 1 as Asian, and 1 as biracial (white and Asian); 4 students (10%) were 13 years old or younger, 35 (83%) were 14 years old, and 3 (7%) were 15 years or older.

Of the 53 students who completed the baseline measure, 37 (86%) reported sending and receiving text messages every day. Most students reported very few depressive symptoms (mean total depression score 5.28 out of 39), but about a quarter of the sample (15 students, 28% of total) reported symptoms above the threshold recommended by Angold et al [62] for identifying those who are likely to have clinically significant depression. Students generally reported very few symptoms of psychological distress (mean 1.75, SD 0.89; possible range 1-5). Students reported very few symptoms of anxiety (mean 0.59, SD 0.86; possible range 0-3). Students reported high use of Sources of Strength coping resources (mean 3.43, SD 0.51; possible range 1-4). Students reported having high levels of support from peers (mean 3.19, SD 0.83), caring adults at school (mean 3.21, SD 0.75), trusted adults at school (mean 3.28, SD 0.70), and other adults (mean 3.35, SD 0.69), where the possible range was from 1 to 4. Students reported sometimes feeling clear about their emotions (mean 2.24, SD 1.00; possible range 1-5) and sometimes having access to emotion regulation strategies (mean 1.82, SD 0.88; possible range 1-5). A total of 51 students (96%)

named at least 1 friend, 17 (32%) named between 1 and 6 friends, and 34 (64%) named 7 friends.

### Interaction With Texts

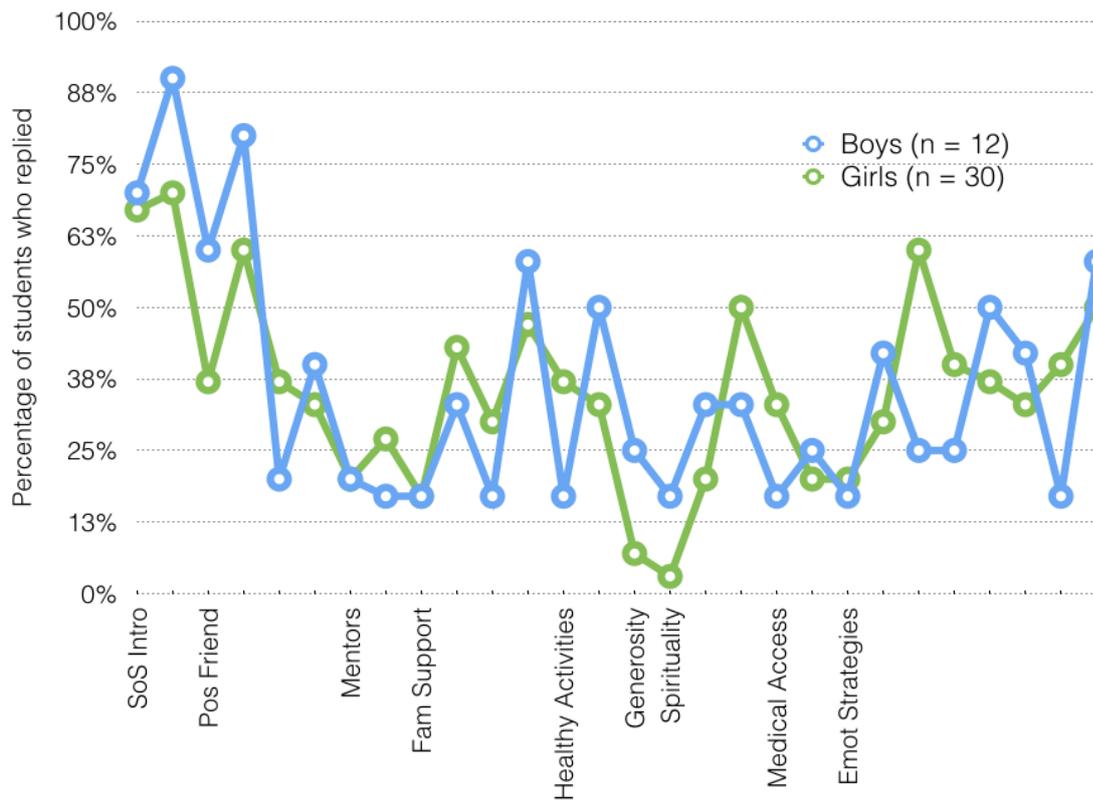
Of the 42 participating students, 38 (91%) responded to 1 or more messages; 22 (52%) replied to at least one-third of the sequences, 13 (31%) replied to at least one-half of the sequences, and 8 (19%) replied to two-thirds or more. The number of students who completed multistep sequences they had started ranged from 35% (6/17) to 100% (3/3 to 28/28). Students who replied to the first text in a sequence completed the whole sequence on average 58% of the time (average of percentage completion).

The proportion of students replying to messages was not related to their sex, except in the generosity and spirituality modules, or to their school, previous reported use of texting, depression (*t* test), psychological distress (using analysis of variance for distress groups), anxiety, or coping and support or emotion regulation scales (correlation). Students with higher depressive symptoms (above the suggested cutoff,  $n=14$ ), high psychological distress (above the suggested cutoff,  $n=5$ ), or high anxiety (upper quartile,  $n=13$ ) replied to a number of texts similar to that of students with few symptoms of depression, distress, or anxiety (8.80 vs 9.00 responses). We did not test the significance of these analyses because of the small cell sizes. As Figure 1 shows, levels of interaction across the 28 message sequences varied significantly, with the proportion of students replying ranging from 7% (3/42) to 70% (28/40), but proportions for each sequence did not, with 2 exceptions, differ significantly by sex (boys: mean 36.01%, SD 20.04%; girls: mean 32.98%, SD 16.41%;  $t_{27}=1.161$ ,  $P=.26$ ). Similar numbers of students responded to most categories of sequences, with the exception of the sequences in the spirituality and generosity modules. The overall number replying to the single message sequence in each of these 2 modules was significantly lower than for any other module. While the number of students replying was within the normal variation for boys, very few girls replied to these 2 sequences. As Figure 2 shows, sequences longer than 4 conversational turns were completed by significantly fewer students.

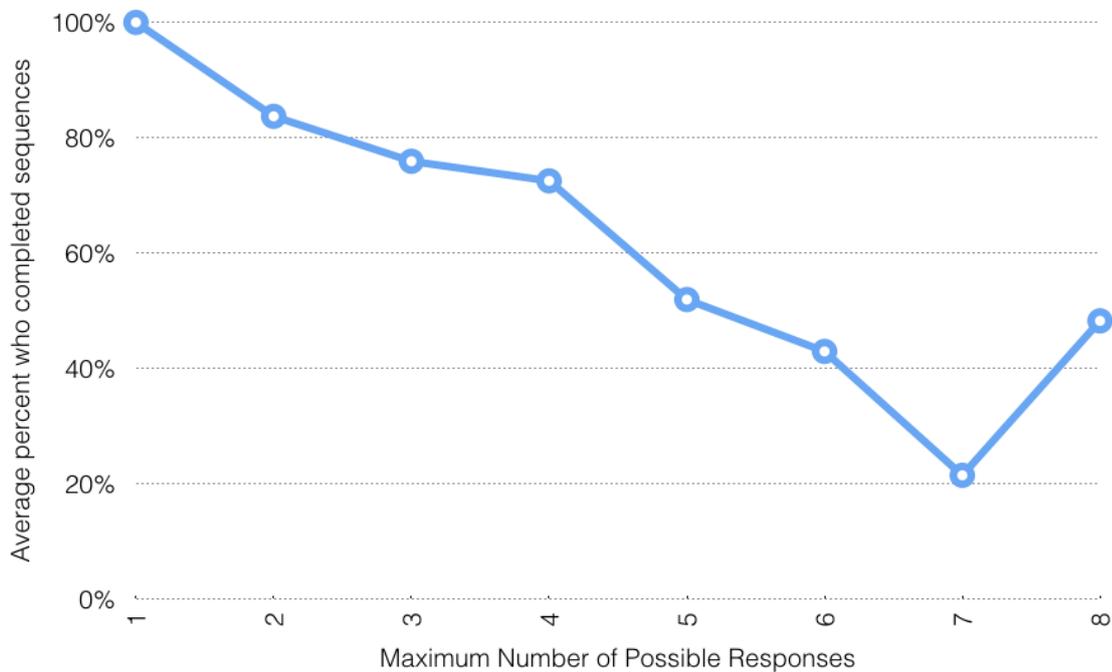
### Interactions With Videos

Very few students followed links to view videos; however, when they did, they usually watched all the way through. As Table 2 shows, when offered a link to a video, between 2 and 22 (5%-52%) students (mean of 20%) watched it. Students who watched viewed an average of 86% of the video they watched (range 58%-100%). Students watched videos all the way through 69% of the times they started them. A total of 14 students (34%) reported that they were not able to view videos on their phones, 7 (50%) because they did not have internet access, 5 (36%) because their phone was slow, and 1 (7%) because the links did not work. Engagement with videos did not vary by sex or school. Students who showed signs of risk on their baseline surveys (high depressive symptoms or psychological distress or anxiety, as defined above), on average, viewed fewer videos than other students (less likely to access videos and watched fewer: 2.36 vs 3.26 videos).

**Figure 1.** Percentage of girls and boys who replied to each of 28 sequences over 9 weeks of intervention. Emot Strategies: emotion regulation strategies; Fam: family; Pos: positive; SoS Intro: Sources of Strength introduction.



**Figure 2.** Average percentage of students who completed sequences by length of sequence (n=41).



**Table 2.** Students' engagement with videos.

Video title	Students who viewed the video, n (%)	Average % of video viewed by those who watched
Finding My Place	22 (55) <sup>a</sup>	92.29
Everyone's Really Cool	12 (30)	85
You Can Love Food and Still Fit In	9 (23) <sup>a</sup>	96.58
You Don't Really Have to Impress Anyone	6 (15) <sup>a</sup>	60.5
Shakespeare Struggle	3 (8)	100
If I Knew Then What I Know Now	10 (24) <sup>a</sup>	77.75
Time Time Time	2 (5)	100
Do Things That Make You Happy	11 (26)	80.35
Find People Who Make You Laugh and Happy	2 (5)	58
Get Your Emotions Out There	22 (55)	73.62
Try New Things	5 (12)	90.13
Don't Be Afraid to Ask for Help	3 (7)	97.75
Talk About It	9 (21)	84.42
Getting Teachers' Attention Puppet Show	6 (14)	100
Bundled Up with Schoolwork and Activities	4 (10)	89.75

<sup>a</sup>Video appears later in message sequence (not in opening line).

### Appeal of Text4Strength

Student ratings of the text messages indicated that they found the texts to be fun, appealing, and easy to use. Most students felt that the frequency of texts (about twice per week) was right ( $n=3$ , 7% too few,  $n=5$ , 12% too many,  $n=33$ , 81% about right). As Table 3 shows, almost all students ( $n=40$ , 98%) read the messages even when they did not reply. A total of 17 (43%) students had talked to either friends or their parents or family about the texts. Among those who watched any videos, 70% (19) of the students liked the videos and only 7% ( $n=2$ ) thought that the program would be better without videos. Students enjoyed hearing personal stories from upperclassmen ( $n=25$ , 93%).

Most students found the system easy to use, and only a few (7-8, 17%-19%) found it complicated or thought it took a while to figure out what to do. A total of 25 students (61%) liked the response they received when they replied with advice or experiences, while 14 students (34%) felt the system needed improvement. The Text4Strength system performed reliably. We had only 1 substantive technical glitch—students from 1 of the schools received multiple, repeat messages on a single day. Our new notification system functioned properly by alerting us to the problem based on unexpected student replies. We fixed the problem and apologized to students.

There were no adverse safety concerns. However, we encountered one situation in which an ambiguous reply text from a student required clarification to be sure she was not expressing distress. Following our approved safety protocol, we contacted the student, notified school partners, and were quickly reassured about her safety. In specific survey questions assessing possible negative effects, 2 students said 1 or 2

messages made them feel sad—in both cases, sadness was in response to hearing about hard situations faced by other students (eg, a parent leaving for military deployment) and feeling empathy for them.

Students participated vigorously in free-response suggestions and feedback. To make texts more enjoyable, 8 students suggested adding more or different games to message sequences. In addition, 6 students requested inserting more humor, such as jokes or cartoons, with more serious message content, and 6 students suggested using a more personal touch in text content and tone. Also, 1 student asked if the program could “make it like it was more of a best friend instead of a program.” This level of personalization came up in different ways throughout the course of the final survey. Students “liked when it asked me questions like how my day was.”

### Perceived Benefit

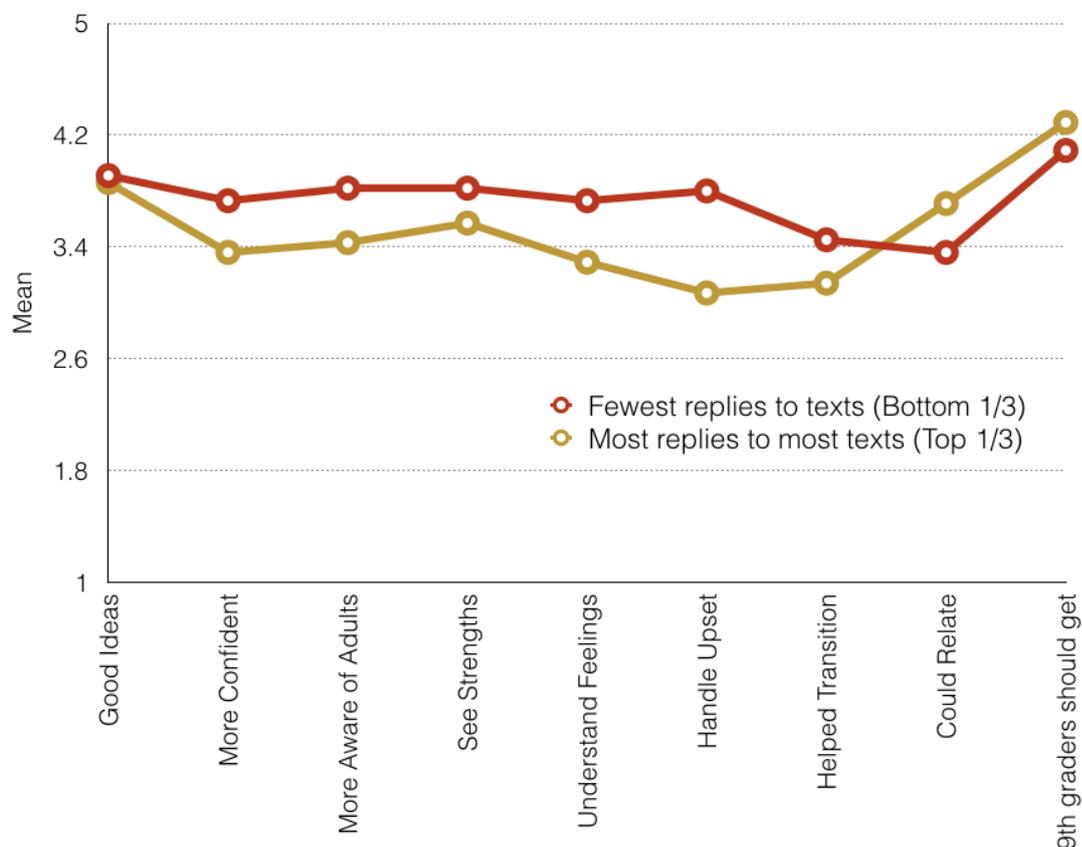
Students found the text messages appealing and useful to the ninth-grade experience (Table 3), regardless of whether they replied frequently or not. Over 70% of students thought the texts gave them good ideas ( $n=34$ , 86%), helped them feel more confident with high school challenges ( $n=31$ , 78%), and made them more aware of adults they could access ( $n=29$ , 73%). In addition, 58% ( $n=23$ ) felt the texts helped them with their transition to high school and 90% ( $n=36$ ) agreed that ninth graders should receive the texts next school year. Students indicated that they had learned new ways to handle emotionally upsetting situations and that they understood their feelings and strengths better. As Figure 3 shows, the top third of students who replied to the most texts and the bottom third of students who replied to the fewest texts found the texts equally useful ( $P=.52$  for difference in mean of items,  $P$  range .10-.90 for items).

**Table 3.** Appeal and usefulness of Text4Strength messages and videos.

Measure	Response, mean (SD)	Response, n (%)				
		Strongly disagree	Disagree	Neither	Agree	Strongly agree
<b>Message appeal (n=41)</b>						
I enjoyed getting text messages from Sources of Strength	4.05 (0.545)	0	0	5 (12)	29 (71)	7 (17)
I read messages even when I didn't reply back	4.41 (0.55)	0	0	1 (2)	22 (54)	18 (44)
It was fun to reply to messages and see what response I'd get	3.93 (0.685)	0	1 (2)	8 (20)	25 (61)	7 (17)
I talked with my friends about texts I received	2.83 (1.05)	4 (10)	13 (32)	11 (27)	12 (29)	1 (2)
I talked with my parents/family about texts I received	3.12 (1.19)	4 (10)	9 (22)	11 (27)	12 (29)	5 (12)
I got bored with the messages after a while	2.73 (0.975)	2 (5)	19 (46)	9 (22)	10 (24)	1 (2)
I didn't take the messages seriously	2.02 (0.85)	12 (29)	18 (44)	9 (22)	2 (5)	0
I liked being able to share my own experiences and advice	3.85 (0.76)	0	2 (5)	9 (22)	23 (56)	7 (17)
I felt comfortable texting personal things when asked	3.51 (0.90)	0	7 (17)	10 (24)	20 (49)	4 (10)
<b>Texting system usability (n=41)</b>						
I liked texting back and forth with the Sources of Strength texting system	3.78 (0.725)	0	2 (5%)	10 (24)	24 (59)	5 (12)
I found texting back and forth with the texting computer too complicated	2.71 (0.955)	4 (10)	13 (32)	16 (39)	7 (17)	1 (2)
It took me a while to understand what I was supposed to do when I got a text from Sources of Strength	2.51 (1.075)	7 (17)	15 (37)	12 (29)	5 (12)	2 (5)
It was easy for me to use keywords or letters to reply to texts	3.85 (0.76)	0	3 (7)	6 (15)	26 (63)	6 (15)
When I replied with advice or experiences, I liked the response I got back	3.61 (0.89)	1 (2)	3 (7)	12 (29)	20 (49)	5 (12)
The back and forth texting system would need to be improved before students will enjoy using it	3.07 (1.08)	3 (7)	9 (22)	15 (37)	10 (24)	4 (10)
<b>Message usefulness for ninth graders (n=40)</b>						
The texts gave good ideas for 9th graders to follow	4.00 (0.72)	0	2 (5)	4 (10)	26 (65)	8 (20)
The texts helped me feel more confident to face challenges in high school	3.70 (0.88)	2 (5)	1 (3)	8 (20)	25 (63)	4 (10)
The texts made me more aware of adults I could talk to	3.75 (0.78)	1 (3)	2 (5)	6 (15)	28 (70)	3 (8)
The texts helped me in my transition to high school	3.50 (1.01)	2 (5)	4 (10)	11 (28)	18 (45)	5 (13)
As a 9th grader, I could relate to the situations described in the texts	3.78 (0.86)	1 (3)	3 (8)	5 (13)	26 (65)	5 (13)
Next year, the 9th graders at my school should get these texts	4.30 (0.65)	0	0	4 (10)	20 (50)	16 (40)
<b>Strengths and emotions (n=40)</b>						
The texts helped me see my own strengths	3.83 (0.90)	2 (5)	1 (3)	5 (13)	26 (65)	6 (15)
The texts helped me understand my own feelings better	3.68 (0.92)	2 (5)	2 (5)	7 (18)	25 (63)	4 (10)
I learned new ways to handle emotionally upsetting situations	3.56 (1.05)	3 (8)	3 (8)	6 (15)	23 (59)	4 (10)
<b>Video appeal (n=27)</b>						
The videos I watched were interesting	3.74 (0.76)	0	2 (7)	6 (22)	16 (59)	3 (11)
I could relate to the peer leaders' stories	3.73 (0.78)	0	2 (8)	6 (23)	15 (58)	3 (12)
My friends and I handle challenges similar to those described	3.59 (0.75)	0	2 (7)	9 (33)	14 (52)	2 (7)
I recognized the students in the videos	4.04 (0.71)	0	1 (4)	3 (11)	17 (63)	6 (22)

Measure	Response, mean (SD)	Response, n (%)				
		Strongly disagree	Disagree	Neither	Agree	Strongly agree
I preferred videos made by peer leaders who go to our school	4.11 (0.85)	0	2 (7)	2 (7)	14 (52)	9 (33)
I thought peer leaders were being really honest in the videos	4.07 (0.73)	0	1 (4)	3 (11)	16 (59)	7 (26)
I didn't have time to watch videos	2.44 (1.09)	5 (19)	11 (41)	6 (22)	4 (15)	1 (4)
The program would be better without videos	2.00 (0.96)	10 (37)	9 (33)	6 (22)	2 (7)	0
The videos gave me a good impression of Sources of Strength	3.93 (0.88)	0	1 (4)	4 (15)	18 (67)	4 (15)
I liked hearing personal stories from upperclassmen	4.00 (0.555)	0	1 (4)	1 (4)	22 (82)	3 (11)
Peer leaders didn't talk about things I'm going through	3.12 (0.95)	1 (4)	6 (23)	9 (35)	9 (35)	1 (4)

**Figure 3.** Equally "useful" for least- and most-engaged students.



### Student Feedback

In free-response feedback, students made suggestions for increasing the intervention's usefulness for ninth graders in the future. One student said "I think that each student's survey should be taken into consideration [so they] receive personalized messages [they] could relate to." Along with suggestions for improvement, there were some complaints. When asked what would make the program more useful, 1 student wrote "nothing really, the texts didn't really help all that much." Several students asked that the program no longer include its automatic response at the end of each sequence: "don't say 'thank you for your message'." Overall, however, the responses received in the final surveys were positive and constructive in nature, and

students seemed genuinely invested in helping create a better program for future student participants. A sampling of common responses from the final survey follows.

In reply to the question "What was most useful to you as a 9th grader?":

*Knowing that some other people felt the same way or were going through the same things i could and could relate.*

*The most useful thing as a 9th grade related to the text was the ideas and advice about how to handle situations that have happened to me or could happen because it prepared me for the situations.*

*The reassurance that I COULD get through each and every day, Although some days felt as though there were more struggles than others, at the end of the day I was able to look at situations and events more-so optimistically and from various perspectives.*

In reply to the question “What would make the texts more fun or enjoyable?”:

*If there were more games that resulted in real life scenarios.*

*Getting replies from people instead of a computer.*

*Doing little cartoon videos about the things and problems kids are facing, so that if they are sad or down it would/could make them laugh.*

In reply to the question “What would make the program more useful to 9th graders?”:

*...maybe more meetings and activities, instead of just texting...because its easier to talk about your feelings with someone, instead of text them so someone.*

*The program would be more useful if there was more stories about situations other students were in that they could tell future 9th graders.*

*...make messages more interactive.*

In reply to the question “What suggestions do you have for improving students’ experience of texting back and forth with the computer?”:

*To make it for the kids who need it the most or seem like they need advice.*

*Maybe the computer can turn the question into a poem once in a while, but not a big poem, a small one.*

*...don’t have the same automated response every time a students texts and is not responding to a question.*

In reply to the question “The video I remember most is:”

*One of the videos I remember the most is one where I recognized the student and talked about how she got through a rough situation.*

*A girl’s dad going to Afghanistan.*

*The girl with from my school talking about your problems to others.*

In reply to the question “What would make the videos more interesting and useful?”:

*I think the videos would be more interesting if the videos were all from students I recognize.*

*...if they were based off of issues that have really happened to them.*

*If they were more fun.*

## Discussion

### Principal Findings

Students who participated in this field test found Text4Strength to be appealing and useful, indicating that the text messaging program has potential for extending school-based interventions that promote protective factors for suicide. Ninth-grade students

across a spectrum of risk and distress engaged with diverse text messages aimed at building coping resources and encouraging communication with trusted adults. Similar levels of interaction between those with higher and lower levels of risk and distress suggest that both struggling and relatively healthy adolescents may be willing to engage on their phones with material aimed at building protective factors if it is presented in the form of positive, fun, and appealing text messages. This is especially notable given that the sample included few highly distressed students. Most importantly, students reported that they gained awareness of their own feelings and learned new ways to handle upsetting situations.

Students found the texting system easy to use and there were no technical difficulties. Levels of student engagement with the text sequences were promising even though a substantial portion of students chose to reply to only 1 or 2 messages. Almost all students replied to at least 1 message and read messages even when they didn’t reply. A third of students engaged actively, replying to at least one-half of the sequences, and most students completed the text sequences and videos they started. Significantly, students found texts useful whether or not they replied often and recommended that the program be offered to students in the future, suggesting that they saw the texts as invitations to interact when an interest or need arose. Understanding this attitude can help us set realistic expectations about participation and adjust content so that modest use results in sufficient exposure.

To our knowledge, our study is the first to use text messaging to extend a universal school-based intervention specifically for ninth graders. As they transition to high school, ninth graders face several new and unique challenges and are in a period ideally suited for an intervention that engages internal and social protective factors for suicide prevention [29]. Text4Strength targets messages to a broad population, going beyond the clinical populations on which previous research has focused [14-17]. Even among text messaging interventions aimed at nonclinical populations [20-25], Text4Strength is the only one with a high degree of two-way interactivity and a variety of message formats [73].

Lessons from this field test and feedback from students can inform the next iteration of this intervention and the development of future text messaging interventions. First, the number of students replying to messages in most modules was fairly consistent, but almost no girls replied to messages we sent about spirituality and generosity. Future implementations of Text4Strength will need to improve on the content of these two categories if they are to be retained. Second, based on the observation that the number of students replying dropped significantly after the fourth message in a sequence, future iterations should either limit sequence length or experiment with new ways to hook students’ interest midsequence. Third, few students watched the videos. Students reported being limited by time, location, and bandwidth or capability. Text messaging is an on-the-go medium but videos require stopping to watch. Future universal texting interventions should carefully weigh the cost and value of producing videos. Fourth, Text4Strength leveraged peer voices through text- and video-based testimonials, but it was not tightly integrated with schoolwide

messaging activities. More explicit links with school-based prevention activities might increase engagement with text message and video content. Fifth, consistent with other studies [18,74], in this study, students reported wanting more humor and personalization.

### Limitations

Several limitations should be noted. First, the primary limitation is that this was a field test with a small convenience sample of ninth-grade students in 2 rural high schools. It was designed specifically to inform a future pilot RCT. Despite the small sample, participants did not vary greatly from the populations of their respective schools on broad demographic factors or on Cronbach alphas and means for scales. The one exception was in the sex of participants; proportionally more girls than boys participated in the field test. Second, because of the novelty of the intervention, we lack data from the literature with which to benchmark the proportion of students interacting with texts and videos and to judge “successful” engagement. We hope that the proportions of students we documented replying to texts and viewing videos will provide that context for future research. Third, we tested only one style of video, namely peer testimonials. Thus, we cannot conclude definitively that video

links in text messages could never work. Students who watched videos liked them and usually watched them all the way through, so perhaps a better description or “hook” for the videos could have resulted in more views.

### Conclusion

In this field test, Text4Strength was appealing and useful to students and technically feasible. Text4Strength offers a potential way to extend school-based interventions aimed at promoting protective factors for suicide. Text4Strength is ready to be revised, based on findings and student feedback from this field test, and rigorously tested for efficacy, including its effect on suicide-related outcomes. The most important revisions will be (1) making text messages more humorous and fun (including more games), (2) personalizing messages with students’ names and other tailoring, (3) reducing reliance on videos, and (4) integrating messages into concurrent school-based prevention activities of Sources of Strength. In addition, an efficacy trial of this intervention should include testing outcomes for higher-risk students, as well as the broader population. These changes are expected to increase overall engagement, leading to better retention and application of concepts and skills.

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### Conflicts of Interest

None declared.

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## Abbreviations

**RCT:** randomized controlled trial

**SMS:** short message service

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Original Paper

# Using Neural Networks with Routine Health Records to Identify Suicide Risk: Feasibility Study

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## Abstract

**Background:** Each year, approximately 800,000 people die by suicide worldwide, accounting for 1–2 in every 100 deaths. It is always a tragic event with a huge impact on family, friends, the community and health professionals. Unfortunately, suicide prevention and the development of risk assessment tools have been hindered by the complexity of the underlying mechanisms and the dynamic nature of a person's motivation and intent. Many of those who die by suicide had contact with health services in the preceding year but identifying those most at risk remains a challenge.

**Objective:** To explore the feasibility of using artificial neural networks with routinely collected electronic health records to support the identification of those at high risk of suicide when in contact with health services.

**Methods:** Using the Secure Anonymised Information Linkage Databank UK, we extracted the data of those who died by suicide between 2001 and 2015 and paired controls. Looking at primary (general practice) and secondary (hospital admissions) electronic health records, we built a binary feature vector coding the presence of risk factors at different times prior to death. Risk factors included: general practice contact and hospital admission; diagnosis of mental health issues; injury and poisoning; substance misuse; maltreatment; sleep disorders; and the prescription of opiates and psychotropics. Basic artificial neural networks were trained to differentiate between the suicide cases and paired controls. We interpreted the output score as the estimated suicide risk. System performance was assessed with 10x10-fold repeated cross-validation, and its behavior was studied by representing the distribution of estimated risk across the cases and controls, and the distribution of factors across estimated risks.

**Results:** We extracted a total of 2604 suicide cases and 20 paired controls per case. Our best system attained a mean error rate of 26.78% (SD 1.46; 64.57% of sensitivity and 81.86% of specificity). While the distribution of controls was concentrated around estimated risks < 0.5, cases were almost uniformly distributed between 0 and 1. Prescription of psychotropics, depression and anxiety, and self-harm increased the estimated risk by ~0.4. At least 95% of those presenting these factors were identified as suicide cases.

**Conclusions:** Despite the simplicity of the implemented system, the proposed methodology obtained an accuracy like other published methods based on specialized questionnaire generated data. Most of the errors came from the heterogeneity of patterns shown by suicide cases, some of which were identical to those of the paired controls. Prescription of psychotropics, depression

and anxiety, and self-harm were strongly linked with higher estimated risk scores, followed by hospital admission and long-term drug and alcohol misuse. Other risk factors like sleep disorders and maltreatment had more complex effects.

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## KEYWORDS

suicide prevention; risk assessment; electronic health records; routine data; machine learning; artificial neural networks

## Introduction

### Background

The World Health Organization recognizes suicide as a public health priority. The World Health Organization Member States are committed to working towards the global reduction of suicide rates worldwide by 10% by 2020 [1]. In Wales alone, approximately 300 people die each year by suicide, accounting for about 1% of all deaths, and three times the rate of fatalities following traffic accidents [2]. The suicide rate has barely altered over the last decade, and any change that has occurred has generally been an increase [3]. Each death by suicide in the UK is estimated to cost more than £1,370,000 (direct and indirect costs) [4]. Considering these observations, adopting a public health approach to suicide prevention “has to be a national priority” [5].

Unfortunately, the prediction of suicide risk has proven to be a challenging problem for epidemiological studies and how they apply to health care practice. The pathways to suicide are mediated by highly complex processes, integrating many interdependent risk factor variables [6-9]. This creates difficulties around the positive identification of the relatively small number of individuals who will take their own lives from the much larger group of people in whom some or all the various risk factors have been identified. Assessment of immediate suicide risk requires a clinical evaluation. However, the majority of those who take their own lives present to health services other than mental health specialists in their final year. The identification of those at risk—so appropriate questions can be asked in relation to suicidality—would support ongoing suicide prevention efforts across a range of health services.

Short-term suicide risk prediction (ie, days, weeks, or months) is particularly useful for targeted interventions; but less is known about the processes underlying short-term suicidality than longer-term presentations [10]. Distal, or identified long-term risk factors, have complex effects on short-term risk and therefore separate, specific research is needed.

At the same time, we have databanks curating a wealth of electronic health records (EHRs), and administrative information which, when linked, could provide a representative picture of the biological, societal and health status of an individual at any point in time. Use of this data at scale is expected to make a pivotal contribution to the study of many diseases [11], especially those with complex longitudinal histories like suicide. However, the sheer volume of data and the complexity of the suicide factors-risk model have proven to be a challenge for traditional epidemiological and statistical modelling methods. As a result, existing screening tools are reportedly inefficient [12]. Thus, advanced artificial intelligence (AI) techniques are

currently better positioned to tackle the combined challenges of big data and suicide risk prediction.

### Prior Work

Although the application of AI techniques in different areas of medicine is extensive [13,14], the difficulties of processing routinely collected EHRs and big data in general have been reported elsewhere [15-18]. These include the volume, complexity, heterogeneity and changing nature of medical data as well as its poor mathematical characterization; the importance of physician’s interpretations; and the legal, ethical and social implications. It is only recently that we have had the resources to record, maintain and analyze routinely collected EHRs with millions of records.

In the last decade, the use of machine learning (a branch of AI) to analyze EHRs has grown dramatically, spurred in part by advances in artificial neural networks (ANNs) and deep learning [19]. Miotto and colleagues [20] created a deep ANN that received hospital diagnosis codes and created a “patient representation” vector of 500 features. This vector was fed to a random forest to predict 78 different diseases, including mental disorders such as schizophrenia. This model generated an accuracy of more than 90% for (more than) 76,000 patients, but suicide risk was not part of the study.

Indeed, the application of AI in psychiatry is a field that has received relatively little attention but has great potential for innovation [11]. Some proposals found in the literature are optimization of the delivery of momentary cognitive-behavioral interventions [21], early identification of post-traumatic stress disorder [22], and analysis of social-network information for mental health research [23]. AI studies specifically focusing on suicide risk estimation are more recent and scarce.

Passos and colleagues [24] administered questionnaires to 144 participants with major depressive disorder or bipolar disorder to extract risk-factor information. Suicidality was estimated based on a previous history of suicide attempts. This data was then fed into various machine learning algorithms with the aim of identifying those at high risk of attempting suicide. A best performance of 72% accuracy was obtained with a relevance vector machine.

Kessler and colleagues [25] used a population cohort of non-deployed US Regular Army soldiers who had a diagnosed mental disorder and at least one outpatient visit. Their cohort included 147 deaths through suicide. Between 10 and 14 factors were extracted after outpatient visits followed by suicide (cases) and visits not followed by suicide (controls) and used to build a logistic regression with elastic net regularization to predict suicidality in the five weeks after these visits. Their system obtained a sensitivity of 48% and a specificity of 84% when

predicting suicidality. The authors concluded that their system “outperformed mental health professionals to a large margin.”

### Goal of This Study

We aim to explore the use of ANNs with routinely collected EHRs to estimate suicide risk within the general population. This approach builds on Passos et al and Kessler et al research, taking it a step further by relying on routinely collected EHRs across health settings rather than mental health questionnaires. Hence, our system would not depend on information that is collected only in specific circumstances (eg, outpatient visits or hospital admissions), and could therefore be used to screen the entire population without increasing the workload of health care practitioners.

Our system aims to improve not only the quality of suicide risk assessment, but also its coverage. This is a crucial factor when considering that only 35% of those who died in Wales by suicide between 2010 and 2015, were admitted to hospital in the year prior to death, and around 40% had an emergency department admission. Furthermore, of those who died in Wales by suicide between 2001 and 2015, 65% did not have a mental health records in the year prior to death; and 40% never had. However, approximately 83% of these suicide cases had at least one contact with their general practitioner (GP) during that period. Therefore, our system seeks to utilize these contacts to assess suicide risk and increase population coverage.

Additionally, our system has the potential to perform risk assessment continuously over time and in the background (ie, without human intervention) across healthcare settings. Rather than using this as an assessment of immediate “at risk” or “not at risk,” it will be used to flag patients, even those attending for reasons other than mental health, so that appropriate questions can be asked. The UK National Institute for Health and Care Excellence recommends that risk assessment tools and scales should not be used to predict future suicide or repetition of self-harm [26]. This is because of the dynamic nature of suicide risk. An individual assessed as “not at risk” on one occasion could subsequently become “at risk,” but professionals may not be as responsive to these changes because of labelling effects. The proposed system aims to flag at risk individuals upon any contact with health services so that relevant questions are asked and appropriately addressed.

The goal of this study is to test the feasibility of this concept, validating the methodology from functionality (performance) and medical (validity of factors-risk model) points of view. Using an oversimplified system (shallow ANN), conservative results regarding model complexity and performance are ensured. We combine data from primary and secondary care, use repeated cross-validation during evaluation, and explore the distribution of factors across different levels of estimated suicide risk to describe the system’s behavior.

In the remainder of this article, we describe the data sources used, how we defined our cohorts of suicide cases and controls, and the risk factors used during experimentation. A brief introduction to ANNs is provided, followed by a detailed description of the models evaluated here. We detail the analyses that were run to assess raw performance and the resulting

factors-risk model. Following the presentation of the results, we discuss their interpretation as well as the potential of the proposed model, how it compares with the current state of the art approaches, its limitations and implications for practice, and conclusions.

## Methods

### Materials

#### Data Sources

Data available within the Secure Anonymized Information Linkage (SAIL) Databank [27] was used. The HIRU Information Governance Review Panel (IGRP) granted ethical approval. IGRP is an independent body consisting of a range of government, regulatory and professional agencies, that oversee study approvals in line with permissions already granted to the analysis of data in the SAIL databank [28,29]. The current research took place under the SID-Cymru project [30] (approval number 0204).

For this study, we linked and analyzed the National Statistics Annual District Deaths Extract (ADDE), the Welsh Demographic Service (WDS), the Welsh Primary Care GP dataset (WGP), the Patient Episode Database for Wales (PEDW) and the Emergency Department Data Set (EDDS). While all datasets were used to define the study case-control cohort, only WDS, WGP and PEDW were used to build the feature vectors for experimentation.

Data availability varied across individuals and databases. While ADDE and PEDW datasets have a nationwide coverage, WGP contains data from 348 out of 474 (73%) GP practices in Wales. This variation was reduced by restrictions applied during the cohort definition (see below). At the same time, while the WGP and PEDW datasets were available over the full study period (2001 to 2015), ADDE was only available from 2009. However, ADDE data was used only to determine a key date before death, not to train or test the ANN system, and therefore we do not expect this has significantly biased our results.

#### Cohort Definition

We extracted our cohort from SID-Cymru, a population based electronic case-control study on completed suicide in Wales between 2001 and 2015 defined within SAIL [30]. Approximately 32,000 deaths of Welsh residents are registered each year, of which approximately 350 are suicides or events of undetermined intent. It is conventional research practice to include the latter in the definition of suicide [31].

The case-control study cohort was built according to the following steps:

1. We identified those that died through suicide at age 10 or older between 2001 and 2015. Deaths of undetermined intent in those under 10 years of age may be related to abuse or neglect and thus were excluded.
2. We followed individuals’ health histories retrospectively from death date to identify the full calendar of health services contact leading up to death (CLD). This could include multiple entries within the WGP, PEDW and EDDS

- databases (eg, attendance at A and E, admission to hospital, transfer to another hospital, and finally GP letters received from hospitals notifying of deaths). A maximum CLD duration of one month was considered to avoid including unrelated hospital stays. The CLD was subsequently removed from the analysis to avoid using information directly linked with the death of cases.
- Only those residing in Wales at the time of their death, with GP data available for at least 80% of the five years prior to CLD were included in the study. This ensured that similar data coverage was available for all cases and controls. The value of five years was chosen to balance between the length of health history and number of cases retained.
  - For each case, 20 controls were randomly selected, without replacement and excluding cases, after matching by gender and week of birth ( $\pm 1$  year). During control selection, those with a similar period of Welsh residency and GP data coverage were prioritized to ensure similar coverage quality. Although this number is unnecessarily large for traditional paired case-control studies, the proposed methodology benefitted from increased data availability during training.

A total of 2604 suicide cases were identified—2012 (77.3%) of which were males, and 58,080 controls. These had a perfect (deterministic) or very high (probabilistic) linkage score (between 0.95 and 1) within SAIL.

### Feature Vector

Only data from WDS, WGP and PEDW were used during experimentation. Not all events recorded in WGP and PEDW represent face-to-face contact with the patient, and a single event may have multiple associated entries (eg, multiple diagnoses).

Each entry was categorized in WGP and PEDW into types of health event: depression and anxiety; other common mental disorders; other mental health; non-intentional injury and poisoning; self-harm; alcohol misuse; drugs misuse; possible maltreatment; physical sleep disorders; non-physical sleep disorders; and “others.” We also identified the prescription of opiates and psychotropics from WGP (PEDW has no prescription information) and recorded whether there were any entries recorded in WGP or PEDW (representing a hospital admission). This made a total of 15 factors (11 diagnoses, two prescriptions, WGP entries and hospital admissions).

The above categories were defined in terms of ReadCodes for WGP and ICD10 for PEDW with the help of expert clinicians and based on previous publications when available (depression and anxiety [32], other common mental disorders [33], non-intentional and intentional (self-harm) injury and poisoning [34,35], alcohol misuse [36], drugs misuse [36,37], possible maltreatment [38] and psychotropics [39]). Full code definitions can be seen in Tables A1 and A2, [Multimedia Appendix 1](#).

We identified the presence of the above 15 health events during four non-overlapping time-frames:

- 1M: Between CLD and 1 month before CLD [CLD – 1 month, CLD].
- 6M: Between 1 and 6 months before CLD [CLD – 6 months, CLD – 1 month).
- 1Y: Between 6 and 12 months before CLD [CLD – 1 year, CLD – 6 months).
- 5Y: Between 1 and 5 years before CLD [CLD – 5 years, CLD – 1 year).

The final feature vector also included age at CLD and sex, resulting in a length of 62: 1 float age + 1 binary sex + 15 binary health events \* 4 time-frames. This feature vector does not include data directly related to the CLD. Interactions between these factors are automatically taken into account by the ANN.

## System Design

### Artificial Neural Networks

Artificial neural networks (ANNs) are biologically inspired computing systems capable of learning tasks through examples and experience, without the need of explicit programming of task-specific rules or any a priori knowledge of the solution [40].

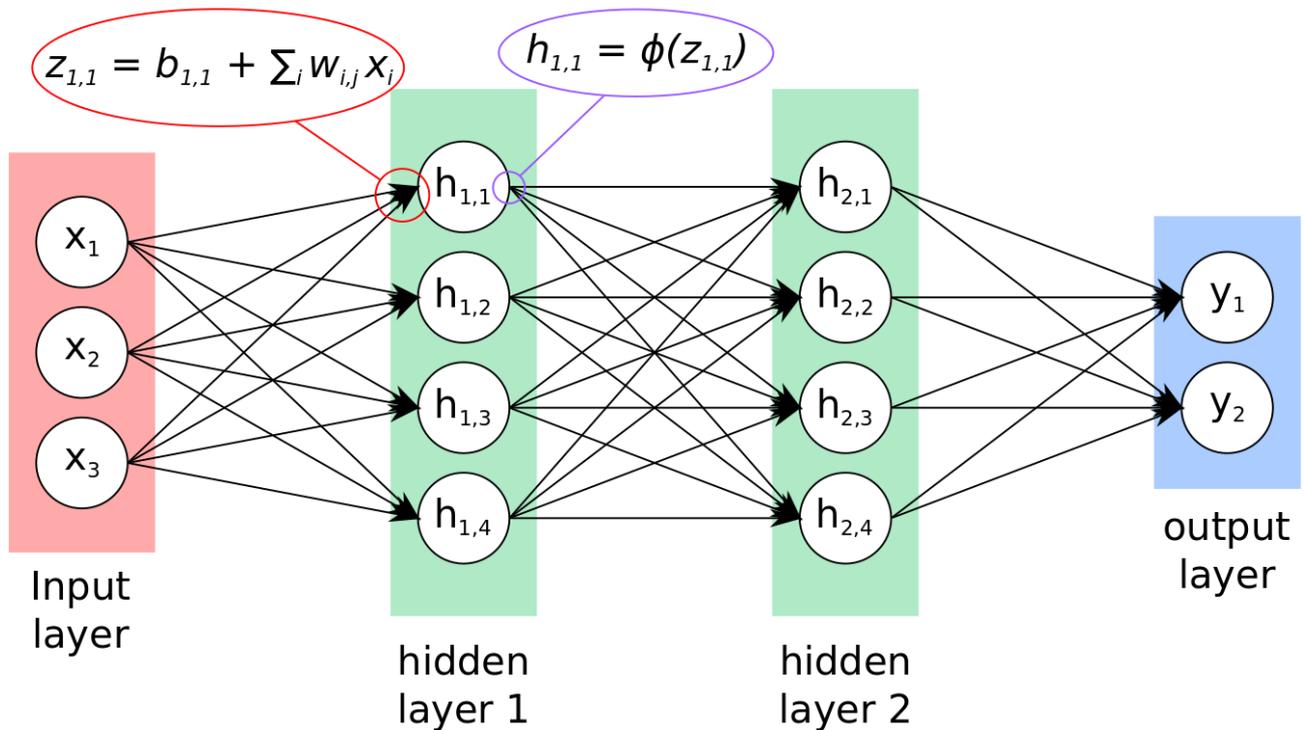
ANNs are typically composed of an input layer, one or more hidden layers and an output layer ([Figure 1](#)). Each unit (artificial neuron) in the input or output layer corresponds to one dimension of the input or output vector respectively, with each dimension corresponding to one input or output variable. The complexity of the input-output model is governed by the activation function of neurons, the number of hidden layers, the number of neurons in each layer and the connection between neurons and layers.

The term “black-box” is sometimes used to describe ANNs. This has contributed to the widespread misconception of ANNs not being transparent, which in turn has gained them a bad reputation in fields such as medicine, where understanding how and why decisions are taken is important. However, “black-box” alludes to the fact that the input-output model generated by the network is too complex to be expressed by a set of simple rules that are syntactically meaningful. Such a model can nevertheless be expressed as a mathematical equation. For example, a simple ANN composed of no hidden layers and a single output neuron with a logistic activation function is equivalent to the logistic regression model;

$$y = S(b + \sum \forall_i w_{ji} x_i)$$

where  $x_i$  are each of the input neurons (ie, variables),  $w_{ji}$  are the weights from the  $i$ -th input to the  $j$ -th neuron,  $b$  is a bias term,  $S(\cdot)$  is the sigmoid function and  $y$  is the output neuron (ie, result). Typically, the input-output equation quickly grows in complexity, and therefore we opt not to represent it.

**Figure 1.** Structure of an artificial neural network with 1 input layer (red), 2 hidden layers (green) and one output layer (blue) all fully connected.  $\phi$ : Activation function



### Evaluated Architecture

A simple ANN was implemented with seven different configurations: no hidden layers (nn0), one hidden layer of size 10, 50 or 100 (nn10, nn50, nn100) and two hidden layers with sizes 10, 50 or 100 (nn10-10, nn50-50, nn100-100). All layers were fully connected (ie, each neuron in layer  $i$  was connected to all neurons of the previous layer  $i-1$ ). The input layer was composed of the feature vector described above (ie, 62 neurons). Hidden layers, when present, had a tanh activation function. The output layer had a single neuron with a sigmoid activation function, returning the score  $r$  of a sample belonging to a (suicide) case ( $r=1$ ) or a control ( $r=0$ ). A decision threshold of 0.5 was used, ie, samples with  $r>0.5$  were classified as cases while samples with  $r \leq 0.5$  were classified as controls. We interpreted this score  $r$  as the estimated risk of suicide, differentiating between very low risk (VLR;  $r \leq 0.17$ ), low risk (LR;  $0.17 < r \leq 0.33$ ), moderate-low risk (MLR;  $0.33 < r \leq 0.5$ ), moderate-high risk (MHR;  $0.5 < r \leq 0.67$ ), high risk (HR;  $0.67 < r \leq 0.83$ ) and very high risk (VHR;  $r > 0.83$ ).

The mean square error was adjusted to account for data imbalance (20 controls per case) so that the resulting cost of both classes (case and control) was equal to 1. The final cost included 12 weight regularization with scale 0.01.

All ANNs were trained with the gradient descent algorithm and exponential learning rate decay starting at 1. Training was performed sequentially with three different batch sizes: 25, 100 and all cases and their respective controls (ie, total batch size 525, 2100 and full). The learning rate was reset with every change in batch size. Training within each batch size continued until a maximum number of epochs was reached, the change of cost function evaluated on the validation set was lower than a

threshold or the change was in the negative direction (ie, not improving).

Using the oversimplified system (ie, small number of features and shallow ANNs) described above, we favored obtaining conservative results in terms of model complexity and performance, which we hope would counteract some of the limitations of the study (described below). In addition, in a practical application the cost of misidentifying suicide cases and controls will probably not be the same. Whether the system should be tuned to have a high sensitivity at the cost of low specificity or vice versa depends on many factors and is beyond the scope of this study. For simplicity, we equalized this cost to be the same for cases and controls. Hence, accounting for the unbalanced 1:20 distribution of cases and controls, the cost of misclassifying a case was 1, while the cost of misclassifying a control was 1/20. All experiments and ANNs were designed and executed using TensorFlow in Python.

### Statistical Analysis

#### System Performance

We followed a 10x10-fold cross-validation approach to evaluate the performance of the ANNs. On each iteration, one-fold was used for testing, one for validation (used to inform the early stopping training algorithm) and eight for training. Cases were randomly distributed across folds, followed by their respective controls so that case-control pairs were always maintained during partitioning (this partitioning rule was also applied during batch partitioning in training).

On each iteration, as well as measuring the classification error obtained with the threshold resulting from training, the threshold was varied to compute the receiving operating characteristics (ROC) curve and the area under the ROC curve (AUC). We

compared performance between systems using a corrected resampled  $t$  test [41] based on the average over sorted runs [42] for 10x10-fold, and  $P$  values were further adjusted ( $Q$  values) for multiple testing using the false discovery rate Benjamini and Hochberg method [43].

Finally, we repeated the above analysis shuffling the labels of each samples, ie, we randomly assigned the label “case” to one of the 20 paired controls of a case and rebranded the original case as “control.” This aims at evaluating whether our initial results are due to real relationships between labels and data, rather than to random idiosyncratic patterns in the data.

### System Behavior

In addition to measuring system performance, we attempted to assess the factors-risk model obtained by the best performing ANN. Due to the dimensionality of the feature vector (ie, number of input factors) and the freedom of the ANN to build complex models with numerous non-linear interactions, getting the full representation of the factors-risk model was not practical. However, the following results gave us insight into how large a role each factor played in the computation of the risk score:

- The histogram of the number of cases and controls across estimated risk scores. This will provide information additional to the performance measurements about the classification capability for cases and controls.
- The histogram of the estimated risk difference when turning specific factors “on” and “off” across the whole dataset. This will show an estimated role of each individual factor in the computation of the risk score, and how it varies due to interactions with other factors.
- The distribution of each factor (ie, individuals presenting a factor) across estimated risk scores. This will work in conjunction with the previous point to draw an estimate of the role of each individual factor.
- The incidence of each factor within estimated risk scores. This will allow us to compare incidences across risk levels for cases and controls.

Results of this analysis refer to the factor-risk model built by our ANN and do not necessarily agree with the real factor-risk model. Our confidence of how similar these two are depends on the size and quality of the testing data and on the performance of our system. This is true for any AI application, but it is especially important in medical applications such as the one proposed here.

## Results

### System Performance

The error rate of the described ANNs decreased slightly from 28.9% to 26.8% when increasing the number of hidden layers from 0 to 2 (Table 1). Overall, nn0 performed worse than the rest. The performance difference between networks with 1 and 2 hidden layers, although small, is statistically significant ( $q < 0.05$ ) (Table A3 of Multimedia Appendix 1).

Figure 2 shows the ROC curve of the best performing network for each number of hidden layers (ie, nn0, nn50 and nn10-10). ROC curves of nn10, nn50 and nn100 were virtually identical, as were curves of nn10-10, nn50-50 and nn100-100. In the false positive rate (fpr=1-specificity) range between 0 and 15%, nn50 and nn10-10 perform better than nn0. Past this point, the ROC curves get closer together and for fpr>30% they become virtually identical. Despite the similarity between ROCs of nn50 and nn10-10, the difference in AUCs between them is statistically significant ( $q < 0.05$ ) (Table A4 of Multimedia Appendix 1). In general terms, nn10-10 and nn50 can obtain better sensitivity for more restrictive specificity values than nn0 but perform similarly well for higher specificity.

Crucially, results after shuffling the labels were characteristic of a random process (ie, 50% error rate and 0.5 AUC).

### System Behavior

The distribution of cases and controls across estimated risk scores reflects the results of Table 1 (Figure 3). Controls were mostly concentrated on scores below 0.5 (hence, high specificity). Cases on the other hand were almost uniformly distributed (hence, low sensitivity). Overall, few individuals received an estimated risk score  $\leq 0.2$ .

Prescription of psychotropics, depression and anxiety, and self-harm seem to have the strongest effect on the estimated risk, increasing  $r$  by  $\sim 0.4$  when changing from “off” to “on” across all time-frames (Figure 4). Most of the risk increase from prescription of psychotropics and depression and anxiety came on the first six months before CLD ( $\Delta r \approx 0.3$ ), while self-harm had a more linear effect across time-frames. The distribution of  $\Delta r$  for prescription of psychotropics was the most concentrated around the peak. These three factors were followed in strength by hospital admissions and alcohol misuse, with  $\Delta r \approx 0.25$ . WGP entries, on the other hand, reduced the estimated risk by around 0.2.

Most samples were assigned a risk below the 0.5 threshold, with only 70 individuals resulting in a very low risk  $r \leq 0.17$  (Table 2). In contrast, as many as 1366 individuals obtained a very high estimated risk ( $r > 0.83$ ). Age and gender distributions were virtually identical across risk levels, except for the very low risk range ( $r \leq 0.17$ ) which was mainly composed of women (Table 2).

Looking at how factors (individuals with factors “on”) were distributed across risk scores (Figure 5, and Tables A5 to A8 of Multimedia Appendix 1), in the month before CLD, 97% of those with a prescription of psychotropics, 96% of those with depression and anxiety and 95% of those with self-harm were classified as being at risk of suicide ( $r > 0.5$ ) (Figure 5). More than 78% of those presenting with one of these factors or drugs or alcohol misuse across most of the considered time-frames (i.e. 1M, 6M, 1Y and 5Y) were classified as at risk. Moreover, more than half of the individuals with recorded self-harm in the five years before CLD, or depression and anxiety or alcohol or drugs misuse in the month before CLD, received a very high estimated suicide risk score ( $r > 0.83$ ).

**Table 1.** Mean and standard deviation of the error rate, sensitivity, specificity and AUC obtained on the 10x10-fold experiments for each neural network.

ANN <sup>a</sup> model	Error rate, mean (SD)	Sensitivity, mean (SD)	Specificity, mean (SD)	AUC <sup>b</sup> , mean (SD)
nn0 <sup>c</sup>	28.89% (1.47)	57.28% (2.97)	84.94% (0.54)	0.78 (0.02)
nn10 <sup>d</sup>	27.12% (1.42)	64.19% (2.94)	81.57% (0.57)	0.79 (0.02)
nn50 <sup>e</sup>	27.09% (1.42)	64.25% (2.92)	81.57% (0.58)	0.79 (0.02)
nn100 <sup>f</sup>	27.11% (1.42)	64.18% (2.93)	81.61% (0.61)	0.79 (0.02)
nn10-10 <sup>g</sup>	26.78% (1.46)	64.57% (3.00)	81.86% (0.58)	0.80 (0.02)
nn50-50 <sup>h</sup>	26.83% (1.43)	64.52% (2.92)	81.82% (0.59)	0.80 (0.02)
nn100-100 <sup>i</sup>	26.83% (1.47)	64.54% (3.04)	81.79% (0.61)	0.80 (0.02)

<sup>a</sup>ANN: artificial neural network.

<sup>b</sup>AUC: area under the ROC curve.

<sup>c</sup>nn0: No hidden layers.

<sup>d</sup>nn10: 1 hidden layer with 10 neurons.

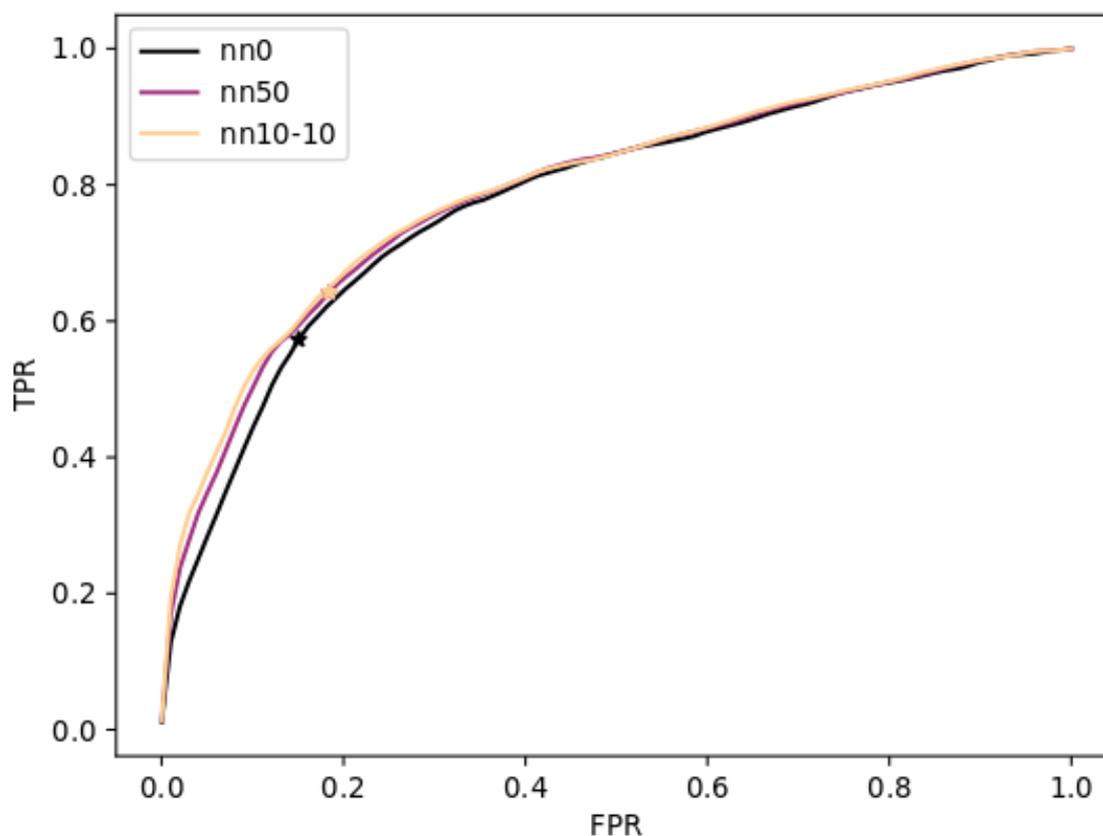
<sup>e</sup>nn50: 1 hidden layer with 50 neurons.

<sup>f</sup>nn100: 1 hidden layer with 100 neurons.

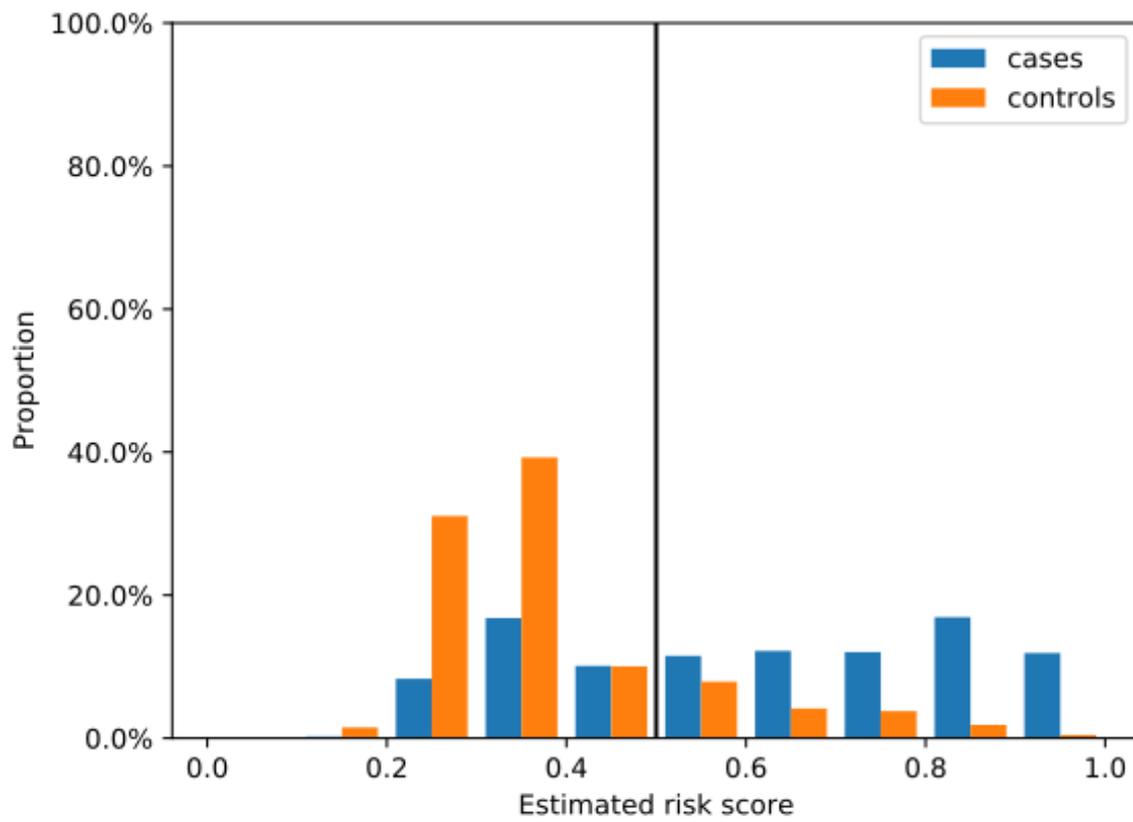
<sup>g</sup>nn10-10: 2 hidden layers with 10 neurons.

<sup>h</sup>nn50-50: 2 hidden layers with 50 neurons.

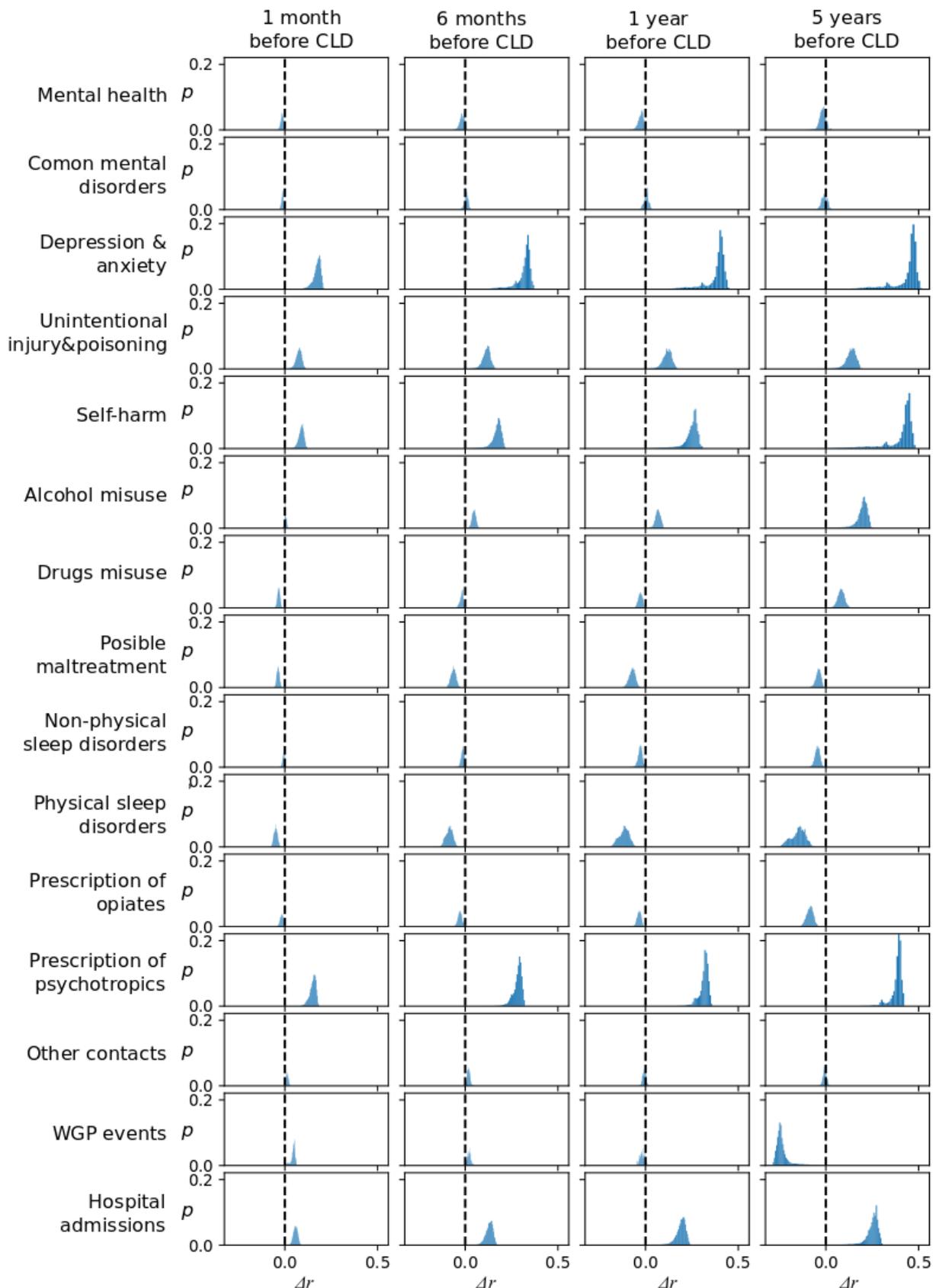
<sup>i</sup>nn100-100: 2 hidden layers with 100 neurons.

**Figure 2.** Receiving operating characteristics (ROC) curve for nn0, nn50 and nn10-10. FPR: false positive rate; TPR: true positive rate; nn0: no hidden layers; nn50: 1 hidden layer with 50 neurons; nn10-10: 2 hidden layers with 10 neurons.

**Figure 3.** Distribution of cases and controls across estimated risk score levels. Those with risk score  $>0.5$  were identified as “cases.”.



**Figure 4.** Histogram of the difference in estimated risk score when turning specific factors ‘on’ and ‘off’ across the whole dataset.

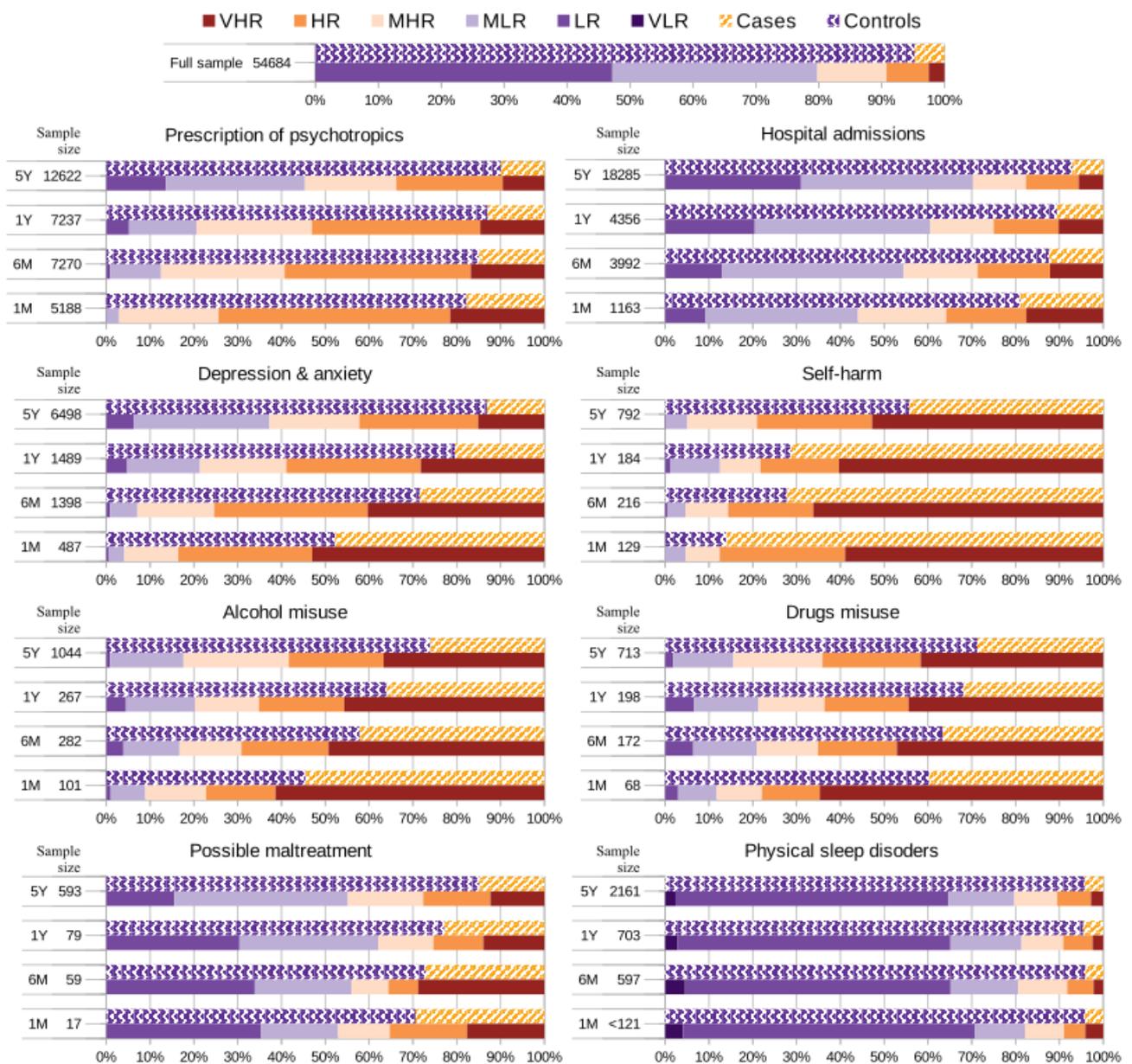


$\Delta r = r_{on} - r_{off}$ , where  $r_{off} / r_{on}$  is the estimated risk with factors off/on  
 $p$  = Proportion of samples

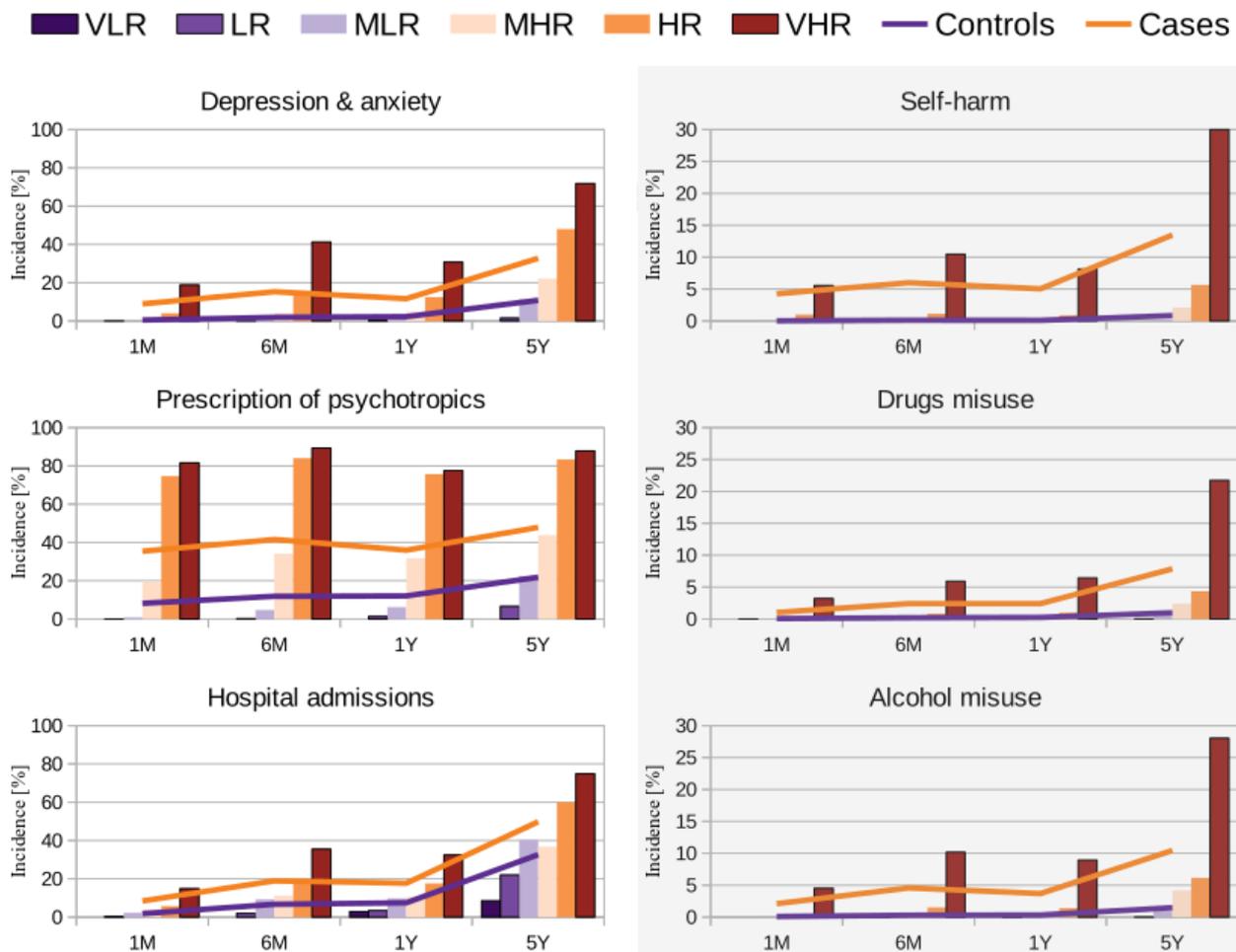
**Table 2.** Number of individuals, gender and mean age for controls, cases and estimated risk levels from very low to very high.

Description	Number of Individuals	Number of Males, n (%; 95% CI)	Mean age, years
Controls	52080	40240 (77.37%; 76.9%-77.6%)	48.04
Cases	2604	2012 (77.27%; 75.9%-78.6%)	48.04
Very low risk ( $r \leq 0.17$ )	70	4 (5.7%; 2.6%-12.1%)	54.32
Low risk ( $0.17 < r \leq 0.33$ )	25744	17884 (69.5%; 68.9%-69.9%)	48.07
Moderate-low risk ( $0.33 < r \leq 0.5$ )	17818	15850 (88.9%; 88.6%-89.3%)	46.52
Moderate-high risk ( $0.5 < r \leq 0.67$ )	6011	4765 (79.3%; 78.4%-80.1%)	49.31
High risk ( $0.67 < r \leq 0.83$ )	3675	2703 (73.5%; 72.3%-74.7%)	53.03
Very high risk ( $r > 0.83$ )	1366	1046 (76.6%; 74.6%-78.4%)	47.75

**Figure 5.** Samples presenting a specific factor and their distribution across cases and controls, and across estimated risks from very low (VLR) to very high (VHR). To the left of each bar group, the total number of individuals presenting the factor (sample size). At the top, the distribution of the full population.



**Figure 6.** Incidence of factors for cases, controls and estimated risk levels from very low (VLR) to very high (VHR). Panels on the right hand column (shaded) have y-axis limits between 0% and 30% to facilitate visualization.



In terms of incidence (Figure 6, and Tables A9 to A12 of Multimedia Appendix 1), prescription of psychotropics across time-frames had an incidence between 77% and 90% on those with very high risk ( $r > 0.83$ ), and lower than 7% on those not at risk ( $r \leq 0.5$ ), except on the 5Y period, which had an incidence of 22% on those with moderate-low risk ( $0.33 < r \leq 0.5$ ) (Figure 6). In comparison, between 35% and 48% of actual cases presented this factor. More than 70% had a depression and anxiety event and a hospital event between one year and five years before CLD.

## Discussion

### Principal Results

The presented oversimplified system successfully differentiated between 2604 suicide cases and 52,080 matched controls in 73.22% of tested instances during 10x10-fold cross-validation. It achieved this using only routinely collected EHRs from GP and hospital admissions in the five years before the case's CLD.

The reduction in error rate as the number of hidden layers increased is representative of the complexity of the underlying suicide factors-risk model. In our case, results barely changed when the number of neurons in the hidden layers increased. In fact, performance differences between networks with the same

number of layers came from a better tuning of the output scores resulting in an operational point closer to the optimal (ie, equal error rate). Overall, we expect the advantages of having more layers and neurons to become obvious when more factors are fed into the model.

The disparity that was observed between sensitivity and specificity and on the score distribution between cases and controls highlights the variation in the level of difficulty experienced when analyzing both groups. Controls seem to follow more uniform patterns and are therefore easier to identify, hence the higher specificity and the clustering of controls below a 0.5 score. On the other hand, patterns of the cases are more heterogeneous, with some having feature vectors identical to controls, which explains the lower sensitivity and the almost uniform distribution of cases across risk scores.

The presented behavioral evaluations do not unequivocally explain the factor-risk model built by the network. However, they do provide a general idea of what is driving the output score upwards. The input factors prescription of psychotropics, depression and anxiety, and self-harm, and, to a lower degree, drugs and alcohol misuse, were strongly linked with increasing estimated risk scores. This is in keeping with previous literature [6-8] and provides evidence for proof of concept and the feasibility of identifying high risk individuals using ANNs and

routinely collected EHRs. Similarly, gender and age were not related with risk estimation, also in line with findings of short-term risk studies [10].

On the other hand, some risk factors identified in the literature did not exhibit the same behavior in our results. Physical sleep disorders seemed to decrease rather than increase the estimated risk. Due to the relatively low incidence of this factor in our data, its effect may be attenuated by and highly dependent on more active factors. This would also explain the dispersion of its effect on the estimated risk score (Figure 4). Furthermore, possible maltreatment also seemed to reduce the estimated risk. However, after a closer look, its effect seems to change sign as the maltreatment gets further away from the CLD, with possible maltreatment in the 5Y time-frame increasing the estimated risk. This may be related to long lasting effects of maltreatment and with help and support received in the first year after the maltreatment.

Due to the non-perfect specificity and relatively low sensitivity obtained, results from the behavioral analysis should not be directly extrapolated to the real-world factor-risk model. Having said that, the remarkable agreement between our model and the existing literature works as an indication of the feasibility of our proposal. Additionally, we expect to substantially improve performance with a more complex system design, which will in turn increase our confidence in the validity of the obtained factors-risk model.

### Potential of the Proposal

Perfect estimation of suicide risk using EHRs will never be possible, mainly because some individuals take their own life without ever seeking help or without presenting to health care services with signs of being at risk. In addition, of those that seek help or present with evidence, signs may be missed or inaccurately or insufficiently recorded. Others may simply present insufficient evidence to distinguish them from controls (ie, having a pattern identical to controls).

According to our data, around 90% of those that died through suicide in Wales had one or more contacts with health services in the year prior to their CLD, and approximately 30% of them had a contact related to their mental health. Therefore, the proposed methodology still has a good scope for application.

### Comparison with Prior Work

To our knowledge, Passos' [24] and Kessler's [25] are the only two publications to date with proposals comparable to ours. They reported 72% and 66% of accuracy respectively, compared to 73% obtained by our best system. However, these results cannot be directly compared due to differences in the application setting, data used and the evaluation process. Firstly, they applied and tested their systems in a hospital setting with only mental health patients. Secondly, their systems used smaller datasets and data extracted from questionnaires or outpatients visits with a specialist. Here we used diagnoses in primary and secondary care which are less specific, and primary care records have little indication of severity.

Interestingly, while Kessler's method also suffered from low sensitivity, Passos' system obtained comparable sensitivity and

specificity. This may be due to the latter using data from the questionnaire Structured Clinical Interview for DSM-IV axis-I Disorders, which records highly specific diagnoses. In addition, Passos' system aimed at differentiating previous suicide attempters from non-attempters, rather than identifying future risk.

### Limitations

The results presented here are limited by the purposely oversimplified system design used both in terms of the number of factors considered (only 15 over four time-frames) and the design of the ANN (a maximum of two hidden layers). Still, our system improved chance identification by almost 50%. As we move from feasibility to pilot study and increase the complexity of the system we expect to increase performance substantially.

The problem of suicide risk estimation suffers not only from a highly complex factors-risk model, but also from a lack of a quantitative measure of the real risk of suicide which is only known with certainty within a short time span before a recorded attempt. At any other time-point, we do not know the real risk for any individual. Someone at risk may refrain from ever attempting suicide, whereas another person may become at risk and attempt suicide within a very short period. This will have implications for a more practical evaluation (compared to the feasibility analysis presented here), as we will need to find ways to assess performance fairly without knowing the real risk ourselves.

Without properly labelled data, we need to rely on clinicians to assess the factors-risk model constructed by the algorithm. In our case, most of the individuals with a self-harm event were classified as cases or as being at risk (ie,  $r > 0.5$ ). Some of them belonged to the control group, and we considered these as errors in our evaluation. However, should all these instances be considered errors? The answer to this question is not trivial, and has technical, clinical and ethical implications that we need to explore in more depth.

### Implications for Practice

Our proposal will be most practical in settings where professionals do not have specialist mental health training but are in contact with individuals at risk of suicide. Nurses, emergency department staff, ambulance services, police and prison workers would be among the ones benefiting the most from the tool proposed here. These professionals face both the challenge of seeing large numbers of people where it is difficult to discern those at risk, and of assessing the suicidality of individuals often without having received sufficient training and under staff shortages [44,45]. As a result, it can be a challenge to identify individuals for appropriate assessment and care [46]. Having an advanced assessment tool with complex factors-risk models that produces good estimations would be invaluable in these cases.

### Conclusions

Prescription of psychotropics, depression and anxiety, and self-harm were strongly linked with higher estimated risk scores, followed by hospital admissions and long-term drugs and

alcohol misuse which is in keeping with the current literature. Other risk factors such as sleep disorders and maltreatment had more complex effects.

The system presented here is an oversimplified one, using a short feature vector and shallow ANNs to assess the practicality of using EHRs in this way. As a feasibility study, we are more interested in (a) confirming the existence of discriminant information, and (b) validating the proposed methodology, than obtaining high accuracy rates. Nevertheless, our system obtained an accuracy like other published methods based on specialized questionnaire data.

Prescription of psychotropics, depression and anxiety, and self-harm were strongly linked with higher estimated risk scores,

followed by hospital admissions and long-term drugs and alcohol misuse. Age and gender had no effect on risk. Interestingly, possible maltreatment had the opposite effects in the short and long terms, decreasing risk when recent and increasing it when more than a year before CLD.

The promising performance obtained with a basic ANN, and the fact that the resulting factors-risk model was in line for the most part with the literature, supports the hypothesis of the possibility of building a tool capable of estimating suicide risk in the general population using only routinely collected EHRs. We are a long way from employing such methods in clinical practice, but this is a first step to harness the potential of routinely collected electronic health records to support clinical practice in real time.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Untitled.

[[PDF File \(Adobe PDF File\), 787 KB - mental\\_v5i2e10144\\_app1.pdf](#)]

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## Abbreviations

**ADDE:** National Statistics Annual District Deaths Extract

**AI:** artificial intelligence

**ANN:** artificial neural networks

**AUC:** area under the ROC curve

**CLD:** contact leading to death

**EDDS:** Emergency Department Data Set

**EHR:** electronic health records

**GP:** general practice

**HR:** high risk ( $0.67 < r \leq 0.83$ )

**LR:** low risk ( $0.17 < r \leq 0.33$ )

**MHR:** moderate-high risk ( $0.5 < r \leq 0.67$ )

**MLR:** moderate-low risk ( $0.33 < r \leq 0.5$ )

**PEDW:** Patient Episode Database for Wales

**ROC:** receiving operating characteristics

**SAIL:** Secure Anonymised Information Linkage databank

**VHR:** very high risk ( $r > 0.83$ )

**VLR:** very low risk ( $r \leq 0.17$ )

**WDS:** Welsh Demographic Service

**WGP:** Welsh Primary Care GP dataset

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Original Paper

# Data-Driven Learning in High-Resolution Activity Sampling From Patients With Bipolar Depression: Mixed-Methods Study

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## Abstract

**Background:** Behavioral activation is a pen and paper-based therapy form for treating depression. The patient registers their activity hourly, and together with the therapist, they agree on a plan to change behavior. However, with the limited clinical personnel, and a growing patient population, new methods are needed to advance behavioral activation.

**Objective:** The objectives of this paper were to (1) automatically identify behavioral patterns through statistical analysis of the paper-based activity diaries, and (2) determine whether it is feasible to move the behavioral activation therapy format to a digital solution.

**Methods:** We collected activity diaries from seven patients with bipolar depression, covering in total 2,480 hours of self-reported activities. A pleasure score, on a 1-10 rating scale, was reported for each activity. The activities were digitalized into 6 activity categories, and statistical analyses were conducted.

**Results:** Across all patients, movement-related activities were associated with the highest pleasure score followed by social activities. On an individual level, through a nonparametric Wilcoxon Signed-Rank test, one patient had a statistically significant larger amount of spare time activities when feeling bad ( $z=-2.045$ ,  $P=.041$ ). Through a within-subject analysis of covariance, the patients were found to have a better day than the previous, if that previous day followed their diurnal rhythm ( $\rho=.265$ ,  $P=.029$ ). Furthermore, a second-order trend indicated that two hours of daily social activity was optimal for the patients ( $\beta_2=-0.08$ ,  $t(63)=-1.22$ ,  $P=.23$ ).

**Conclusions:** The data-driven statistical approach was able to find patterns within the behavioral traits that could assist the therapist in as well as help design future technologies for behavioral activation.

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## KEYWORDS

activities; behavior; behavioral activation; bipolar disorder; circadian rhythm; depression; hourly planning; psychotherapy; statistics

## Introduction

Unipolar and bipolar depression has a high yearly prevalence in all age groups from children [1], adolescent [2] to older adults

[3,4]. The high prevalence imposes significant adverse consequences, including increased mortality, societal costs, loss of productivity, and lower well-being [5,6]. Treatment for bipolar depression consists of pharmacotherapy, psychotherapy,

or a combination[7]. One of the most efficient and successful methods of psychotherapy for bipolar depression and many other mental disorders is cognitive behavioral therapy (CBT) due to its short-term consultations and problem-solving technique[8]. CBT may be as effective as pharmacotherapy in unipolar depression [9] and provides long-term protection against relapse. However, it is still unclear whether CBT has that effect in bipolar depression [10]. Further, CBT is complicated and time-consuming, and its effectiveness is dependent on the skills of psychological therapists, who are expensive to train and employ [11]. This leads to long waiting lists for cognitive therapy, resulting in a treatment gap of 56% for depression where less than half of the patients received proper treatment [12].

Behavioral activation (BA) is a more straightforward therapy approach focusing entirely on changing behavior. It can be performed by less trained therapist and junior mental health workers. BA includes activity-monitoring, scheduling and regulation of sleep and daily routines which helps to reduce both depressive and manic symptoms [13,14]. Alone it may be as effective as pharmacotherapy and better than cognitive therapy in unipolar depression [13] but has not been thoroughly tested for bipolar depression [8].

BA relies on the patient to collect detailed hour-by-hour activity information daily. As shown in Figure 1, this is normally done in a paper-based diary detailing activities like “sleeping,” “going for a walk,” “meeting with a friend ” or “watching TV.” Each activity is rated with a “pleasure score.” This detailed information is later used by the therapist to identify activities that alleviate, maintain or worsen symptoms and help the patient to change his or her behavior in a healthier direction.

Recent research has suggested using mobile technology to support BA [15-17]. This can have several potential benefits.

First, it has been shown that using a mobile app is less subject to retrofitting of self-assessment data as compared to paper-based schedules [18]. Second, recording activities can be done semiautomatic by, eg, using mobile phone-based sensors to collect information on physical activity like walking. Third, by using modern data analysis methods, the system could potentially be able to present recommendations to the patient [19]. As such, mobile technology would have the potential to improve existing BA methods by assisting inexperienced therapists to locate possible healthy reinforcers and to provide the patient with a powerful data-driven insight into their behavior.

However, BA requires the patient to do detailed self-reporting of daily activities. This can be a cumbersome task, whether it is done on paper or a mobile phone. Therefore, to investigate the feasibility of the design of mobile phone-based BA systems, there is a need to understand the details of current BA activity sampling and the kind of insight, which can be gained from such dense activity data.

To investigate this, we present a detailed analysis of a set of paper-based activity schedules filled in by 7 patients with bipolar depression covering in total 2,480 hours of activity sampling. The analysis of realworld BA self-reporting, helps us understand the following relevant factors:

1. What type (categories) of activities are patients doing?
2. What is the relationship between activities and the patient's daily pleasure?
3. What is the relationship between having a good day and the kind of activities done?
4. What is the relationship between circadian rhythm and pleasure?
5. What is the optimal number of different types of activities a patient should do during a day?

**Figure 1.** A one-week paper-based behavioral activation schedule, in Danish, from patient P3. Activities have been filled out from Monday till Sunday between 7 am and 10 pm, with a pleasure score from 1-5. Sensitive information has been blurred.

uge 20	Mandag	Tirsdag	Onsdag	Torsdag	Fredag	Lørdag	Søndag
07:00	[blurred]	Op i bed spise nr 3	op i bed spise nr 3			stærk + spise 3	
08:00	Ugentplan Medlem 3		far 3	stærk spise morgensmad 3			stærk 5 spise 3
09:00	Placern 3	møde 3	Jobcenter 2		10 spise 3		Handle 3
10:00	Frøkest 3	frøkest 3	[blurred] 3		Pakke 3	ride	
11:00	Møde 3	w/ eg 3		ride (4+5)	lejlighed	4-5	Pakke 3
12:00	Grøde 3	Placern 3	frøkest 3		Centret 3		lejlighed
13:00	Hjem 3	Hjem 3	[blurred] hjem	frøkest 3		frøkest 4	
14:00	hule 3	hule 3	[blurred] huse	hule 3	hule + morgen 3	Tshopp 4	
15:00	Mosleparken 2		bil sm far 2	film 3			hule 3
16:00	Bugsærd 2			film 3		haver 3	-11-
17:00	[blurred] 4	lejlighed 3	Pi tur til kon. 3	Spise 3	film i 3	spille	ligge
18:00	[blurred] 4	spise 5	is med 3	Spille 3	haver	bordspil	sengen 1
19:00	Spise 2	Praktisk 2	spise 3	TV 3	spise 3	spise	poang
20:00	Cykle 3	Iseng 2	TV 3	TV 3	Iseng 3		Iseng
21:00	Iseng		Iseng 3	Iseng 3		Iseng	
22:00							

Answering these questions generates possibilities of assisting the therapist with data-driven insights and automatically generated suggestions. This could potentially be of great help during consultations and lower the requirements for BA training. Moreover, this kind of insights is equally relevant for the patient him or herself. Finally, even though the use of paper-based schedules does not predict engagement or feasibility of using a mobile phone-based approach, this study provides insight into the details of how patients fill in BA schedules and help the design of technologies for BA.

## Methods

### Participants and Procedure

Paper-based BA schedules were collected from patients diagnosed with bipolar disorder (BD) who experienced a mild to moderate bipolar depression, corresponding to a score on the 17-item Hamilton Depression Rating scale <20, and currently enrolled in BA therapy. The BA therapy was done at the Psychiatric Center Copenhagen, Rigshospitalet, Denmark. Patients were instructed to fill out hourly activities between 7 am and 10 pm on a weekly schema as shown in Figure 1. Patients were asked to fill in the activity details 'as soon as possible'.

For each activity, the patient registers a *pleasure score* (PS), indicating "how much did you enjoy doing that activity" on a 1-10 numerical rating scale.

A nurse or a psychologist collected schedules. Patients provided informed consent to use their schedules in an anonymized manner for this study. Activity examples from the schedules that are presented throughout the paper are translated from Danish into English for the convenience of the readers. The handwritten activity schedules were transcribed into comma-separated values (CSV) files by categorizing each activity to an *activity category* (AC), with the corresponding PS. Transcription was performed by 2 independent researchers (DAR, JEB). The intercategorization agreement was assessed by Cohen kappa ( $\kappa$ ).

The ACs consist of 7 distinct classes to cover all types of activities and have been previously presented [15,16]. They were developed in close collaboration with a psychologist by the approach presented in Mørch and Rosenberg and Lejuez et al [20,21] combined with the primary activities introduced in the American Time Use Survey (ATUS) by the Bureau of Labor Statistics [22]. The 7 AC's are presented in Textbox 1.

**Textbox 1.** A list of the 7 activity categories (AC). The ACs are listed with a brief explanation and with real examples from the patients, in parenthesis.

Movement: Activities that involve physical activity (eg, "training," "go for a walk," "horse riding ")
Work & education: Task involving work, learning, or treatment (eg, "work," "lecture," "outpatient consultation ")
Spare time: Time spend alone on hobbies or similar (eg, "relaxing," "watching a movie ")
Daily-living: Basic daily activities of living (eg, "sleeping," "having breakfast," "bathing ")
Practical things: Practical daily activities (eg, "cleaning," "pick up kids," "shopping ")
Social: Spending time with others (eg, "cinema," "concert," "football ")
Other: Uncategorized activities (eg, "transport," "crying," "migraine attack ")

### Statistical Analysis

The data analysis was performed in MATLAB version R2017A. From the digitalized CSV files, we investigated the following topics on both individual and group level to gain data-driven insights from the schedules.

#### Activity Categories

The activity categories have not been used in previous analyses of paper-based BA. Therefore, an initial analysis of the 7 ACs was performed by calculating summary statistics including distribution, variability, and their daily average PS.

#### Activity Category on Good Days

To further examine the activity categories we investigated, on an individual level, whether the extent of specific ACs was different between days that had a larger average PS (eg, *good days*) and days with a lower average PS (eg, *worse days*). The grouping into *good days* and *worse days* was done by calculating the median from the patients' daily average PS. The days above the median were classified as *good days* and vice versa. The amount of AC, weighted by the distance from the median, was then subject to a nonparametric, uncorrected for multiple comparisons, Wilcoxon Signed-Rank for each category. The null hypothesis stated that the number of daily hours of a category in the *worse days* did not differ from the daily hours in the *good days* at a type I error level of  $\alpha=0.05$ .

#### Circadian Rhythm

To keep a circadian rhythm, denoted here as *diurnal rhythm*, have shown a positive statistically significant correlation with mood [23]. This relation is explored by defining *diurnal rhythm* as the most common AC within each hour. The Jaccard similarity coefficient (JAC) was then calculated by matching each hour slot for the day with the corresponding slot in the *diurnal rhythm*. A timeslot match equals a value of one, and the total number of hour slots then divides the summation across all the hours for that day. Hence, a JAC of 1 indicates that the entire day followed the *diurnal rhythm* exactly. JAC of  $day_x$  was correlated with the change in PS ( $day_{x+1}-day_x$ ). An analysis of covariance (ANCOVA) was then conducted to investigate the within-subject correlation value with JAC as an independent variable, change in PS as the dependent variable and subject ID as a dummy coded grouping variable. The analysis was only done on weekdays since the weekends yield different behavioral characteristics [24].

### Activity Category Frequency

Lastly, on a daily basis we sought to investigate whether there was a relationship between the amount of an AC and the resulting average PS. To address this, for each AC we performed a cross-sectional linear regression analysis using the least squares method of the daily hours as a function of the average PS. A quadratic model defined as  $dPS_S = \beta_0 + \beta_1 X_S + \beta_2 X_S^2$  was fitted the data, where  $dPS_S$  represents the daily average PS for patients,  $\beta$  the weightings, and  $X$  is the number of hours of the specific AC. If the quadratic term was insignificant, we re-ran the analysis as a linear model.

## Results

BA forms from 7 patients were collected, covering in total 24 weeks, 153 days and 2,480 hours of self-reported activity data. Demographics data, level of reporting, and Cohen kappa are listed in [Table 1](#). A total of 4 patients had reported PS.

The transcription of the handwritten activities to the ACs was done with a high agreement across all subjects with mean kappa=.81 among the independent raters. The majority of disagreement was within activities that combined two or more AC's, such as P6: "fixing riding equipment" which was classified for 1 rater as *Practical things*, and the other *Spare time*. In one case (P7) the value kappa=.66 fell below the threshold of kappa=.75, and therefore subject to a discussion among the raters. The disagreement was related to one recurrent entry labeled "computer" which was falsely classified as *Work & education* by one rater, and afterward was agreed to be *Spare Time* since the computer was used for watching movie series online.

The total average PS for each AC is shown in [Figure 2](#). The distribution in the percentage of the AC for each patient is given in [Table 2](#). The overall AC classifications, in the same order as [Table 2](#) where 6% roughly corresponds to an hour, is 5.11%, 13.48%, 14.70%, 25.36%, 12.20%, 23.97%, and 5.17% respectively. Socially based activities correspond to 534/2230 (24.0%) of all activities, while movement-related activities are

on average represented less than 115/2230 (5.1%) which corresponds to under an hour daily. However, *Movement* was on average the activity that scored highest on the PS with a mean of 6.70 (SD 1.72).

Time series of the daily average PS is shown in [Figure 3](#). The median for each patient was 4.94, 5.67, 5.50, and 4.31 respectively, and is plotted as a dotted horizontal line. The *good days* group created by days above the median was for P1 Wednesday and Friday in week one and Tuesday until Friday week 2, with the rest classified as *worse days*. The largest *worse days* weight was on the last day and the largest *good days* weight on Thursday week two. The result, when comparing the 2 classes with the nonparametric Wilcoxon Signed-Rank, is visualized in [Figure 4](#). The null hypothesis was rejected in 3 cases. There was a statistical significant difference for *Daily living* in P2 ( $z=-2.381, P=.017$ ), *Daily living* for P3 ( $z=-2.589, P=.01$ ), and *Spare time* in P6 ( $z=-2.045, P=.041$ ). The negative direction in all the cases indicates that the patients had more hours of the given category during *worse days*.

The most frequent AC for each timeslot of each patient is shown in [Multimedia Appendix 1](#). The JAC was calculated for each day, and the within-subject ANCOVA, testing the correlation value between JAC and the change in PS, was significant (correlation=.265,  $P=.029$ ). A post hoc test of P3, visualized in [Figure 5](#), was also significant (correlation=.317,  $P=.002$ ). The zero point of the change was found to be JAC=.44, which indicates that the daily activities produced a positive change in PS the following day if the similarity between the day and the *diurnal rhythm* was  $>.44$ .

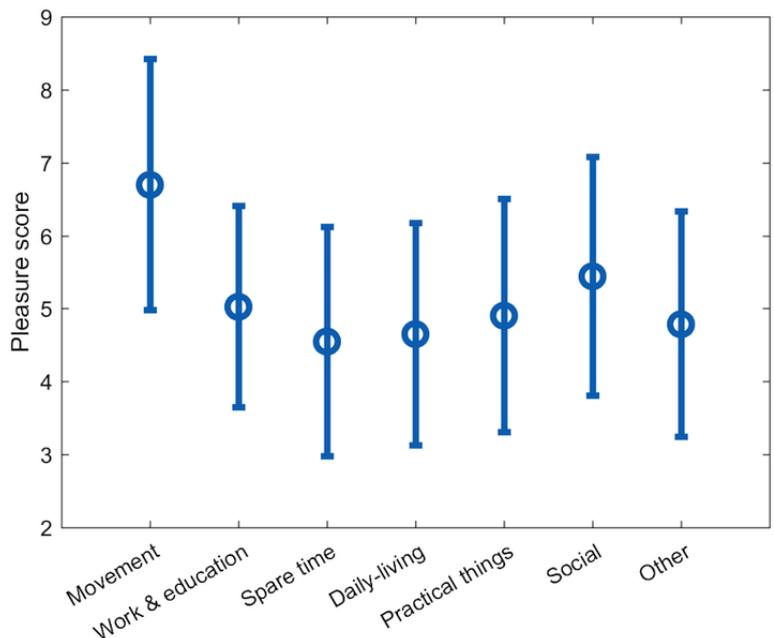
A cross-sectional day analysis was performed where we looked at the number of hours of an AC and the corresponding average PS. A linear regression analysis revealed no significant parameters besides the intercept term, which represents the average PS at zero hours of the AC. However, a pattern was revealed for the linear regression model with second order parameter in the category *Social* ( $\beta_2=-0.08, t(63)=-1.22, P=.23$ ) and visualized in [Figure 6](#) for further discussion.

**Table 1.** An overview of the patients, identified by their patient identification (ID). The amount of days with handwritten activity registrations is shown as "Days" and the number of reported activities as "Activities", followed by the "Hourly compliance rate." The agreement of the translation between the 2 independent researchers was assessed with Cohen kappa. The last column identifies the cases where pleasure scores were reported by the patients.

Patient ID	Age	Gender	Days of activity reporting	Activities reported	Hourly compliance rate	kappa	Pleasure score
P1	30	Female	12	185	96%	.78	Yes
P2	44	Female	17	251	92%	.78	Yes
P3	27	Female	28	399	89%	.77	Yes
P4	44	Female	51	680	83%	.84	No
P5	21	Female	7	108	96%	.79	No
P6	27	Female	19	306	95%	.87	Yes
P7	29	Female	19	301	99%	.82 <sup>a</sup>	No

<sup>a</sup>This patient was object for reassessment due to an initial value kappa=.66 below the threshold kappa=.75.

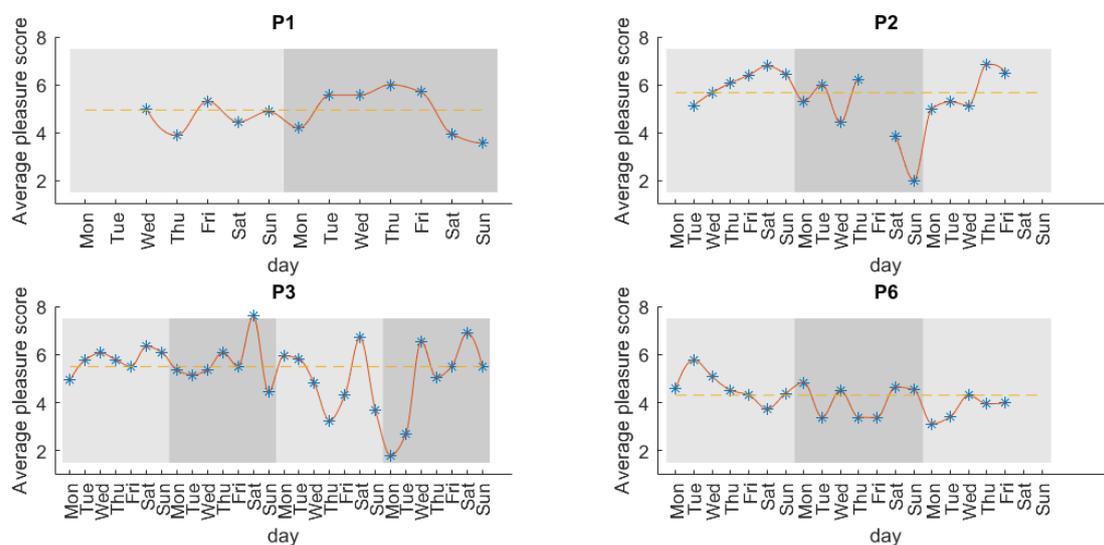
**Figure 2.** The total average pleasure score is shown for the seven activity categories as a circular marker.  $\pm 1$  SD is shown as error bars for each average value.



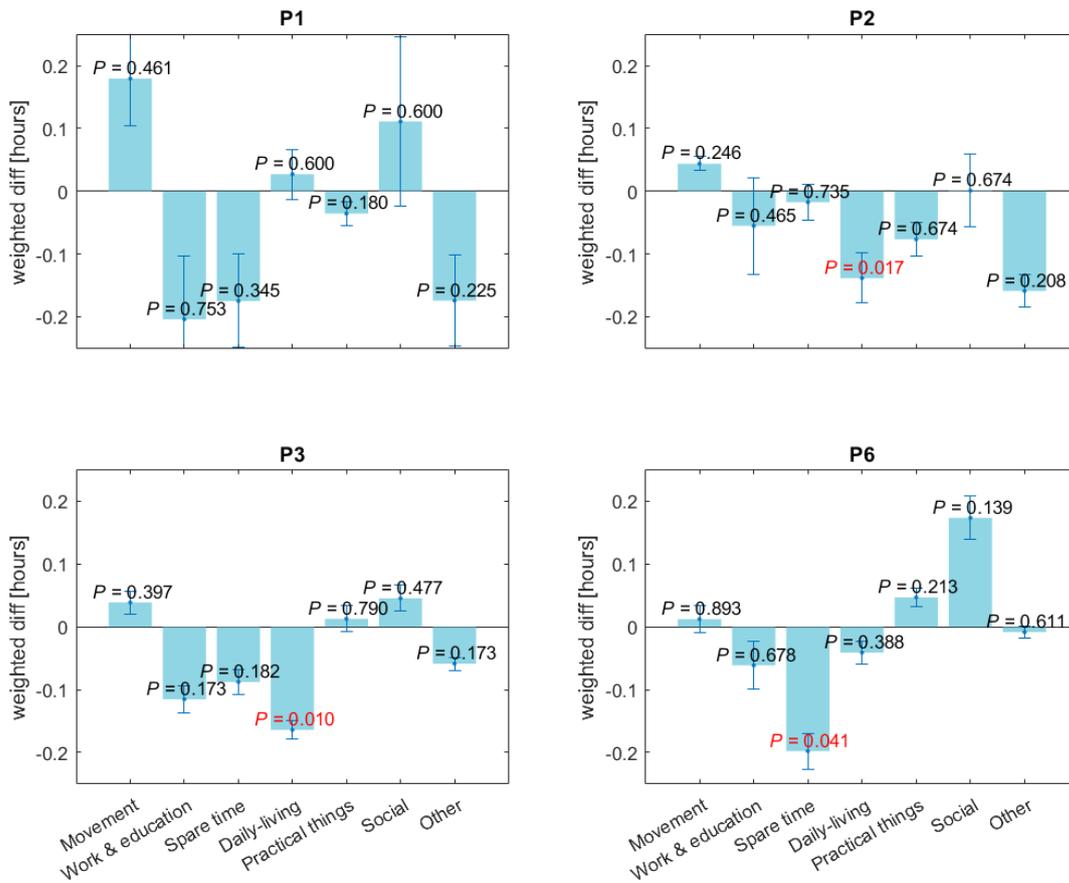
**Table 2.** The distribution of hours within each translated activity category for the patients.

Patient ID	Movement %	Work & education %	Spare time %	Daily living %	Practical %	Social %	Other %
P1	6.77	20.83	13.54	23.44	1.56	21.35	12.50
P2	3.25	16.26	7.32	27.64	19.11	15.85	10.57
P3	7.75	11.75	18.00	32.50	14.25	11.25	4.50
P4	2.85	9.27	18.40	20.97	11.98	33.52	3.00
P5	8.04	0	2.68	15.18	18.75	55.36	0
P6	5.35	20.40	19.40	26.76	8.70	15.72	3.68
P7	5.98	19.93	9.97	39.20	2.99	16.28	5.65

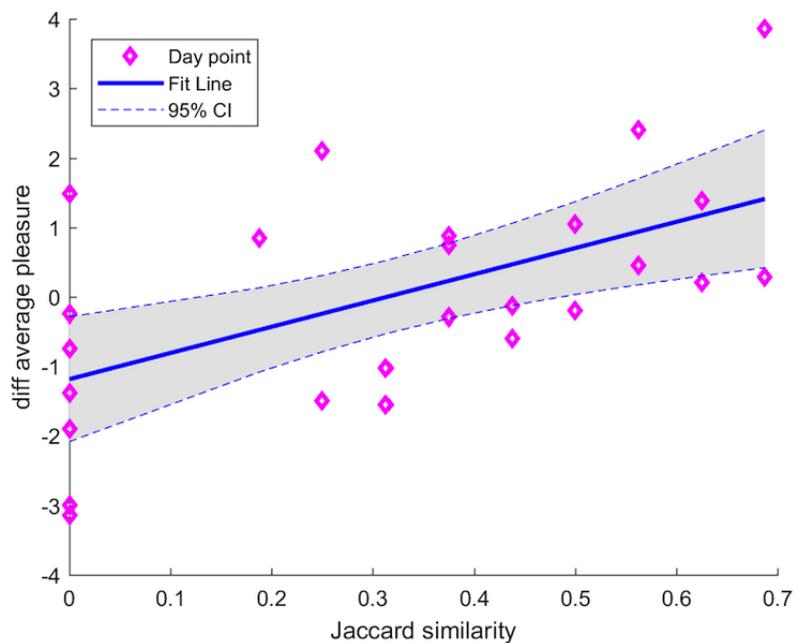
**Figure 3.** The avg PS for each day, interpolated by a shape-preserving piecewise cubic interpolation, is shown for all valid subjects. The background color indicates change in week. Empty values indicate missing data entry from the patient.



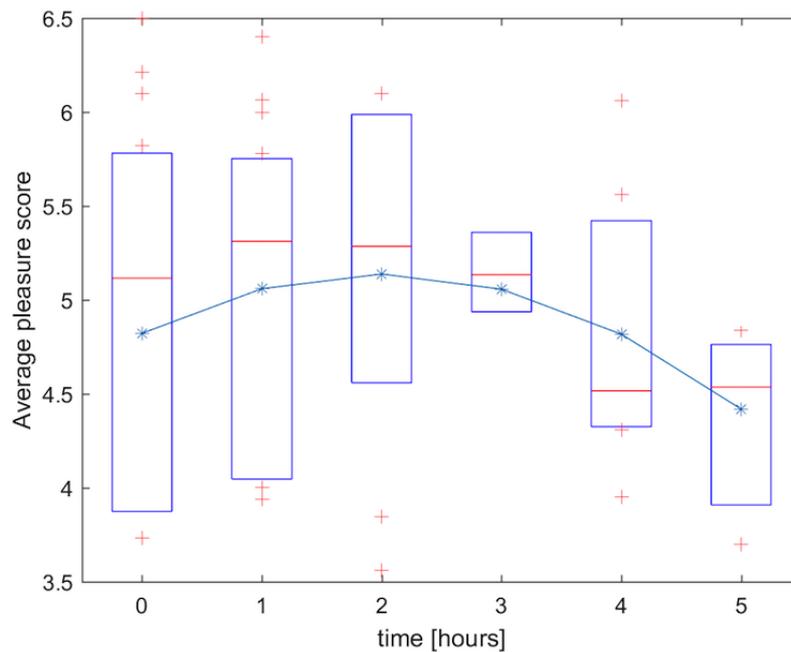
**Figure 4.** Four subplots, for each patient, illustrates the difference in the weighted hours between “good days” and “worse days” for each category. The error bar shows the SD. The result of a non-parametric Wilcoxon Signed-Rank on the weighted hour difference is visualized as an attached P value, colored red for the statistically significant results.



**Figure 5.** The change of the following day average pleasure score from the current day average pleasure score as a function of the Jaccardian similarity coefficient of the current day. The data is visualized as purple marks. The linear least square fit is shown as the blue line with its corresponding 95% CI as the dotted blue line.



**Figure 6.** Across all subject, the days with 0 till 5 hours of “Social” activity is plotted with their corresponding average pleasure score. For each hour, a box-plot is visualized, which represents the median and the 25% and 75% quantiles. The blue line represents the fitted linear regression model.



## Discussion

To the best of our knowledge, no previous study has analyzed hourly sampled activity data with the purpose of a data-driven method to learn from the patients' behavior. This analysis is useful for two goals: First, this data-driven approach provides an insight into the behavioral patterns of patients, which might be useful by therapists in BA therapy sessions. Second, since obtaining high-resolution activity data is challenging, this study and its statistical analysis have implications for how technology can be used in the design of BA technologies.

### Implications for the Use of Behavioral Activation in Therapy Sessions

A data-driven approach to analyzing behavior can provide an insight into the relationship between activity and the disease progression for patients on an individual level and more generally. In particular, this analysis can help identify (1) what activities are done on *good* and *bad* days, (2) what is the relationship between having a regular activity pattern and symptoms, and (3) and if there is a relationship between the amount of an AC and PS.

### What Activities Are Done on Good and Worse Days?

In Figure 3 it is apparent that the patients' mental state changes. P3 had two weeks with a stable PS, but that changed the last two weeks dramatically with variations from 1.80 to 6.90. To analyze the fluctuations, we separate the days that fluctuated below and above the median PS into two groups. The difference in the amount of AC for those two groups is illustrated in Figure 4.

All patients have registered more hours of *Movement* and *Social* in *good* days. The *Movement* category had the highest average PS across all subjects and days when looking at Figure 2. This was seen when inspecting the activity plan. For instance, P3

had a general PS of 5.5 during the day but the time slots registered as “horse riding” was always in the upper range of 7.8-10.0. P1 had an average PS from 7-8 pm of 5.4 but then went for a “night run” from 8-11 pm with an average PS of 7.0. This association can be related to the correlations studies on depressive symptoms and physical activity. In a study by Edwards et al [25], they found a significant increase in depression scores in the group of healthy young adults that were asked to minimize physical steps for one week. In a systematic review, Rohani et al [23] revealed a consistent negative correlation among studies between vigorous activity and depressive symptoms.

In the *worse* days, the patients registered more hours within *Work & education*, *Spare time*, and *Other*. *Spare time* covered a majority of activities with low PS as visualized in Figure 2 and 4 such as P6: “resting” and P3: “home on the couch.” These activities could represent sedentary depressed behavior unlike enjoyable activities that received high PS such as “reading,” and “knitting.” A greater, although nonsignificant, amount of *Work & education* –based activities during worse days, was a surprising observation. Usually, the likelihood of attending class or work is seen in days with less depressive symptoms [26]. Note, however, that a full-time work week in Denmark is 37 hours [27], and since the activity schema covers 112 hours including weekends, registration of work activity should correspond to 36/112 (32%). As shown in Table 2, no patients achieve this and only 4/153 (2.6%) days of activity data had more than 7 work hours. Hence, the considerable amount of work hours does not represent that the patient is back in a full-time work period.

In 3 cases there was a statistically significant difference in the number of hours between *good* days and *worse* days. Both P2 and P3 had a larger amount of *Daily living* AC during *worse* days. In the case of P3, when looking at the day with the largest *worse* days weighting with average PS=1.80, she had 2 hours

of “*getting up*” from the bed and eating “*breakfast*.” Alternatively, the Wednesday and Saturday of week 4 which were classified as *good days*, she merged the *Daily living* activities into a single hour slot: “*getting up+shower+breakfast*.” P2 had more hours of “*sleep*” during the days with more weighting for *worse days*. For instance, Wednesday and Sunday of week two she had put in “*sleep*” from 8 pm already. Moreover, when the patient reported lower PS, small and short activities tend to fill their day more such as P2 on Saturday week 2: “*home again*” which on other days is registered as: “*cleaning-relaxing*.”

P6 had *Spare time* as a significant AC that occurs more on *worse days*. This was due to more registered hours of “*resting*” contrary to *good days* that were filled with social activities such as watching TV with her son or doing practical work such as laundry.

Although the analysis was done on an individual basis and revealed distinct interpersonal behavior, some general AC patterns for all patients were revealed. For instance, the positive relationship between *Movement* and PS, and the negative relationship between *Spare time* and PS. The following investigation on *diurnal rhythm* was done as a within-subject analysis to continue the search for general relations.

### Circadian Rhythm

We found that the more the patient followed their *diurnal rhythm* a better average PS was reported the following day, and the positive correlation was statistically significant. More precisely, scoring above a similarity of  $JAC=0.44$  would yield a larger average PS the following day. This is in agreement with previous studies that use a comparable method. They find that keeping a regular location based circadian rhythm was significantly negatively correlated with depressive symptoms [28] and have a positive effect on mood [29]. The strong correlation from P3 mostly dominates the within-subject analysis. Interestingly, this is the patient with the most data entries (ie, 28 days) of the ones that provided PS scores as noted in Table 1.

### Activity Category Frequency

A compelling observation was done by McKercher et al [30]. They show that male participants with depression were taking 7500-9999 steps per day, contrary to healthy controls that were in the lower or upper levels of respectively <7500 or >9999 step per day. Within personality traits, it is observed that introvert people have a lower threshold for outside stimuli such as social gatherings. After a certain number of hours, they would retreat [31]. Both observations demonstrate that there could exist an amount of, whether it is hours or steps, optimal for healthy living. In the same sense, we were interested to know if there is a relationship between the number of hours that are dedicated to a specific AC and the resulting average PS.

The cross-sectional model for all the participants did not reveal any significant relationship between the hours of an activity and the corresponding average PS. The AC, as already seen in Figure 4, has been shown to be highly interpersonal, which contributes to the high variability as depicted by the large box plots for each hour in Figure 6. Incorporating a larger dataset, by having patient registering more weeks or including more

patients, could help to mitigate the interpersonal variance. Nevertheless, an interesting pattern was revealed with the *Social AC* as shown in Figure 6. We see a peak at 2 hours of social activity, which indicates that there may exist an optimal number of hours of a specific AC.

### Implications for the Design of Behavioral Activation Technology

The benefit of BA for managing depressive disorders had led to the design of several BA technologies in the form of standalone mobile phone apps within mental health, which are publicly available [32-34]. From this study, we want to draw three design implications related to (1) compliance rate, (2) semiautomatic activity collection, and (3) active use of data analysis for increased disease insight.

#### Designing for a High Compliance Rate

The usefulness of the system, as well as the validity of the collected data, is highly dependent on the engagement of the user. Figure 3 illustrates the problem with missing data. Data from P2 is missing the entire Friday in week two. We can observe that the average PS dropped dramatically from 6.21 to 3.85, but we do not know what happened. It could be that some events took place during that Friday, or maybe it was Saturday morning that was the cause of the low PS.

A core question in these BA technologies is, therefore, to what degree users will do the detailed hour-by-hour planning and registration of activities and associated mood or pleasure scores. This study has shown that the compliance rate of the paper-based diaries is rather high 5/7 (71.4%) is above 90% (Table 1). Note, a nonclinical sample of students who had to report data 8 times daily on a mobile phone had an average compliance rate of 87% [35]. This is contrary to the sample in this study, in which patients were included with mild to moderate depressive symptoms. Combining this with the fact that compliance rate is reported to be higher in digital solutions as compared to paper-based diaries [36], this yields the possibility of designing for a highly reliable collection of activity and mood data.

It is, however, essential to design for a high compliance rate as this does not come automatically. Therefore, easy-to-use and efficient ways to input data are needed (eg, using simple predefined activities and categories). Moreover, personalization to the individual user can be obtained by letting the system learn from the users and both reuse and suggest activities specific to a user and what he or she often does.

#### Designing for Semiautomatic Activity Collection

A consistent and standardized method of inputting activity data is required to design data-driven technology. Across all activity diaries, we identified 12 ways of reporting sleep such as “*sleep*,” “*sleeping*,” “*half-asleep*,” and “*went to bed*.” Therefore, designing and applying standardized activity categories will achieve a consistent data entry, and ease the activity entry workload for the patient.

This study has suggested 6 such activity categories (see Textbox 1), which can be used in the design of technologies for BA. A question is the degree of coverage of these categories. For example, are they broad enough to cover all possible activities,

and at the same time narrow enough to avoid loss of information? As seen in Table 2, only a few activities ranging from 0%-12.50% were classified as *Other*, which indicates that a clear majority of the patients' activities could be categorized in the 6 categories.

Entries of "transport" accounted for 96/116 (82.7%) of the *Other* classifications, which might make it a candidate for a seventh category. However, transportation can be inferred from the mobile phone embedded sensors [37]. Similarly, the *Daily living* category covered both the activity of "eating dinner" as well as "sleeping." These are 2 very different activities, which suggest that "sleeping" should maybe be separated into a distinct category. Again, however, several studies have provided objective ways to infer sleep by using the mobile phone's sensors or a wearable sensor [38,39], which can be utilized in automatic detection and logging of sleep.

Hence, activities can be collected semiautomatic. Both entered by the user using a set of predefined activity categories as well as automatically inferred from sensors in a mobile phone.

### Designing for Disease Insight

In a qualitative study within self-tracking for mental wellness [40] the participants reported that they felt more confident in the information they shared with their doctor because it was highly detailed and data-driven. The present study suggests opportunities for data-driven learning from self-tracked activities that could equip the user and his or her therapist with knowledge about personal behavioral traits. This feature is missing in current systems.

By taking inspiration from the type of statistical analysis done in this paper, a semiautomatic BA system could help a patient and the therapist with a personalized insight into the linkage between activities and disease progression. For example, a simple correlation analysis between activity types and mood (as shown in Figure 2) or the relationship between activity types and good or bad days, might help the patient understand what activities impact mood and vice versa. More advanced insight from a longitudinal collection of activity data might help the patient understand his circadian rhythms as shown in Figure 5 and finding an optimal level of different activities as shown in Figure 6.

### Limitations

This study was based on 7 patients, of which only 4/7 (57%) had reported pleasure scores. Despite covering an extended period, a total of 2,480 hours of activity sampling, this is a limited number of patients, which limits the generalizability of the analysis. Moreover, since these patients were part therapy session with a psychologist who asked the patient to report her daily activities, this is highly motivating for patients and hence leads to the high compliance rates revealed in the study.

In the analysis of the activity category frequency, we had to combine the data to a group level analysis, even though the theory behind it advocates for an individualized model. However, it is still important to note that the group level analysis used data on an hourly basis, which were based on 2,480 samples.

When transcribing specific activities into categories, some information gets lost. For instance, "eating dinner" during the evening would be classified as *Daily Living* which is the same category if the person was sleeping instead. Similarly, when the person is talking on the phone, it would be classified as *Social* which is the same classification if the person went out to a cafe with a friend or family member. Hence, the classification is rather coarse-grained.

### Conclusions

Several insights were gained by performing statistical analysis on paper-based activity diaries. First, patients undergoing BA therapy had a much lower *Work & education* load than the general population, and they had a significant portion of *Daily living* related activities such as "sleep" and "eating." Second, in the days that the patient felt better, they had registered more hours of *Movement*, and *Social* related activities. Oppositely, the patients registered more hours of *Work & education*, *Spare time* and undefined activities when they felt an overall lower pleasure. However, there were several individual differences in the relationship between activities and corresponding pleasure, which was statistically significant. Third, there was a statistically significant increase in the pleasure score the next day if they followed their daily routine. Fourth, we did not find any general relationship between the amount of an activity you should do during a day and the resulting average pleasure. So even though *Movement* related activities produce a high pleasure score, it did not indicate that you should do as many hours as possible within the same day.

Some of these findings would be hard to discover during face-to-face consultations with a patient. Therefore, we suggest that a data-driven approach to learning behavioral traits could help to assist the psychologist in BA therapy sessions.

The compliance rate was above 90% for 5/7 (71.4%) of the patients, which indicates that this kind of activity registration is realizable to ask patients to perform. Moreover, the 6 proposed activity categories proved to cover 2114/2230 (94.8%) of all reported activities. This provides positive evidence for the feasibility of designing a digital platform supporting behavioral activation. A mobile phone solution could be designed to support such highly compliant and accurate data collection by applying a semiautomatic data collection approach. This can then provide personalized disease insight to the patient by revealing the connection between activity and mood, as outlined in this paper.

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## Conflicts of Interest

LVK has within the preceding three years been a consultant for Sunovion. JEB is a shareholder in Monsenso ApS and has been a consultant for Lundbeck A/S. Other authors report no financial activities.

## Multimedia Appendix 1

The most frequent AC for each timeslot (*diurnal rhythm*) of each patient

[[PNG File, 20KB - mental\\_v5i2e10122\\_app1.png](#)]

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## Abbreviations

**AC:** activity category  
**ANCOVA:** analysis of covariance  
**BA:** behavioral activation  
**BD:** bipolar disorder  
**CBT:** Cognitive Behavioral Therapy  
**CSV:** comma-separated values  
**JAC:** Jaccardian similarity coefficient  
**PS:** pleasure score

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Viewpoint

# Ethical Issues for Direct-to-Consumer Digital Psychotherapy Apps: Addressing Accountability, Data Protection, and Consent

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## Abstract

This paper focuses on the ethical challenges presented by direct-to-consumer (DTC) digital psychotherapy services that do not involve oversight by a professional mental health provider. DTC digital psychotherapy services can potentially assist in improving access to mental health care for the many people who would otherwise not have the resources or ability to connect with a therapist. However, the lack of adequate regulation in this area exacerbates concerns over how safety, privacy, accountability, and other ethical obligations to protect an individual in therapy are addressed within these services. In the traditional therapeutic relationship, there are ethical obligations that serve to protect the interests of the client and provide warnings. In contrast, in a DTC therapy app, there are no clear lines of accountability or associated ethical obligations to protect the user seeking mental health services. The types of DTC services that present ethical challenges include apps that use a digital platform to connect users to minimally trained nonprofessional counselors, as well as services that provide counseling steered by artificial intelligence and conversational agents. There is a need for adequate oversight of DTC nonprofessional psychotherapy services and additional empirical research to inform policy that will provide protection to the consumer.

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**KEYWORDS**

ethics; ethical issues; mental health; technology; telemedicine; mHealth; psychotherapy

## Introduction

Given the pressing need for expanding mental health care options [1], there is an understandable enthusiasm for applying digital technology—including mobile phones, apps, and wearables—for improving mental health care and making therapy more accessible. Mobile phones are owned by at least 80% of the Americans [2], and digital technology allows for innovations in delivering therapy to users wherever they are located. The number of mental health therapy apps is rapidly proliferating, and many do not involve mental health professionals, or even humans, in providing talk therapy for consumers. However, many of the ethical obligations concerning mental health care are rooted in the traditional therapist-patient relationship [3]. But what becomes of professional ethical obligations when the therapist is an algorithm? Attention needs to be paid to the ways that disrupting mental health care can also disrupt the relationships and obligations meant to provide

a foundation of trust, transparency, and safety for mental health care.

This paper focuses on the ethical challenges presented by direct-to-consumer (DTC) digital psychotherapy that does not involve oversight by a mental health professional. Previous scholarship has raised ethical concerns regarding the broader landscape of digital mental health technology, identifying safety, transparency, and privacy as key challenges [4-8]. However, questions regarding appropriate oversight and what ethical duties are owed to consumers, and by whom, present particular ethical challenges for DTC digital psychotherapy services. We seek to outline the ethical challenges regarding accountability, safety, informed consent, and protection of consumer data in order to provide a foundation for development of appropriate guidelines and practices that support innovation in DTC digital mental health care while protecting against ethical risks.

The issues raised in this paper are, for the most part, specific to the US regulatory context. It should be noted, however, that the

European Union (EU) provides significantly more protection for personal data and informed consent, as well as more stringent regulation of health apps and devices, and thus most of the concerns raised here would not apply to the EU [9,10]. In the United States, there is currently minimal regulation [4,11] of digital mental health technology. Some digital talk therapy apps may be classified as a “medical device” and thus subject to regulation by the Food and Drug Administration (FDA) [10-12]. The FDA has announced new initiatives to regulate digital health technology; however, it is not yet clear the extent to which, and how, the FDA will opt to regulate DTC digital psychotherapy apps [13]. Furthermore, while safety and effectiveness are important issues, increased FDA regulation of DTC psychotherapy would not address other important ethical challenges such as privacy and informed consent.

The American Psychological Association has made an effort to provide guidance to their members regarding appropriate standards for the use of digital technology in mental health practice [7,14]. However, this guidance is aimed more at mental health professionals, and it is not clear that consumers will rely upon these avenues of guidance. Additionally, while some states and professional organizations may have the resources to address specific DTC services that can be said to be practicing mental health therapy without a license, there is a larger policy question that needs to be engaged regarding which professional ethical obligations will need to be applied to this growing domain from which people can receive mental health care. Certain ethical challenges, such as privacy, will need to be addressed with effective policy and guidelines for protecting the consumers of DTC digital psychotherapy.

## *Types of Direct-to-Consumer Digital Psychotherapy*

The types of digital mental health psychotherapy examined in this paper are DTC digital psychotherapy services that are not mediated or overseen by a professional mental health provider, such as psychiatrist or licensed mental health therapist, and for which the ethical obligations of a professional therapist therefore do not apply. There are a variety of approaches being used to deliver DTC psychotherapy with digital technology. The services examined here include (1) digital technology services that connect the user to talk therapy (via text or voice) provided by a person with minimal to no training in mental health services or (2) services that provide an interactive software platform (eg, chatbot, conversational agent) to provide psychotherapy. Digital mental health services that utilize individuals with minimal or no mental health training as therapist-substitutes could be considered simply analogous to peer counselors. However, we include these types of “peer counseling” services in our discussion of ethical challenges because, when moved to a digital platform and conducted without any professional oversight, there needs to be a better understanding of how to ensure that the potential benefits of these services are sufficient to outweigh potential risks to users, particularly when it comes to privacy and safety.

## *Protecting User Data*

Privacy is a major concern when it comes to protecting the interests of users of DTC digital psychotherapy. Psychotherapy involves the sharing of deeply personal and sensitive information by a patient [15]. With DTC digital psychotherapy, behavioral health information is shared, stored, and potentially sold to third parties in the consumer domain, outside of HIPAA or the health care institutions that traditionally protect health information [16,17]. Business models for services that provide low-cost or free digital psychotherapy may share or sell user data for marketing or other purposes for which the user may not understand or be able to foresee. Furthermore, digital psychotherapy apps available through employer wellness programs can leave users vulnerable to invasion of privacy and employment discrimination [18]. Although it is sometimes argued that the Internet has made people less concerned about protecting their privacy, users may feel greater concerns when it comes to the uses of sensitive behavioral data. Recently, Facebook was revealed to have allowed marketers to target anxious and depressed teenagers with ads [19], and Google was exposed for providing a platform for referrals to substandard substance abuse centers [20]. These incidents highlight how digital behavioral data can be shared and sold for practices that put the consumer at risk.

Consumers may not be aware of the various ways the service may collect and analyze their data. An app may not be collecting just the talk therapy chats but even location and other data. Therapy apps can potentially utilize computational behavioral analyses and machine learning to analyze user information such as voice inflection, location data, or screen taps, collected passively or actively through apps or wearables, in order to assess and predict cognitive and behavioral states [21,22]. For example, changes in voice can be used to predict risk of psychotic episodes [23]. Thus, new kinds of behavioral risk data may be created, making it difficult to foresee the potential repercussions for consumers regarding the data being shared. There will need to be further research to support guidelines for how these kinds of data from behavioral analytics should be protected and used. For example, if an algorithm determines that a user presents a threat of imminent harm to themselves or another [24,25], should there be an accompanying duty to report that information to someone? At a minimum, information for these services should make it clear to users who will have access to the data, what kind of data is being collected, and how it is being used and stored. However, even with transparency, there needs to be attention at a policy level regarding legitimate uses of consumer behavioral data. For an example of stronger data protections, the EU will soon be implementing General Data Protection Regulation (GDPR). The GDPR expands protection for personal data in the digital domain, including giving consumers easier access to their own data and requiring that companies explain how data will be used in a clear, understandable terms [26].

Confidentiality involves the obligations of providers regarding keeping data private. Confidentiality is considered necessary for effective therapy in order to allow clients an environment to share personal information for therapeutic purposes.

Nonprofessional DTC digital psychotherapy providers do not have a duty to keep consumer data confidential and generally state so in the terms and conditions. For example, 7 Cups of Tea, a service that uses minimally trained peer listeners to provide talk therapy, advises clients that “chats or transcripts, being captured in any format, [can be] controlled, processed and shared by 7 Cups of Tea with third parties as designated solely by 7 Cups of Tea” [27]. However, consumers may not adequately read through dense terms and conditions and thus may be unaware of the fact that their digital psychotherapy service does not keep data confidential. Consumers may also be unaware that, with many mental health apps, their data could be accessed by subpoena and/or for legal proceedings [28]. Furthermore, concerns over lack of confidentiality could impede consumer uptake of otherwise safe and effective DTC digital psychotherapy services. It will be important to consider what the proper limits for confidentiality might be, such as how DTC digital psychotherapy services should approach a duty to warn. At a policy level, there is a need for stakeholders, from industry, developers, mental health consumers, clinicians and activists, to contribute to establishing regulations and industry guidelines to protect consumer privacy and establish a foundation of trust for DTC digital therapeutic interactions.

## Safety

Evaluating safety and effectiveness has been identified as a key challenge for digital health technology in general, given that only a small proportion of the thousands of mental health apps are backed by evidence-based studies [29]. For DTC digital psychotherapy specifically, in order to be ethically justified, the services must deliver sufficient benefits to balance against any risks to the consumers. Substandard therapy provided by DTC digital psychotherapy can cause direct harms through incorrect advice, or, it could divert people from reaching appropriate and more effective mental health services [30]. Empirical research into how consumers engage with DTC digital psychotherapy in real-world conditions is needed to help inform the types of oversight or standards that can help ensure that the benefits of DTC digital psychotherapy outweigh potential risks and that risks are minimized.

The “commercialization gap” in digital health technology means that apps developed by clinical researchers are subjected to more rigorous testing for safety and effectiveness, while private sector products are more likely to be designed to maximize user engagement [31]. That can lead to a situation where less effective DTC digital psychotherapy apps end up being more engaging and popular with consumers. Consumer apps contain features that have a primary goal of getting people to use the app as often as possible. Features that activate the reward systems in the brain can be useful to keep people engaged in therapy but also may have downsides, such as addictive behavior and anxiety, which would be in conflict with therapeutic goals [32-35]. The potential for conflict between the design features of the technology and the goals and effectiveness of treatment need to be better understood [36,37]. This is an area where encouraging collaboration between industry and clinical researchers can be useful to find an appropriate balance for development of digital technology that is safe and effective

while also sufficiently engaging. Such collaboration can also improve how values are prioritized and incorporated into the technology design, such as utilizing design to provide ways to give users more control over and benefit from their data. At the same time, given the rush for investment and general high enthusiasm for digital mental health technology [38], attention is needed to ensure that the incentives to produce a winning app do not override meticulous empirical research standards.

Current research indicates that digital psychotherapy that involves professional oversight is safer and more effective than DTC services [39,40]. DTC digital therapy services seem to be most appropriately targeted at users with comparatively mild or straightforward mental health issues—and indeed many services generally include a statement in terms and conditions that consumers with severe mental disorders should seek assistance elsewhere [41]. However, empirical research is still needed to inform industry standards and best practices regarding design features, business models, and best practices for safe and effective DTC digital psychotherapy use for specific populations. For example, 7 Cups of Tea, in its user information, advises people with severe mental illness to go elsewhere, but, in its main interface, bipolar disorder, eating disorders and cutting are included in the list of issues that nonprofessional “listeners” can address for clients [27], despite these being complicated conditions that can present serious risks. Evidence-based standards for the safe use of these DTC services by adolescents are also needed, because of potential differences in patterns of usage and expectations, as well as differences in the impact of these interventions on that population [42-44]. Nonprofessional mental health care that may be effective in face-to-face circumstances, such as peer counseling [45,46], requires sufficient research to ascertain best practices in the digital realm. Some digital services encourage users as young as 13 years old and allow “peer counselors” as young as 15 years [47] to provide advice on issues that can range in severity. Such practices highlight the importance of developing evidence-based guidelines for how adolescents use these services.

## Accountability and Liability

The professional codes of ethics guiding professional mental health therapists and clinicians contain duties to maintain confidentiality, provide competent care, a duty to protect, and generally safeguard the interests of the client [48-50]. When there are questions of malpractice or liability, professional therapy codes are meant to provide avenues for patients to report the therapist, identify duties breached, and outline standards for evaluating that liability. A primary challenge regarding DTC digital psychotherapy is that these types of obligations do not clearly apply to DTC providers. DTC digital therapy services hold themselves out as a reasonable alternative to therapy, yet there is little accountability for chatbots, untrained peers, and algorithms for entering into a safe and trusting therapeutic relationship with clients [15,51].

Product liability laws could provide an avenue to address certain harms. However, many DTC digital psychotherapy services effectively limit liability with statements in the terms and

conditions that they are not providing professional therapy and that minimize any responsibilities to the consumer. For example, 7 Cups of Tea, “makes no representation or warranty” as to the accuracy of advice or abilities of the listeners on its service [27]. While this may provide legal protections for the company, there is a gap in accountability for providing a foundation of trust and safety for consumers with mental health needs seeking therapy. On a policy level, there needs to be consideration of whether there are certain ethical obligations that will need to apply to DTC digital psychotherapy.

## *Informed Consent*

Informed consent requires that patients have a clear understanding of the risks and benefits, available alternatives, and relevant facts pertaining to a therapy [52]. For DTC digital psychotherapy services, statements advising consumers of potential risks or how data are handled are generally provided through the terms and conditions section or user agreement. The set of disclaimers found in these services’ user agreements are generally presented in dense and formal language that many people find difficult to parse. Most people do not spend the time to carefully read through terms and conditions language on websites or apps [53,54]. Because the DTC digital therapy services present themselves as a kind of therapy, consumers may assume that their interactions with the service involve the kind of ethical obligations that are a part of professional therapy, making it particularly important to ensure that users understand that those obligations do not apply. Considering that potential users of these services are people with mental health issues, including adolescents, more attention needs to be paid to ensure that consumers are presented with an appropriate overview of risks and benefits before using the service. Basic measures to improve user agreements include making sure that the reading level of the user agreement is not too high [55,56]. There are also innovations available for improving informed consent on digital technology platforms, such as slowing down the consent

process with interactive screens, having bullet-point summaries of the most important risks or warnings, or providing video/audio content to clarify risks and benefits [57,58]. Furthermore, note that in the EU, the GDPR does not allow for general broad consent to unspecified uses of the consumer’s data as they arise, although it is less strict when it comes to use of data for scientific research [59]. Such protections in the United States would protect consumers from practices that bury key information, such as how personal data will be stored, shared, and used, in the terms and conditions.

## *Conclusions*

The use of digital technology for mental health care is exciting and, in addition to improving treatment, could make mental health care less expensive and easier to access for many people with mental health problems. Addressing the ethical challenges presented by DTC digital psychotherapy may also help to encourage consumers to take advantage of safe and convenient digital mental health resources. There is a need for stakeholders, from software developers, health care, and consumers, to be involved in the creation of standards and best practices that adequately address the ethical challenges raised in this paper. Additionally, appropriate regulatory oversight, particularly when it comes to safety and the protection of consumer’s behavioral data, will be critical. Further empirical research into DTC digital psychotherapy practices is needed to inform appropriate policy and best practices. For certain services, there also may be a need to improve the authentication of users, in order to reduce potential risks from children or other vulnerable groups using inappropriate DTC digital therapy. It will also be important to encourage collaboration between industry and developers, mental health consumers, clinicians, and ethicists in order to consider how values may be prioritized in design, such as improvements in informed consent or considering how programming interfaces may be used to give users more control over their data.

## **Conflicts of Interest**

None declared.

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## Abbreviations

**DTC:** direct-to-consumer

**EU:** European Union

**FDA:** Food and Drug Administration

**GDPR:** General Data Protection Regulation

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Original Paper

# “Wish You Were Here”: Examining Characteristics, Outcomes, and Statistical Solutions for Missing Cases in Web-Based Psychotherapeutic Trials

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## Abstract

**Background:** Missing cases following treatment are common in Web-based psychotherapy trials. Without the ability to directly measure and evaluate the outcomes for missing cases, the ability to measure and evaluate the effects of treatment is challenging. Although common, little is known about the characteristics of Web-based psychotherapy participants who present as missing cases, their likely clinical outcomes, or the suitability of different statistical assumptions that can characterize missing cases.

**Objective:** Using a large sample of individuals who underwent Web-based psychotherapy for depressive symptoms (n=820), the aim of this study was to explore the characteristics of cases who present as missing cases at posttreatment (n=138), their likely treatment outcomes, and compare between statistical methods for replacing their missing data.

**Methods:** First, common participant and treatment features were tested through binary logistic regression models, evaluating the ability to predict missing cases. Second, the same variables were screened for their ability to increase or impede the rate symptom change that was observed following treatment. Third, using recontacted cases at 3-month follow-up to proximally represent missing cases outcomes following treatment, various simulated replacement scores were compared and evaluated against observed clinical follow-up scores.

**Results:** Missing cases were dominantly predicted by lower treatment adherence and increased symptoms at pretreatment. Statistical methods that ignored these characteristics can overlook an important clinical phenomenon and consequently produce inaccurate replacement outcomes, with symptoms estimates that can swing from -32% to 70% from the observed outcomes of recontacted cases. In contrast, longitudinal statistical methods that adjusted their estimates for missing cases outcomes by treatment adherence rates and baseline symptoms scores resulted in minimal measurement bias (<8%).

**Conclusions:** Certain variables can characterize and predict missing cases likelihood and jointly predict lesser clinical improvement. Under such circumstances, individuals with potentially worst off treatment outcomes can become concealed, and failure to adjust for this can lead to substantial clinical measurement bias. Together, this preliminary research suggests that missing cases in Web-based psychotherapeutic interventions may not occur as random events and can be systematically predicted. Critically, at the same time, missing cases may experience outcomes that are distinct and important for a complete understanding of the treatment effect.

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**KEYWORDS**

psychotherapy; treatment adherence and compliance; missing data; treatment efficacy; statistical bias

## Introduction

### Background

Missing cases are often encountered in Web-based psychotherapeutic trials, with the likely frequency of participants to become absent from posttreatment surveys ranging from 1 in every 5, to 1 in every 3 patients [1,2]. Missing cases present a significant challenge to the accuracy of results by reducing the sample size and the statistical power available to estimate the effects of treatment [3]. Furthermore, missing cases can produce measurement bias by systematically concealing important clinical information such as the experience of negative outcomes in treatment.

Although multiple definitions of missing cases are possible (eg, unit, item) [4], this paper will consider missing cases as those individuals who conceal their treatment outcomes as absent cases at the point of posttreatment surveys. Without any information about the outcomes of missing cases, the challenge that these cases pose is that the clinical effect itself cannot be completely understood [3].

The problems associated with missing data are well recognized in the clinical literature, and reflecting this, requirements to account for missing cases are embedded in leading guidelines such as the Consolidated Standards of Reporting Trials statement [5] and other methodological guidelines [6-9]. Such guidelines require clinical researchers to make estimates about the treatment outcomes for missing cases and incorporate these estimates in the measurement and evaluation of treatment effects [7]. The statistical methods employed to account for missing cases' outcomes typically attempt to mimic the remaining observed cases and simulate replacement treatment outcomes [6]. Examples of such statistical methods include model-based imputations and multiple imputations [9,10]. These statistical methods aim to resolve both issues of reduced sample size and potential measurement bias associated with overlooking missing cases outcomes [6,9,11].

When attempting to approximate and replace missing cases outcomes, statistical and methodological guidelines first advise that research explore for evidence about the characteristics and likely outcomes of missing cases. This is a first and pivotal step in the process of handling missing cases, which can lead to a more educated guess about the kind of clinical outcomes missing cases that would have likely occurred [6,9,12,13]. In more statistical terms, researchers are required to make an informed assumption about the unknown outcomes for missing cases and effectively decide whether missing cases are a distinct subgroup with distinct and important outcomes or a random and ignorable extension of the whole sample [6,13]. It is also important to note that any characterization of missing cases and the replacement of their outcomes is made under one of three possible assumptions [8]. First, the assumption that missing cases and their outcomes are comparable with the characteristics and outcomes of the overall remaining sample is named the missing completely at random (MCAR) assumption. Similarly,

the assumption when missing cases show some distinct characteristics but are assumed to be comparable in outcomes with a similar subgroup of remaining cases (stratified subgroup) is named the missing at random (MAR) assumption. Alternatively, if missing cases are assumed to have characteristics and outcomes that are not comparable to any subset of the remaining cases, the assumption of missing not at random (MNAR) is made.

Notwithstanding the range of statistical solutions [14], guidelines [15], and theoretical discussions [4] about missing cases in psychotherapy or Web-based psychotherapy, questions remain about the characteristics and solutions that could be applied to missing cases following treatment.

The first question regards the characteristics of missing cases and the ability to identify any systematic predictors of missingness. Currently, no concerted empirical studies are available to identify and assess those participant characteristics that are likely to increase the likelihood of becoming missing at posttreatment. As separate from the dropout and treatment adherence literature [2,16-18], factors that predict whether a case will become missing have not been explored within large-scale psychotherapeutic studies; although it is conceivable that these overlap [19].

A second related question concerns the ability to identify variables that describe why missing cases occurred and at the same time give reason to suspect that the outcomes for missing cases are distinct from the overall sample [2,6,7]. For example, if missing cases were characterized by lower treatment adherence, the treatment outcomes of missing cases should also be impacted by lower treatment dosage. This hypothetical example illustrates a scenario where individuals with poorer fit to treatment remove themselves from treatment, conceal their outcomes as missing cases, and leave the evaluation of treatment results to be determined by a margin of people to whom the treatment appeals. In these circumstances, recognizing the role of predictors, such as treatment adherence, is critical for the ability to detect both the increased risk of cases to become missing, as well as for the ability to approximate accurate replacement outcomes for such cases [6,9,10,15].

A third consequent unanswered question concerns the relative accuracy of replacing missing psychotherapy cases under different statistical missing cases strategies and assumptions. Without studies that investigate missing cases and their likely outcomes in the context of psychotherapy, Web-based psychotherapy, or other similar clinical fields, uncertainty remains about the ability to replace and handle missing cases [9]. To explore the suitability of different missing cases solutions, comprehensive clinical research is required that can compare simulated outcomes for missing cases against a proximal outcome of missing cases. Currently, no solutions are available within the Web-based psychotherapy literature to suggest a benchmark for proximally measuring the outcomes for missing cases. As a consequence, no evidence is currently available to support or refute the suitability of any type of

statistical strategy or quantify the implications missing cases have for the estimation of treatment effects.

### This Study

The primary aim of this study was to empirically explore evidence from a large naturalistic Web-based psychotherapy sample and provide evidence toward three interrelated questions about missing cases. Specifically, this study sought to (1) identify the characteristics and dominant predictors of missing cases, (2) identify predictors that may have joint influence on likelihood of missing cases and clinical outcomes, and (3) identify a suitable clinical measurement benchmark that can then be used to test the accuracy and suitability of different statistical replacements strategies.

Three hypotheses were made about the characteristics of missing cases and the ability to approximate their outcomes. Consistent with previous theoretical discussions of missing cases in psychotherapy [2,19] and clinical trials [8,20], it was hypothesized that missing cases do not occur as a random event (H1), and participant and treatment features such as treatment adherence would predict the likelihood of participants to present as missing cases following treatment. Second, consistent with the dropout and adherence literature [2,19], it was hypothesized that cases that became missing during posttreatment would be characterized with lower treatment adherence (H2). Third, consistent with statistical guidelines [9,15], it was hypothesized that the replacement of clinical outcomes for missing cases would be made with minimal measurement bias, on the condition of adjusting for key predictors (H3).

## Methods

### The Sample

This study employed clinical data from three large randomized controlled trials (RCTs;  $n = 820$ ) investigating the efficacy of Web-based cognitive behavioral therapy (CBT) interventions for reducing symptoms of anxiety and depression [21-23]. These trials employed a similar recruitment methodology and treatment procedures under the Macquarie University Web-based Model (MUM) [24], involving the weekly delivery of Web-based materials organized into psychotherapeutic lessons, together with notifications, emails, and survey reminders over a period of 8 weeks. Telephone contact by a trained clinician was attempted in combination with reminder emails in efforts to engage participants and increase survey participation following treatment. This contact protocol was uniformly applied before treatment, at the end of treatment, and at the point of 3-month follow-up to facilitate participant engagement and adherence.

To be included in these trials, participants were selected on the basis of (1) Demonstrating at least minimal symptoms of anxiety or depression, as determined by the presence of at least mild symptoms of depression or anxiety (a minimum score  $\geq 5$  on either the Patient Health Questionnaire 9-item, PHQ-9 [25]; or the Generalized Anxiety Disorder Scale 7-item, GAD-7 [26]); (2) Being over the age of 18 years; (3) Being an Australian

resident; and (4) Having Internet access for the period of the trial. In addition, applicants who reported a score of 3 (considered severe) on item 9 of the PHQ-9 measuring suicide-risk were referred to another service.

In combination, these trials represent a random intake of adults seeking treatment for symptoms of depression and anxiety over a period of 2 years within the eCentreClinic [27]. The demographic and symptom characteristics of the participating sample are shown in Table 1.

It is important to note that Web-based psychotherapy data can present a unique opportunity for investigating missing cases and their trajectories in treatment. The standardization of treatment engagement and materials can be considered to reduce the outcome measurement variance associated with treatment delivery. With reduced treatment related variance, the individual's response to treatment remains the main source of statistical variation. In more statistical terms, this sample represents a unique opportunity to measure missing cases influences and outcomes with increased internal validity and within a large sample, enabling a robust statistical testing of the first and second hypotheses. In addition, this sample collates a unique subsample of individuals who are missing at posttreatment but are successfully recontacted during a clinical follow-up, enabling a niche subsample that can be used to test the third hypothesis.

### Measures

The primary outcome measure for this study was the PHQ-9, a quantitative measure of depressive symptoms [25]. The PHQ-9 is widely used in psychotherapy and Web-based psychotherapy, is sensitive to the presence and severity of depressive symptoms, and is illustrative of high internal consistency [24,28]. Total scores range from 0 to 27, and the scale comprises 9 items, each offering four responses ranging from 0 to 3. Total scores are clinically interpreted: no depression (total score: 0-4), mild depression (total score: 5-9), moderate depression (total score: 10-14), moderately severe depression (total score: 15-19), and very severe depression (total scores: 20-27). PHQ-9 baseline symptom of the sample are presented in Table 1.

The PHQ-9 scale was administered to measure symptoms at pretreatment (baseline), posttreatment, and again 3 months after the completing of treatment. The original trials comprising the dataset all demonstrated significant and similar average symptom reductions from baseline to posttreatment (46%-53%), which were maintained at 3-month follow-up (50%-53%).

Comorbidity, demographic measures, and treatment adherence were also included as independent variables, aiming to predict missing cases and their clinical trajectories through treatment.

### Comorbidity

Participants were defined as having comorbidity if they demonstrated scores of anxiety and depression above a predetermined clinical threshold (GAD-7 $\geq 8$  and PHQ-9 $\geq 10$  at baseline; GAD-7 [25]; PHQ-9 [29]).

**Table 1.** Demographic and clinical sample characteristics. GAD-7: Generalized Anxiety Disorder Scale 7-item; N/A: not applicable; PHQ-9: Patient Health Questionnaire 9-item.

Characteristics	Total sample collated, value (n=820)	Completers <sup>a</sup> , value (n=682)	Missing cases <sup>b</sup> , value (n=138)	Recontacted cases <sup>c</sup> , value (n=55)
<b>Gender, n (%)</b>				
Female	606 (73.9)	465 (75.2)	95 (68.8)	39 (71)
Male	214 (26.1)	153 (24.8)	43 (31.2)	16 (29)
Age, mean (SD)	43.2 (11.1)	44.1 (11.4)	40.4 (11.1)	38.1 (11.4)
<b>Treatment adherence, n (%)</b>				
Completed (1 of 5)	65 (7.9)	9 (1.5)	49 (35.5)	14 (25)
Completed (2 of 5)	53 (6.5)	26 (4.2)	24 (17.4)	6 (11)
Completed (3 of 5)	76 (9.3)	39 (6.3)	23 (16.7)	13 (24)
Completed (4 of 5)	145 (17.7)	101 (16.3)	22 (15.9)	10 (18)
Completed all modules	481 (58.7)	443 (71.7)	20 (14.5)	12 (22)
<b>Relationship status, n (%)</b>				
Otherwise	306 (37.3)	215 (34.8)	62 (44.9)	23 (42)
In a relationship	514 (62.7)	403 (65.2)	76 (55.1)	32 (58)
<b>Education, n (%)</b>				
Non-tertiary	356 (43.4)	254 (41.1)	71 (51.4)	26 (47)
Tertiary	464 (56.6)	364 (58.9)	67 (48.6)	29 (53)
GAD-7 baseline, mean (SD)	11.3 (4.6)	11.0 (4.6)	12.0 (4.6)	11.9 (4.8)
PHQ-9 baseline, mean (SD)	12.3 (4.7)	11.9 (4.8)	13.9 (4.4)	13.7 (4.5)
<b>Comorbidity, n (%)</b>				
None	345 (42.1)	277 (44.8)	44 (31.9)	17 (31)
Comorbid	475 (57.9)	341 (55.2)	94 (68.1)	38 (69)
Missing at posttreatment, n (%)	138 (16.8)	N/A <sup>d</sup>	N/A	55 (40)
Missing at follow-up, n (%)	147 (17.9)	N/A	N/A	N/A

<sup>a</sup>Individuals that completed all surveys.

<sup>b</sup>Individuals with any missing posttreatment data.

<sup>c</sup>Individuals recontacted at 3-month follow-up (n=55).

<sup>d</sup>N/A: not applicable.

### Demographic Measures

Age in years at the start of treatment, relationship status, pretreatment symptom scores, pretreatment anxiety scores, and education background were considered. The categories created to measure levels of education, relationship status, treatment adherence, and gender are presented in [Table 1](#).

### Treatment Adherence

Under the MUM Internet CBT (iCBT) model, treatment material was organized through five Web-based lessons over a period of 8 weeks. Each lesson comprised introductory CBT explanations, homework assignments, cases stories, and other materials [24]. Participants were required to complete each of the five Web-based lessons in sequence to gain access to the subsequent lesson. Adherence to treatment was therefore measured in this study as the incremental indication that an individual has logged on to the assigned secured website and

accessed the Web-based material as these were made available over time. In this way, treatment adherence was measured as the minimal but continued progression of participants through the intended course design.

### Recontacted Follow-Up Cases as a Proximal Outcome for Missing Cases at Posttreatment

A key subsample of interest in this study were those participants who presented as missing cases at posttreatment but recontacted at follow-up. In total, 83.2% of participants (682/820) completed the self-report symptom questionnaires at posttreatment. Out of those 138 participants who did not complete the posttreatment survey, 60.1% (83/138) also did not complete questionnaires at the 3-month follow-up. However, 40.0% (55/138) of participants who were missing at posttreatment were successfully surveyed through a 3-month clinical follow-up effort. These recontacted individuals were considered as cases who were partly missing at posttreatment, who would have been

completely missing within study designs that followed a pre-post only protocol. Recontacted cases could be used as a proximal measurement of missing posttreatment outcomes, on the condition that recontacted cases show similarities to cases who were missing at both post and follow-up; as individuals belonging to a broader category of individuals with missing cases.

### Analytical Plan

Statistical analysis was conducted with three steps. The first step aimed to characterize missing cases by testing for significant predictors of missing cases (H1, H2). Initially, all possible predictors of missing cases were tested through separate logistic regression models. Within those logistic regression models, missing posttreatment cases versus nonmissing were the binary dependent variable. Following a series of univariate models, a stepwise model building analysis was attempted with the intention to identify a multivariate but parsimonious model of missing cases predictors. This was done by considering all possible predictors in a saturated binary logistic model, including treatment adherence, baseline depression score, baseline anxiety score, and demographic variables of gender, age, employment status, education status, and relationship status. Following, a stepwise variable selection strategy was taken, as outlined by Harrell [30], where predictors that increased the odds of becoming a missing case were retained in a final model. These remaining predictors were interpreted as dominant predictors that statistically characterize the features of missing cases. Each possible predictor of missing cases was assessed for statistical significance at an adjusted *P* value of .01 or less. In addition, the pseud-*R* squared, associated with each missing cases predictor was reported, aiming to convey the known, or model related, proportion of missing cases probability variance; with larger pseud-*R* squared indicating greater outcome predicative success, with a maximum of 1 [31]. In parallel to the prediction of missing cases, longitudinal models of symptom remission were conducted. These models intended to identify those participant characteristics that jointly predict missing cases and increased or decreased rate of symptom improvement following treatment. Longitudinal predictors of symptom change were examined with generalized estimating equation (GEE) models [32], as a series of separate univariate models. In combination, this step intended to test the ability of any one variable to predict missing cases likelihood, as well the outcomes those individuals were likely to experience at posttreatment.

In a second step, the 55 participants who were missing at posttreatment, but successfully recontacted at the 3-month follow-up, were also tested for their ability to represent missing cases who remained missing at both posttreatment and follow-up. The intention of this step was to suggest evidence that recontacted cases could be used as a proxy for missing posttreatment cases as a broader group. This was achieved by (1) Comparing the baseline symptom scores of cases with complete information (“completers”), missing cases at both time points (“completely missing cases”), and cases who are missing at post but are recontacted at 3-month follow-up (“recontacted cases”); (2) The characteristics of recontacted cases and completely missing cases were compared in a binary logistic regression seeking to test for differences between those

recontacted cases and cases who were missing at both time points; and (3) To determine whether scores at 3-month follow-up could approximate posttreatment scores more broadly, a comparison between posttreatment and follow-up scores was conducted. In other words, testing whether missing cases who were recontacted at 3-month follow-up were likely to have similar treatment outcomes at posttreatment. Overall symptom change between post treatment and follow-up was tested with a longitudinal GEE model, testing for any additional symptom change between posttreatment and follow-up symptom outcomes.

In a third step, the third hypothesis was operationalized. This step compared simulated replacement scores, approximated by various adjusted models, against known outcome scores from recontacted cases. The aim of the third step was to quantify and test the relative accuracy of predicted replacement scores against known, proximal recontacted cases outcomes. Simulated follow-up scores were generated using longitudinal GEE and mixed models [33] as common longitudinal methods in clinical trials [34]. All models included a gamma scale, unstructured pattern of within subjects’ correlation over time, and log link function to account for positive skewness and proportional remitting symptoms from baseline [21-24].

Various simulated scores were evaluated as either overestimating, underestimating, or being equivalent to recontacted cases scores in accordance to the degree they predicted the observed outcomes of recontacted cases. Specifically, if the mean CI of the simulated symptom replacement scores included the mean symptom outcome of the recontacted cases, statistical equivalence was interpreted [35]. If the CI interval of the mean replacement scores would exclude the mean of the recontacted cases, the simulation models were considered to overestimate or underestimate the outcomes of missing cases.

Statistical analysis was conducted using Statistical Package for the Social Sciences (SPSS) [36] version 22 (IBM Corp).

## Results

### Step 1 (H1, H2)—Joint Predictors of Missing Cases and Clinical Outcomes

Results from the first step, testing for predictors of missing values at posttreatment through univariate and multiple logistic regression models, are presented in Table 2.

These results demonstrate that as separate univariate models, and as a multivariate model, the stepwise variable selection identified baseline depressive symptoms (Wald  $\chi^2_{1}=152.4$ ,  $P<.001$ ) and treatment adherence (Wald  $\chi^2_{4}=10.1$ ,  $P<.01$ ) were the dominant predictors of missing cases probability. Together, these variables predicted 40.3% of the probability variance (Nagelkerke pseudo *R* squared=0.403), with treatment adherence accounting for the majority of that variance as a single dominant predictor (39%).

The impact of increased baseline severity demonstrated that for every one additional unit on the PHQ-9 at baseline, the odds of a participant to become a missing posttreatment case increased

relatively by 8.4% (1.5% as a relative risk). The predictor of treatment adherence demonstrated a strong but nonlinear predictor of missing cases probability. Specifically, participants who completed the entire program had only a 4% probability of becoming missing at posttreatment. In contrast, participants who completed only one lesson were over 70 times more likely to have missing posttreatment values relative to participants who attempted all five lessons (odds ratio=0.014).

An interaction between depressive baseline severity and treatment adherence was also explored and was found to be nonsignificant (Wald  $\chi^2_4=3.0$ ,  $P=.56$ ). The nonsignificant

interaction implies that baseline severity and treatment adherence were separate in their influences on missing cases.

Variables that influenced (moderated) the rate of symptom improvement were also tested. These analyses aimed to identify those participant characteristics that predicted the likelihood of an individual to become missing at posttreatment and at the same time, predict an individual's clinical outcome. Each of the nine variables were examined for their ability to predict increased symptom reduction following treatment through the statistical testing of a time by covariate interaction term. These interaction coefficients are presented in Table 3.

**Table 2.** Logistical regression model testing for predictor of missing cases of posttreatment. GAD-7: Generalized Anxiety Disorder Scale 7-item; PHQ-9: Patient Health Questionnaire 9-item.

Predictors of missing values	Univariate models				Multivariate models ( $P=.05$ ) <sup>a</sup>		
	<i>P</i>	Odds ratio	Percentage of missing cases <sup>b</sup> (95% CI)	Variance explained, %	<i>P</i>	Percentage of missing cases <sup>b</sup> (95% CI)	Variance explained, %
<b>Demographic</b>							
Age (% per year)	<.001	0.97	-3 (-2 to -5]	3	—	—	
<b>Gender</b>							
Female	.14		16 (13-19)		—	—	
Male		0.74	20 (15 to 20)	<1			
<b>Relationship status</b>							
In a relationship	.04		15 (12 to 18)		—	—	
Otherwise		1.46	20 (16 to 25)	1			
<b>Education level</b>							
Tertiary education	.047		14 (12 to 18)		—	—	
Otherwise		1.48	20 (16 to 24)	1			
<b>Initial severity</b>							
Baseline anxiety symptoms (% per GAD-7 point)	.03	1.05	5 (0.5 to 9)	1	—	—	
Baseline depression symptoms (% per PHQ-9 point)	<.001	1.09	9 (5 to 14) <sup>c</sup>	4	.002	8 (3 to 14) <sup>c</sup>	40
Comorbidity at baseline: (PHQ-9 $\geq$ 10 and GAD-7 $\geq$ 8)	.01		20 (16 to 24)		—	—	
None		0.59	13 (10 to 17)	2			
<b>Treatment adherence</b>							
Completed all modules	<.001		4 (3 to 6) <sup>c</sup>	39		4 (3 to 6) <sup>c</sup>	40
Completed (4 of 5)		4.12	15 (10 to 22)		<.001	14 (9 to 21)	
Completed (3 of 5)		10	30 (21 to 41)		<.001	27 (18 to 38)	
Completed (2 of 5)		19.08	45 (33 to 59)		<.001	42 (29 to 56)	
Completed (1 of 5)		70.59	75 (64 to 84)		<.001	75 (63 to 84)	

<sup>a</sup>All models are based on a logistic regression model, including a log link function. Overall model accuracy for classification of missing values outcomes was 87.4%, with a specificity of 96.6% and sensitivity of 42%.

<sup>b</sup>Percentage of relative risk of an individual to become becoming missing at posttreatment.

<sup>c</sup>Relative odds of an individual to become a missing case with every additional unit increase.

**Table 3.** Association of predictor variables with clinical symptom change from baseline. GAD-7: Generalized Anxiety Disorder Scale 7-item; GEE: generalized estimating equation; PHQ-9: Patient Health Questionnaire 9-item.

Predictor of rate of clinical change	GEE <sup>a</sup> univariate models			Mixed univariate models		
	Moderation of symptom change (Time×IV) at posttreatment			Moderation of symptom change (Time×IV) at posttreatment		
	<i>P</i>	Wald chi-square (degrees of freedom)	Percentage change <sup>b,c</sup> (95% CI)	<i>P</i>	<i>F</i> statistic (degrees of freedom)	Percentage change <sup>b,c</sup> (95% CI)
<b>Demographic</b>						
Age (years, % per year)	.03	7.1 (1)	-1 (0 to -2)	.007	1.8 (1,1071)	<1 (<1 to <1)
<b>Gender</b>						
Female (versus male)	.43	1.7 (1)		.27	1.3 (1,1071)	
<b>Relationship status</b>						
In a relationship (versus otherwise)	.21	3.2 (1)		.22	1.5 (1,1071)	
<b>Education level</b>						
Tertiary (versus otherwise)	.17	3.5 (1)		.15	1.9 (1,1071)	
<b>Initial severity</b>						
Baseline anxiety symptoms (% per GAD-7 point)	>.99	0.1 (1)		.98	<0.1 (1,1071)	
Baseline depression symptoms (% per PHQ-9 point)	<.001	22.3 (1)	2 (1 to 3)	<.001	11.6 (1,1071)	2 (1 to 3)
Comorbidity at baseline: (PHQ-9≥10 and GAD-7≥8)	.16	3.6 (1)		.10	2.3 (1,1071)	
None						
<b>Treatment adherence</b>						
Completed all modules	<.001	39.0 (4)	49 (45 to 52)	<.001	3.6 (4,1071)	40 (16 to 56)
Completed (4 of 5)			40 (32 to 47)			29 (0 to 50)
Completed (3 of 5)			46 (36 to 55)			26 (-7 to 49)
Completed (2 of 5)			42 (27 to 53)			35 (2 to 57)
Completed (1 of 5)			21 (-8 to 43)			19 (-11 to 41)

<sup>a</sup>All models are based on a GEE model of change over time, interacting with a covariate.

<sup>b</sup>Percentage indication of a change from baseline.

<sup>c</sup>Marginal means reported for predictors with statistical significance ( $P < .05$ ).

From Table 3, treatment adherence, baseline symptom levels, and age significantly moderated rate of symptom improvement following therapy. Greater rates of symptom improvement were observed with higher levels of treatment adherence and higher baseline depression scores.

Taken together, the predictors of treatment adherence and baseline PHQ-9 symptoms demonstrated a joint association with both the rate of clinical improvement and the likelihood of missing data at posttreatment. The ability of treatment adherence and PHQ-9 baseline symptoms to influence both clinical outcomes and missing cases probability is graphically illustrated in Figure 1 (missing cases likelihood and symptom change trends associated with program adherence) and Figure 2 (missing cases likelihood and symptom outcome trends associated with baseline severity).

## Step 2—Testing Recontacted Cases as a Proxy of the Broader Group of Missing Cases

This step intended to establish evidence that recontacted cases at 3-month follow-up could be used as a proxy for the unknown outcomes of posttreatment missing cases. Initially, the baseline symptoms scores of the 3 missing cases subgroups were compared with a simple analysis of variance. A pairwise comparison of the PHQ-9 baseline symptom scores among the 3 groups indicated that participants who completed the surveys at both time points demonstrated overall lower PHQ-9 symptoms at baseline (PHQ-9 of 12.0; 95% CI 11.6-12.3) compared with recontacted cases (PHQ-9 of 13.7; 95% CI 12.5-15.0;  $P < 0.001$ ) and cases who were missing at posttreatment and 3-month follow-up (PHQ-9 of 13.6; 95% CI 12.6-14.1;  $P < 0.001$ ). However, participants who were recontacted at follow-up demonstrated equivalent symptom scores ( $P = 0.54$ ) to those participants who were completely missing. This finding indicated that missing cases and recontacted cases shared

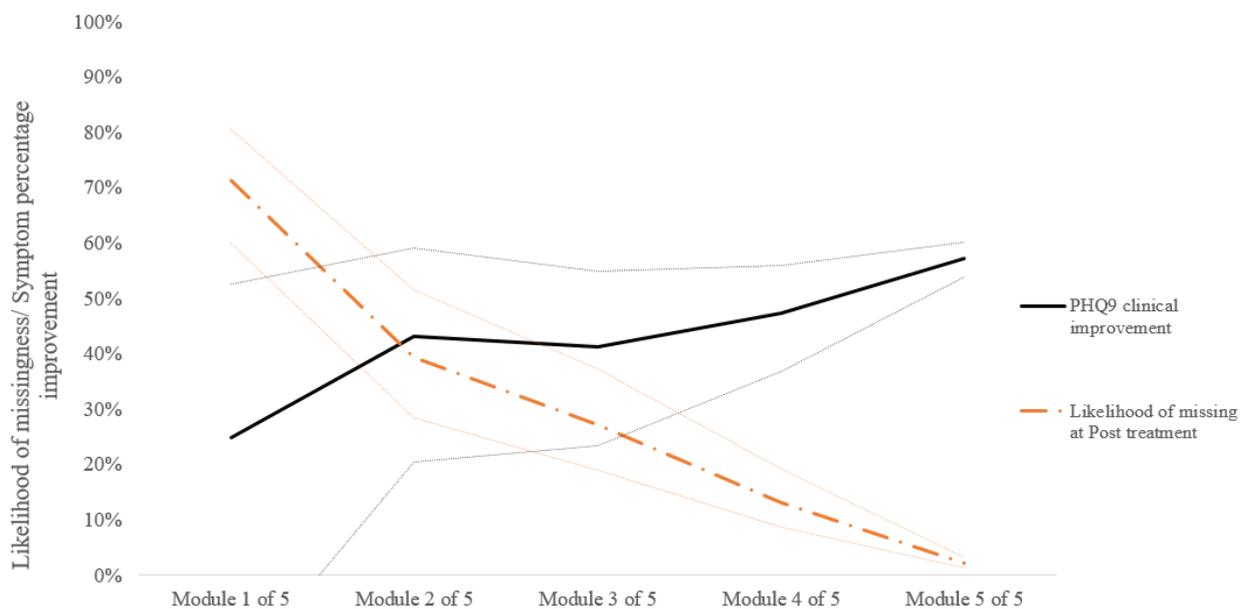
similarities as a group of individuals who present with missing cases.

A second analysis was conducted attempting to identify differences between those individuals who were missing cases and recontacted (55/138) and those individuals who were missing at posttreatment and follow-up (83/138). A logistic regression that specified recontacts and completely missing cases as its binary outcome was conducted. All possible predictors of missing cases were considered and assessed for statistical significance at a *P* value of .05 or less to account for the size of the subgroup (n=138). The resulting logistic

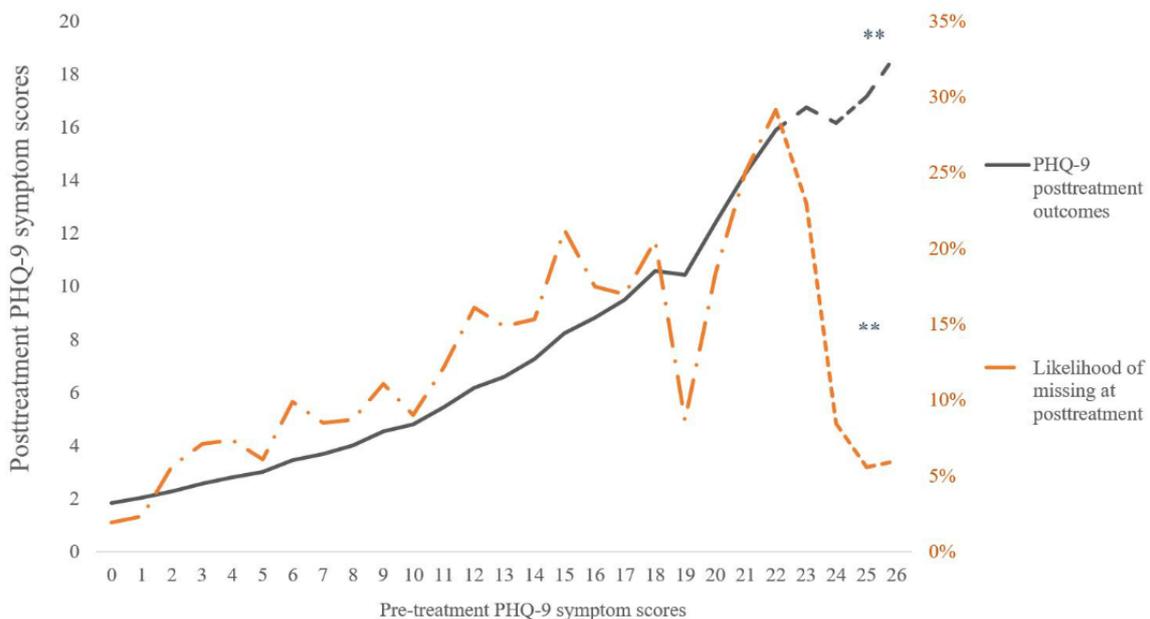
regression models did not identify any one predictor that could explain the probability of missing or recontacted status.

A third longitudinal GEE analysis was conducted to corroborate that posttreatment and follow-up symptom scores were similar enough on average to be used interchangeably. Consistent with previous findings [23], a 45% reduction in symptoms was observed from baseline (PHQ-9 of 12.3 [95% CI 12.0-12.7]) to posttreatment (PHQ-9 of 6.4; 95% CI 6.0-6.8; Wald  $\chi^2_2=572.1$ ; *P* < 0.001), with only a smaller (>7%) but significant additional improvement (PHQ-9 of 5.9; 95% CI 5.6-6.3; Wald  $\chi^2_2=6.4$ ; *P* < 0.001) detected between posttreatment and follow-up time points.

**Figure 1.** Treatment adherence (completion out of five modules) and the likelihood of missing cases or symptom improvement from pretreatment levels (%); dotted lines illustrate 95% CI of the estimate. PHQ-9: Patient Health Questionnaire 9-item.



**Figure 2.** Pretreatment Patient Health Questionnaire 9-item (PHQ-9) symptoms influencing likelihood of missing cases or symptom outcomes. The \*\*-dotted line implies a sample size of <10 participants from the sample of 820.



Together, these 3 results illustrated that the recontacted follow-up cases of this study present as a close, albeit imperfect, proxy for the outcomes of the broader group of individuals with missing posttreatment cases.

### Step 3 (H3)—Using Recontacted Cases to Test the Accuracy of Simulated Replacement Score Under the Missing at Random, Missing Completely at Random, and Missing Not at Random Assumptions

In this step, the suitability of simulated replacement scores was explored by comparing the various predicted replacement scores against the known follow-up symptom outcome scores from recontacted individuals (Mean=8.11, 95% CI 6.53-10.07).

Table 6 presents the simulated mean PHQ-9 scores and CIs for replacement scores generated under different unadjusted and adjusted statistical models, as well as through the last observation carried forward (LOCF) and baseline observation carried forward (BOCF) methodology.

Table 6 illustrates those models that overlooked missing cases characteristics and did not adjust the approximation of missing cases; *underestimated* the symptom outcome scores of

recontacted cases by as much as 30%. Similarly, replacement methods such as LOCF and BOCF both produced *significantly higher* estimates of symptom outcomes following treatment (24% and 69%, respectively).

Table 7 presents the mean and CIs generated through models that conditionally adjusted their estimation of missing cases outcomes. The approximated scores generated from each model are presented in Table 7 in descending order of accuracy; relative to the actual scores observed for recontacted cases. These results demonstrated that from the range adjusted models, models that included either treatment adherence or baseline severity in the prediction of outcomes could be interpreted as statistically equivalent to actual scores observed at 3-month follow-up. Specifically, both the GEE model and mixed model that adjust their estimates for treatment adherence and baseline severity resulted in the minimal approximation error (8%) relatively to the observed mean from actual outcomes.

Together, given some of the adjusted models were able to capture close approximations of the observed recontacted cases outcomes, the assumption of that missing cases cannot be conditionally compared with the remaining cases was refuted (MNAR).

**Table 6.** Depression (Patient Health Questionnaire 9-item, PHQ-9) simulate (approximated) replacement scores—unadjusted (missing completely at random, MCAR) models, last observation carried forward (LOCF), and baseline observation carried forward (BOCF). GEE: generalized estimating equation; N/A: not applicable.

Source of PHQ-9 estimates	Mean (95% CI)	Relative percentage accuracy from recontacted cases (95% CI)	Conclusion drawn about accuracy <sup>a</sup>
Recontacted cases	8.11 (6.53-10.07)	N/A	
BOCF	13.75 (12.57-15.03)	69 (55-85)	Significant overestimation
LOCF	9.96 (8.65-11.48)	24 (7-42)	Significant overestimation
MCAR (GEE)	5.93 (5.58-6.3)	-27 (-22 to -31)	Significant underestimation
MCAR (mixed)	5.96 (5.62-6.34)	-26 (-14 to -37)	Significant underestimation

<sup>a</sup>Relative accuracy from observed recontacted cases following a clinical follow-up.

**Table 7.** Depression (Patient Health Questionnaire 9-item; PHQ-9) simulate (approximated) replacement scores from various adjusted models. GAD-7: Generalized Anxiety Disorder Scale 7-item; GEE: generalized estimating equation; MAR: missing at random; N/A: not applicable.

Source of PHQ-9 estimates	Mean score (95% CI)	Relative percentage accuracy from recontacted cases (95% CI)	Conclusion drawn about accuracy <sup>a</sup>
Observed symptom score from recontacted cases	8.11 (6.53-10.07)	N/A	N/A
MAR PHQ-9 baseline and treatment adherence (GEE)	7.47 (6.84-8.15)	-8 (-16 to 0)	Statistical equivalence
MAR PHQ-9 baseline and treatment adherence (mixed)	7.5 (6.89-8.16)	-8 (-19 to 6)	
MAR GAD-7 baseline and treatment adherence (GEE)	7.15 (6.7-7.63)	-12 (-24 to 3)	Statistical equivalence
MAR GAD-7 baseline and treatment adherence (mixed)	7.28 (6.81-7.78)	-10 (-23 to 4)	
MAR treatment adherence (GEE)	6.91 (6.6-7.25)	-15 (-19 to -11)	Statistical equivalence
MAR treatment adherence (mixed)	7.06 (6.71-7.43)	-13 (-26 to 3)	
MAR PHQ-9 baseline (GEE)	6.57 (6.07-7.12)	-19 (-25 to -12)	Statistical equivalence
MAR PHQ-9 baseline (mixed)	6.54 (6.05-7.07)	-19 (-30 to -7)	
MAR comorbidity and education, and age (GEE)	6.31 (5.99-6.65)	-22 (-26 to -18)	Significant underestimation
MAR comorbidity and education, and age (mixed)	6.33 (6.01-6.66)	-22 (-34 to -8)	
MAR comorbidity (GEE)	6.23 (5.9-6.57)	-23 (-27 to -19)	Significant underestimation
MAR comorbidity (mixed)	6.24 (5.93-6.58)	-23 (-35 to -9)	
MAR GAD-7 baseline (GEE)	6.09 (5.82-6.37)	-25 (-28 to -21)	Significant underestimation
MAR GAD-7 baseline (mixed)	6.12 (5.85-6.4)	-25 (-36 to -10)	
MAR age (GEE)	6.03 (5.97-6.08)	-26 (-26 to -25)	Significant underestimation
MAR age (mixed)	6.07 (6.01-6.13)	-25 (-39 to -8)	
MAR Marital Status (GEE)	6 (5.83-6.17)	-26 (-28 to -24)	Significant underestimation
MAR marital Status (mixed)	6.03 (5.87-6.2)	-26 (-38 to -10)	
MAR education (GEE)	5.96 (5.88-6.04)	-27 (-28 to -26)	Significant underestimation
MAR education (mixed)	5.99 (5.91-6.07)	-26 (-40 to -9)	
MAR gender (GEE)	5.94 (5.89-6)	-27 (-27 to -26)	Significant underestimation
MAR gender (mixed)	5.98 (5.93-6.03)	-26 (-40 to -9)	

<sup>a</sup>Relative accuracy from observed recontacted cases following a clinical follow-up.

## Discussion

### Principal Findings

The primary aim of this study was to examine the characteristics, likely clinical outcomes, and statistical solutions that could be applied when missing cases in Web-based psychotherapy are encountered. This was done by first exploring the characteristics of missing cases within a large, naturalistic Web-based treatment sample; specifically identifying those participant characteristics that could predict the likelihood an individual would become missing following treatment, and at the same time, predict the outcomes such individual was likely to experience. In addition, this study attempted to test the suitability and accuracy of different statistical solutions for replacing missing cases (eg, adjusted and unadjusted model approximations, LOCF, and BOCF replacement strategies) through the comparison of statistically approximated outcomes against known outcomes from cases who were missing and were successfully recontacted (recontacted cases). The results were organized with three interrelated steps.

In a fundamental first step, the features of treatment adherence rates and baseline symptom severity were identified as predictors that can significantly increase the likelihood of participants to become missing at posttreatment. Together, treatment adherence and baseline symptoms explained 41% of the probability variance of missing cases status and were identified as the dominant predictor from a range of alternatives predictors initially included in the model. In this way, the first hypothesis, stating that missing cases were not occurring at random, was supported. This result demonstrated support for the first hypothesis, stating that missing cases were not occurring at random.

Critically, the variables of treatment adherence and baseline symptoms also shaped the clinical outcomes missing cases were likely to experience. Specifically, poorer treatment adherence was also associated with increased symptoms and distinct symptom outcomes. Similarly, higher pretreatment symptoms were associated with higher symptoms following treatment. This finding supported the second hypothesis and is consistent with research about the role of dosage, adherence, and treatment

outcomes [37-39]. At the same time, the association of increased symptoms and missing cases is also in line with previous research, suggesting that severely depressed participants are more likely to drop out [1,2,38]; and in parallel, an association between baseline severity and increased residual symptoms at posttreatment [40]. Recognizing treatment adherence and baseline severity as variables that predict both who will become missing and their likely clinical outcomes is key for understanding the likely clinical trajectory of missing cases.

In more statistical terms, this study demonstrated that missing cases cannot be assumed to be a random portion of the overall sample (MCAR), and overlooking the specific pattern of treatment adherence and baseline severity can result in overestimation of treatment efficacy and underestimate remaining symptom. The additional comparison of proximal recontacted cases with replacement methods such as LOCF and BOCF also demonstrated significant measurement error with overestimation that is as high as 70%; consistent with previous research [41,42], indicating these methods lead to overly conservative underestimates of treatment benefits.

Finally, testing of the third hypothesis demonstrated that missing cases could be predicted with minimal error; however, only by accounting for the specific variables that influence both missing cases likelihood and clinical outcomes. Specifically, among all the available model-based approximation methods, models that adjust their estimate of clinical outcomes by treatment adherence and baseline symptom severity demonstrated acceptable statistical accuracy. Using either GEE or mixed methodologies, models that adjusted for both treatment adherence and baseline severity of symptoms resulted in prediction that were only 8% lower than actual values of recontacted cases and were considered statistically equivocal. This result can also be interpreted as a verification of the suitability of replacing missing cases through adjusted replacement strategies under conditional MAR assumption; that is, given that the approximation of missing cases outcomes resulted in minimum differences from the observed outcomes of recontacted cases, the suitability of the statistical approximation is supported. In addition, these results could be interpreted as refuting of the MNAR assumption, given that missing cases were accurately captured under conditionally adjusted models (adjusted for treatment adherence and baseline symptoms).

To our knowledge, this is the first study to use naturalistic measurement to verify whether missing psychotherapy cases conceal poorer clinical outcomes, as well as explore both the bias and underpinning causes. These findings are, however, consistent with current thinking about the potential causes of, and outcomes for, missing cases [1,2,9,20], as well as a long standing statistical requirement to take steps to identify and resolve missing cases bias [6,9,10].

The importance of recognizing key predictors of missing cases, as well as their clinical outcomes can be considerable. Missing cases in psychotherapy research are common [1,2] and can pose a fundamental challenge for measurement and interpretation of clinical effects [43]. On the basis of the present findings, researchers seeking to produce accurate and more complete estimates of treatment outcomes should consider whether

missing cases in their own datasets show an association with variables such as treatment adherence and baseline treatments. If these trends are present, missing cases and their outcomes may not be random, and further steps would be needed to truly estimate the effects treatment. Although the implications missing cases pose for other aspects of clinical measurement is beyond the scope of this paper, the pattern of results demonstrated in this paper may certainly impact additional clinical measurement practices. For example, research aiming to identify clinical moderators, quantify patient risk, evaluate treatment efficacy, or make treatment comparison may certainly be impacted by missing cases patterns, such as those identified in this study, or additional patterns that could be identified through similar other research.

### Limitations and Future Directions

Although this study relied on a large clinical sample with high internal reliability, the results and conclusions drawn must be considered with several limitations. First, and foremost, the demonstration of missing cases characteristics, their approximated outcomes, and the suitability of replacing missing cases is preliminary and specific to a treatment model (iCBT) [30]. As shown by previous research [1], the proportion of missing values and clinical outcomes vary widely between trials. This variability may suggest that different clinical samples could also show both different predictors of missing cases and different outcome trajectories experienced by missing cases. However, broadly speaking, given that treatment engagement and initial depressive symptom rate commonly associated with both treatment adherence [2] and outcomes [41], these variable may reflect a critical starting point for the examination of missing cases in other Web-based psychotherapy trials, if not psychotherapy in general.

A second limitation relates to the use of recontacted cases to verify the suitability of statistical methods to replace missing cases. This sample of recontacted cases relied on a modest sample of 55 recontacted cases. Despite efforts to empirically compare recontacted cases with completely missing cases, recontacted cases can only be assumed to represent the larger group of missing cases. Albeit the uncertainty associated with recontacted cases, it is important to note that recontacted cases embody naturally occurring proximal outcomes that cannot be researched with artificial statistical studies. Given that no alternative is currently available to verify the outcomes for missing cases, recontacted cases may prove a novel future measurement proxy for missing cases as a broader group.

To address both limitations, replication of these missing patterns and research methodology in other similar treatment samples is key. It is important to note that investigating missing cases in naturalistic, clinical settings, as well as collating a sizeable group of recontacted cases is not straightforward given their rarity (eg, 55/820). However, increasingly large and standardized psychotherapy databases are becoming available [1], and these large databases may enable to similarly research methodology and exploration of predictors, outcomes and proximal measurements for missing cases.

In addition, it is important to acknowledge that this study does not pertain to exhaust the theoretical causes, or the identification

of predictors that may underpin missing cases and their outcomes. Other alternative important participant variables could indeed play a role in underpinning why cases become missing and how their outcomes should be approximated. For example, the presence of a major depression diagnosis [39], credibility, or motivation [38] may lead to different rates of treatment adherence and at the same time, better capture the trajectory of missing cases in treatment. For this reason, similar future studies may consider a more direct measurement of participant engagement that may underpin their trajectory in treatment. For example, measurements of motivation, enthusiasm, clinical barriers, treatment credibility, or other clinical consideration may offer a more interruptible means to profile missing cases and their likely clinical outcomes.

Furthermore, it is important to consider that the ability to use adjusted approximation models that factor both treatment adherence and baseline symptoms may not be realistic in small samples. For example, a psychotherapy sample of 30 or less, may be underpowered, or show insufficient variance for the use of complex adjusted statistical models. For this reason, more parsimonious and more robust solutions for replacing missing cases in smaller samples should be explored. For example, methods that are less statistically demanding, such as the application of LOCF for cases who do not complete treatment, could be coupled with unadjusted (MCAR), approximation of outcome for those cases that adhere to treatment in full. This type of hybrid solution may result in a less statistically demanding strategy, which hyphenates the LOCF overly conservative approximation of outcomes, with the MCAR assumption, which is overly liberal as a method that underestimates symptom outcomes. Such solutions are beyond the scope of this paper; however, the application of corrective missing cases methods for small samples may be key for psychotherapy trials such as pilots and small RCTs.

Finally, it is important to note that results of this study imply that within Web-based psychotherapeutic interventions such as CBT-based interventions, the role of adherence and baseline symptoms could likely be important and implicit. Recognizing such patterns can lead to clearer understanding of missing cases, the assumptions that can be made about missing cases, and a more accurate consideration of their outcomes. Although these results should be considered as possible fundamental pattern in the application of any statistical replacement strategy, it important to note that this study does not advocate the use of any one statistical approach over another as means for handling missing cases. Rather, this study intended to explore the implicit characteristics that influence Web-based psychotherapy cases and suggest those measurement considerations that would likely improve the application of missing cases strategies.

In summary, this research aimed to create a more concrete awareness of missing cases and ways to handle missing cases in Web-based psychotherapeutic trials. Using concrete and transparent statistical modeling, this research demonstrated that missing cases can occur systematically and with clinical outcomes that are dissimilar to the outcomes of those individuals who are surveyed following treatment. This study also offered (1) a research design framework that can concretely quantify the outcome bias associated with naturalistically occurring missing cases, (2) highlight important predictors that explain both missing cases and their outcomes, and (3) suggest a naturalistic benchmark (recontacted cases) that could be conditionally used for quantifying the outcomes for missing cases and verifying the suitability of various statistical solutions that approximate missing cases. Together, all three aspects of characteristics, bias in outcomes, and methods to resolve the bias in outcomes should be considered preliminary and pendent on future replication.

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## Conflicts of Interest

None declared.

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## Abbreviations

- BOCF:** baseline observation carried forward
- CBT:** cognitive behavioral therapy
- GEE:** generalized estimating equation
- GAD-7:** Generalized Anxiety Disorder Scale 7-item
- iCBT:** Internet cognitive behavioral therapy
- LOCF:** last observation carried forward
- MAR:** missing at random
- MCAR:** missing completely at random
- MNAR:** missing not at random
- MUM:** Macquarie University Web-based Model
- RCT:** randomized controlled trial
- PHQ-9:** Patient Health Questionnaire 9-item

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Original Paper

# Cognitive Assessment of Patients With Alzheimer's Disease by Telemedicine: Pilot Study

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## Abstract

**Background:** Approximately 46.8 million people are living with dementia worldwide and their number will grow in the next years. Any potential treatment should be administered as early as possible because it is important to provide an early cognitive assessment and to regularly monitor the mental function of patients. Information and communication technologies can be helpful to reach and follow patients without displacing them, but there may be doubts about the reliability of cognitive tests performed by telemedicine.

**Objective:** The purpose of this study was to evaluate the reliability of the Mini Mental State Examination (MMSE) and the Alzheimer's Disease Assessment Scale cognitive subscale (ADAS-cog) tests administered in hospital by videoconference to patients with mild to moderate Alzheimer's disease.

**Methods:** The tests were administered to 28 Alzheimer's disease outpatients (8 male, mean age 73.88, SD 7.45 years; 20 female mean age 76.00, SD 5.40 years) recruited and followed in the Alzheimer's Unit of the A Cardarelli National Hospital (Naples, Italy) at baseline and after 6, 12, 18, and 24 months of observation. Patients were evaluated first face-to-face by a psychologist and then, after 2 weeks, by another psychologist via videoconference in hospital.

**Results:** This study showed no differences in the MMSE and ADAS-cog scores when the tests were administered face-to-face or by videoconference, except in patients with more pronounced cognitive deficits (MMSE<17), in which the assessment via videoconference overestimated the cognitive impairment (face to face, MMSE mean 13.9, SD 4.9 and ADAS-cog mean 9.0, SD 3.8; videoconference, MMSE mean 42.8, SD 12.5 and ADAS-cog mean 56.9, SD 5.5).

**Conclusions:** We found that videoconferencing is a reliable approach to document cognitive stability or decline, and to measure treatment effects in patients with mild to moderate dementia. A more extended study is needed to confirm these results.

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**KEYWORDS**

dementia; telemedicine; videoconference; telepsychology; MMSE by videoconference; ADAS-cog by videoconference

## Introduction

Approximately 46.8 million people are living with dementia worldwide and it is expected that this figure will double every 20 years [1]. The number of people affected by dementia will

probably reach 74.7 million in 2030 and 131.5 million in 2050 [2]. Alzheimer's disease (AD) is the most common type of dementia, representing between 60% and 80% of dementia cases [3]. The costs of this disease are very high now and will become even higher in the future, and will impact severely, directly,

and indirectly on health systems and patients' families [4]. No therapy has been found to stop dementia progression, but any potential treatment should be administered as early as possible. Therefore, it is crucial to provide a cognitive assessment of elderly patients as early as possible and continue monitoring it [5-7]. Information and communication technologies have been employed in dementia and they are particularly helpful [8], allowing physicians, psychologists, and nurses to reach patients without displacing them [9,10]. Several studies have evaluated the use of telemedicine for dementia disorders, but doubts still exist about the reliability of cognitive tests applied by videoconference [11,12].

In this field, telemedicine shows benefits and limitations. Among the benefits, there is the possibility to include patients who prefer to stay at home rather than going to the hospital or clinics [13] and for their caregivers to not be alone in providing better care. Costs and the displacement of patients can be reduced, more frequent monitoring can be assured, and waiting lists and hospital staff work are lowered and the caregiver time is preserved [14]. These benefits justify why cognitive assessment via videoconferencing is potentially useful and valid in dementia patients.

However, telemedicine also has some risks: older adults are frequently resistant to use new technologies and their use requires necessary skills. The security of sensitive data, the identification of the evaluator, and the quality of data transmission may represent further limitations [15].

The main concern is the reliability of data obtained by telemedicine. The assessment of AD requires the evaluation of cognitive functions, which is done through specific tests. These include the Mini Mental State Examination (MMSE), the most used for clinical purposes, and the Alzheimer's Disease Assessment Scale cognitive subscale (ADAS-cog), the most used for measuring the effect of treatments. The feasibility of the MMSE by videoconference has been investigated by several authors [16-23] (Table 1). One of these studies was done in an Italian population. No differences were reported between the scores obtained when the MMSE was administered face-to-face versus videoconference, except in one study in which it was found for 40% of the patients the videoconference MMSE was two points lower than the face-to-face MMSE [21].

The majority of previous studies have considered mild to moderate AD outpatients, living in different contexts, more often in rural areas. All studies have used the traditional 30-item MMSE, except one which has used a 28-item MMSE [17]. In summary, MMSE studies in videoconference have not yet evaluated the follow-up of AD patients. No study, to our knowledge, has evaluated the reliability and feasibility of the ADAS-cog test by videoconference modality. Moreover, the feasibility of MMSE has not been fully evaluated. On this basis, we wanted to assess if MMSE and ADAS-cog are reliable at follow-up.

**Table 1.** Articles reviewed on "cognition screening tests by telemedicine" that used videoconferencing. AD: Alzheimer's disease; GDS: Global Deterioration Scale; MCI: mild cognitive impairment; MMSE: Mini Mental State Examination; VMMSE: Videoconference-based Mini Mental State Examination.

Authors	Year	Demographics of patients	Patients investigated	Results
Cullum et al [22]	2014	N=202; age: mean 68.5 (SD 9.5) years; education: mean 14.1 (SD 2.7) years	59% healthy controls and 41% with MCI or AD	VMMSE and face-to-face MMSE was comparable (with the score is >15)
Kim et al [16]	2017	N=188; age: mean 78 (SD 24) years; education: telemedicine (2.4 years) and face-to-face (3.4 years)	Mild-moderate dementia	The mean annual VMMSE changes were less than the mean face-to-face MMSE score changes (0.60 vs 1.03 points), but not statistically significant. More than 95% of participants were treated with cholinesterase inhibitors
Timpano et al [17]	2013	N=342 (134 male); age: range 50-94 years; education: range 0-18 years	Cognitively impaired and healthy patients	VMMSE is comparable with face-to-face MMSE, but with cut-off 28
Ciemins et al [18]	2009	N=63 (45% female); age: mean 61 years (range 36-90)	Type 2 diabetics, 17% with associated depression	≥95% concordance in the 80% of the items of VMMSE with face-to-face MMSE
Mc Eachern et al [20]	2008	N=71 (34 male); age: mean 72 (SD 11) years	37 AD, 11 MCI, 4 vascular dementia, 10 other pathology, 9 normal	No difference between VMMSE and face-to-face ( $P=.23$ )
Loh et al [19]	2007	N=20 (9 male); age: range 65-79 years	Cognitively impaired	The mean face-to-face MMSE was 23.3 (SD 3.6), MMSE by videoconference was 24.2 (SD 3.7)
Loh et al [21]	2004	N=20; age: mean 82 (range 72-95) years	Demented	VMMSE yielded similar results to face-to-face MMSE in 60% of patients; however, there was a moderate difference in 40% of two points or more on the MMSE on face-to-face MMSE
Montani et al [23]	1997	N=14; age: mean 88 (SD 5) years	Mixed	Mean scores VMMSE (22.2) were similar with face-to-face MMSE (23.7)

On this basis, our aims were (1) to evaluate if the videoconference administration of MMSE and ADAS-cog were comparable to the face-to-face administration, and (2) to assess the acceptance of patients and caregivers of the videoconference modality. Our study was focused on these aspects and not on the diagnosis of AD that in the majority of cases requires more extensive and articulated diagnostic procedures.

## Methods

### Participants

The study sample consisted of 28 AD outpatients (8 male, 20 female) followed by the Alzheimer and Neurodegenerative Diseases Unit, Neurology Department, A Cardarelli National Hospital in Naples, Italy. Supervision, organization, and informatics support and statistics were provided by the Clinical Research Centre of Camerino University in Camerino, Italy. Clinical diagnosis of AD was performed by a neurologist according to the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria. Moreover, brain magnetic resonance imaging was used to confirm the diagnosis. The severity of dementia was assessed by the MMSE, the Activities of Daily Living (ADL), the Instrumental Activities of Daily Living (IADL), the Clinical Dementia Rating, and other neuropsychological tests scores.

Inclusion criteria were age older than 50 years, MMSE score between 24 and 12, education for more than 5 years, good visual-hearing ability, and living with or in contact with a caregiver willing to cooperate in the evaluation of effectiveness. All patients were community dwelling and were enrolled in the study at least 6 months after the diagnosis. Exclusion criteria were decompensated heart disease, chronic renal failure, severe liver failure, uncorrected dysthyroidism, cancer; diagnosis of major depression (according to *DSM-IV* criteria), and a different diagnosis of AD. Patients were randomly recruited among outpatients followed by the Alzheimer and Neurodegenerative Diseases Unit.

The mean age of male patients was 73.88 (SD 7.45) years and of female patients was 76.00 (SD 5.40) years. All 28 patients had a mean education of 7.61 (SD 4.07) years. Sixteen patients were widowed and 12 were married. All were retired and lived at home, with 12 patients living with their spouse, 11 with a child, and 5 with non-family caregivers. Six patients were left-handed. Comorbid health conditions were high blood pressure (n=27), hypercholesterolemia (n=26), diabetes (n=4), and ischemic cardiopathy (n=6). No patients had comorbidities of psychiatric disorders, although 14 patients had anxiety. All patients and their caregivers signed an informed consent form. A questionnaire developed specifically for this study was used to assess the level of acceptance of the telehealth procedures. This study was reviewed and approved by the ethical committee of A Cardarelli Hospital.

### Tests and Questionnaire

The Italian versions of the MMSE [24] and ADAS-cog [25] were used for each participant in both the face-to-face and videoconference modalities.

The MMSE is a brief, quantitative measure of the cognitive status of adults. It can be used to screen for cognitive impairment, to estimate the severity of cognitive impairment at a given point in time, to follow the course of cognitive changes in an individual over time, and to document a patient's response to treatment. It consists of 30 items (questions), which refer to seven different cognitive areas: time orientation, spatial orientation, registration, attention and calculation, recall, language, and praxis. The total score ranges from a minimum of zero and a maximum of 30 points [26]. The normative study in an Italian elderly population found that a score of 24 or less, corrected by age and educational level using the score-adjustment coefficients, is suggestive of dementia; lower scores indicate greater cognitive impairment [24]. Administration time is approximately 10 to 15 minutes. A meta-analysis showed that the MMSE has a sensitivity of 79.8%, a specificity of 81.3%, a positive predictive value of 86.3%, and a negative predictive value of 73.0% for dementia [27]. For conversion from mild cognitive impairment (MCI) to AD, the accuracy of MMSE scores ranged from sensitivities of 27% to 89% and specificities from 32% to 90% [28].

The ADAS-cog measures the cognitive performance of six broad areas of cognition: memory; language; ability to orient oneself to time, place, and person; construction of simple designs and planning; and performing simple behaviors in pursuit of a basic, predefined goal [29]. The ADAS-cog is scored from zero to 70; higher scores indicate greater cognitive impairment. Administration time is approximately 30 to 45 minutes. The Italian study of ADAS-cog on psychometric and normative data was based on a sample of 95 healthy volunteers. Results indicated a specific influence of patient educational level on the cognitive subscale total score of ADAS and the need for an adequate correction was observed [25]. The ADAS-cog cut-off score for dementia was 12 or less with sensitivity and specificity values of 89.19% and 88.53%, respectively [30]. The best cut-off score of ADAS-cog to distinguish between MCI and AD was 12 or higher with sensitivity of 0.86, specificity of 0.89, positive predictive values of 0.99, and negative predictive values of 0.32 [31].

A questionnaire on the acceptance of the videoconference modality for cognitive testing included five questions with a response ranging from 1 to 5, where 1=I strongly disagree and 5=I strongly agree. This questionnaire assessed the experience of videoconferencing, including an overall evaluation, if participants wanted to repeat the experience, attitudes toward data privacy, and clarity of instructions. The questionnaire was administered to both the patient and the caregiver.

### Materials and Videoconferencing System Utilized in Hospital

Two Sony VAIO laptops were used for videoconferencing and data collection. The Sony VAIO laptops contained an IntelCore Duo CPU P8400 2.26 GHz processor, 4 GB memory, Intel Media Accelerator X3100 graphics card, and a 17.3" LCD LED (1920×1080) integrated screen. The videoconferencing system used was the BCC950 Logitech, with integrated microphone and video camera. Computers operated under the corporate domain, restriction of use policies, and antivirus systems.

Administration of the MMSE and ADAS-cog tests took place through real-time videoconferencing, on both terminals, with Microsoft Skype. Connection speed of the local area network of Cardarelli Hospital connection averaged 100 Mbit/s and had perimeter firewalls to guarantee security protection of the connection.

To evaluate the reliability of the videoconference, both the psychologist's and patient's computers were connected to the same LAN. Videoconference ensured high levels of security and encrypted communication. Patients were prepared in advance for the possibility of occasional technological problems, such as when calls "drop out" or the video image becomes frozen. Remote control of the audiovisual system was done with Virtual Network Computing software.

### Procedure

After obtaining informed consent by a research assistant, the MMSE and ADAS-cog tests were administered by face-to-face assessment and videoconference modalities. Both the face-to-face and videoconference assessments were done in the hospital. Tests were administered at baseline and after 6, 12, 18, and 24 months. All patients had been previously diagnosed in the Alzheimer Unit of Cardarelli Hospital by a neurologist. The screening for eligibility criteria was made by the neurologist. Patients were evaluated first face-to-face by a psychologist for inclusion criteria (MMSE score between 24 and 12). For each patient, tests were administered five times (baseline and after 6, 12, 18, and 24 months) in both face-to-face and videoconference modalities. The interval between each administration was 2 weeks to minimize any practice effect. The administration was done by two blinded psychologists independently (rater 1 and rater 2).

In the task of "naming objects," real objects were used, whereas the "close your eyes" command was presented in full screen and shown to the patient via the webcam as well as the pentagon drawing task. Psychologists were trained in administering the MMSE and ADAS-cog by face-to-face and by videoconference, and had more than 10 years' of experience. Caregivers were not present during the cognitive assessments, but an assistant was present in case of technical issues.

The videoconference modalities took place in a hospital room equipped with the instruments and an informatics operator participated to check if the visual and audio settings were

adequate. The time required in both conditions (face-to-face and videoconference) was also measured.

### Statistics

The ANOVA test was used to assess if the administration modality (independent variable) was associated with any difference in total scores of MMSE and ADAS-cog tests (dependent variables). A further analysis considered the subgroups of patients according to their MMSE at baseline. For this analysis, they were grouped by MMSE score as slightly impaired (score 21-24), moderately impaired (score 18-20), and severely impaired (score 15-17). The ANOVA test was used for assessing the significance of differences between the preceding patient groups.

### Results

A total of 28 AD patients (8 male, 20 female) with a mean baseline MMSE of 19.6 (SD 3.0), ADL mean 3.1 (SD 1.0), and IADL mean 2.0 (SD 0.8) were evaluated by administering the MMSE and ADAS-cog in both a face-to-face and videoconference modality. All participants reached the end of the study period of 2 years.

Baseline and follow-up MMSE scores obtained by face-to-face or videoconference modality are summarized in Table 2. As shown, no significant differences were noticeable between face-to-face or videoconference testings. The same was true for baseline and follow-up ADAS-cog scores, shown in Table 2. The time required for performing the tests was also comparable, with mean 37 (SD 8) minutes in the face-to-face modality and mean 38 (SD 10) minutes in the videoconferencing modality.

Data derived from the MMSE and ADAS-cog tests were also analyzed separately, dividing patients into three groups according to their MMSE scores at baseline recorded at the enrollment (eg, severely impaired, moderately impaired, and slightly impaired). As shown in Table 3, at baseline and follow-up, the two modalities did not influence the MMSE scores of the first and second groups of patients. Patients in the third group, who had a lower MMSE, obtained lower scores by the videoconference modality compared to the face-to-face modality. The same differences were observed in the ADAS-cog test (Table 4) with patients in the third group having higher scores by videoconference than in the face-to-face modality.

**Table 2.** The Mini Mental State Examination (MMSE) and Alzheimer's Disease Assessment Scale cognitive subscale (ADAS-cog) values obtained by face-to-face or videoconference modalities.

Tests	Baseline	6 months	12 months	18 months	24 months
<b>MMSE</b>					
Face-to-face, mean (SD)	19.6 (3.0)	19.5 (5.0)	18.4 (5.8)	18.3 (6.1)	17.8 (6.8)
Videoconference, mean (SD)	18.8 (4.5)	18.7 (5.4)	17.7 (6.5)	17.3 (7.1)	16.3 (7.7)
<i>P</i> value	.37	.56	.68	.61	.42
<b>ADAS-cog</b>					
Face-to-face, mean (SD)	28.6 (19.3)	29.3 (19.8)	31.9 (20.3)	33.9 (20.7)	34.8 (20.0)
Videoconference, mean (SD)	34.1 (17.4)	34.5 (17.4)	36.5 (17.4)	39.7 (15.1)	40.4 (13.5)
<i>P</i> value	.07	.07	.19	.12	.17

**Table 3.** The Mini Mental State Examination (MMSE) values obtained by face-to-face or videoconference in patients with baseline MMSE showing slight (21-24), moderate (18-20), or severe (15-17) impairment.

MMSE impairment level	Baseline	6 months	12 months	18 months	24 months
<b>Slight</b>					
Face-to-face, mean (SD)	23.0 (1.1)	24.5 (3.2)	24.6 (2.7)	25.4 (2.5)	24.7 (3.3)
Videoconference, mean (SD)	23.1 (1.5)	24.30 (2.3)	24.5 (2.3)	25.6 (2.5)	24.7 (2.9)
<i>P</i> value	.87	.88	.93	.93	>.99
<b>Moderate</b>					
Face-to-face, mean (SD)	19.3 (0.9)	18.0 (2.2)	16.4 (2.9)	16.1 (2.9)	14.1 (5.1)
Videoconference, mean (SD)	19.0 (1.2)	18.3 (2.1)	17.1 (2.8)	16.2 (3.1)	14.1 (4.9)
<i>P</i> value	.51	.75	.63	.94	>.99
<b>Severe</b>					
Face-to-face, mean (SD)	16.1 (0.8)	15.4 (3.9)	13.3 (3.9)	13.2 (3.9)	13.9 (4.9)
Videoconference, mean (SD)	12.7 (1.5)	12.8 (2.6)	10.7 (3.8)	10.2 (3.7)	9.0 (3.8)
<i>P</i> value	<.001	.11	.17	.11	.03

**Table 4.** The Alzheimer's Disease Assessment Scale cognitive subscale (ADAS-cog) values obtained by face-to-face or videoconference in patients with baseline Mini Mental State Examination (MMSE) showing slight (21-24), moderate (18-20), or severe (15-17) impairment.

MMSE impairment level	Baseline	6 months	12 months	18 months	24 months
<b>Slight</b>					
Face-to-face, mean (SD)	22.5 (5.7)	21.8 (3.8)	22.5 (9.7)	23.8 (11.1)	24.0 (11.4)
Videoconference, mean (SD)	23.0 (5.3)	22.0 (3.5)	22.8 (6.8)	26.0 (12.8)	24.5 (11.6)
<i>P</i> value	.84	.90	.94	.70	.92
<b>Moderate</b>					
Face-to-face, mean (SD)	29.2 (4.4)	31.8 (4.8)	34.0 (5.7)	35.6 (7.2)	38.8 (10.5)
Videoconference, mean (SD)	30.2 (4.9)	33.0 (4.1)	34.9 (5.1)	38.7 (6.7)	41.4 (9.5)
<i>P</i> value	.65	.57	.73	.36	.58
<b>Severe</b>					
Face-to-face, mean (SD)	34.9 (7.0)	35.1 (7.3)	40.3 (9.5)	42.4 (10.3)	42.8 (12.5)
Videoconference, mean (SD)	52.4 (7.6)	49.9 (6.9)	53.2 (7.7)	54.6 (6.7)	56.9 (5.5)
<i>P</i> value	<.001	<.001	.01	.01	.01

**Table 5.** Results of the questionnaire<sup>a</sup> on acceptance of the videoconference modality for cognitive testing.

Questions	Patients, mean (SD)	Caregivers, mean (SD)
1. Instructions are clear and understandable	4.4 (1.3)	4.6 (0.9)
2. Data privacy is assured	4.8 (0.6)	4.5 (1.1)
3. I saved my time	4.0 (0.8)	4.8 (0.5)
4. I would like to repeat the experience	4.5 (0.8)	4.3 (1.3)
5. I prefer the Web modality than coming to the hospital	3.3 (1.5)	4.3 (1.5)

<sup>a</sup>Significance of questionnaire's ranking: 5=strongly agree; 4=agree; 3=neutral; 2=disagree; 1=strongly disagree.

The acceptance of videoconference examination documented by a short questionnaire was quite high, with both patients and caregivers appreciating this modality. In particular, the preference for the web modality versus coming to the hospital was very high for both patients (mean 3.3, SD 1.5) and caregivers (mean 4.3, SD 1.5; [Table 5](#)).

## Discussion

In this study, we evaluated the reliability and feasibility of the MMSE and ADAS-cog tests by videoconference in mild to moderate AD outpatients. Two blinded raters administered the

tests by face-to-face and videoconference modalities and compared the results. The MMSE results were the same in the two modalities. Only in nine patients with more pronounced cognitive deficits (MMSE<17) did the videoconference modality overestimate the impairment.

The results from the MMSE are consistent with findings reported by other studies [16-23]. Most studies evaluated patients affected by dementia or MCI, except in one study [18] that examined the reliability of MMSE administration via remote administration in a group of 72 patients with diabetes. These studies did not find differences between the scores of the MMSE administered face-to-face versus videoconference or telephone interviews [16-23]. In contrast to a larger previous study by another group [17], we used the traditional 30-item MMSE, which includes the writing and drawing tasks.

For the ADAS-cog test, this is the first study, to our knowledge, using a videoconference modality. In our investigation, we observed that the face-to-face or videoconference modalities did not influence the ADAS-cog scores of the first and second group of patients (MMSE scores 21-24 and 18-20, respectively), whereas patients in the third group, who had a lower MMSE (15-17), obtained more severe (higher) scores by videoconference compared to the face-to-face modality. This is probably due to the difficulty of understanding the meaning of specific questions. These findings suggest using the videoconference modality with patients with mild to moderate AD and excluding those with a moderate to severe AD.

Videoconferencing has been shown to be reliable not only in AD, but to assess the cognitive functions in other pathologies. Interesting results were provided for psychiatric patients [32-33], patients with Parkinson disease [34], and stroke patients [35], as well as in older adults [36]. Furthermore, videoconferencing has been found useful to evaluate the clinical status [37] and rehabilitation [38] of patients affected by different neurological disorders. All the preceding studies confirm that videoconference instructions are clear enough. This also was observed in our sample of patients, who reported that for saving time they preferred the teleconference modality than coming to the hospital. That is one good reason for supporting the videoconference approach. The patients and their caregivers were informed that videoconference evaluation ensured high levels of security and encrypted communication. From responses to the questionnaire on acceptance, they did not have concerns about the privacy of their medical information. The acceptability of the videoconference modality in this study is consistent with previous investigations in AD, which reported that 98% of the patients were satisfied and felt at ease with it [32,39].

Previous studies found that women, older patients, and less educated patients may be less receptive to technology. In contrast, men, younger patients, and those with higher education are more receptive to telemedicine and report less anxiety [40,41]. The link found between education and technology

acceptability is worth being considered. Studies have revealed that higher levels of education are associated with higher levels of both computer knowledge and computer interest and lower levels of computer anxiety [42].

The range of settings where videoconferencing can be used is wide and it can represent a useful and effective method for assessing cognitive functions. However, continued validation studies and adaptation of neuropsychological instruments is warranted.

Ethical and legal consequences of assessing cognitive functions via telemedicine deserve to be discussed as well. Caring for patients suffering from dementia poses complex ethical problems because of the nature of dementia and the way that dominant ethical principles apply to its clinical features [43]. These problems include informed consent, the duty to maintain the confidentiality, and privacy of patient examination and records [44-48]. In this study, patients and/or their caregivers were informed about potentiality and the limits of the videoconference approach used and in our sample and none reported any issues regarding privacy. However, the study was performed in a dedicated hospital setting where patients were routinely examined. The option of carrying out remote videoconferences with patients staying at home was not applied; therefore, all ethical implications of home-based cognitive function assessment should be further investigated.

Our study has strengths and limitations. The long duration (24 months) of observation, the well-defined diagnosis, and comparable clinical characteristics of all patients, which make the sample quite homogenous, are strengths of our study. In fact, only sparse studies have evaluated MMSE and ADAS-cog by videoconference for follow-up. The presence of two independent and blinded raters with specific experiences should be also positively considered.

On the other side, we recognize that the number of patients investigated is obviously small because this was a pilot study. We are also aware that we observed patients in a hospital setting with the presence of an assistant. This was done to check the audiovisual system. However, we cannot exclude that the same patients could behave differently if they were at home. These limits should be addressed in a future study with a larger sample group.

Despite these possible limitations, the MMSE and ADAS-cog administration via telemedicine is useful to simplify the assessment of patients and to allow wider participation to clinical trials of people living in remote geographical areas. Further research with a larger sample group and a remote geographical location are required.

In conclusion, videoconferencing can be used to assess patients with mild to moderate dementia, document their cognitive stability or decline, and measure the effects of the treatments.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AD:** Alzheimer's disease

**ADAS-cog:** Alzheimer's Disease Assessment Scale cognitive subscale

**ADL:** Activities of Daily Living

**IADL:** Instrumental Activities of Daily Living

**MCI:** mild cognitive impairment

**MMSE:** Mini Mental State Examination

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Original Paper

# Predicting Caller Type From a Mental Health and Well-Being Helpline: Analysis of Call Log Data

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## Abstract

**Background:** This paper presents an analysis of call data records pertaining to a telephone helpline in Ireland among individuals seeking mental health and well-being support and among those who are in a suicidal crisis.

**Objective:** The objective of our study was to examine whether rule sets generated from decision tree classification, trained using features derived from callers' several initial calls, could be used to predict what caller type they would become.

**Methods:** Machine learning techniques were applied to the call log data, and five distinct patterns of caller behaviors were revealed, each impacting the helpline capacity in different ways.

**Results:** The primary findings of this study indicate that a significant model ( $P < .001$ ) for predicting caller type from call log data obtained from the first 8 calls is possible. This indicates an association between callers' behavior exhibited during initial calls and their behavior over the lifetime of using the service.

**Conclusions:** These data-driven findings contribute to advanced workload forecasting for operational management of the telephone-based helpline and inform the literature on helpline caller behavior in general.

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**KEYWORDS**

data mining; machine learning; clustering; classification; mental health; suicide

## Introduction

Telephone support services, crisis lines, and mental health helplines are provided in several countries as a way of addressing social and mental health problems, including loneliness. They are also provided as a means of supporting people who are suicidal and helping people access appropriate treatments. Additionally, they feature in suicide prevention antistigma campaigns, whereby people are encouraged to disclose mental health problems and seek help [1]. Although helplines are often the key elements of mental well-being and suicide prevention strategies, little is known about how these services are used. The analysis of call patterns and caller

behavior data can help us understand how helplines are used and may also help understand more about the role of these services and the needs of the client groups who use them. Connectedness is an important feature of the models of suicidal behavior [2]. Seeking support can mitigate the effects of stress, and contacting a supportive listener may assist a person in overcoming suicidal thoughts and feelings [3,4].

This study involves the analysis of digital telephony data from Samaritans Ireland, a charity organization with a helpline to provide emotional support to anyone in distress or at risk of suicide. Although the organization offers support via short message service text messaging, email, and face-to-face, 95.0% of their contacts remain via telephone [5]. Data were provided

for all calls made to the organization in the Republic of Ireland for almost a 4-year period (April 2013 to December 2016), comprising a total of 3.449 million calls. This amounts to 725 calls per 1000 population in the Republic of Ireland.

A review of the literature indicated that caller behavior has been the subject of several studies. Research has classified callers as “one-off” or “repeat callers,” and studies have found that 3.0% of callers take up 47.0%-60.0% of the service capacity [6-10]. Furthermore, research on call demand has shown that calls to helplines peak at weekends and in the evening during weekdays [11].

Suicide prevention and mental health antistigma campaigns frequently encourage the use of helplines for individuals in a mental health crisis, and Helplines Partnership has identified a trend of year-on-year increasing demand in UK helplines [12]. Reports on multiple helplines have also described an increase in the complexity of calls received [13-15].

However, none of these cited studies are specific to caller behavior derived from a large telephony dataset. We could not find any study that incorporated the analysis of a large dataset over a prolonged period to provide an understanding of call patterns and caller behavior. This study extends previous research by analyzing a much larger dataset and also using data analytics or data mining techniques [6-10]. We aimed to predict the caller type based on call log data derived from their initial calls. We used the calling history of a caller identity (ID) and attempted to predict whether that caller would become prolific.

In the operational research literature, call centers are studied as queuing systems, with a view to optimize the processing of the stream of call arrivals by adjusting the number and service properties of human phone operators or automated agents [16]. From the queuing theory standpoint, the organization operates a human-staffed, multiple-server system that processes inbound calls only, has a null-length queue (an arriving call is either immediately answered or dropped), retries (a caller redials after meeting an engaged tone), and reconnects (conversations spanning more than one call).

Due to commercial and data protection issues, call center datasets usually carry no information to differentiate one caller from another; hence, most operational research studies work with overall call volume and other aggregate characteristics of a call stream and a call center.

This paper reports on successful interdisciplinary research between computer science and psychology researchers and also technically concentrates on using machine learning to automatically classify callers into caller types. For example, to investigate whether we can use initial call data to predict if a caller is prolific, the caller could be served to specially trained staff, allowing for an enhanced service.

In summary, this paper attempts to answer the following research questions: (1) Can rudimentary data from call logs be used to determine caller types associated with specific calling patterns? (2) Can early use of the service or data from initial calls be used to predict this caller type?

The objective was to build a machine learning system that would be trained using attributes or features derived from callers' several initial calls to predict what caller type they would become.

## Methods

### Overview

The dataset used in this study comprised several million records of calls made to the mental health helpline, with data fields including a unique caller ID, the date and time of a call, and the duration of the call. Several attributes of the callers were used as a basis for clustering, which is a form of unsupervised learning where data are explored without any a priori knowledge provided. The number of calls, mean duration of call, and SD of a caller's calls were all used as a basis for clustering. The clusters that emerged from this process were then used as a starting point to generate a model that could be used to predict caller behavior, if successful. The number of calls, mean duration of call, and SD of a caller's calls were again used as a basis for the predictive model building process, generating rule sets that were evaluated using commonly used measures, including accuracy and specificity. The methods are discussed in more detail in the following subsections.

### Dataset

The dataset comprises numerous fields; however, only the following fields were used in this study: (1) the date-time stamp of the call arrival precise to the last second, (2) the answered flag meaning that the call was passed to a Samaritans Ireland volunteer, (3) the duration of the call (seconds), and (4) the unique caller ID.

Each record in the organization's dataset carries a caller ID that uniquely enumerates the caller, while revealing no personally identifying information. These IDs are associated with most, but not all, calls (around 20% of the calls have the caller ID missing).

### Caller Types or Classes of Interest

In this study, we restricted our view to the calls that were accompanied by non-null caller IDs, flagged as answered, and showed a positive duration. The dataset contained a total of 1.387 million of such calls in 2013-2016, coming from 53,629 unique caller IDs. This restriction excluded engaged or dropped calls; a helpline volunteer has no information on the number of redials a caller had to make to get through. This also excluded a small minority of imperfect records, such as answered calls with zero durations or dropped calls with positive durations.

The data showed that only 20,527 callers made two or more answered calls to the organization. A majority of these (12,258) got through for the second time within 7 days of the first call. The interarrival time between the arrivals of the first and the second answered calls ranged from 2 s to nearly 44 months, with the median time being 26.32 h and mean time being 2.67 months. This demonstrates a tendency to call again soon if a conversation has to be continued. This also indicates that more than half of the caller population talks to the organization once only.

## Discerning Caller Types: Clustering

Cluster analysis involves grouping a set of objects (ie, in this case, callers based on selected attributes) in such a way that objects in the same group (called a cluster) are more similar to each other compared with those in other groups (clusters).

Callers were clustered using the following three caller attributes: (1) number of calls, (2) mean call duration in seconds, and (3) SD of call duration, also in seconds. We selected these attributes due to their explanatory power: the number of calls a person makes indicates his or her frequency of help-seeking behavior; the mean call duration indicates call length; and SD of call durations indicates a person's variability and consistency in conversation length.

We used K-means clustering algorithm because it is the most widely used and established clustering algorithm in the unsupervised machine learning literature. The number of cluster centroids is a user-defined parameter. Using the elbow method, we discerned that 5 is a reasonably small number of clusters that would provide a reasonable resolution in terms of explained variability.

We performed an experiment with a smaller and a larger number of clusters. A 3-cluster solution yielded a substantial reduction in the explained variability as follows: ~54% with 3 clusters versus ~74% with 5 clusters. Attempts to build a solution with 6-11 clusters exacerbated the issues in explaining the ever-finer distinctions between the clusters, whereas the explained variability of the data increased only moderately, never exceeding 86%. The Elite Prolific cluster (callers who call several times) remained very stable throughout, and the largest Typical cluster (callers who call 5 or 6 times) remained more than 3.5 times as large as the second largest cluster. Overall, 5 clusters provided intuitively the best picture that is rich enough to be of interest to psychologists and simple enough to interpret.

## Predictive Classifier Algorithm

The predictive models used in this experiment were based on the C5.0 algorithm that works using decision trees or rule sets. This algorithm was used due to its reliability and success in classification problems [17]. Decision trees and rule sets form one of the pellucid techniques used in data mining as opposed to black-box techniques, such as artificial neural networks. An example of a model generated using C5.0 from our dataset is shown in the Discussion section.

## Models Cascade

Once we discerned the caller type of each caller by clustering the 4-year worth of calls to the organization, we approached the question of predicting the eventual caller cluster or type from a few initial observations of the caller. We were not interested in the callers who call only once. Their behavior is defined by their single answered call. Therefore, we concentrated on those who had at least two answered calls. There were 20,527 such callers. This spawned the following questions: how many calls from each caller would be required in order to be able to provide a prediction on caller type, and what would be a reasonable observation timespan within which to collect those initial calls?

To address these subquestions, we built a cascade of predictive classification models, for which the data were collected subject to a system of the following three conditions:

1. Condition 1: at most N calls. A model was to be built using the initial N calls by each caller. If a caller made less than the answered N calls, we collected that lower number of calls. The values of N cascaded through the following sequence: 2, 4, 8, 16, 24, 32, 48, 64, 256, 1024, 2048, 4096, and 8192. We hoped that low values of N would reasonably suffice overall. However, the decisive property of the Elite Prolific cluster was a high volume of calls made in any given time period (see the Results section). Therefore, we needed high values of N to view how our models fared at detecting the callers from the Elite Prolific cluster. The callers from other clusters made no more than 5,384 calls each; thus, any number of calls higher than that would unambiguously point to Elite Prolific cluster. This decided for us the sufficient ceiling of N to be at 8,192 calls.
2. Condition 2: observation timespan. The initial 2 to N calls per caller had to be collected within a restricted timespan starting from the arrival of the first call by that caller. We chose the following cascade of observation timespans: up to 7 days (1 week), up to 30 days, up to 120 days (4 nominal months), up to 52 weeks (1 business year), and (for completeness) an unrestricted timespan. It has to be emphasized that the observation timespan was calculated individually for each caller, starting at the arrival timestamp of the first call by that caller. This created a relative timescale that enabled capturing similar behavior of different callers, over, say, 30 days of observation, regardless of the individual starting points.
3. Condition 3: number of classes. We examined three different ways to predict the caller type. First, a 5-class model classified the callers according to the 5 caller types discerned from clustering. Second, a 3-class model classified Elite Prolific callers distinctly from Standard Prolific callers, while a class called Other labeled the remaining caller types. Finally, a 2-class model labeled the callers as either Prolific or Other, where the Prolific class comprised the callers from Elite Prolific and Standard Prolific clusters and the Other class comprised callers from Typical, Unpredictable, and One-Off clusters.

## Classification Features

Subject to the conditions listed in the previous section, for each model, we computed the following features associated with each individual caller ID: (1) Count (number of the calls actually collected out of the N calls allowed), (2) MeanDur (mean duration of these initial calls, in seconds), and (3) SDDur (SD of this duration, in seconds). This ensured that the per caller metrics computed for classification matched the metrics computed in clustering (see the section "Discerning call types: clustering" above).

Because we limited the number of initial calls fed to the classifier at N, it became important to enable the classifier algorithm to see the information related to the individual length of time actually taken by each caller to generate up to the requisite number of answered call "arrivals." For example, 20

of the 40 Elite Prolific callers made their initial 4 calls within 2 h from the start of the first call. In contrast, for 3,192 Typical callers who actually made 4 or more calls, the median time to generate these 4 call arrivals was more than 164 h, or almost 7 days. The slowest 25% of callers of all types had generated their first 4 call arrivals in more than 19 days.

For our predictive models to account for this variation in the individual call arrival dynamic, we introduced a feature in addition to the above-listed three features. The new feature was named IATLife, Inter-Arrival-Time “Life,” and computed as the number of seconds between the first and the last call arrival of those initial count calls.

Altogether, every one of the 195 classification variants was performed against the following features: Count, MeanDur, SDDur, and IATLife.

### Evaluation Metrics and Cross-Validation

A suite of conventional metrics was used to evaluate the decision tree, including accuracy, kappa, sensitivity, and specificity. To avoid accuracy paradoxes, significance tests of accuracy rates against the no-information rate (NIR) were conducted (where  $P < .05$  equates a significant model that has some value). NIR is simply the proportion of the most popular caller type or class in the dataset.

We specified a 4-fold cross-validation to produce reliable evaluation metrics, instead of the traditional 10-fold

cross-validation. We chose 4-folds because we had only 40 Elite Prolific callers (see Table 1). A 75:25 hold-out split reserves 10 of them for testing and leaves 30 of them for training. When training with 4-fold cross-validation, each fold receives between 7 and 8 Elite Prolific callers. If the training is done with the default 10-fold cross-validation, each fold would receive fewer than 5 Elite Prolific callers, making them look like outliers among the mass of callers.

Our decision to simplify cross-validation left confusion matrices practically unchanged; data for 16 initial calls are presented in Table 2.

Performance metrics did not show any noticeable change either; see Table 3.

In all, using a 4-fold cross-validation detracted nothing from the models’ reliability, while improving the speed of training by a factor of more than 2.5.

### Software

R programming language and R Studio were used for data wrangling and to implement the analysis. R libraries were used namely dplyr, readr, tibble, tidyr, scales, and DescTools for wrangling; ggplot2 and DescTools for generating the visuals; fpc and cluster for clustering diagnostics; and caret and C50 for classification, while the base package stats provided routines for K-means clustering.

**Table 1.** Clustering results showing cluster averages for each of the three features as well as cluster sizes and values of the within-cluster sum of squares, using 5-cluster data for years 2013-2016 and explained variability of 73.77%.

Name	Volume	Mean	SD	Size	Within_SS <sup>a</sup>
ElitePro <sup>b</sup>	11042.03	194.60	380.60	40	7481.88
Typical	4.80	314.61	33.71	35218	7395.90
StandPro <sup>c</sup>	88.71	944.70	737.24	7895	12656.26
Unpredic <sup>d</sup>	24.66	1886.14	1605.73	2727	5890.24
OneOff <sup>e</sup>	1.16	2162.42	32.15	7749	8780.66

<sup>a</sup>Within\_SS: within-cluster sum of squares.

<sup>b</sup>ElitePro: Elite Prolific callers.

<sup>c</sup>StandPro: Standard Prolific callers.

<sup>d</sup>Unpredic: Unpredictable erratic callers.

<sup>e</sup>OneOff: One-off chatty callers.

**Table 2.** Confusion matrices.

Prediction	Reference	
	Prolific	Other
<b>4-fold cross-validation</b>		
Prolific	1869	70
Other	114	3078
<b>10-fold cross-validation</b>		
Prolific	1886	75
Other	97	3073

**Table 3.** Performance metrics for 16 initial calls.

Cross-validation	Acc <sup>a</sup>	95% CI	NIR <sup>b</sup>	P value (Acc > NIR)	Kappa	Sens <sup>c</sup>	Spec <sup>d</sup>	PPV <sup>e</sup>	NPV <sup>f</sup>	F1 <sup>g</sup>	Prevalence	Detection rate	Detection prevalence	Balanced accuracy
4-fold cross-validation	0.96	(0.96-0.97)	0.61	<.001	0.92	0.94	0.98	0.96	0.96	0.95	0.39	0.36	0.38	0.96
10-fold cross-validation	0.97	(0.96-0.97)	0.61	<.001	0.93	0.95	0.98	0.96	0.97	0.96	0.39	0.37	0.38	0.97

<sup>a</sup>Acc: accuracy.

<sup>b</sup>NIR: no-information rate.

<sup>c</sup>Sens: sensitivity.

<sup>d</sup>Spec: specificity.

<sup>e</sup>PPV: positive predictive value.

<sup>f</sup>NPV: negative predictive value.

<sup>g</sup>F1: F1 score.

## Results

The existence of different caller types was initially suggested by observed distribution of call durations. For example, fitting simple distribution curves (e.g., negative exponential, gamma, etc) to this distribution revealed the presence of a systematic variation in the residuals, which was suggestive of a stratified nature of the underlying population of callers.

### Caller Types Emerged From Clustering

Table 1 and Figure 1 show the clusters (caller types) and their properties for a 5-cluster split using the entire 2013-2016 data timespan. The properties are as follows:

1. Name: see the interpretation below.
2. Volume: in-cluster mean of the number of calls made from each caller within that cluster.
3. Mean: in-cluster mean of the personal mean duration (seconds) of calls within that cluster.
4. SD: in-cluster mean of SD of call durations (seconds) from callers in that cluster.
5. Size: cluster size; number of callers captured in the cluster.
6. Within\_SS: sum of squares characterizing the dissimilarity of callers captured within this cluster. The smaller this number, the more the homogeneity exhibited in the cluster.

We interpreted the 5 clusters shown in Table 1 as follows:

1. Cluster “ElitePro” (Elite Prolific callers): the largest average number of calls per caller in the cluster and the smallest cluster size. These were a handful (fewer than 50 callers over the 4-year timespan) of extremely prolific callers responsible for 20.0% of the total call volume. They called thousands of times, with half the call durations not exceeding 2.5 min and a small minority of calls lasting about 10 min.
2. Cluster “Typical” (Typical callers): the largest cluster size. These were the majority of callers who called 1-5 times and, in most cases, had a short 2.5- to 9-minute conversation. This cluster comprised about 66.0% of all the callers.
3. Cluster “StandPro” (Standard Prolific callers): second largest average number of calls per caller, middling average

call duration and the largest unexplained variability encompassed by the cluster. About 15.0% of the callers were prolific, each making half a dozen to several dozens of calls and generating call durations that were moderate in length (10 min to half an hour long).

4. Cluster “Unpredic” (Unpredictable erratic callers): the largest average SD of the call duration. These were about 5.0% of the callers whose call duration varied considerably, with some calls lasting 9 min and some over 1.5 h.
5. Cluster “OneOff” (One-off chatty callers): the smallest average number of calls per caller accompanied by the largest average call duration. These were about 14.0% of the callers who called only 1-2 times; most had a lengthy 30-min- to 1-h-long conversation and did not return for any sustained support. These were the operational opposite to prolific caller clusters. One exceptional conversation in this cluster lasted for 3.44 h, the absolute record of duration in the dataset.

Principal component axes form a plane in the feature space oriented such that the projection of the scaled dataset onto this plane shows the widest possible 2-dimensional footprint of the dataset. The feature space in this case is 3-dimensional because we cluster with the values of the following 3 numeric features: volume, mean, and SD.

We experimented with the robustness of the emerged clusters against time slicing. The 5-cluster split was first done for the 2013-2015 timespan, then for the 2013-2016 timespan, and then rerun for each of the years 2013, 2014, 2015, and 2016, separately. In all these time slices, the prominent features of the identified clusters remained invariant. The graphical images of the clusters in terms of the principal components retained their visual features, such as the shape and the relative position in the feature space of each cluster. For example, the Elite Prolific cluster in each case produced a shape that dictated the direction of the second principal component axis; refer to the image of cluster ElitePro in Figure 1.

The “explained variability” in Table 1 and Figure 1 is the ratio of the amount of variability explained by clustering to the total amount of variability in the dataset. The statistical variability is measured in terms of the sums-of-squares of deviation of

individual observations from the cluster center point. In all of our reruns of the 5-cluster split, the variability explained by clusters fluctuated at slightly under 74%, which was marginally lower than the variability explained by the principal components.

Notably, the caller distribution to classes was quite unbalanced; see the column “size” in Table I. A no-information model that always classifies new cases into the dominant class (“Typical” cluster in our case) would be correct 66% of the time ( $[35,218/53,629] \times 100$ ). Therefore, the predictive ability of the developed models needs to be, at minimum, better than 66% and, ideally, much higher.

### Classification Results

Altogether, we had 13 ways to specify the number of calls, 5 ways to specify the observation timespan, and 3 types of class specification, as described above in Models Cascade under Methods section. In total, the cascade contained 195 variants of our predictive model.

For brevity of description, in what follows, we will be using a Whyte-like notation to refer to a specific model: L-N-T, where L shows the number of target classes, N shows the maximum number of calls collected per caller, and T specifies the observation timespan. For example, the expression “2-16-30D model” means “2-class model built with up to 16 calls collected within the first 30 days of observation of each caller.” The expression “5-1024-U model” means “5-class model built with up to 1024 initial calls and unrestricted timespan.” The expression “2-\*-52W models” denotes a collection of all 2-class models with a 52-week (1 nominal year) observation timespan

for every number N of initial calls examined; see Condition 1 above.

### 2-\*-U Models

Figure 2 shows the results based on a model to predict Prolific callers distinctly from all the Others.

### 3-\*-U Models

Figure 3 shows the results of a model to predict one of the three classes or caller types.

The key observation is that the 3-class models are mildly sensitive to Elite Prolific callers—picking up some from 32 calls on, notably so from more than 200 calls on, and picking all of them from 4096 calls on. NIR, that is, the prevalence of the dominant Other class, was 0.61 for this group of models. An example confusion matrix, for the 3-1024-U model, is shown in Table 4.

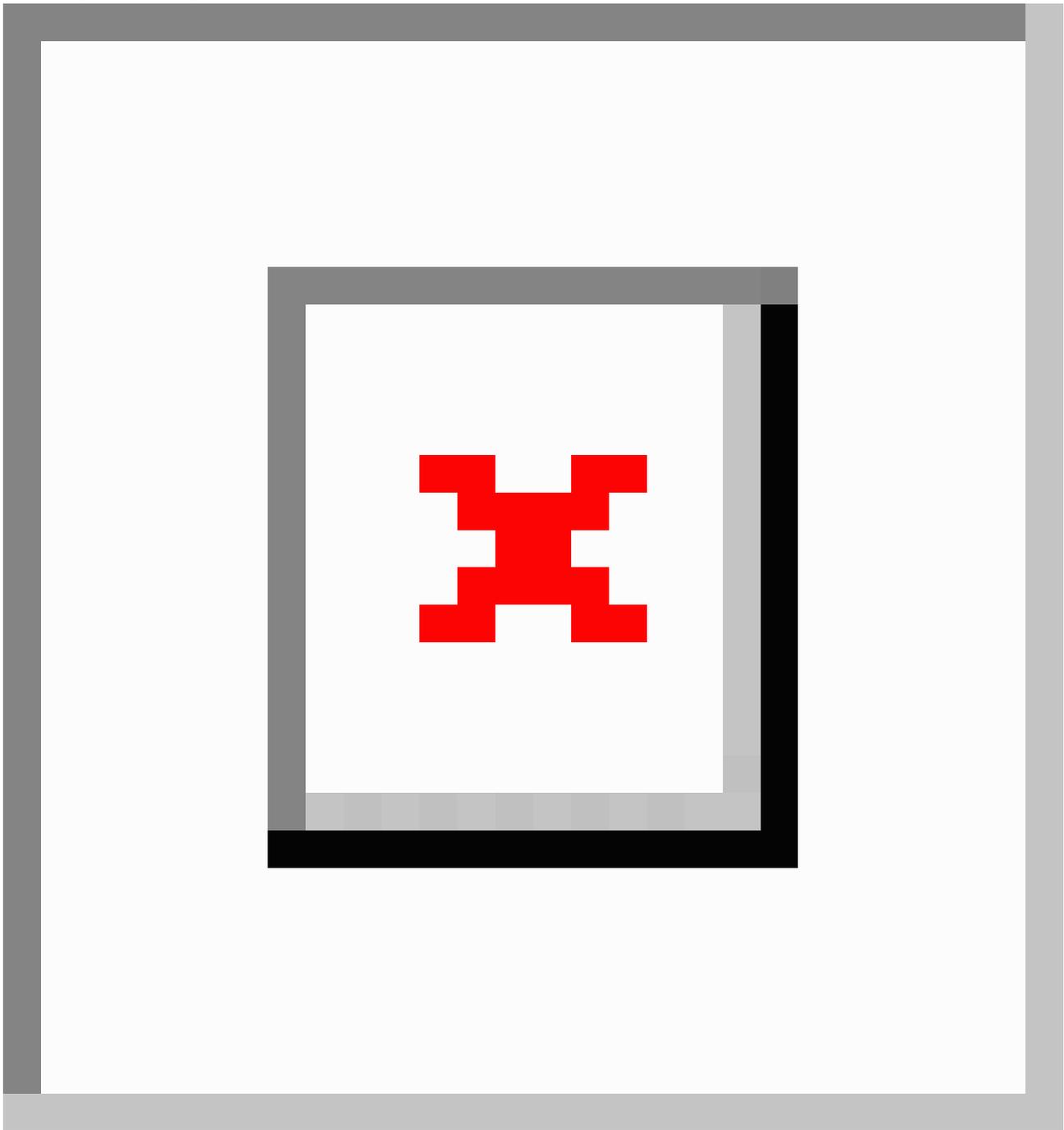
The sensitivity for Elite Prolific callers reached 0.5; furthermore, 5 of the 10 such callers were predicted correctly.

### 5-\*-U Models

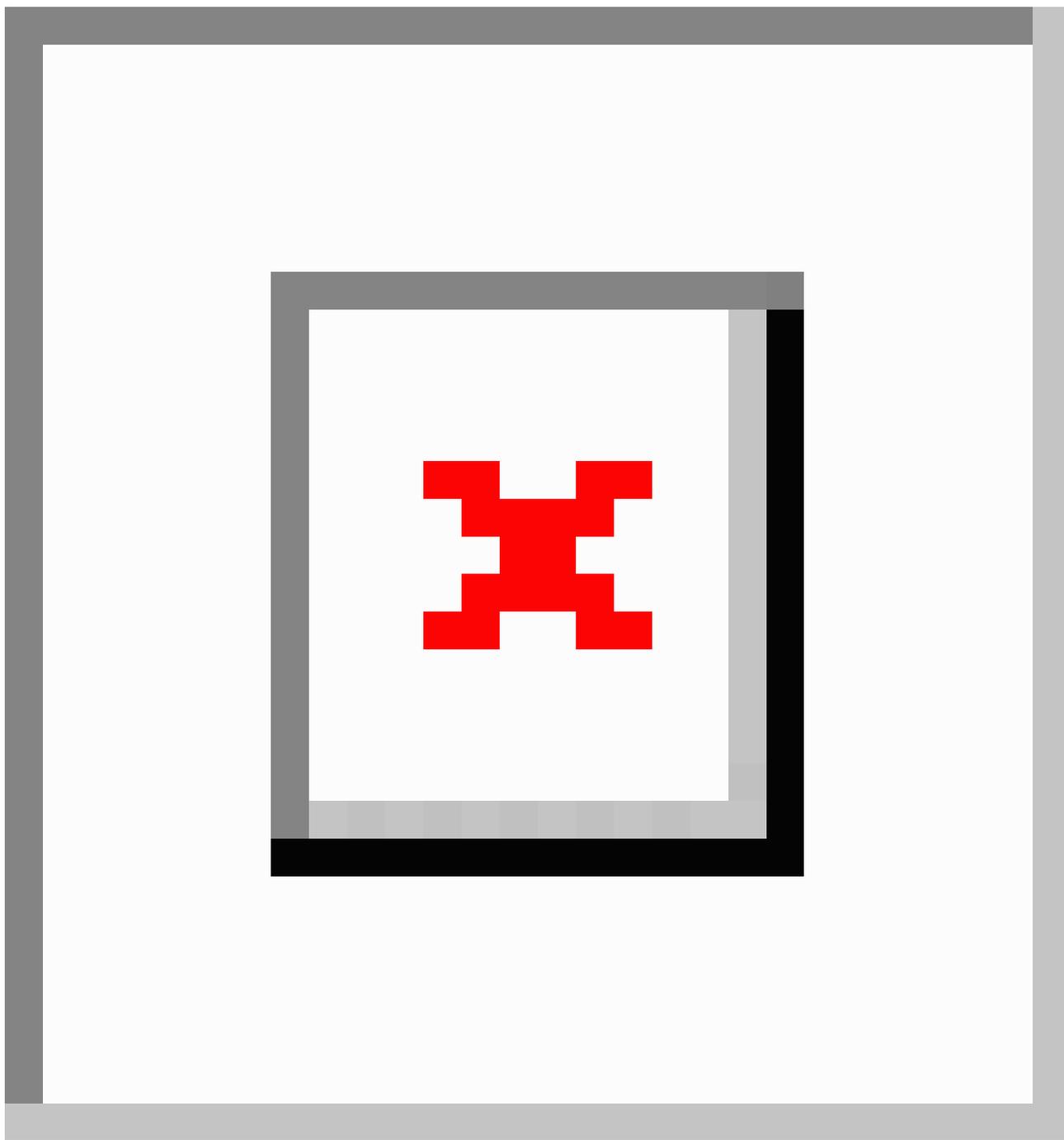
Figure 4 shows the results of a model to predict one of the 5 caller types.

The sensitivity and specificity values are plotted for the Elite Prolific class and Standard Prolific class, but not for the remaining 3 classes. The NIR, that is, the prevalence of the dominant Typical class, was 0.44 for this group of models. An example confusion matrix, for the 5-1024-U model, is shown in Table 5.

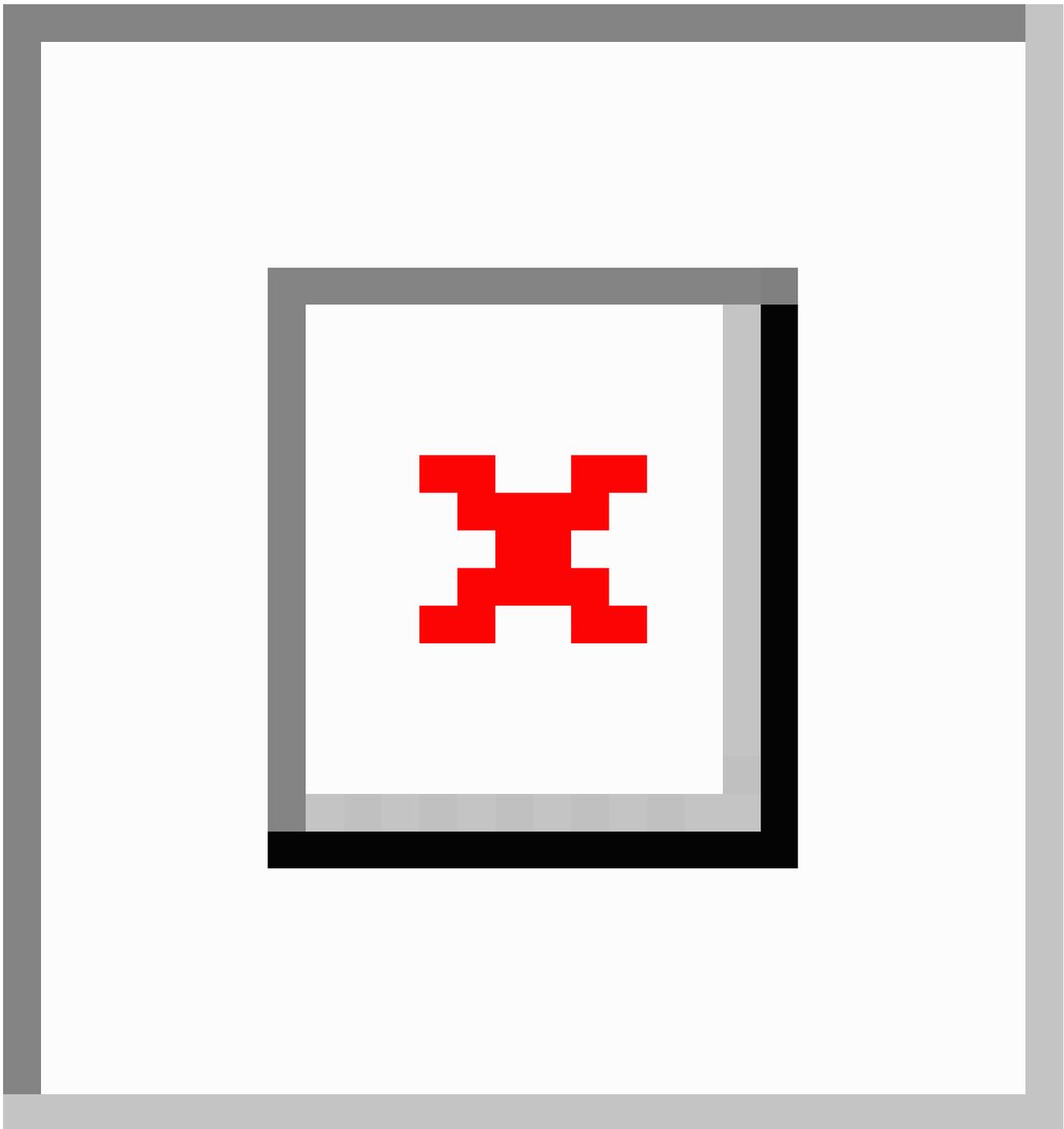
**Figure 1.** Clustering results, showing a projection from the feature space onto the plane of two principal components. These two components explain 77.54% of the point variability.



**Figure 2.** Performance of the 2-class models. The 4 performance metrics reach or exceed 0.9 (90%) for 8 calls and above, exceed 0.95 (95%) for 64 calls.



**Figure 3.** Performance of the 3-class models. Accuracy and Kappa are performance metrics for the model overall. Sensit.Elite and Specif.Elite are the sensitivity and specificity for the Elite Prolific class. Sensit.Proli and Specif.Proli are the sensitivity and specificity for the Standard Prolific class. Notice that the model begins to sense Elite Prolific callers as a separate class when fed over 200 initial calls, and about 4000 initial calls are needed to detect Elite callers reliably (both sensitivity and specificity are close to 100%).



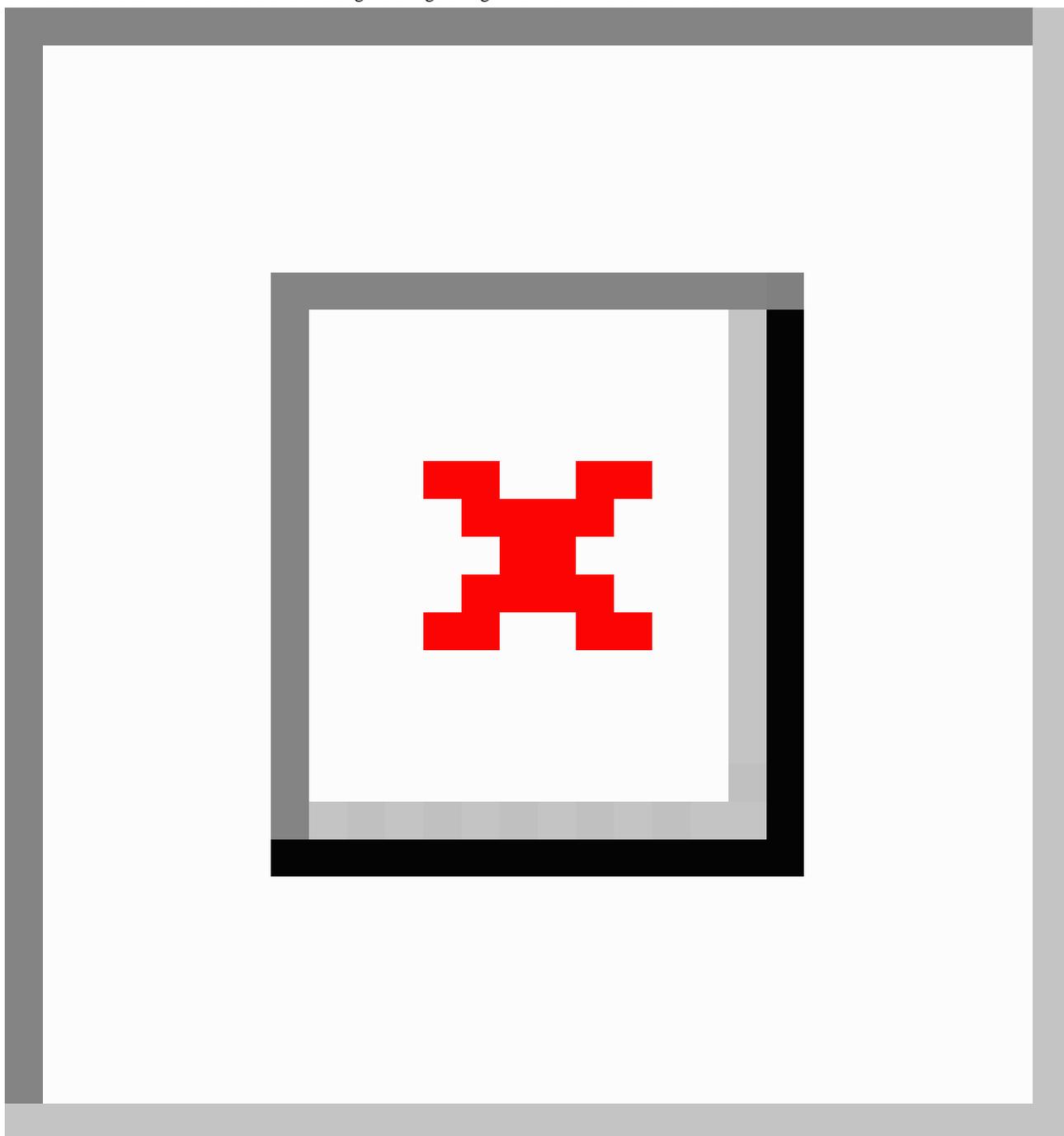
**Table 4.** Confusion matrix for the 3-1024-U model.

Prediction	Reference		
	ElitePro	StandPro	Other
ElitePro <sup>a</sup>	5	7	00
StandPro <sup>b</sup>	4	1947	16
Other	1	19	3132

<sup>a</sup>ElitePro: Elite Prolific callers.

<sup>b</sup>StandPro: Standard Prolific callers.

**Figure 4.** Performance of the 5-class models. Accuracy and Kappa are performance metrics for the model overall. Sensit.Elite and Specif.Elite are the sensitivity and specificity for the Elite Prolific class. Sensit.Proli and Specif.Proli are the sensitivity and specificity for the Standard Prolific class. The model needs over 1000 initial calls to be able to begin distinguishing Elite Prolific callers from others.



**Table 5.** Confusion matrix for the 5-1024-U model.

Prediction	Reference				
	ElitePro	StandPro	Typical	Unpredic	OneOff
ElitePro <sup>a</sup>	2	5	1	0	0
StandPro <sup>b</sup>	8	1949	9	3	0
Typical	0	5	2268	0	0
Unpredic <sup>c</sup>	0	9	0	678	0
OneOff <sup>d</sup>	0	5	1	0	187

<sup>a</sup>ElitePro: Elite Prolific callers

<sup>b</sup>StandPro: Standard Prolific callers

<sup>c</sup>Unpredic: Unpredictable erratic callers.

<sup>d</sup>OneOff: One-off chatty callers

The sensitivity for Elite Prolific callers remained at 0.2; only 2 of the 10 such callers were predicted correctly.

Notably, despite being more balanced in terms of class proportions than the abovementioned 3-class models, the 5-class models tended to perform less well at correctly identifying Elite Prolific callers; the Sensit. Elite values plotted in [Figure 4](#) increase slower than the respective values shown in [Figure 3](#).

It has to be emphasized that the 5- and 3-class models discussed in this and previous subsections were built without any limit to the call collection timespan. That is, to pick out Elite Prolific callers, one must be willing to collect arrival timestamps and durations of thousands of calls per caller, as well as be prepared to wait for quite a long time, the total timespan for this dataset being 45 months.

As soon as we began training models with restricted timespans, we found that the ability of both the 3- and 5-class models to

predict Elite Prolific callers diminished quickly. Whether such a time-constrained observation of a caller provides enough statistical evidence to tell the difference between the Elite Prolific type and other types remains to be investigated.

We then moved on to investigate how well can our approach tell apart Prolific callers in general from Other callers in general under the condition of a restricted timespan. The results are shown in the next subsection.

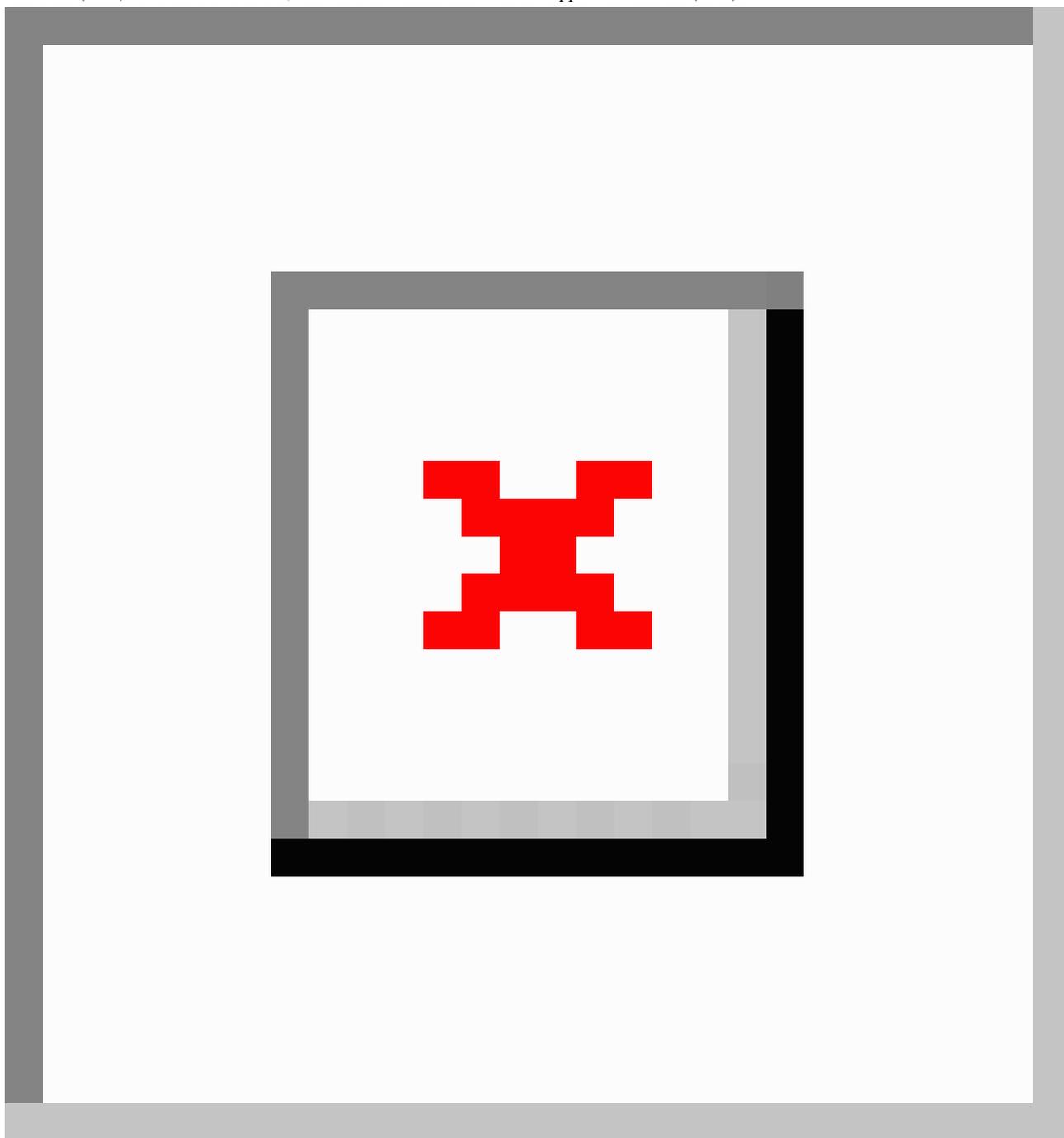
### **2-Class Models With Restricted Timespan**

[Figure 5](#) depicts the results shown by the 2-\*-52W models.

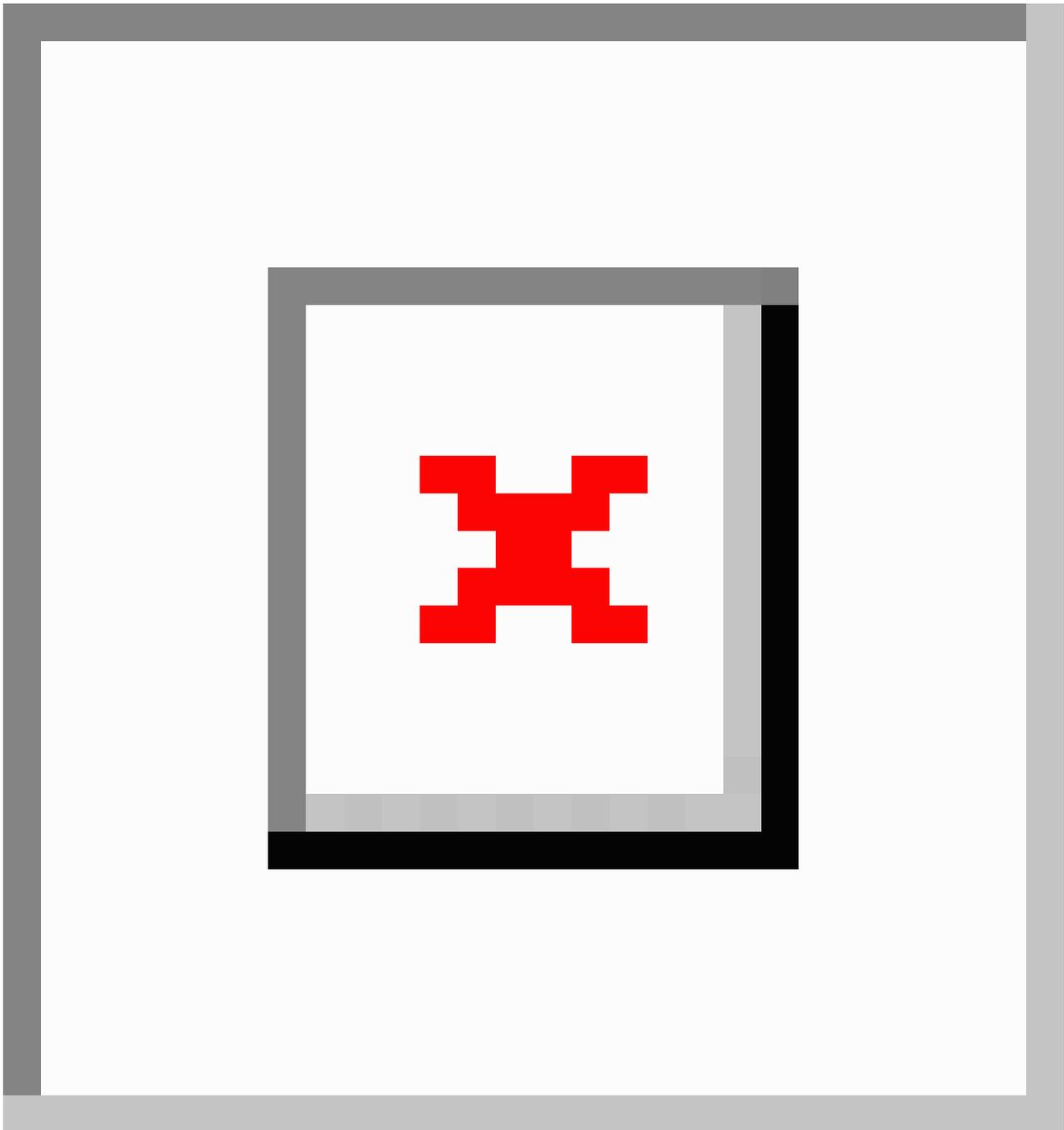
Compared with the unrestricted 2-\*-U models, shown in [Figure 2](#), about 10% of accuracy was lost by all metrics for 8 initial calls.

[Figure 6](#) shows the 2-\*-120D model results (timespan of 4 months).

**Figure 5.** Performance of the 2-class model. Call collection timespan is restricted to 52 weeks (364 days) from the first call. Accuracy metrics reach or exceed 0.8 (80%) for 8 calls and above, it takes over 200 calls to lift the Kappa metric to 0.9 (90%).



**Figure 6.** Performance of the 2-class model. Call collection timespan is restricted to 4 months (120 days) from the first call. Accuracy metrics reach or exceed 0.8 (80%) for 8 calls and above. Neither Sensitivity nor Kappa metrics reach values over 0.9 (90%).



Accuracy limitations became apparent: Kappa and sensitivity reached a ceiling below 0.9. These metrics reached their ceiling between 80%, for kappa, and 95%, for specificity, when the model was built using between 8 and 16 initial calls. Sampling more calls showed virtually no effect on performance metrics.

Figure 7 shows the 2-\*-30D model results (timespan of 1 month).

Metrics reached their ceilings and stayed at the levels they achieved when the model was built using 8-16 initial calls. Kappa reached a ceiling at 75%, etc. It was remarkable that reducing the watching time 4-fold—from 120 down to 30 days—resulted in a rather small reduction of performance. This

means that in most cases, caller behavior becomes apparent within the first month of their contact with the organization and the caller type can be inferred from the initial 8 calls or so.

Figure 8 shows the 2-\*-7D model results (timespan of 1 week).

Kappa was firmly below 80%; its value stabilized when callers were classified using between 8 and 16 initial calls.

The results showed that we can obtain a decent accuracy of predicting the binary Prolific/Other caller type when using attributes from the first 8 calls and the first 30 days—whichever comes first, that is, the 2-8-30D model. Decision rules for this scenario are shown in Table 6, where attribute usage was 100.00% for standard deviation of initial calls (SDDur), 71.38%

for mean duration of initial calls (MeanDur), 17.27% for Count; and 14.25% for Inter-Arrival-Time Life (IATLife).

This decision rule set consists of 16 rules. Each rule comprises one or more antecedents that must be fulfilled for the rule to trigger, along with the class predicted by this rule, and the confidence value of the class prediction shown in square brackets and ranging from 0 to 1. Each rule is accompanied by an (n/m) expression, where n shows the number of training cases that trigger this rule and m shows how many of those n cases are misclassified by this rule. Several rules, with possibly conflicting predictions, may be applicable to classify a new case. To decide the final predicted class value, the applicable rules vote for their predictions with the voting weight equal to the confidence value reported. The votes are accumulated, and

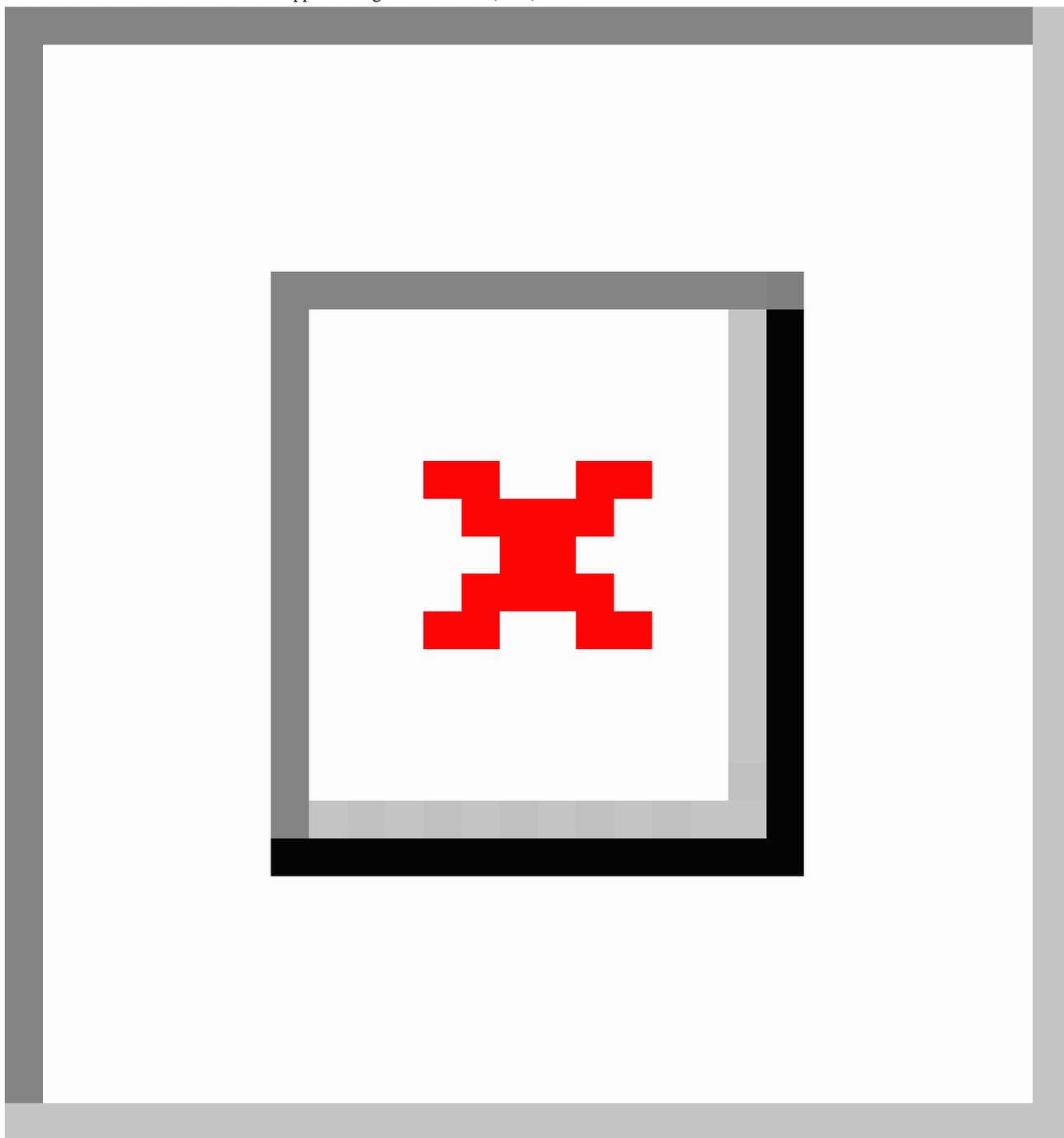
the predicted class with the highest total vote is chosen as the result. If none of the rules apply, the Default class is chosen.

For example, a case of a caller comprising 6 calls with MeanDur equal to 600 s and SDDur equal to 330 s triggers Rule 2, Rule 8, and Rule 14, with accumulated votes resulting in the predicted class Prolific.

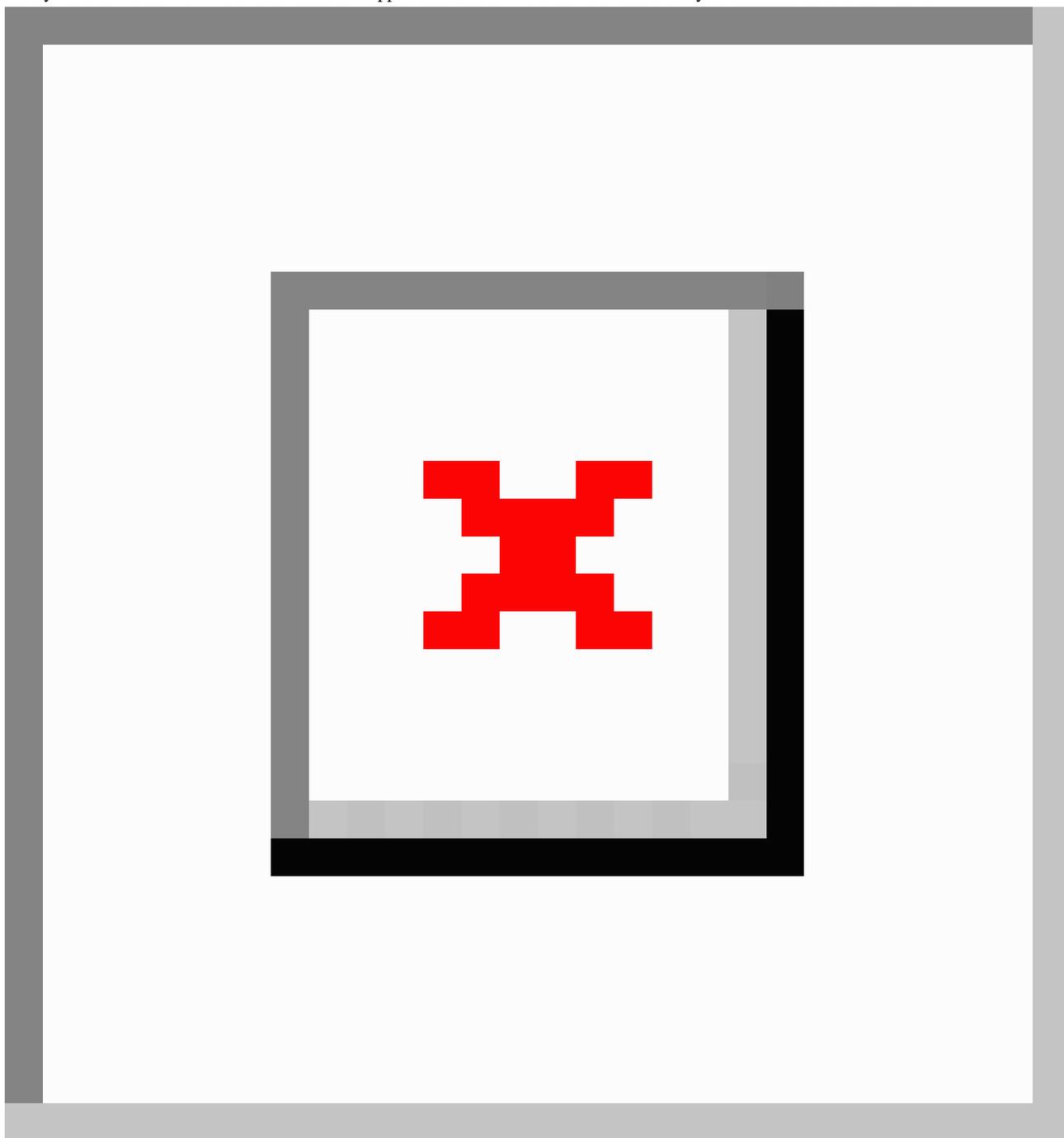
The attribute usage statistics reproduced at the bottom of [Table 6](#) for each of our features show values in excess of 10%, confirming that every feature should be kept, and the C5.0 algorithm has not done feature reduction (despite attempting to do so by default).

The confusion matrices obtained upon testing this 2-8-30D model on the caller data it has not seen during training are shown in [Table 7](#).

**Figure 7.** Performance of the 2-class model. Call collection timespan is restricted to 30 days from the first call. All accuracy stabilize at the levels they have achieved with initial 8 to 16 calls. Kappa no longer reaches 0.8 (80%) level.



**Figure 8.** Performance of the 2-class model. Call collection timespan is restricted to 1 week (7 days) from the first call. All accuracy stabilizes at the levels they have achieved with initial 8 to 16 calls. Kappa fluctuates at mid-70% level. Sensitivity fluctuates around 80% mark.



**Table 6.** C5.0 decision rules for the 2-8-30D model.

Rule number (training cases applicable/misclassified)	Class predicted (confidence)	Antecedents
Rule 1 (516/26)	Prolific (0.948)	Count $\leq$ 7 MeanDur <sup>a</sup> > 646.875 MeanDur $\leq$ 837 SDDur <sup>b</sup> > 391.805 SDDur $\leq$ 1290.503
Rule 2 (367/23)	Prolific (0.935)	MeanDur > 549 MeanDur $\leq$ 646.875 SDDur > 386.0335
Rule 3 (169/11)	Prolific (0.930)	MeanDur > 837 MeanDur $\leq$ 1632.125 SDDur > 320.4684 SDDur $\leq$ 433.749
Rule 4 (120/8)	Prolific (0.926)	Count > 7 MeanDur > 646.875 MeanDur $\leq$ 837 SDDur > 320.4684 SDDur $\leq$ 1290.503
Rule 5 (269/39)	Prolific (0.852)	Count > 7 MeanDur > 930.5 MeanDur $\leq$ 1678.5 SDDur > 320.4684 SDDur $\leq$ 1810.193 IATLife <sup>c</sup> $\leq$ 2420253
Rule 6 (332/51)	Prolific (0.844)	MeanDur > 776.125 MeanDur $\leq$ 1575 IATLife > 1886978
Rule 7 (96/15)	Prolific (0.837)	MeanDur > 930.5 MeanDur $\leq$ 2126.5 SDDur > 320.4684 SDDur $\leq$ 1810.193 IATLife > 2420253
Rule 8 (5432/1917)	Prolific (0.647)	SDDur > 320.4684
Rule 9 (4703/310)	Other (0.934)	MeanDur $\leq$ 353 SDDur $\leq$ 464.1454
Rule 10 (806/97)	Other (0.879)	Count $\leq$ 7 SDDur > 1376.03
Rule 11 (664/80)	Other (0.878)	Count $\leq$ 3 MeanDur > 1124 SDDur > 1197.839

Rule number (training cases applicable/misclassified)	Class predicted (confidence)	Antecedents
Rule 12 (63/7)	Other (0.877)	Count > 7 MeanDur > 930.5 SDDur > 1290.503 IATLife > 456108 IATLife ≤ 2420253
Rule 13 (564/69)	Other (0.876)	MeanDur > 1716 SDDur > 1124.133
Rule 14 (6178/855)	Other (0.861)	SDDur ≤ 433.749
Rule 15 (990/139)	Other (0.859)	MeanDur > 930.5 SDDur > 1290.503 IATLife ≤ 2420253
Rule 16 (590/102)	Other (0.826)	MeanDur > 2062.667 SDDur > 320.4684
Default	Other	

<sup>a</sup>MeanDur: mean duration of initial calls

<sup>b</sup>SDDur: standard deviation of initial calls.

<sup>c</sup>IATLife: Inter-Arrival-Time Life

**Table 7.** Confusion matrices for 2-8-30D rule set model.

Prediction	Reference	
	Prolific	Other
Prolific	1057	113
Other	287	2147

## Discussion

### Overview

The use of machine learning can provide crisis support and suicide prevention helplines with the knowledge of a caller's behavior patterns, generally, and the knowledge of what caller type any individual is likely to become, specifically, based on his or her initial behavior. This may be useful for providing basic business intelligence for operational management or for simply internally signposting callers to specialized teams who may be better placed to offer them the support they require. However, as with most machine learning tasks, there is a question of ethics. For example, one must consider the impact of falsely allocating an individual to an inappropriate service or failing to recognize patterns associated with an increased risk of suicide. The greater concern is predicting a caller to become a Prolific caller and signposting him or her to a specially trained team when in fact the caller is actually a Typical caller.

### Future Work

Our future work will involve using other machine learning techniques such as artificial neural networks and support vector machines to determine the best performing model. Decision rules were used here due to their transparency and to obtain a benchmark for future studies.

Figuring out whether a restricted observation timespan, of say 30 days, is sufficient to detect statistical differences between Elite Prolific callers and the callers of other types is an important future issue that would determine the possibility of success at early detection of the rare, but influential, Elite Prolific caller type.

Early identification of Elite Prolific caller type and routing the calls of these callers to specialized advisers informs the modeling of health care service usage, offering insights for evidence-based practice and operational decision making.

### Limitations of This Study

The dataset is anonymous and uses a unique identifier to determine repeat callers. The limitation is that this identifier is based on a phone number, and although there is no corroborating evidence of multiple users of a single phone number from the helpline provider, the possibility exists that there could be more than one service user using the same phone line. The analysis is partly limited by not filtering the data based on caller tenure and recency. For example, callers may be ending their tenure at the start of our observable dataset time window and other callers may be starting their tenure at the end of our window. This results in some misclassifications; for example, Prolific callers ending their tenure at the start of our window could be misclassified as Typical callers. However, this limitation is mitigated given the length of the observable time window in

our dataset. This is evidenced by the fact that we achieve a high accuracy rate for classification caller types. We would, however, recognize that higher accuracy rates may be achieved by filtering the caller dataset based on the each caller's exposure of their tenure.

### Conclusions

This work shows that a significant model ( $P < .001$ ) for predicting caller type from the data obtained from the first ~8 or ~16 calls can be achieved. For example, Table 3 indicates that the accuracy of the model was 96.41%, which is +35.06% greater than NIR (61.35%). This indicates an association between caller behavior exhibited in the initial calls and their behavior over the lifetime of using the service.

Additionally, this work shows that one can model the different types of service users (callers) and the complex nature of caller behavior and patterns to optimize resource management, volunteer productivity, and forecast demand. The groups of callers may have different levels of risk in relation to mental health and suicide, which may then direct the care required. For

example, the callers who use the service for a short period of time during a crisis or a recurrence of mental illness might be managed differently from those prolific callers who may be at risk of overdependence on the service. Further analysis to understand the needs of these groups, their demographic profile, and the topics discussed would, therefore, be of value. This analysis offers an opportunity to review the skillset and the training needed by volunteers to best support service users. Matching skillsets and training to caller needs serves to improve job satisfaction and productivity.

Data mining of the association of caller IDs with the volume and duration of calls revealed several caller clusters, each describing a distinctive behavior type. The most striking of these clusters, termed Elite Prolific callers by us, encompassed a small number of caller IDs responsible for a substantial share of the total call volume that Samaritans Ireland received. Further research is needed to identify whether the identified caller groups have specific types of mental health and support needs to inform staff training and caller management guidance.

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### Conflicts of Interest

None declared.

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## Abbreviations

**IATLife:** Inter-Arrival-Time Life  
**ID:** identity  
**MeanDur:** mean duration of calls  
**NIR:** no-information rate  
**SDDur:** SD of duration

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Original Paper

# Recovery After Psychosis: Qualitative Study of Service User Experiences of Lived Experience Videos on a Recovery-Oriented Website

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## Abstract

**Background:** Digital interventions offer an innovative way to make the experiences of people living with mental illness available to others. As part of the Self-Management And Recovery Technology (SMART) research program on the use of digital resources in mental health services, an interactive website was developed including videos of people with lived experience of mental illness discussing their recovery. These peer videos were designed to be watched on a tablet device with a mental health worker, or independently.

**Objective:** Our aim was to explore how service users experienced viewing the lived experience videos on this interactive website, as well as its influence on their recovery journey.

**Methods:** In total, 36 service users with experience of using the website participated in individual semistructured qualitative interviews. All participants had experience of psychosis. Data analysis occurred alongside data collection, following principles of constructivist grounded theory methodology.

**Results:** According to participants, engaging with lived experience videos was a pivotal experience of using the website. Participants engaged with peers through choosing and watching the videos and reflecting on their own experience in discussions that opened up with a mental health worker. Benefits of seeing others talking about their experience included “being inspired,” “knowing I’m not alone,” and “believing recovery is possible.” Experiences of watching the videos were influenced by the participants’ intrapersonal context, particularly their ways of coping with life and use of technology. The interpersonal context of watching the videos with a worker, who guided website use and facilitated reflection, enriched the experience.

**Conclusions:** Engaging with lived experience videos was powerful for participants, contributing to their feeling connected and hopeful. Making websites with lived experience video content available to service users and mental health workers demonstrates strong potential to support service users’ recovery.

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**KEYWORDS**

mental health recovery; telemedicine; mental health services; psychotic disorders; schizophrenia; qualitative research

## *Introduction*

Experiences of psychosis have the potential to be prolonged over many years and to significantly disrupt social, emotional, occupational, and financial pathways through life [1]. Early experiences of psychosis often occur during adolescence to early adulthood, which regardless of illness course can lead to persistent social disadvantage [2]. Close relationships, socializing with others, and employment can be difficult to maintain [2-5]. Approximately 23-33% [1,2] of people with psychotic disorders also experience ongoing symptoms and disability, typically leading to continued engagement with mental health services [1].

Personal recovery—a process of rebuilding a meaningful life in the context of living with a mental illness—has become an influential way of understanding how people manage their lives after experiencing psychosis [3,5-7]. This understanding has arisen primarily from people's own accounts of recovery and is often contrasted with recovery being framed in terms of symptom remission [3]. Based on an extensive narrative review and synthesis of literature about recovery, Leamy et al [8] summarize recovery as being an active, individual, and nonlinear journey that may occur in phases and is influenced by five recovery processes: Connectedness, Hope, Identity, Meaning, and Empowerment (CHIME). Recovery-oriented practices that support these processes are now expected of mental health services and practitioners working with service users [9-11]. Ways of promoting recovery may include supporting service users to self-manage their mental health [12], offering peer support [13], and fostering recovery-promoting relationships with mental health workers [14].

Using contemporary technologies and the Internet to support recovery [15-18] and self-management [19] among people experiencing psychosis is a relatively recent phenomenon. The Internet, coupled with the widespread uptake of mobile devices, has the potential to increase access to and use of evidence-based resources that can empower users in self-management [16]. Digital health interventions are feasible and acceptable among people experiencing psychosis [20-22], although (as with other populations) engagement over time can be difficult to sustain [15,19] and the cost of continuing Internet access may be prohibitive [17]. Naslund et al [23] contend that peer-to-peer support gained through self-forming, online communities on social media sites such as Facebook and Twitter could be the future of mental health care. However, they also outline drawbacks, including the potential for unreliable online information, unhelpful online relationships, and difficulty transferring learning into the offline environment.

Incorporating digital health interventions and peer support into existing mental health services presents a way forward. Strand et al's [24] recent scoping review asserted that "e-recovery" can "potentially facilitate recovery-oriented care" (p. 11) in mental health services. Peer support was central to five of six interventions included in their review, of which two involved

experience-sharing with peers through forums, stories, or videos [25,26]. These included a Finnish Web-based psychoeducation program undertaken by inpatients with the support of psychiatric nurses [25], and a website used to facilitate shared decision-making about medication prescription by outpatients with the support of peer workers in the United States [26]. However, in the context of rapidly developing technology and the wide reach of the Internet, there have been surprisingly few advancements in integrating recovery-focused digital health interventions into mental health services. This study reports on service users' experience of an innovative Web-based resource with potential to address this gap.

The Self-Management And Recovery Technology (SMART) research program has involved the development of an interactive website of recovery-oriented resources primarily based on videos of people with lived experience of psychosis, communicating how they have navigated issues in their own recovery [27]. Content was co-designed with people with experience of mental illness and founded on the conceptual framework of the CHIME recovery processes [8]. A range of potential applications of this digital technology were envisioned [27,28]. The website was designed to be used both as a therapeutic tool for workers and service users to access together on a tablet computer during appointments and to be accessible directly by service users from their own devices.

As part of the overall SMART research program led by author NT, qualitative research aimed to explore how service users experienced using this interactive website and how this influenced their recovery journey. This paper focuses specifically on service users' experiences of viewing the lived experience videos on the website, as this was identified as a pivotal element of the overall experience.

## *Methods*

### **Research Design**

This study was guided by constructivist grounded theory (CGT) [29], with a focus on actions and social processes occurring within a specific context. This methodology was selected as attending to social processes [29] corresponded with introducing an Internet-based resource into an inherently interactive relationship between a service user and mental health worker in community mental health services [30]. We were interested in exploring how both parties experienced using the Internet-based resources and how the experience influenced their interactions. CGT involves an iterative process of collecting rich empirical data with concurrent data analysis, followed by further data collection in areas of progressively more specific conceptual interest [29]. This paper portrays one of the areas of conceptual interest identified in the study, that is, the service users' experiences of the lived experience videos. Furthermore, the CGT method recognizes that the research process involves a shared construction of meaning between participants and researchers [29]. People with lived experience of psychosis who were members of a reference group for the SMART research

program contributed to the development of the research design and data collection tool. The emerging themes were shared with participants and others with lived experience to seek their feedback on the interpretation of the data.

### Recruitment and Setting

This qualitative study was conducted in two Australian clinical community mental health services that provide psychiatric treatment and recovery-oriented services and four nonclinical community mental health services that provide psychosocial rehabilitation and recovery support [4]. Eligible service users were over 18 years of age, with a diagnosis of a psychotic disorder, and had sufficient English proficiency to participate in an interview. They had either completed use of the SMART website with a mental health worker employed by the SMART research program or had used the website for at least 3 months with their usual mental health worker (both are hereafter abbreviated to workers). Workers came from disciplines including psychiatric nursing, social work, occupational therapy, psychology, and community work. Invitations to participate in this qualitative study were sent to SMART research program participants, who met these criteria and had agreed to receive invitations about SMART-related studies, by mail or email. A participant information and consent form was subsequently sent to those who were interested. In total, 36 service users (hereafter referred to as participants) consented to participate. They were predominantly women (24/36, 67%), had a mean age of 41 years (range 19-64 years), and described having experienced illnesses such as schizophrenia, bipolar disorder, and psychotic depression, most often with a duration of more than 10 years (Table 1). All were living in the community, in predominantly urban areas, and receiving one of, or both clinical and nonclinical community mental health services. Participants rated themselves as confident using computers and the Internet (average self-rating of 4.2/5 where 5=highly confident); 58% (21/36) of participants had access to more than one device to connect to the Internet; and 61% (22/36) used the Internet “sometimes” or “often” for understanding or managing their health (Table 1).

### Digital Health Intervention

The SMART interactive website aimed to promote recovery, be accessible to people experiencing psychosis, and enable optimal use on a tablet computer or mobile phone [27]. It includes material on recovery (introduction and promoting hope), managing stress (common stressors and coping strategies), health (self-managing physical health, medication, diet, and sleep), me (identity and stigma from a strengths approach), relationships (interpersonal relationships and mental health), empowerment (interactions with mental health services, rights and advocacy), and life (meaning, values, and goals in life). The website has 37 videos embedded throughout of 2-3 minutes length, featuring 7 male and 4 female peers (full details in [27]). Of these, 11 videos introduce each of the peers, who are of diverse age, ethnicity, employment status, and sexuality [27], and 26 videos show 4-6 peers talking about their experiences, views, and actions in relation to specified topics, for example, “experiences of making changes” (health topic),

“identifying our strengths” (me topic), and “views on getting the most out of services” (empowerment topic; Figure 1). Participants can post their response to questions that follow videos using an online name, read comments written by others, and save videos to a “personal favorites” area. The website also includes a peer discussion forum open to users with lived experience only, tools for charting personal experiences (eg, stress or mood), additional videos of peer leaders who introduce the topics, videos of clinicians and academics discussing topics such as “making plans and taking action” (life topic), and links to other evidence-based websites.

In this qualitative study, 26 participants interviewed used the SMART website with a trained worker employed in the research program, and 10 used the website with their usual worker at the mental health service they attended. The website was available for use in individual meetings occurring in mental health services or in participants’ homes. All participants were given a personal login in the first meeting and could use the website between meetings if they had access to an Internet-enabled device. Use with a trained worker entailed up to eight 50-minute meetings integrating use of the website, held over a 3-month period. Website use with a usual worker occurred in routine meetings for up to 6 months, with flexibility regarding when the website was used alongside other usual work undertaken by the pair. Routine meeting frequency varied considerably from weekly to monthly, as did the length of these meetings, from approximately half an hour to 2 hours.

Workers brought an Internet-connected tablet computer to meetings, to facilitate access to the website. Participants logged into the website, were initially introduced to the first topic called “recovery,” and could then explore the application as they chose. The workers provided technological and navigational support and guidance and discussed the content with the participant. Participants explored topics in the website at their own pace, with some moving through a new topic in each meeting and others choosing to concentrate on fewer topics. Despite this variation, all topics included peer-based content. Those who used the website between meetings using their personal devices could review videos, use tools to monitor their experiences, record personal goals or values, or communicate with peers through the forum. All participants continued to receive their usual clinical, rehabilitation, and support services throughout the research and had ongoing access to the website once the research period ended.

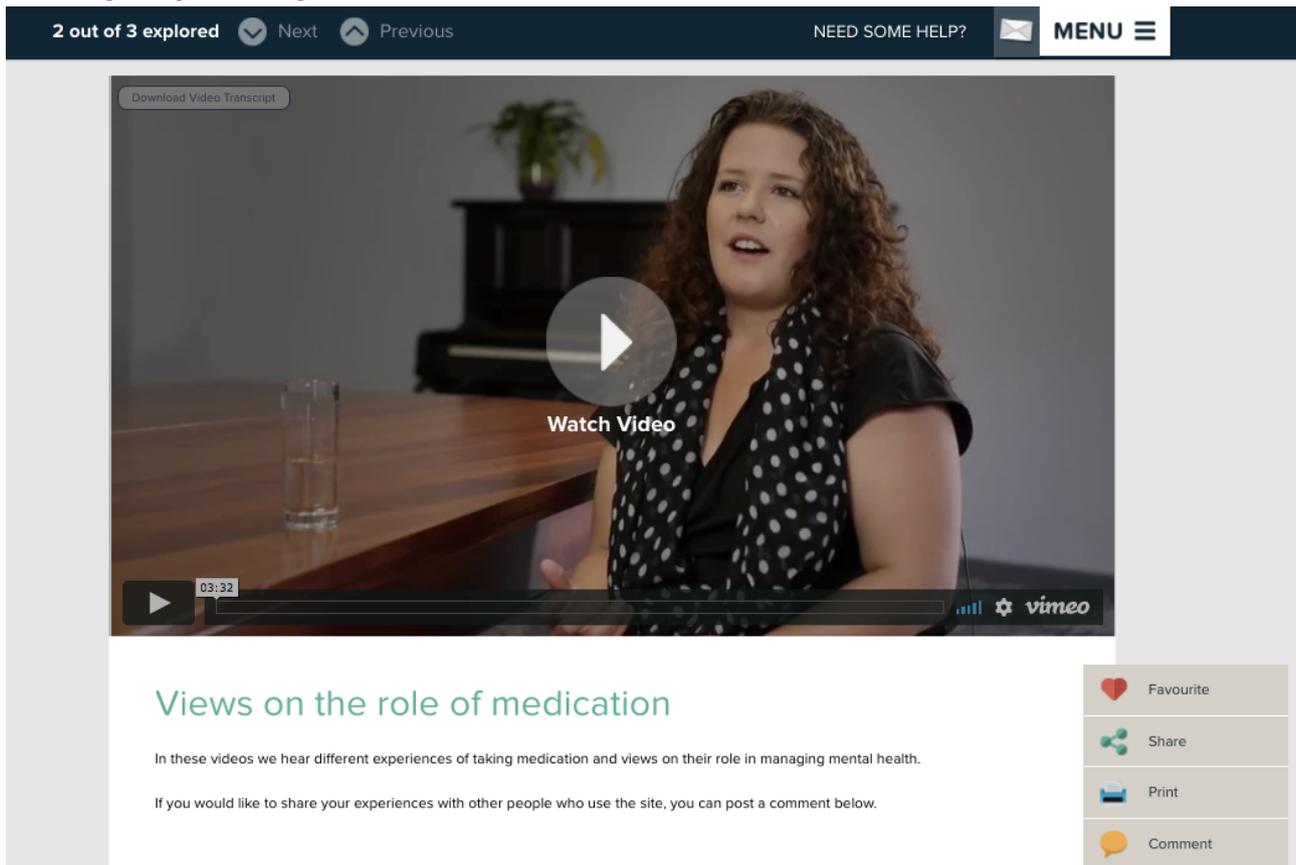
### Data Collection

Data were collected in individual interviews conducted by the first author, who had no prior relationship with any of the participants. A semistructured interview guide with broad questions enabled exploring the overall experience of using the website resources (see Multimedia Appendix 1). Open-ended questions were pre-determined yet flexible [31], to enable following up responses in subsequent interviews [29]. Interviews occurred shortly after participants had completed their sessions with the trained worker, or after having website access for at least 3 months for participants who used SMART with their usual worker.

**Table 1.** Participant characteristics (N=36).

Characteristics	Participants, n (%)
<b>Website use</b>	
Used with trained mental health worker for 8 sessions	26 (72)
Used with usual mental health worker for up to 6 months	10 (28)
Used with worker only	12 (33)
Used between sessions with worker	24 (67)
<b>Gender</b>	
Female	24 (67)
Male	12 (33)
<b>Age, years</b>	
<30	7 (19)
30-45	14 (39)
>45	15 (42)
<b>Experience of mental health issues, years</b>	
1-5	5 (14)
5-10	5 (14)
>10	26 (72)
<b>Income</b>	
Disability support pension	29 (80)
Other government allowance	5 (14)
No government allowance/Unstated	2 (6)
Part-time employment (in addition to allowance)	6 (17)
<b>Devices used to access the Internet</b>	
Own computer	22 (61)
Own tablet device	13 (36)
Own mobile phone	24 (67)
Community or service computer	10 (28)
No access	1 (3)
<b>Frequency of Internet use in a typical week</b>	
Every day	18 (50)
Most days	4 (11)
A few days	5 (14)
Once or twice	6 (16)
Not at all	3 (8)
<b>Typical use of the Internet for health information</b>	
Often	6 (17)
Sometimes	16 (44)
Rarely	9 (25)
Never	5 (14)

**Figure 1.** Sample image of lived experience video.



Interviews occurred face-to-face in mental health services (n=24) or over the telephone (n=12) and lasted on average 41 minutes (range 18-65 minutes). They were audio recorded and transcribed, or handwritten notes were made if the participant preferred. All participants were sent a transcript of their interview. Six service users participated in a second individual interview, 2-3 months after their first interview, to explore their experiences using the SMART website over time. Participants were reimbursed Aus \$30 per interview. Researcher reflection occurred alongside data collection to enhance the interviewer's awareness of self, relationship, process, and content in each interview, as suggested by Mruck and Mey [32].

### Data Analysis

Data analysis followed principles of CGT [29] and occurred concurrently with data collection. The first author completed initial line-by-line coding of interview transcripts using gerunds to identify actions in the data [29]. Concurrent memo-writing allowed reflection on recurring and contrasting codes, which were subsequently checked with the first 8 participants in two follow-up interviews and via an initial newsletter mailed to participants. The importance of the lived experience videos to participants was identified early in the analysis, as indicated by the following excerpt from a memo written after the third interview:

*The peer videos seemed to be the most important aspect of the site (to the participant) as she identified emotions that she feels but cannot express and recognized a sense of self-identity that she does not express (outside of her family). Despite the*

*connections being virtual, she felt connected to this greater community of people whose experiences she could relate to.*

This lead was followed-up in subsequent interviews. As further interviews were conducted, analysis shifted to include focused coding and category development, as demonstrated for the category "Knowing I'm not alone" in Table 2. Clustering, which involved creating a nonlinear and visual chart to map a central category [29] and analysis using QSR International's N-Vivo 11 qualitative data analysis software [33] were used to further consider the meaning of the data. The first 3 authors reviewed the evolving analysis in regular meetings. Additional member checking included discussing developing findings twice with a university-hosted panel of people with lived experience of mental illness, a presentation to a conference with an audience including people with lived experience of mental illness, and sharing findings with participants in a second newsletter.

### Ethics and Credibility

Ethical review and approval for the study was obtained from all participating sites and two university human ethics committees. All participants provided informed consent prior to participating. Credibility was enhanced by collecting background data to portray the context in which participants used SMART and by seeking sufficient detailed and multiple accounts of views and actions from participants who varied in age, background, and experiences [29]. Participants were diverse in how much (from minimal to extensive) they used the SMART website and the extent to which they used it by themselves outside of their meetings with a worker.

**Table 2.** Coding examples.

Initial codes	Focused code	Category
<ul style="list-style-type: none"> <li>Realizing I am not alone               <ul style="list-style-type: none"> <li>Feeling not as alone; Feeling like you're not alone</li> <li>Feeling connected</li> <li>Feeling like I belong</li> <li>Being part of something</li> <li>Connecting with others going through the same thing</li> <li>Not having to go through it by myself</li> <li>Connecting with peers straight up</li> <li>Knowing you're not alone</li> <li>Knowing I'm not the only one</li> <li>Realizing I'm not the only one</li> </ul> </li> <li>Thinking I was on my own</li> <li>Needing to isolate myself; needing solitude</li> </ul>	<ul style="list-style-type: none"> <li>Realizing I am not alone               <ul style="list-style-type: none"> <li>This code relates to service users realizing that they are not alone. The feeling of not being alone encompasses feeling connected, feeling like I belong, and being part of something. There is implied relief at not having to go through this by myself. This contrasts with prior thinking that I was on my own.</li> <li>One participant discussed how she had needed to isolate herself and needed solitude when unwell: some alone time was necessary.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Knowing I'm not alone               <ul style="list-style-type: none"> <li>Incorporates focused codes                   <ul style="list-style-type: none"> <li>Realizing I am not alone</li> <li>Hearing hidden views</li> <li>Feeling exactly the same</li> </ul> </li> <li>Hearing and seeing peers talking about their experiences in the website led participants to realize that others shared their experiences and that they were not alone. Participants described feeling connected, belonging, or being part of something after exploring the lived experience content in the website, in contrast to previously "thinking I was on my own".</li> <li>Knowing I'm not alone was strengthened by "hearing hidden views" that were otherwise not available to participants in the community and "feeling exactly the same" as the peers.</li> </ul> </li> </ul>

## Results

### Overview

In total, 36 participants who used the SMART website attended one interview, and 6 of them agreed to a follow-up interview. The analytical process identified that having access to videos of peers speaking about their experience was important to many participants in (1) "knowing I'm not alone," (2) "being inspired," and (3) "believing that recovery is possible." Figure 2 represents these categories and their focused codes and includes contextual factors that influenced participants' experiences. The intrapersonal context included their prior actions to manage their health and their use of technology. The interpersonal context included using the resources with a worker who guided them and facilitated reflection. Quotes are attributed to participants using their self-selected pseudonyms and are used to illustrate each category and context.

### "Knowing I'm Not Alone"

Participants were quickly drawn into the website when the life circumstances and events discussed by peers in the videos resonated with their own experiences. Participants frequently reported feeling less alone after watching others talking about their experiences, as Reese explained:

*I found quite a few of the videos quite helpful, especially when they were saying things that I agreed with, which was really, really cool...made me feel like I wasn't alone and quite a few of my illnesses, they actually do make you feel quite, quite alone a lot of the time, so for me to be able to see that there were other people out there struggling just as much as I was, or were struggling just as much as I was...was quite helpful.*

Participants also discussed feeling connected or belonging after watching and listening to lived experience videos, as Amelia described:

*There were other people going through a similar situation and they were telling about their story and*

*then it just seemed like I can relate somehow, and...it just seemed that I'm not the only one with this type of problem, there are other people with other different types of problems, I don't have to go through it by myself.*

Jamin conveyed his sense of personal connection when he stated: "I'd love to meet them sometime because they're awesome people...I made friends that don't even know me."

"Knowing I'm not alone" was strengthened by hearing hidden views that were otherwise not available to participants in the community and "feeling exactly the same" (Suzanne) as the peers. Realizing that others shared their experiences provided a sense of relief and differentiated their engagement from their previous help-seeking, as Amy noted:

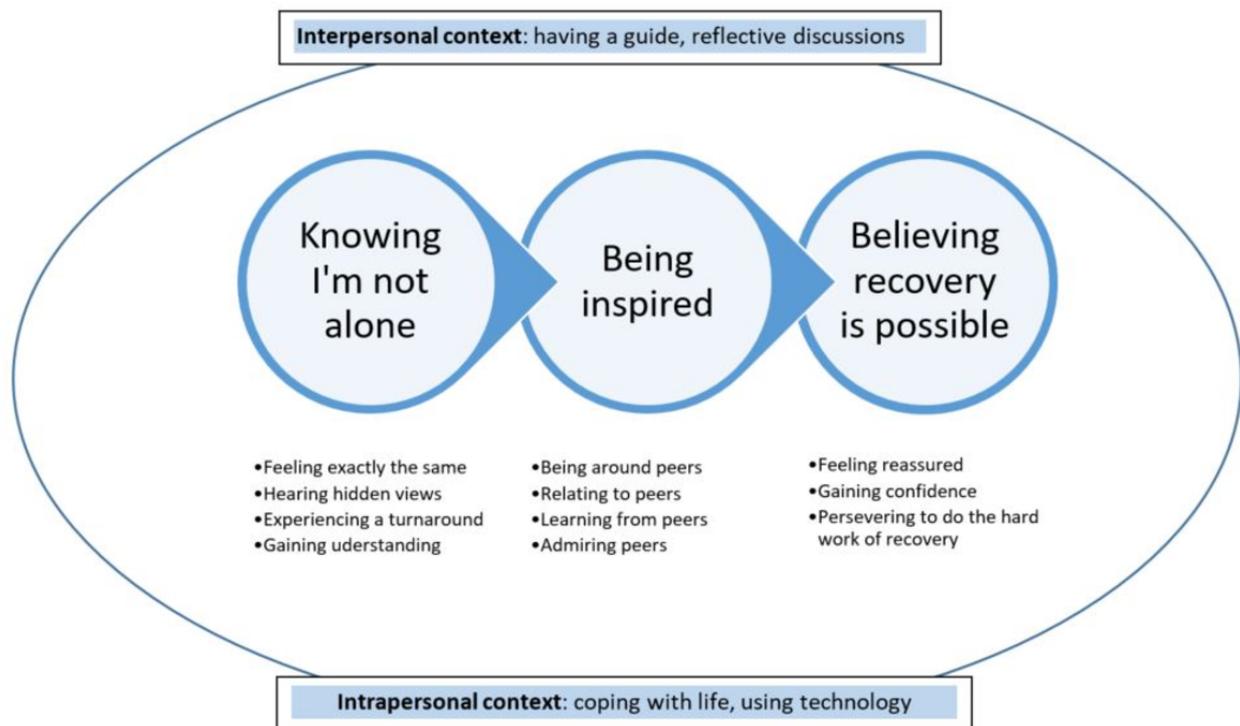
*I'd never seen that stuff before and stuff that was being said out loud and being recorded, and I was like "wow," this is stuff that I think in my head, that I've come to a conclusion to for being mature in my illness, a 10-year maturity in my illness, but no one's ever told me it like this.*

Connecting with the peers through the videos was initially made possible by the interpersonal context of using the website with the worker who supported participants to "get the hang of it" (Melanie), "remind(ed) me how to find certain things" (Bill), or "prompted me to put something (my views) down" (Kali). As Paul said, "having a person beside you guiding you through the Internet, it's very handy." Personal reflection about topics arising in the videos was also enriched by discussions that opened up with workers during the sessions:

*What I liked at the beginning of the topics were the peer discussions—"the videos where peers talked about an issue". They were "really beneficial." I could identify things that I had done. They began a discussion (between me and worker). "[Worker] helped me apply the information to what mattered."*

[Sue]

**Figure 2.** Categories, codes, and contexts related to engaging with lived experience videos.



Amy described the value that using the website with a worker added to her experience:

*She let me lead the whole thing. So every time I'd see her, "I want to see the SMART website with you because it actually motivates me to do it rather than just doing it at home alone..." When I went on to the website, I said to her, "actually I would like some assistance with this, in reflecting on this topic, because I don't quite understand it and I do need someone to talk to about it."*

Participants' intrapersonal context, in particular their own experiences of coping over time, impacted which videos they chose to watch. Experiences discussed by peers could be personally challenging, leading participants to avoid some topics, such as "Empowerment" or "Relationships". For Kate, it was the "Me" topic:

*I would have had trouble with that because I don't identify with myself all that well. I probably would have got a lot out of the peer videos with that one I think, 'cos they would have identified themselves, and I would have been able to relate to them.*

However, using the website with a worker who invited participants to choose the topics that they wished to explore supported participants to engage with videos addressing difficult topics when they felt ready. The consequences of hearing about challenging experiences from the peers could be transformative, such as Pam described:

*I suppose it made me feel less ashamed about having mental illness because even though I have been in the system for quite some time, I still felt quite bad about*

*myself, and just having—a listen to some of the peer workers in what they said about stigma and that, it just really, it felt very empowering...so that was a big turnaround for me.*

### **"Being Inspired"**

The majority of participants who watched the videos in the SMART website also spoke of gaining inspiration, describing the peers as "uplifting" (Awareness), "encouraging" (Julie), "confidence building" (Kali), and "reassuring" (Vlad). As Kali elaborated:

*I used it for confidence building and also relate, relate to other...people out there that have schizophrenia or other mental health issues, to feel like I belong...and I found it really reassuring, especially knowing that the people that I was watching that had recorded their stories are now in recovery and they've stayed that, some have stayed that way, some are working, it was inspiring stuff.*

Learning from the peers, including learning unexpected, new information, or alternatively solidifying existing knowledge, contributed to being inspired. For example, Harley said, "After watching the videos I saw that I was doing things the wrong way and I could try doing things a new way." Omar valued how "watching the videos did put things in perspective, because they were people who had lived experiences."

Being inspired by peers included expressing admiration for them and their willingness to share their successes and challenges. Furthermore, reciprocity was possible when participants like Ingrid were "able to relate to their stories, understand them and have empathy." Jamin also perceived that

by adding his comments on the videos he was giving peers “encouragement to keep on doing what they are doing, a great big tick because they were really, really doing it very well.” The diversity of experiences and views shared in the videos provided opportunities for participants to find different points of connection with the peers. For example, participants recognized that differing recovery perspectives and experiences were possible, agreeing with some peers but disagreeing with others. Zara said:

*It was reinforcement, which was useful because you sort of think you know stuff but then it sort of solidifies what you know...listening to the different characters that were speaking, just to get their point of view, just to get the broad spectrum of what people experience and how it can be very similar to me or very different to me, or something in between.*

Intrapersonal factors, including past experiences of coping with life, influenced how participants felt about the peers and whether or not they found them inspiring. For example, Athalia found watching the videos “draining” and “tiring,” as she felt the need to try to support the peers, as she had done in other Internet-based peer networks. Latte and Guilia wanted to “move on” from focusing on their mental illness and did not want to be connected to others who shared this experience, while Tricia’s experience did not align with what she heard from the peers:

*I just couldn’t sort of relate to it at all. Thought, you know sometimes I thought you’re just really lucky, you’re really lucky that things are that way for you because, if things are simple and you think that’s how you can recover like that, but it’s just not my experience.*

None of these few participants reported negative consequences from watching peer videos. Instead, after deciding that the videos were not useful for them, they chose to use other resources in the website that supported their self-management. For example, they used charts to monitor their stress, sleep, or diet; watched videos from clinicians; and talked with the worker about topics in the website. Having used the website infrequently with their usual worker, 2 other participants reported insufficient use to gain benefit from the peer videos.

### “Believing that Recovery is Possible”

Videos exploring peers’ perspectives on recovery supported participants to reflect on their understanding of this sometimes-confusing idea, such as Kelly demonstrates: “I didn’t understand what recovery was, but now I understand it’s sort of like getting back to normal...like you know, having positive thoughts and things.” Sylvester experienced a transformation in his understanding:

*the one that sticks in my mind, would be about, about having recovery and me thinking that recovery was about, like me trying to be...well, but a traditional well, like thinking that I was going to be, going to get better and not have a mental illness for the rest of my life and then watching, watching different videos on the SMART website and that, and them saying that*

*recovery is a different, you’ve got different terms of recovery. That was a real breakthrough for me.*

Participants who felt connected to the peers and inspired by them, listened to the peers’ recovery experiences and believed that their own recovery was possible. Reese said, “Looking at the videos it was, wow, they seem a lot like me and if they can do it, I can too.” Viv’s experience was similar: “I suppose I looked up to these people on the site and thought, well if other people can, with a mental illness, can be articulate and have a voice and have meaning in their life, well that means perhaps I can too.”

The intrapersonal context of having used coping strategies over many years influenced participants’ response to the lived experience videos. Watching a video of a peer saying that recovery is hard work confirmed Pam’s experience and deepened her resolve to persevere. Participants who perceived that they were “on the road to recovery” (Jacqui-Maree) gained confidence that they were indeed doing the right thing and felt able to continue “full speed ahead” (Zara). After completing eight sessions of SMART, Libby, who like others had experienced past trauma, expressed her strengthened determination: “I can see it, I’m going to recover, I want to recover, I have to recover.”

Hearing about actions that peers took in their recovery and discussing these with a worker was empowering and provided participants with new strategies that they could try out in their lives. Bruce stated that, “being able to talk to someone while discussing this sort of stuff, I think it was great... it was making me think about the things that would help you, sort of get you back on your feet.”

Personal access to technology also affected participants’ engagement with the videos beyond meetings with the worker. Being able to hear the peers “over and over” through logging into the site and watching the videos at home supported the information to “sink in” for Viv. Participants who had no or limited Internet access at home due to reception, accommodation, or financial difficulties, did not have this opportunity.

The lived experience videos stood out in the memories of the 6 participants who had a second interview up to 3 months later, even when these participants had not viewed the website for some time. Ingrid described the value of having ongoing access to the videos like this:

*To have those videos there to view them, especially at your own viewing time, like it’s private, so you can cry, you can laugh, you can basically go through whatever you want, no one can see what you’re doing, it’s in the privacy of your own home...So there’s no judgement, there’s no judgement of who you are or what you’ve been.*

Additionally, in second interviews participants related how what they had seen in the peer videos had influenced their actions. For example, Sue stated:

*I remember the “people talking about their experiences” [in the videos]. Some of the issues, like relationships, that are “prominent for me now”. I*

*remember the “medication and negotiating in the mental health system”. I was on a medication at the time that was having terrible side-effects. After I saw different ways you could talk about medication, I realized that they had to listen to my experience. I kept “pushing it” with the doctor, I wouldn’t take no for an answer.*

In summary, engaging with peers’ lived experience on the SMART website through videos and discussing the content with a worker prompted reflection on the personal meaning of recovery, provided strategies to support recovery, and generated or affirmed participants’ determination to strive for recovery.

## Discussion

### Principal Findings

This study explored service users’ experiences of using an innovative and interactive recovery-oriented website, SMART [27,28]. Overall the findings show that using the SMART website was viewed as positively supporting participants in their personal recovery journeys. More specifically, watching the videos of people with lived experience of psychosis on the website supported recovery processes by providing relief to service users that they were not alone, inspiring hope, and supporting them to revise and affirm a personal meaning of recovery. These findings provide evidence that from the perspective of service users, watching lived experience videos on a website can contribute to participants feeling less alone and more hopeful as they recognize that they share experiences with other people who they admire. Engaging with lived experience through the videos appeared to provide similar benefits to meeting other people with experience of mental illness, which has been identified as a source of hope [5,34,35] and of acceptance and self-esteem [36] for people with psychosis. This finding extends on the SMART pilot study in which participants felt more connected with people (7 out of 10 participants) and more hopeful (9 out of 10) after using the SMART program [27]. Our findings also have striking similarities with Naslund et al’s [37] analysis of comments made by viewers of lived experience videos uploaded to YouTube, strengthening the evidence that peer support can be experienced through the Internet. Using videos developed with people with lived experience and informed by ideas about recovery [27] overcame the limitations in trustworthiness of videos posted to public Internet sites such as YouTube, as described by Naslund et al [37].

Including lived experience videos in digital health interventions may be particularly helpful for service users who are unable to access person-to-person peer support. For example, in Australia in 2010, only 4.7% of people experiencing psychosis and connected to mental health services reported that they participated in peer-led support groups [4]. Lived experience videos could also be offered to people experiencing psychosis who have difficulty socializing [1] or to those who do not have paid employment and are therefore missing out on the contribution that work can make to self-identity and self-esteem in recovery [5,34]. While social media provides another route to online peer-to-peer support, using curated peer-based content

may help in reaching groups who use social media less, such as mental health service users aged over 45 [38]. Structured peer-based content in Internet-based interventions may also appeal to young people experiencing psychosis who lack knowledge about how to search the Internet for mental health information [39] or to people experiencing schizophrenia who are interested in sharing information and emotions anonymously with peers [18].

Peers in the videos appeared to be viewed as role models by participants, similar to how peer support workers have been perceived by people in recovery [40] and consistent with psychosocial processes underlying peer support [13,35]. This finding supports further development of peer-based digital resources and research into their benefit for mental health service users. However, as noted in this study, peer-based videos are unlikely to be appealing to all service users. Walker and Bryant [40] noted that peer workers may not be viewed as role models if they are perceived to lack training or as being limited in their helpfulness by illness factors. In our study, responses to the videos appeared to be influenced by the participants’ existing ways of coping with life and managing their recovery, as well as by how they used technology. Participants who did not relate to the peers as role models perceived that their ways of coping were too different, or they were at a point in their recovery journey where they did not want to identify with peers. As Tew et al [36] argue, some people experiencing mental illness may reject being overly invested in mental health, preferring to foster broader relationships. Perceptions of technology and information on the Internet could also impact whether participants believed the lived experience videos to be trustworthy. Attention to the intrapersonal context may therefore help workers understand the choices that service users make about using digital lived experience materials. Additionally, providing a range of resources, content presented from different viewpoints, and choices about which resources to use seems important when designing future websites for this population, so that everyone can find content that matches their interests and values.

Watching the lived experience videos with a worker opened discussions about meaningful topics, thus enhancing the experience of using the website among participants in our study. The worker supported initial website use by guiding participants to navigate the website and to use the technology, when needed. One third of our participants only used SMART with the worker and close to 40% rarely or never used the Internet to access health information. Additionally, privacy is likely to be an important consideration regarding where service users choose to view videos with mental health content [41]. Thus, watching videos with a worker demonstrates potential to connect service users to peers’ experiences that they would be unlikely to access online themselves. The worker also offered choices and facilitated discussion that linked the peer videos to participants’ lives. Similarly, psychiatric nurses identified that supporting inpatients to use an educative website with peer videos facilitated discussions between them [25]. These findings provide further evidence that social presence from a clinician or researcher supports adherence to and engagement with Web-based and mobile technologies used by people with psychosis [42].

Embedding lived experience videos into service provision appears to offer a way of providing service users with hope-inspiring experiences when they meet with workers. This finding is particularly encouraging given that feeling hopeless and not getting support from their mental health services can hinder a person's recovery [7]. Viewing and discussing the videos with a worker brought the topic of recovery to the fore in a way that would not occur if service users used the website autonomously. Hearing peers' experiences supported participants to have confidence that their own recovery was possible and to persevere with the "hard work" of recovery [3,5]. The peer videos elicited conversations about the participant's life experiences over time and what worked for them, rather than focusing on problems and deficits as can occur in mental health services [13]. Our focus on the experience of watching lived experience videos together contrasts with the experience of using an Internet portal for asynchronous communication [43], which was found to enrich the working relationship if service user and worker expectations about portal use were aligned, but to cause relationship tensions if expectations were not aligned. In our study, regular shared use of the website appeared to create a clear focus on recovery in interactions between the service user and worker from service users' perspectives, potentially reducing the goal ambiguity that can characterize these relationships [30]. Together, these findings contribute to emerging evidence that using an Internet-based resource with a mental health worker, particularly a resource that includes lived experience content, can enhance mental health service provision when expectations about its use are agreed and implemented. Given the potential benefits to recovery-oriented practice, this is a strategy worthy of further investigation.

## Limitations

Limitations of this study include participants being involved in a research project, with many expressing a desire to help others experiencing mental illness through their involvement, a purpose that may influence the way that they responded in the interview [44]. Further research into using lived experience videos in other mental health practice settings would support transferability of the findings. Focusing on one element of the website, the lived experience videos, means that participants' full use of this digital health intervention is not covered in this analysis. However, focusing on the videos, designed as a central component of the intervention, illuminated that participants experienced them as especially impactful. Understanding participants' experience of watching videos in depth is therefore important to informing future developments in digital health interventions for people experiencing psychosis.

## Conclusions

The experience of engaging with videos featuring peers in the SMART website was powerful for participants. Hearing from peers enabled participants to feel less alone, to be inspired, and to believe that their own recovery was possible. Aspects of the intrapersonal and interpersonal contexts that existed when watching lived experience videos together shaped the way that participants perceived the experience. Contextual factors are therefore important to consider when using digital health interventions in mental health services. This study adds to emerging evidence that digital health interventions with lived experience content used by service users and mental health workers together have strong potential to support service users' recovery and are therefore worthy of further development, implementation, and research.

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## Authors' Contributions

All authors are affiliated with the SMART research project, which is led by NT and managed by FF. All authors collaborated on the qualitative research component of the project. This was implemented by AW, EF, and JF. All authors contributed to the final manuscript.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Service user semistructured interview guide.

[[PDF File \(Adobe PDF File\), 50KB - mental\\_v5i2e37\\_app1.pdf](#) ]

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## Abbreviations

**CGT:** constructivist grounded theory

**CHIME:** Connectedness, Hope, Identity, Meaning, Empowerment

**SMART: Self-Management And Recovery Technology**

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Original Paper

# Worker Preferences for a Mental Health App Within Male-Dominated Industries: Participatory Study

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## Abstract

**Background:** Men are less likely to seek help for mental health problems, possibly because of stigma imposed by cultural masculine norms. These tendencies may be amplified within male-dominated workplaces such as the emergency services or transport industries. Mobile apps present a promising way to provide access to mental health support. However, little is known about the kinds of mental health technologies men would be willing to engage with, and no app can be effective if the intended users do not engage with it.

**Objective:** The goal of this participatory user research study was to explore the perceptions, preferences, and ideas of workers in male-dominated workplaces to define requirements for a mental health app that would be engaging and effective at improving psychological well-being.

**Methods:** Workers from male-dominated workplaces in rural, suburban, and urban locations took part in an exploratory qualitative study involving participatory workshops designed to elicit their perspectives and preferences for mental health support and the design of an app for mental health. Participants generated a number of artifacts (including draft screen designs and promotional material) designed to reify their perceptions, tacit knowledge, and ideas.

**Results:** A total of 60 workers aged between 26 and 65 years, 92% (55/60) male, from male-dominated workplaces in rural (16/60, 27%), suburban (14/60, 23%), and urban (30/60, 50%) locations participated in one of the 6 workshops, resulting in 49 unique feature ideas and 81 participant-generated artifacts. Thematic analysis resulted in a set of feature, language, and style preferences, as well as characteristics considered important by participants for a mental health app. The term “mental health” was highly stigmatized and disliked by participants. Tools including a mood tracker, self-assessment, and mood-fix tool were highly valued, and app characteristics such as brevity of interactions, minimal on-screen text, and a solutions-oriented approach were considered essential by participants. Some implementation strategies based on these findings are included in the discussion.

**Conclusions:** Future mental health mobile phone apps targeting workers in male-dominated workplaces need to consider language use and preferred features, as well as balance the preferences of users with the demands of evidence-based intervention. In addition to informing the development of mental health apps for workers in male-dominated industries, these findings may also provide insights for mental health technologies, for men in general, and for others in high-stigma environments.

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**KEYWORDS**

mental health; mhealth; mobile apps; workplace; men; participatory design

## Introduction

Men account for 75% of suicides but are less likely to seek help for mental health problems and are more likely to use unhelpful coping strategies [1]. Low rates of help-seeking in men are likely due in part to the stigma imposed by dominant cultural masculine norms that discourage emotional expression and help-seeking as signs of weakness [2-4]. This effect and its impact on mental health are likely to be amplified within hyper-masculinized cultures such as male-dominated workplaces [5]. Furthermore, some male-dominated industries, such as emergency services, mining, and transport, involve additional risks and obstacles to mental health, including isolation (in rural and remote locations) and increased exposure to traumatic incidents [6].

Owing to the prevalence of mobile phone use, mobile phone-based mental health interventions have become an increasingly popular approach to overcoming traditional barriers to access of mental health services [7]. However, an app can only be effective if it is engaged with by the population it is intended for, which means knowledge of user perceptions, values, and preferences with regard to app-based support is critical.

Participatory design, as a methodology for involving users in the design process, provides a set of methods and user-centered orientation for eliciting user perspectives, preferences, and ideas for the codesign of technologies [8]. Participatory design is also increasingly used as a method for the design of health and mental health technologies to empower patients or end users by involving them in development and to ensure tools are more likely to be engaging and effective [9-11]. Furthermore, participatory methods provide a way to create a democratic and destigmatized space in which to discuss mental health issues. Previous qualitative studies have shown that when men are provided with relevant information in a safe space, they can be willing to discuss mental health issues [10].

In this paper, we present results from the user research phase of the development of an app intended to improve the well-being of workers in male-dominated workplaces. A participatory design approach was selected with the intention of gleaning insights that would help guide the design in ways that avoided triggering stigma (ie, via language and style) and that would ensure elements of clear value for users would be built into the app to increase uptake and ongoing engagement.

Our aim was to help address some of the difficulties in engaging men with mental health support by (1) presenting qualitative results of their perceptions, preferences, and ideas related to mental health technologies and (2) providing an example of how a research-based app for mental health might be designed

in alignment with these perceptions and preferences. For the latter, we include examples of how conflicts between user requirements and research-based mental health practice might be resolved via interaction design.

## Methods

### Recruitment

Workers were invited to participate in the study via email announcements distributed to employees of 2 male-dominated organizations who were partners on the project: a state fire and rescue service (the seventh largest urban fire service in the world) and a multinational freight transport company based in Australia.

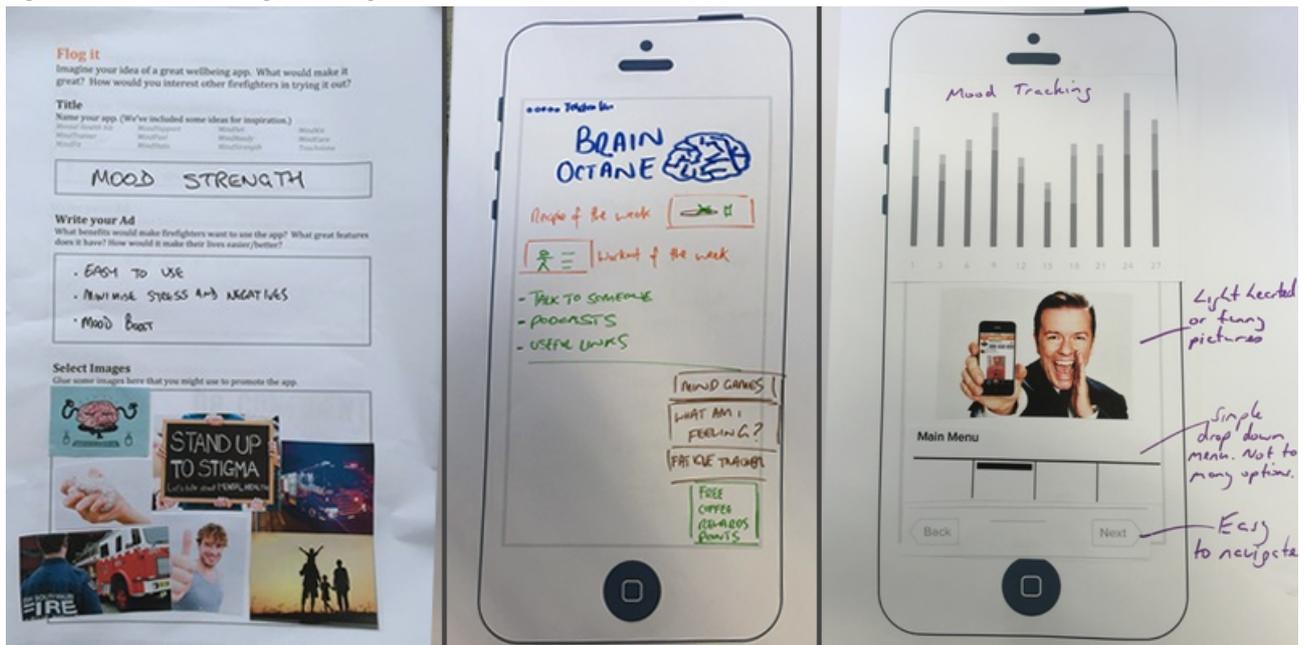
The only eligibility criterion for the study was that participants worked in a male-dominated industry, which was described in the recruitment material as “a largely male industry (eg, transport, fire and rescue, construction).” Before participating in the workshops, participants were provided with an information sheet describing the study and a consent form in alignment with University of New South Wales ethics committee requirements. This research was approved by the Research Ethics Committee at the University of New South Wales (HC16646).

### Participatory Design Workshops

Activity-based workshops (2.5 hours each) were carried out with groups of participants (consisting of a minimum of 5 and a maximum of 17 participants per group). During each workshop, the first author, a user experience specialist, guided participants through a series of activities designed to elicit: (1) their current experience of issues and ideas to do with mental health support in their workplace (a preparatory exercise), and (2) their ideas and preferences for an app that would support mental health for themselves and other workers in male-dominated industries.

Activities were selected to fulfill a series of user research questions defined by the research team and were drawn from the literature on participatory design [8,12,13]. Activities included individual reflection, collaborative ideation, and paper prototyping. Participants were facilitated in generating ideas for desirable functionalities and characteristics and were provided with templates and materials with which to draft screen designs and promotional materials for the app, which elicited preferred use of language and imagery (please see [Multimedia Appendix 1](#) for a detailed outline of the workshop process). Data collected included participant-generated artifacts from each of the activities (ie, filled-in advertisement templates and screen designs), collections of feature ideas on sticky notes, field notes, and audio recordings of each workshop.

**Figure 1.** Examples of artifacts generated by participants during workshops (an advertisement template on the left side and 2 screen designs from participants at different workshops on the right side).



In addition to the workshops, a group of 106 workers (different to participants of the workshops) completed a questionnaire intended to collect quantitative information on mobile phone and technology use (results reported in the study by Deady et al [14]). Although this survey focused on separate data, it does provide corroborating evidence for 2 findings emerging from the workshops described herein. First, the survey found that respondents “preferred terms such as ‘well-being’ and ‘mental fitness’ for referring to mental health” (made clear by participants in our workshops). Second, behavioral therapeutic techniques were regarded most favorably (which is also reflected in the feature ideas generated by our workshop participants).

### Data Analysis

Using thematic analysis [15] and consistent with methods for the analysis of generative participatory data [6], the text, imagery from workshop artifacts, as well as verbal transcripts of audio recordings (transcribed using NVivo, a qualitative data analysis software developed by QSR International) were analyzed and categorized into themes. User research was conducted toward a specific outcome (the development of an app), and therefore, analysis was guided by the research questions in support of that outcome. Therefore, of the issues discussed by the participants, analysis focused on those categories of data that would inform app development, namely, themes associated with app features, app characteristics, motivations for engagement, and attitudes relating to language use and visual style that would impact acceptability of the app. Categories were created as feature types, eg, a category “notifications and reminders” included “prompts to retake self-assessment” and “alerts to fresh content in the app.” Initial coding attached labels to text segments which appeared to indicate important material in relation to the research questions. Analysis then progressed iteratively to develop a set of themes that identified sets of features, characteristics, language, and style elements. The text and imagery from workshop artifacts were also incorporated into this thematic

analysis (the latter based on the verbal descriptions given the images by participants).

Figure 1 shows examples of the types of artifacts generated by participants during workshops.

## Results

### Participatory Design Workshops: Demographics

A total of 60 workers (mean age 47 years; range 26-65; 55/60 or 92% male) participated in one of the 6 workshops conducted between February and April 2016. Of these, 55 worked for an Australian state fire and rescue service, based at an urban (30/60, 50%), suburban (14/60, 23%), or rural (16/60, 27%) location, whereas 5 worked at a suburban freight transport company. Moreover, 58 (97%) participants reported using a mobile phone.

### Key Features Requested by Participants

Qualitative analysis of 81 participant-generated artifacts (54 screen designs, 27 advertisement templates) together with sets of feature ideas from ideation yielded a set of user-preferred features, functionalities, and characteristics for a mental health app for workers in male-dominated industries. A total of 51 unique feature ideas were generated through these processes (see [Multimedia Appendix 2](#)). Among these, 7 emerged independently and consistently in all workshops:

- Mood tracking
- Mood-fix (for quick fixes of negative mental states)
- Easy access to urgent help
- Links to mental health support organizations (external and employer-provided)
- Guidance on how to deal with specific situations that occur on the job
- Stories of lived experience from respected members of the community
- Notifications and reminders to use the app

Seven more features emerged independently in at least 4 workshops.

- A self-assessment tool
- Solutions or strategies based on the self-assessment
- Something to show your progress
- Guidance on how to have mental health discussions (with friends/family)
- Brain games or puzzles
- A dashboard (showing progress and stats)
- Notifications alerting to fresh content

Below, we elaborate on 6 of these in greater detail including the mood tracking tool, mood-fix tool, guidance on mental health discussions, stories of lived experience (the 4 among the top 7 that warrant further explanation), and self-assessment (because it was a feature important to both participants and researchers).

### **Mood Tracking**

The idea of mood tracking emerged in all the 6 workshops. [Figure 2](#) shows some of the various ways in which mood tracking was envisioned by participants as part of workshop activities.

Specific ideas about design implementations of the mood tracker varied widely, with some participants reporting they would only use a very simple tracker (eg, a set of smiley faces), whereas others suggesting the app should provide the ability to label one's emotions in detail to improve self-awareness. Some requested the ability to record reasons for current moods, whereas others wanted to link moods to activities such as sleep and exercise. There were also varied perspectives on whether mood logging should occur once a day, more often, or at random times. The following quotations demonstrate some of the ways participants expressed a desire for mood tracking:

*So that people can have visual feedback at the end of every week, month, cause most people won't track back, they'll just go, "I feel like shit," but they won't necessarily track back and go "this is why I feel like shit" ... When you get visual things you might go "Oh, well actually, maybe I've had a lot of stuff going on--maybe it's not that weird that I'm not feeling great now."*

*How you're feeling, what your sleep's like and you can track that.*

*I wouldn't do it once a day, I'd probably only do it if I felt shit.*

*I'm having a great day 'cause this happened or, I'm having a shit day 'cause this happened.*

*By identifying what emotion they feel, because most people aren't actually sure what emotion they're feeling. Like "Oh, am I disappointed or am I sad?" The process of having to identify, that's actually what*

*I feel—because a lot of people are not happy or sad or angry. That's the three, there's nothing else.*

### **Mood-Fix Tool**

Participants highly valued the notion of a tool that could be used for instant relief in moments of distress, and they described this in various ways including a "mood boost," "stress button" help to "reset your mind," or a tool to "change focus":

*Mood boost...trying to get yourself back into a happy place.*

*Just buttons you can press on. Stress relieving games, stress relieving ideas, ideas to try and change your train of thought.*

### **Self-Assessment Tool**

There was strong interest among participants in having a way to judge one's own state of mental health, with some participants highlighting the difficulty some people have in realizing they need help:

*Hard hitting questions to identify whether your mind is where you think it is.*

*Quick stress check that identifies you may require help.*

*Over here is a bit of a resilience status, so maybe you could gauge...how resilient you are to mental health issues.*

*For the assessment bit it's "how are you feeling? Are you feeling happy, sad, fatigued, mood swings?" You can self-assess and see how you're going and that can allow you to progress to the next stage in sorting things out.*

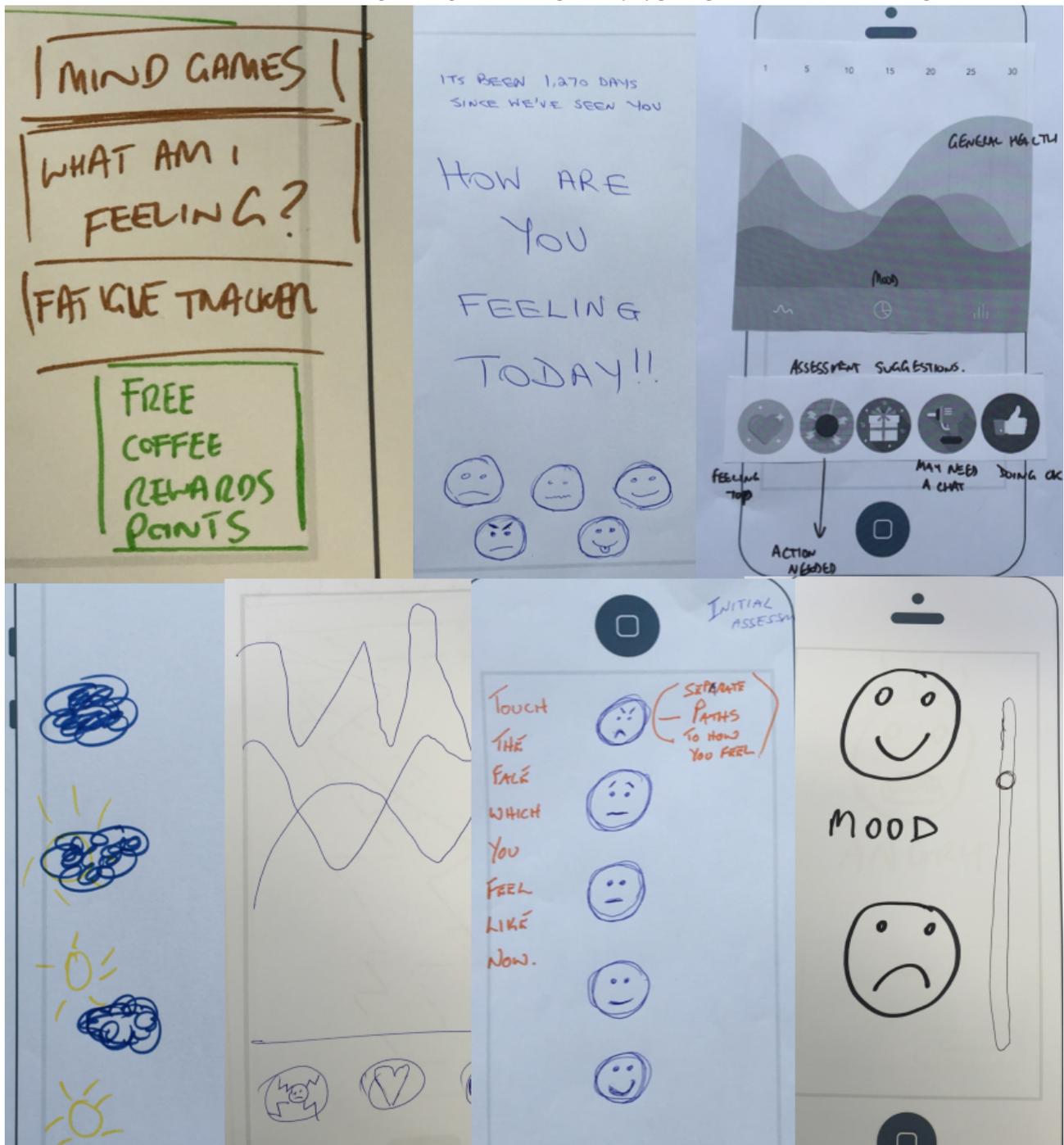
*Sometimes, you don't realize you're in that position until someone drags it out of you, so I don't know if there's a way to identify that you're not yourself.*

### **Guidance on Having Mental Health Discussions**

Participants expressed a desire for help in determining how they could discuss mental health with others and how they might help someone they suspected of struggling with a mental health issue. Specifically, they requested tips on ways to talk to family about mental health and on how to help a friend:

*What if, as part of the app, you had coaching techniques on how to guide conversations, how to bring things up very casually—it could be for your own benefit, like if I need to talk about this, how do I raise that with my crew? how do I raise it with my family? But also if you can see in one of your workmates, or one your family members, someone is struggling, how do I raise that with them and put them in a position where they feel comfortable talking to me about it or where they feel open and trusting of me to express how they're feeling? That would be really useful.*

Figure 2. Seven different instances of a mood tracking feature generated independently by participants from different workshops.



**Tackling Stigma Through Personal Stories**

Participants were openly aware of the problem of stigma within their population and proposed various possible solutions in relation to technology design. First, they reported that selection of terminology would be very important as some language carries a high stigma burden (as described further below). Second, participants across workshops independently recommended the use of personal stories of lived experience (preferably in the form of videos) as an effective method of reducing stigma, in particular, if the personal stories are told by respected members of the public or celebrities:

*Find cool people that have mental health issues.*

*Sometimes if someone's gone through something and they're willing to admit to it and go on to show how it affected them and how they got through it, that's a good way 'cause you can relate to that.*

**Language and Style Preferences**

Many of the preferences expressed by participants are related to language, style, or technical characteristics (ie, "easy-to-use," "highly visual," and "accessible off-line") rather than features or functionalities. These characteristics are included below:

*I like graphic sort-of-things. On our Intranet we have two screens: one is all the details, the second screen is a graphic representation of what the watch desk is*

*and I go there all the time--it's a lot easier for me to go to that and click on what I need.*

*I find it frustrating reading too much information—long-winded, too wordy, what are you trying to say? Push the button, tell me! I don't really feel like reading. I'm not feeling well, do you really want me to work at it, as well?*

There was apparent consensus among participants that the term “mental health” equated to serious illness, being “crazy,” and was highly stigmatized and something many would not want to be associated with. In contrast, the terms “wellbeing,” “resilience,” and “mental fitness” were perceived as more positive and therefore preferable:

*I think the more serious you make the issue, the more stigma there is attached to it. Like if you break down and you can have guys talking about it on a colloquial level, then more people are going to be likely to engage with it. If you make it out to be a very like “oh, he has mental health problems, that's a big deal” people are going to step away from it in a big way.*

*We just like the word MindFit. People seem to be using fitness apps, and it's got the same word... It's got a positive connotation—nothing negative about it.*

*Mental health goes hand in hand with physical fitness to a certain point of view 'cause while exercise is probably one of the best things you can do if you're struggling with mental health... but if you get some sort of link, like an offshoot of the fitness thing... So, you go, “I'm gonna do my 4K run in 11 mins and then going around the track and getting better” but it's also linked to your mental health app.*

In conversation, participants themselves opted for these terms to describe mental health issues.

Negative terms used by participants were as follows:

- Stress or feeling stressed
- Struggling
- Not yourself
- Feeling shithouse, having a shit day
- Depressed
- Feeling a bit “How ya' going”
- Having negative thoughts and behaviors

Positive terms used by participants were as follows:

- Change your mindset
- Relax and release
- Just get it all out
- Mood boost

### Motivators for Mental Health Self-Care

The 3 most salient motivators for either help-seeking or proactively maintaining mental health were concern for family, preparedness or prevention (preventing problems before they occur and being prepared for psychologically challenging situations), and social influence.

In terms of the family as motivator, there was a widely expressed concern to do with one's own stress and mental health having a negative impact on the family and a desire not to take work stress home but to be one's best self for one's family:

*Trying to get yourself back in a happy place, especially if you have a young family, as we said before, any negative thoughts are going to impact negatively on the family as well.*

With regard to preparedness, many participants (particularly those who worked in first responder settings) expressed a strong interest in proactively strengthening resilience as a component of overall health to prevent mental health problems and to be prepared for psychologically challenging situations:

*[The app's] not for somebody who's in the process of severe mental problems. This is more along the lines of getting it before it happens.*

*More resilience coaching and training before you have issues... to prepare you for what you're doing.*

*What can we do to build resilience?... Like how do we get in before a major issue?*

Finally, participants also reported being influenced by the attitudes and behaviors of friends and coworkers in relation to technology use:

*Most of the apps I use have been recommended by one of our mates...*

*If your mate is a bit overweight and they started using Strava, and they got addicted to it, and you say “he lost 10 kilos and is riding 100 K's every morning; gee he's doing alright, maybe that's helped him do that.” So probably results from something is going to make you share it.*

More broadly, participant data revealed a preference for a practical and active solutions-based approach. For example, participants commonly requested “tips,” “strategies,” “tools,” “exercises,” “direct links to solutions,” and suggested actions that can be taken:

*The guide might say “you're a low risk, do this” or “you're a high risk, do something else.”*

## Discussion

### Principal Findings

This participatory user research study aimed to explore the preferences of those in male-dominated industries with regard to mental health mobile phone apps. Given the well-documented difficulties engaging workers from these types of industries in mental health promotion, such insights are likely to be crucial to the successful development of new e-mental health interventions. Our results highlight that this group of workers does have a set of features, language, and style preferences that they feel are essential in any future mental health app. The term “mental health” was highly stigmatized, with alternative positive expressions for mental health, like “mental fitness,” being greatly preferred. A range of specific features including mood tracking, self-assessment, and “mood boost” tools were highly

valued in addition to characteristics such as brevity, minimal on-screen text, and a solutions-oriented approach.

Men have traditionally poor rates of mental health help-seeking among face-to-face services and poor engagement with health promotion activities more generally, although relatively little work has focused on the specific preferences of this group regarding eHealth technologies for mental health. Recent studies reporting on young men's attitudes and behaviors in relation to mental health and technology allow for comparison with the perspectives and preferences identified among our participants [16,17]. Ellis et al [16] found that young men shared a preference for action-oriented strategies (rather than talk-based strategies) for self-help. In addition, the adolescent and young male participants expressed interest in content featuring celebrities or role models, just as our cohort endorsed the use of respected community members as a strategy to battle stigma. Finally, Ellis et al report a broad interest among young men in tools to help "identify, discuss and manage mental health issues" also shared by the participants in our study. In spite of these similarities, our cohort of working aged men (compared with Ellis' young study population) expressed a number of additional concerns. For example, the adults in our population expressed motivational drivers and concerns stemming from being the head of a family or in a "caretaker" role. The adults in our study also demonstrated a greater diversity with regard to technology use owing both to some older participants having less experience and less free time to engage with mobile technology. Finally, although Ellis et al report that many young men "tended to believe they would never be personally affected by a mental health difficulty," this was not prevalent among our adult male cohort where participants demonstrated significant lived experience of mental health issues, either personally (sometimes due to work-related incidents) or secondhand via experiences of friends' or family members' struggles.

### Translation of Findings Into Design of a Mental Health App

We report on some of the ways we translated the insights from user research into app design, including how we resolved issues of misalignment between user and researcher requirements. Results from user research highlighted the importance of including features of clear and practical value to the users themselves. Interestingly, these features only minimally overlapped with those deemed important by many mental health researchers, and our approach to reconciling the 2 is discussed below.

Evidence-based programs for mental health support generally require lengthy and reflective sessions of interaction with a therapist or with therapeutic content generally consisting largely of written text. In contrast, our participants reported that they would not want to spend more than a few minutes at a time with a mental health app, and that an appealing app should require as little text reading as possible. Furthermore, rather than

programs of self-improvement, they were largely interested in self-tracking, self-assessment, as well as strategies and tools for problem solving in the moment of need (a solutions-based task-oriented approach).

The research team took 2 key approaches to resolving misalignment between user preference and clinical need. First, we incorporated 3 of the top user-preferred features into the app (mood tracking, mood fixing, and self-assessment). One of these (self-assessment) aligned with clinical requirements for the app, and the other 2, although not specified as clinically necessary for the app, are components commonly used in evidence-based interventions, such as cognitive behavioral and behavioral activation therapy [18]. Second, we redesigned the evidenced-based therapeutic content to allow it to meet user requirements for brevity. We describe these approaches in detail below and present them as examples of how a mobile phone app for mental health might be designed to meet user needs. The app has been made available and can be downloaded from both the Apple and Google Play app stores [19].

With regard to a mood-tracking feature, our results indicated that some users wanted to be able to enter specific emotion labels, whereas others insisted they would only use a mood tracker if it were very basic and easy to use. Our proposed design solution, therefore, includes both options in a 2-step process. On the first screen, the user can select from 5 simple mood labels (awful, bad, ok, good, and great). On the next screen, the user can choose to "be more specific" by selecting from 5 additional specific emotion labels that elaborate on the mood already selected or they can ignore this option and just click "save" (see Figure 3).

The desire for a "Mood fix" feature was translated into a "Toolbox" that could act as a container for learned prevention skills and techniques an individual acquires. For our implementation, the "Toolbox" could hold a number of different approaches to managing negative moods as well as tools for other topics mentioned in workshops such as guidance on how to help a friend who is struggling. Finally, the toolbox allowed a series of new tools to be earned as rewards for moving through the therapeutic core of the app, described below. An example of how a toolbox may look is provided in Figure 4.

A key misalignment between the findings of our study and the need for more detailed, lengthy therapeutic interventions is users' desire for brief interactions. The solution we propose for this is to restructure established interventions into small chunks of highly visual interactive content and single exercises that could be undertaken by users once a day (in 2- to 5-min sessions) over a longer period. In this way, longer evidence-based interventions can be translated into "Daily challenges." Figure 5 shows an example of our approach: a 30-day program of evidence-based interventions or "Daily challenges," which included exercises based on behavioral activation theory, mindfulness, and psycho-education.

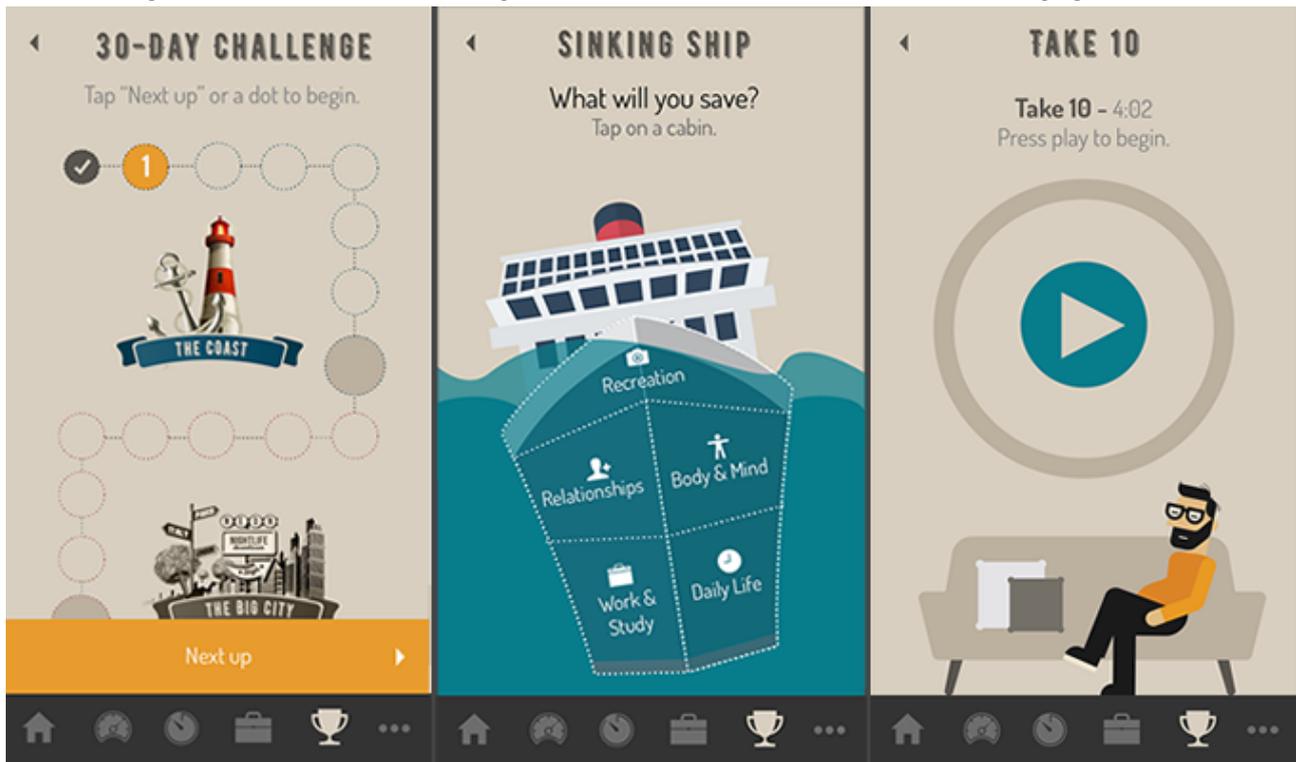
**Figure 3.** The mood tracker allows users to log a mood based on a very simple 5-item scale and also provides the opportunity for those who are interested in being more specific to reflect on a more specific emotion label. Both use cases emerged from varying participant perspectives at workshops.



**Figure 4.** An example of how learned prevention skills and techniques could be presented to users within a mental health mobile phone app.



**Figure 5.** An example of how traditional interventions might be broken into 2- to 5-min sessions delivered over a longer period.



## Limitations

Consistent with Brownhill [20], we found that when given a safe space in which to discuss mental health issues, participants were willing to discuss these issues openly and were highly generative of ideas. However, it should be noted that this is also likely to have been influenced by a self-selection bias in that those who volunteered for the study are likely to represent those more willing to discuss mental health issues. We did not collect information on each participant's previous experience with mental health issues (eg, by proxy, lived experience) or to what extent each participant identified with a strong concept of masculinity. We also acknowledge that there will be limitations related to our particular applied focus to the data analysis. Data were categorized specifically to inform the development of an app, and other approaches to analysis would likely shed light on other aspects of the data. The participant cohort was also limited with respect to geography and the variety of industries represented. The vast majority of participants were drawn from the emergency services (specifically fire and rescue), and all participants were from Australia, meaning their responses may

not be generalizable to other populations. For example, other aspects of emergency service work, apart from being male-dominated, may have influenced the results obtained (eg, that the work is non-sedentary, high-risk, and involves exposure to traumatic incidents).

## Conclusions

In this study, we attempted to address the gap in understanding of male preferences for mental health apps, in light of the high stigma and lower help-seeking behavior associated with men. Results from our user research highlighted the importance of using nonstigmatized language and including features of clear and practical value to the users themselves. Most saliently, the term "mental health" was considered highly stigmatized and should be avoided, especially when the focus is preventative or promotional rather than for treatment. In addition, assessment and ongoing tracking of mood and mental state were highly valued as were highly visual and solution-oriented strategies and tools for fixing problems. Further research involving men from other countries and within other industries would contribute to generalization of these results.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Design outline for participatory workshops.

[[PDF File \(Adobe PDF File\), 80KB - mental\\_v5i2e30\\_app1.pdf](#)]

## Multimedia Appendix 2

Feature ideas generated via participatory design activities.

[[PDF File \(Adobe PDF File\), 43KB - mental\\_v5i2e30\\_app2.pdf](#)]

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Original Paper

# Temporal Associations Between Social Activity and Mood, Fatigue, and Pain in Older Adults With HIV: An Ecological Momentary Assessment Study

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## Abstract

**Background:** Social isolation is associated with an increased risk for mental and physical health problems, especially among older persons living with HIV (PLWH). Thus, there is a need to better understand real-time temporal associations between social activity and mood- and health-related factors in this population to inform possible future interventions.

**Objective:** This study aims to examine real-time relationships between social activity and mood, fatigue, and pain in a sample of older PLWH.

**Methods:** A total of 20 older PLWH, recruited from the University of California, San Diego HIV Neurobehavioral Research Program in 2016, completed smartphone-based ecological momentary assessment (EMA) surveys 5 times per day for 1 week. Participants reported their current social activity (alone vs not alone and number of social interactions) and levels of mood (sadness, happiness, and stress), fatigue, and pain. Mixed-effects regression models were used to analyze concurrent and lagged associations among social activity, mood, fatigue, and pain.

**Results:** Participants (mean age 58.8, SD 4.3 years) reported being alone 63% of the time, on average, (SD 31.5%) during waking hours. Being alone was related to lower concurrent happiness (beta=-.300; 95% CI -.525 to -.079;  $P=.008$ ). In lagged analyses, social activity predicted higher levels of fatigue later in the day (beta=-1.089; 95% CI -1.780 to -0.396;  $P=.002$ ), and higher pain levels predicted being alone in the morning with a reduced likelihood of being alone as the day progressed (odds ratio 0.945, 95% CI 0.901-0.992;  $P=.02$ ).

**Conclusions:** The use of EMA elucidated a high rate of time spent alone among older PLWH. Promoting social activity despite the presence of pain or fatigue may improve happiness and psychological well-being in this population.

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**KEYWORDS**

AIDS; ecological momentary assessment; social isolation; happiness; quality of life

## Introduction

Social isolation is a well-known risk factor for incident mental and physical health problems, including depression [1],

distressing somatic symptoms (eg, pain and fatigue) [2], substance use [3], cognitive impairment [4], heart disease [5], and mortality [6]. In fact, meta-analytic work has shown that having social relationships is associated with reduced mortality

risk comparable with that of well-known health factors such as not smoking (vs smoking), abstaining from alcohol (vs binge drinking), engaging in rigorous physical activity (vs low-to-no physical activity), and being lean (vs obese) [7]. Notably, however, the relationship between social activity and health is also reciprocal, such that chronic illnesses and diminished health can result in physical (eg, disability), emotional (eg, stigma and stress), and financial barriers to engagement in social activities, leading to social isolation [8].

Older persons living with HIV (PLWH) are a rapidly growing population of individuals who are at a significantly increased risk for social isolation compared with older persons without HIV [9]. In addition to social barriers that older HIV-uninfected adults often face (eg, retirement, hearing loss, and mobility impairment) [10], older PLWH face barriers to social support that are specifically related to HIV infection, including HIV-related stigma and discrimination [11], nondisclosure of HIV status [12], and loss of their social support network because of AIDS-related deaths [13]. Furthermore, these individuals also often have several medical comorbidities (eg, chronic diarrhea, lipodystrophy, cardiovascular disease, cancers, kidney and liver diseases, and osteoporosis) that can cause significant emotional distress, fatigue, and pain, leading to further social withdrawal [14-16]. Fatigue and pain are common somatic symptoms of HIV infection and can be critical barriers to engagement in social activity [17,18]. Results from a recent study conducted by Moore et al support findings of decreased social activity among older PLWH such that participants reported spending a majority of their sampled time at home, alone, and engaged in passive leisure activities (eg, watching television) [19]. Furthermore, older PLWH are more likely to live alone compared with both younger PLWH and their seronegative counterparts [9,12], greatly increasing the risk for social isolation.

In addition to the mental and physical health consequences of social isolation in the general population, older PLWH are also particularly vulnerable to worsening HIV disease progression without adequate social support [20]. Possible mechanisms for this include increased depression and reduced psychological well-being in older PLWH who are socially isolated [21], which in turn can contribute to decreased immune function and nonadherence to antiretroviral therapy medication [22,23]. Despite the increased risk for, and long-term detrimental consequences of, social isolation among older PLWH, there is a lack of research on the real-time temporal associations of social activity and mood- and health-related factors in this population.

Ecological momentary assessment (EMA) is a data collection method that has potential to help fill a gap in research on social

activity among older PLWH. EMA is a highly feasible, valid, and reliable way to obtain real-world, real-time evaluations of various behaviors (eg, social activity) and experiences (eg, mood, fatigue, and pain) in a range of clinical and nonclinical samples, including older adults [19,24,25]. Thus, EMA can allow us to examine the temporal dynamics of social activity, in particular whether social activity predicts mood- and health-related factors (ie, fatigue and pain) or vice versa. Previous studies suggest that these relationships are often reciprocal and cyclical—ie, levels of social activity influence mental and physical health, and mental and physical health simultaneously influence levels of social activity, creating a potential downward spiral of decreasing social activity and worsening health outcomes [26]; however, such real-time relationships have yet to be examined among older PLWH.

Therefore, this study aims to use EMA to examine real-time relationships between social activity and mood, fatigue, and pain among older PLWH. Of note, the construct of fatigue in this study is represented by the reported current level of tiredness, consistent with geriatric literature [27]. First, we explored relationships between HIV disease characteristics and social activity (ie, proportion of time alone and number of social interactions per day). Next, we examined concurrent (ie, using responses within the same EMA survey) and lagged (ie, using responses from one survey to predict responses on the next survey) relationships between social activity (ie, alone vs not alone) and sad mood, happy mood, stress, fatigue, and pain level. Regarding concurrent relationships, we hypothesized that being alone would be related to lower ratings of happy mood and higher ratings of sad mood, stress, fatigue, and pain level. Regarding lagged relationships, we hypothesized that being alone on one survey would predict lower ratings of happy mood and higher ratings of sad mood, stress, fatigue, and pain level on the next survey; similarly, we also hypothesized that lower ratings of happy mood and higher ratings of sad mood, stress, fatigue, and pain level on one survey would predict greater likelihood of being alone on the next survey.

## Methods

### Participants

A total of 20 HIV-positive participants aged 51 to 67 years were recruited from ongoing studies at the University of California, San Diego (UCSD) HIV Neurobehavioral Research Program. Inclusion and exclusion criteria are given in [Textboxes 1](#) and [2](#), respectively. The UCSD Human Research Protections Program approved the study, and all participants completed an assessment of capacity to consent [28] before providing written informed consent.

#### Textbox 1. Inclusion criteria for this study.

- HIV seropositive
- Aged 50 years or older at enrollment
- Fluent in English
- Ability to provide written informed consent

**Textbox 2.** Exclusion criteria for this study.

- Psychotic disorders (eg, schizophrenia)
- Severe neurological disease (eg, stroke)
- A positive urine toxicology for substances of abuse (any drugs with the exception of marijuana) or breathalyzer test (for alcohol) on the day of testing

## Measures and Procedure

### *HIV Disease Characteristics*

To assess HIV disease characteristics, the participants completed a neuromedical examination, consisting of a clinical interview and laboratory testing. HIV serostatus was determined by MedMira Miriad rapid test (Nova Scotia, Canada) or by enzyme-linked immunosorbent assays and confirmatory Western blot test. Nadir CD4 count was self-reported unless the laboratory-tested current CD4 count was lower than the self-reported nadir value; in these cases, the current CD4 count was also recorded as the nadir CD4 count. Plasma HIV viral load was considered undetectable with a lower limit of quantification below 40 copies/mL.

### *Baseline Psychiatric Characteristics*

Participants completed the Beck Depression Inventory-II (BDI-II) [29] and the Medical Outcomes Study (MOS) Social Support Survey [30] to assess depressed mood and perceived social support, respectively.

### *Ecological Momentary Assessment Protocol and Procedures*

All participants were provided with an Android operating system smartphone. At the initial study visit, the examiner explained how to access and respond to the survey questions on the smartphone. Participants were also given an informational manual (Flesch-Kincaid readability grade level=4.4) on how to use the smartphone and complete the surveys. In addition, participants completed an in-person practice survey monitored by the examiner to assess any difficulties the participant had with the phone or survey questions. On the first day of the study, the examiner called each participant to verify if they had any questions or difficulties completing the surveys at home. If participants were in possession of a personal smartphone, they agreed to carry the study smartphone along with their personal phone for the duration of the study.

Participants completed 5 EMA surveys per day for 1 week, providing up to 35 data points per person. This frequency of assessment has been previously associated with high rates of survey adherence in psychiatric patients [31,32]. Timing of the surveys was set in collaboration with each participant's preferences and sleep-wake schedules. Time-stamped, de-identified, and encrypted responses were instantly transferred to our password-protected server. At the completion of the EMA assessment period, participants returned the smartphones and completed a follow-up interview regarding their experience carrying and operating the smartphone, as well as their opinion regarding the frequency and duration of the assessments.

### *Ecological Momentary Assessment Survey*

Each EMA survey asked participants about their social activity, mood, fatigue, and pain. Social questions included the following:

1. *Who is with you at this moment?* Response choices: alone, spouse or partner, friends, other family members, pets, health care provider, other known people, and unknown people.
2. *Since the last alarm, how many times did you socialize with someone else (eg, spent more than 5 min talking or communicating with someone else)?* To be consistent with literature on the association between social relationships and health outcomes (in which social relationships include only human interactions) [7], participants were identified as being alone when they stated they were currently "alone" or with "pets."

Mood, fatigue, and pain questions included the following:

1. *How happy do you feel right now?*
2. *How sad do you feel right now?*
3. *How stressed do you feel right now?*
4. *How tired are you right now?*
5. *What is your pain level right now?*

Response choices for happy, sad, stressed, and fatigue were on a 7-point scale from 1=*not at all* to 7=*extremely*, and response choices for pain were on a 10-point scale from 1=*minimal or no pain* to 10=*severe pain*. Regarding the fourth question, we conceptualize fatigue as synonymous with the current level of reported tiredness, consistent with geriatric definitions [27].

### **Statistical Analyses**

All participants included sufficient EMA data points (>50%) to be included in analyses. Separate mixed-effects regressions were completed to evaluate concurrent (within-survey associations) and lagged (one lag, such that responses from one survey predicted responses on the next survey) associations between dichotomous social activity (alone vs not alone) and levels of mood (happy, sad, and stressed), fatigue, and pain based on the time of day. Specifically, 3 sets of analyses were conducted to examine (1) concurrent associations: social activity as a predictor of same-survey mood, fatigue, and pain; (2) lagged associations: social activity as a predictor of next-survey mood, fatigue, and pain; and (3) lagged associations: mood, fatigue, and pain as predictors of next-survey social activity. For the first set of analyses, 5 linear mixed-effect regression models were used to predict happiness, sadness, stress, fatigue, and pain from the time of day and same-survey social activity. For the second set of analyses, 5 linear mixed-effect regression models were used to predict happiness, sadness, stress, fatigue, and pain from the time of day and previous-survey social activity. For the third set of analyses, 5 mixed-effects logistic regression

models were used to predict social activity from the time of day and previous-survey happiness, sadness, stress, fatigue, and pain. In each of the 15 specified mixed-effects regression models (ie, 5 concurrent and 10 lagged models), predictor variables included only time and a single predictor of interest, with the interaction term between time and the predictor of interest included only if significant at  $P < .05$ .

Missing data were not replaced because mixed-effects regressions are robust to missing data. Notably, the time of day was set as a categorical (5 points per day; Time 1-5) or continuous (hours since midnight) variable based on the results of model comparison using the likelihood ratio test (Multimedia Appendix 1). For this model comparison, we considered 2 different types of models: (1) models in which the effect on the response was linear over time—eg, every 6 h the log odds of social activity would increase by X amount; and (2) models that did not have such a restriction. The choice as to which of the 2 was more appropriate was based on the statistical performance of the models. The linear time effect was preferred for happy mood, sad mood, and pain, whereas the categorical time effect was preferred for stress and fatigue. Thus, for all analyses presented, the time of day was set as a continuous variable for happy mood, sad mood, and pain, whereas the time of day was set as a categorical variable for stress and fatigue. In addition, all models include subject-specific random effects. R software (R Foundation for Statistical Computing, Vienna, Australia), was used for all statistical analyses; the lme4 package for R was used for all mixed-effects regression analyses [33].

## Results

### Relationships Among Social Activity, Demographics, HIV Disease Characteristics, and Baseline Psychiatric Characteristics

The demographic and clinical characteristics of participants are displayed in Table 1. Regarding HIV disease burden, participants were relatively healthy and well controlled, with only one participant not on antiretroviral therapy and having a detectable plasma viral load. Participants completed an average of 86% of EMA surveys (mean 30.3, SD 4.2), spent an average of 63% of typical awake time alone (SD 31.5; range 9.7-100), and had an average of 1.6 social interactions per day over the one-week study period (SD 0.9; range 0-3.1). Female participants reported being alone significantly less often than male participants (18.2% and 71.9% of surveys on average, respectively;  $t_{18}=3.39$ ;  $P=.003$ ; although there were only 3 female participants in the study). HIV disease characteristics were unrelated to the proportion of surveys on which participants reported being alone and to the average number of social interactions per day (Multimedia Appendix 2). In addition,

baseline BDI-II scores were unrelated to EMA social activity variables (Multimedia Appendix 2). Higher baseline MOS Social Support scores were significantly related to fewer proportion of surveys on which participants reported being alone ( $r=-.69$ ;  $P<.001$ ) and a greater average number of social interactions per day ( $r=.54$ ;  $P=.02$ ).

### Concurrent Associations: Social Activity as a Predictor of Same-Survey Mood, Fatigue, and Pain

Table 2 displays the linear mixed-effects models for all concurrent associations between social activity (ie, alone vs not alone) and mood, fatigue, and pain. Being alone was related to lower concurrent happiness (beta=-0.300;  $P=.01$ ; Multimedia Appendix 3); however, being alone was unrelated to sadness, stress, fatigue, or pain level. In addition, results showed significant relationships between the time of day and: (1) stress, such that stress was highest at Time 2 (significantly higher than Time 1;  $P=.01$ ) and steadily decreased from Time 2 to Time 5; (2) fatigue, such that fatigue ratings gradually increased over time; and (3) pain level, such that pain levels increased linearly over the course of a day.

### Lagged Associations: Social Activity as a Predictor of Next-Survey Mood, Fatigue, and Pain

Table 3 displays all linear mixed-effects models in which social activity (ie, alone vs not alone) predicts mood, fatigue, and pain on the next EMA survey. There was a significant interaction between social activity and the time of day on fatigue. The examination of reported fatigue at each time point starting from Time 2 (ie, Time 2-5) showed that being alone at Time 4 was associated with being less tired at Time 5 compared with those who were not alone at Time 4 (beta=-1.089; 95% CI -1.780 to -0.396;  $P=.002$ ; Figure 1). There were no other lagged associations between social activity and mood or pain level.

### Lagged Associations: Mood, Fatigue, and Pain as Predictors of Next-Survey Social Activity

Table 4 shows all mixed-effects logistic regression models in which mood, fatigue, and pain predict social activity (ie, alone vs not alone) on the next EMA survey. There was a significant interaction between pain and the time of day on social activity (beta=0.945; 95% CI 0.901-0.992;  $P=.02$ ). Compared with the lowest pain level, higher pain levels are associated with greater likelihood of being alone earlier in the day and lower likelihood of being alone later in the day (Figure 2). There were no other lagged associations between mood or fatigue and social activity. Notably, results for all concurrent and lagged analyses presented in this report do not differ when the classification of being alone does not include being with “pets.” In addition, a sensitivity analysis removing the 3 female participants from the sample led to similar results and conclusions.

**Table 1.** Demographic and clinical characteristics of participants (N=20).

Characteristics	Value
<b>Demographic characteristics</b>	
Age in years, mean (SD); range	58.8 (4.3); 51-67
Education in years, mean (SD); range	13.4 (2.7); 8-20
Sex (male), n (%)	17 (85)
Race and ethnicity (non-Hispanic white), n (%)	14 (70)
Employed, n (%)	4 (20)
Receiving disability (N=11) <sup>a</sup> , n (%)	7 (64)
Smartphone ownership, n (%)	11 (55)
<b>HIV disease characteristics<sup>b</sup></b>	
Current CD4 in cell/mL (N=19), median (IQR <sup>c</sup> ); range	459 (398-562); 108-750
Nadir CD4 in cell/mL, median (IQR); range	105 (23.2-205.0); 7-350
Detectable plasma viral load (N=16), n (%)	1 (6)
Estimated duration of HIV in years, mean (SD); range	20.4 (7.8); 4.8-29.8
On ART <sup>d</sup> , n (%)	19 (95)
History of AIDS (N=18), n (%)	14 (70)
<b>Baseline psychiatric characteristics</b>	
Beck depression inventory-II, median (IQR); range	3.5 (1.0-9.5); 0-38
MOS <sup>e</sup> Social Support, mean (SD)	65.5 (33.3); 0-100
<b>EMA<sup>f</sup> mood ratings<sup>g</sup></b>	
Happy, mean (SD); range	4.5 (1.1); 1-7
Sad, mean (SD); range	1.9 (1.1); 1-7
Stress, mean (SD); range	2.2 (1.2); 1-7
Fatigue, mean (SD); range	2.7 (0.9); 1-7
Pain level, mean (SD); range	2.0 (1.4); 1-10

<sup>a</sup>Disability was not assessed in the first 9 participants.

<sup>b</sup>Number of days from collection of neuromedical data to EMA visit: mean 70.9 (SD 151.2).

<sup>c</sup>IQR: interquartile range.

<sup>d</sup>ART: antiretroviral therapy.

<sup>e</sup>MOS: Medical Outcomes Study.

<sup>f</sup>EMA: ecological momentary assessment.

<sup>g</sup>EMA mood ratings are over one week on study.

**Table 2.** Mixed-effects models for associations between social activity and concurrent mood, fatigue, and pain.

Outcome and predictor	Coefficient (95% CI)	<i>P</i> value <sup>a</sup>
<b>Sad mood</b>		
Alone	0.078 (–0.140 to 0.299)	.48
Time (hours)	–0.011 (–0.028 to 0.007)	.24
<b>Happy mood</b>		
Alone	–0.300 (–0.25 to –0.079)	.008
Time (hours)	0.004 (–0.014 to 0.021)	.69
<b>Stress<sup>b</sup></b>		
Alone	–0.064 (–0.268 to 0.141)	.54
Time 2	0.300 (0.068 to 0.532)	.01
Time 3	0.227 (–0.009 to 0.463)	.06
Time 4	0.155 (–0.083 to 0.393)	.20
Time 5	–0.152 (–0.391 to 0.088)	.22
<b>Fatigue<sup>b</sup></b>		
Alone	0.122 (–0.148 to 0.392)	.38
Time 2	0.260 (–0.054 to 0.574)	.11
Time 3	0.443 (0.126 to 0.760)	.007
Time 4	0.703 (0.383 to 1.024)	<.001
Time 5	1.520 (1.196 to 1.844)	<.001
<b>Pain</b>		
Alone	0.035 (–0.161 to 0.231)	.73
Time (hours)	0.021 (0.005 to 0.036)	.01

<sup>a</sup>Italics indicate  $P < .05$ .

<sup>b</sup>Models for stress and fatigue use time as a categorical variable; coefficient values for Time 2 to Time 5 indicate the change in the outcome variable compared with Time 1.

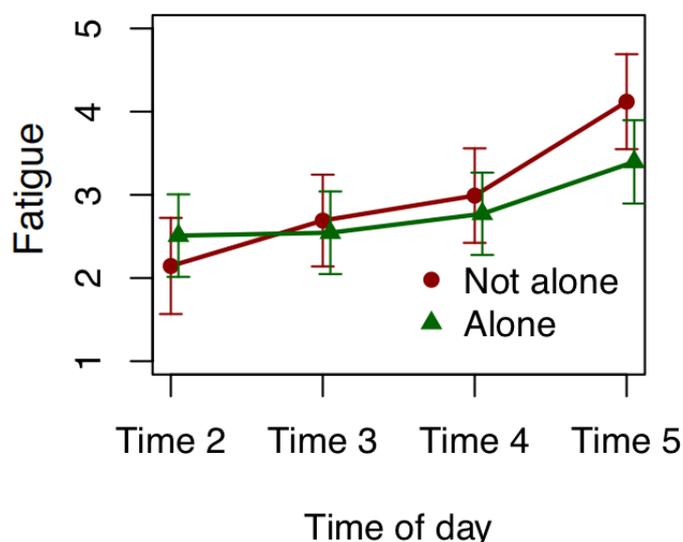
**Table 3.** Mixed-effects models for associations between social activity and next-survey mood, fatigue, and pain.

Outcome and predictor	Coefficient (95% CI)	<i>P</i> value <sup>a</sup>
<b>Sad mood</b>		
Alone	0.102 (−0.141 to 0.348)	.41
Time (hours)	−0.012 (−0.037 to 0.013)	.24
<b>Happy mood</b>		
Alone	−0.034 (−0.301 to 0.226)	.80
Time (hours)	0.011 (−0.016 to 0.038)	.43
<b>Stress<sup>b</sup></b>		
Alone	0.008 (−0.230 to 0.250)	.95
Time 3	−0.100 (−0.353 to 0.154)	.44
Time 4	−0.170 (−0.425 to 0.085)	.19
Time 5	−0.502 (−0.757 to −0.247)	<.001
<b>Fatigue<sup>b</sup></b>		
Alone	0.365 (−0.169 to 0.898)	.18
Time 3	0.546 (0.008 to 1.083)	.048
Time 4	0.846 (0.296 to 1.395)	.003
Time 5	1.975 (1.427 to 2.523)	<.001
Alone × Time 3	−0.511 (−1.196 to 0.176)	.15
Alone × Time 4	−0.584 (−1.273 to 0.110)	.10
Alone × Time 5	−1.089 (−1.780 to −0.396)	.002
<b>Pain</b>		
Alone	−0.016 (−0.240 to 0.206)	.89
Time (hours)	0.027 (0.010 to 0.050)	.02

<sup>a</sup>Italics indicate  $P < .05$ .

<sup>b</sup>Models for stress and fatigue use time as a categorical variable; coefficient values for Time 2 to Time 5 indicate the change in the outcome variable compared with Time 1.

**Figure 1.** Fatigue at each time point within each day (starting from Time 2) predicted by being alone or not alone on the previous survey. Error bar denotes 95% CI for the mean.

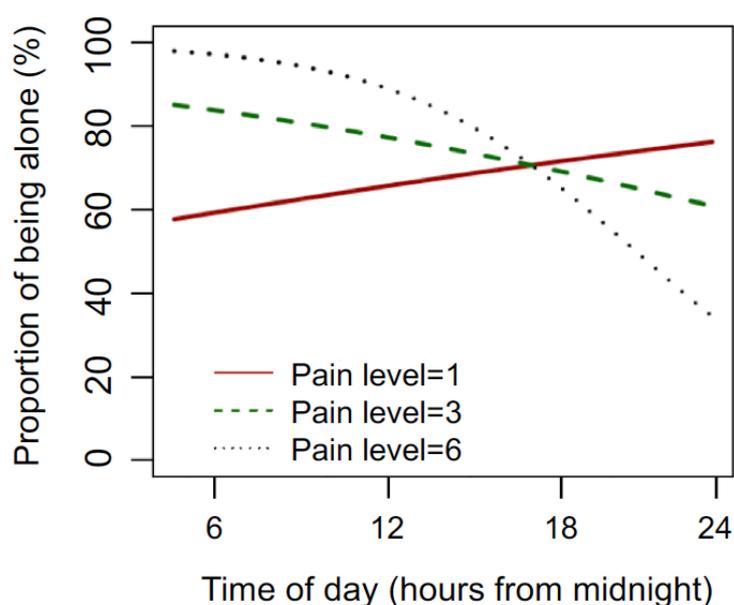


**Table 4.** Mixed-effects logistic regression models for associations between mood, fatigue, and pain and next-survey social activity.

Outcome (social engagement) and predictor	Odds ratio (95% CI)	<i>P</i> value <sup>a</sup>
<b>Model 1</b>		
Sad mood	1.017 (0.799 to 1.294)	.89
Time (hours)	1.002 (0.934 to 1.074)	.96
<b>Model 2</b>		
Happy mood	0.904 (0.713 to 1.147)	.41
Time (hours)	1.007 (0.938 to 1.080)	.85
<b>Model 3</b>		
Stress <sup>b</sup>	0.858 (0.665 to 1.107)	.24
Time 3	1.091 (0.535 to 2.223)	.81
Time 4	0.935 (0.456 to 1.917)	.86
Time 5	0.952 (0.463 to 1.959)	.89
<b>Model 4</b>		
Fatigue <sup>b</sup>	1.064 (0.872 to 1.298)	.54
Time 3	1.01 (0.501 to 2.037)	.98
Time 4	0.771 (0.381 to 1.561)	.47
Time 5	0.854 (0.413 to 1.769)	.67
<b>Model 5</b>		
Pain	2.647 (1.092 to 6.412)	.03
Time (hours)	1.107 (0.991 to 1.235)	.07
Pain × Time	0.945 (0.901 to 0.992)	.02

<sup>a</sup>Italics indicate  $P < .05$ .

<sup>b</sup>Models for stress and fatigue use time as a categorical variable; coefficient values for Time 2 to Time 5 indicate the change in the outcome variable compared with Time 1.

**Figure 2.** The predicted proportion of surveys on which participants reported being alone over time based on pain levels.

## Discussion

Examining real-time, immediate predictors of social activity is an important and novel approach to further our understanding of social experiences of older PLWH. Specifically, our findings provide a framework for understanding social activity in the context of mood, fatigue, and pain among older PLWH. This study found being alone was associated with lower concurrent happiness and later-day fatigue, and higher pain levels predicted greater likelihood of being alone earlier in the day and lower likelihood of being alone later in the day (compared with lower pain levels). Simply stated, although being with others was related to increases in fatigue and pain throughout the day, people were happier when they were with others than when they were alone.

The importance of the association between more social activity and greater happiness warrants a thorough discussion. This finding is critical for our understanding of psychological well-being of older PLWH. Although seemingly contradictory, our finding that participants were happier when they were with others (compared with when they were alone) even though pain and fatigue increased is supported by neurobiological and behavioral medicine literature. Neurobiologically, positive social interactions induce activity in the mesocorticolimbic (ie, reward) system and are experienced as pleasurable [34]; thus, social activity is likely reinforcing beyond potentially limiting factors such as pain or fatigue. Our finding is also consistent with the “stress buffering” theoretical model such that social relationships may “buffer” the adverse effects of a stressor (eg, pain) on health outcomes (eg, mood) [35]. Furthermore, happiness has been associated with a variety of positive health and lifestyle factors among older adults, including physical activity, competence, functional capacity, disease management, quality of social network, and general life satisfaction [36,37]. These positive health and lifestyle factors are critical for maintaining optimal quality of life among older adults, especially those living with a chronic disease such as HIV [38]. Thus, our findings support further examination of the benefits of social activity on real-time happiness and psychological well-being, and whether increased social activity may have longer-term effects on happiness. On the basis of the results of this study and existing literature on associations of overall health and happiness, the immediate positive influence of increased social activity on happiness has potential to improve many aspects of an older adult’s quality of life.

Although there were no significant associations between social activity and concurrent sadness or stress, this is likely because our participants reported overall low levels of sadness and stress with little variability compared with reported levels of happiness. Possible interpretations for this finding include the following: (1) our sample may not be very representative of older PLWH among whom depressive symptoms and stress are common, (2) our measures of sadness and stress may not be sensitive enough for this population, or (3) our measure of positive affect (happiness) may be a more sensitive indicator of mood and well-being in older PLWH with minimal-to-no depressive symptoms (as indicated by baseline BDI-II scores). Future research is needed to understand the clinical relevance of

fluctuations in EMA-measured happiness among older PLWH without clinically elevated depressive symptoms or mood disorders, and whether consistently low happiness ratings in the context of decreased social activity or social isolation may predict feelings of sadness, loneliness, or onset of a depressive episode.

In contrast to our finding regarding increased happiness with social activity, results also showed that spending time with others predicted being more fatigued on the next survey. The relationship between social activity and fatigue is important to consider in the context of the association between social activity and happiness, and provides preliminary evidence to support potential clinical interventions promoting social activity [39-41] while simultaneously improving our understanding of strategies that help older PLWH manage fatigue in an effort to improve happiness and psychological well-being in this population. Notably, lagged analyses also elucidated an interaction effect between pain and time of day on later social activity. Participants reporting higher pain levels were more likely to be alone in the morning and less likely to be alone in the evening and night compared with those reporting lower pain levels. Although we are unable to determine reasons for this relationship with our available data, results show that participants in our sample of older PLWH were engaging in evening social activities despite experiencing high levels of pain. Further examination of this pattern is needed to determine whether this may be evidence of the ability to utilize effective coping techniques (eg, social support) when needed among older PLWH.

As previously reported by Moore et al [19], our sample of PLWH aged 50 years and older reported being alone for a majority of participants’ typical waking hours. This is considerably higher than results reported by the national American Time Use Survey in which adults aged 65 years and older reported spending 23% to 42% of waking, nonwork time alone [42]. Although our results may be influenced by the high rate of unemployment in our sample, our results are consistent with the previous research showing that older PLWH are at an increased risk for reduced social activity [8-10]. Future research on social activity must not only characterize levels of social activity but must also focus on understanding and disentangling different reasons for decreased social activity within different clinical populations, with the ultimate goal of developing targeted interventions.

Results also showed that HIV disease characteristics (ie, current and nadir CD4 counts, detectable plasma viral load, estimated duration of HIV, antiretroviral therapy status, and history of AIDS) were unrelated to the proportion of time spent alone and the average number of reported social interactions per day. Although previous research links social isolation to accelerated HIV disease progression [20], this is often in the context of perceived loneliness and social support. In contrast, the current EMA social activity data capture a more objective level of overall social activity. Findings from this study warrant further examination of the association between HIV disease progression and levels of social activity. Furthermore, participants who reported more social support at baseline (via the MOS Social Support survey) demonstrated a lower proportion of time alone and a higher number of daily social interactions over the 1-week

EMA period. This finding also supports the convergent validity of our EMA social activity measures, and suggests that participants' perceptions of support received from their social networks may be accurately related to their average levels of social activity. These relationships between social support and EMA-assessed social activity were expected, as social support often relates to the number of social contacts and frequency of social interactions across many clinical and nonclinical populations [43]. Finally, we found that females reported spending less time alone compared with males. Because we cannot make any definitive conclusions from a sample that only includes 3 women, further exploration of possible sex differences in social activity and health outcomes is needed among older PLWH in future studies.

This study is strengthened by its use of real-time data; however, there are several limitations. First, the relatively small sample size limits generalizability and statistical power to detect associations between social activity and baseline, laboratory-measured clinical characteristics. Furthermore, our sample was relatively healthy and had little-to-no HIV disease burden, which may not be widely representative of the general population of older PLWH in the United States. Also of note, the majority of participants in our sample were unemployed. Because employment is an activity that often engenders social activity (eg, interactions with coworkers and increases financial resources), our results may not be generalized to older PLWH who are employed; however, our sample also represents a real-world sample of older PLWH among whom unemployment is very common [44]. Future studies would benefit from further understanding associations between reasons for unemployment and levels of social activity. Next, because the data came from a small pilot study with the aim of assessing overall daily functioning in older PLWH, there were no data collected on

other specific factors related to social isolation, such as perceived loneliness, reasons for being alone (eg, preference vs access to social activities), or structural social factors (eg, marital or relationship status). Relatedly, future research may benefit from understanding the real-time impact of pet ownership and time spent with pets on mood and physical health. In addition, the EMA item related to being alone or with others may not be the best representation of social isolation because it only allows us to capture participants' social activity at the exact moment of the survey administration—that is, if participants were alone when completing the survey but were with others right up until the survey completion time, then they will report being alone although they may not be socially isolated. Future studies may consider using mobile sensing technologies and global positioning system data to better characterize social activity [45]. Assessing real-time associations between social activity and markers of mental and physical health, as we have done in this report, also lays the groundwork for developing potential real-time interventions for improving happiness, psychological well-being, and overall quality of life.

Overall, this study provides preliminary evidence for the real-time associations between social activity and mood, fatigue, and pain in older PLWH. Our findings showed that spending time with others was associated with increased happiness. The results of this study warrant additional research on the potential benefits of social activity-based interventions for improving well-being among older PLWH despite presence of fatigue or pain. Furthermore, with mounting evidence showing that older PLWH spend a great deal of time alone, future research must continue to characterize social activity as well as explore causes for and consequences of limited social activity among this population.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Comparisons between mixed-effects models with continuous time and mixed-effects models with categorical time.

[PDF File (Adobe PDF File), 20KB - [mental\\_v5i2e38\\_app1.pdf](#) ]

## Multimedia Appendix 2

Relationships between social activity, demographics, HIV disease characteristics, and baseline psychiatric characteristics.

[PDF File (Adobe PDF File), 58KB - [mental\\_v5i2e38\\_app2.pdf](#) ]

## Multimedia Appendix 3

Average happiness ratings by social activity (alone vs not alone) within participants. Error bar denotes 95% CI for the mean.

[PNG File, 31KB - [mental\\_v5i2e38\\_app3.png](#) ]

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## Abbreviations

- BDI-II:** Beck Depression Inventory-II
- EMA:** ecological momentary assessment
- MOS:** Medical Outcomes Study
- PLWH:** persons living with HIV
- UCSD:** University of California, San Diego

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Review

# eMental Healthcare Technologies for Anxiety and Depression in Childhood and Adolescence: Systematic Review of Studies Reporting Implementation Outcomes

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## Abstract

**Background:** Anxiety disorders and depression are frequent conditions in childhood and adolescence. eMental healthcare technologies may improve access to services, but their uptake within health systems is limited.

**Objective:** The objective of this review was to examine and describe how the implementation of eMental healthcare technologies for anxiety disorders and depression in children and adolescents has been studied.

**Methods:** We conducted a search of 5 electronic databases and gray literature. Eligible studies were those that assessed an eMental healthcare technology for treating or preventing anxiety or depression, included children or adolescents (<18 years), or their parents or healthcare providers and reported findings on technology implementation. The methodological quality of studies was evaluated using the Mixed Methods Appraisal Tool. Outcomes of interest were based on 8 implementation outcomes: acceptability (satisfaction with a technology), adoption (technology uptake and utilization), appropriateness (“fitness for purpose”), cost (financial impact of technology implementation), feasibility (extent to which a technology was successfully used), fidelity (implementation as intended), penetration (“spread” or “reach” of the technology), and sustainability (maintenance or integration of a technology within a healthcare service). For extracted implementation outcome data, we coded favorable ratings on measurement scales as “positive results” and unfavorable ratings on measurement scales as “negative results.” Those studies that reported both positive and negative findings were coded as having “mixed results.”

**Results:** A total of 46 studies met the inclusion criteria, the majority of which were rated as very good to excellent in methodological quality. These studies investigated eMental healthcare technologies for anxiety (n=23), depression (n=18), or both anxiety and depression (n=5). Studies of technologies for anxiety evaluated the following: (1) acceptability (78%) reported high levels of satisfaction, (2) adoption (43%) commonly reported positive results, and (3) feasibility (43%) reported mixed results. Studies of technologies for depression evaluated the following: (1) appropriateness (56%) reported moderate helpfulness and (2) acceptability (50%) described a mix of both positive and negative findings. Studies of technologies designed to aid anxiety and depression commonly reported mixed experiences with acceptability and adoption and positive findings for appropriateness

of the technologies for treatment. Across all studies, cost, fidelity, and penetration and sustainability were the least measured implementation outcomes.

**Conclusions:** Acceptability of eMental healthcare technology is high among users and is the most commonly investigated implementation outcome. Perceptions of the appropriateness and adoption of eMental healthcare technology were varied. Implementation research that identifies, evaluates, and reports on costs, sustainability, and fidelity to clinical guidelines is crucial for making high-quality eMental healthcare available to children and adolescents.

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## KEYWORDS

eHealth; mental health; implementation science; healthcare planning; organizational innovation; decision-making; healthcare organizations

## Introduction

Worldwide, at least 6.5% and 2.6% of children and adolescents meet the criteria for anxiety and depressive disorders, respectively [1]. The burden associated with these disorders rises sharply in childhood and peaks in adolescence and young adulthood (ages, 15-24 years) [2]. The long-term impact of anxiety and depression on children and adolescents includes significant interference with relationships, academic performance, school attendance, and daily functioning, making early intervention vital [3-8].

Underdiagnosis and undertreatment of childhood and adolescent depression and anxiety are well-documented concerns [9,10]. The current distribution, demand, structure, and costs that underpin services for these young people make them relatively unavailable to many who need them [11]. Electronic mental (eMental) healthcare technologies, which include internet-, mobile-, and, computer-based programs as well as mobile phone apps, supposedly improve mental healthcare access and availability [12-17]. In the past 5 years, a number of literature reviews have highlighted the increase in research and development activities for eMental healthcare technologies for children and adolescents [18-22]. While conclusions regarding the efficacy and effectiveness of technologies vary depending on the review and employed methodology, reviews are unified in their assessment that eMental healthcare technologies have potential utility in healthcare systems. However, despite increased emphasis on the potential value for improving health outcomes for children and adolescents, eMental health technologies are not widely adopted within health systems [23-26].

Distinguishing implementation effectiveness from the viewpoint of treatment effectiveness is critical for integrating eMental healthcare technologies. When uptake efforts fail, it is important to know if the failure occurred because the intervention was ineffective in the new setting (eg, lacked cultural relevance), or if an effective intervention was deployed ineffectively (eg, clinicians failed to send reminder emails as the protocol indicated). Current research on eMental healthcare technologies lack implementation frameworks [27], and the implementation literature has traditionally focused on the broadly defined eHealth [28,29], lacking a specific focus on mental healthcare. Conceptualizing and assessing implementation outcomes (ie, how implementation of a program works in specific contexts) can advance the understanding of implementation processes

(eg, cost, required in-service training, required infrastructure), enable studies of the comparative effectiveness of implementation strategies, and enhance efficiency in translating research into practice. The aim of this systematic review was to examine how the implementation of eMental healthcare technologies for children and adolescents with anxiety or depression has been studied (ie, the research questions asked, populations studied, and the rigor of the methodology used) and to describe implementation findings with respect to implementation processes and outcomes.

## Methods

### Design

A protocol for the review was developed and registered with PROSPERO (Registration #CRD42016049884). Reporting of the review adheres to the Preferred Reporting Items of Systematic Reviews and Meta-Analyses statement checklist [30]. Funding for the review was provided by the Canadian Institutes of Health Research (201404KRS). This organization had no involvement in any aspect of the conduct, analysis, and manuscript preparation of this review. This systematic review did not require ethics approval nor does it contain any individual person's data in any form.

### Search Strategy

A research librarian developed the search strategies for 5 databases: MEDLINE, EMBASE, PsycINFO, CINAHL, and the Cochrane Database of Systematic Reviews using date (2000-2016) restrictions. No restriction was placed on the study design or language to capture a broad range of evidence. The strategy was peer reviewed prior to implementation. The searches included literature published until December 5, 2016. Grey literature was searched using Google Scholar and ProQuest Dissertations & Theses Global. Clinical trials were searched using [clinicaltrials.gov](http://clinicaltrials.gov). Conference proceedings of the last 2 years (2014-2016) of the International Society for Research on Internet Interventions were searched as well. Reference lists of included studies were also searched. [Multimedia Appendix 1](#) provides the search terms developed for the MEDLINE database.

### Criteria for Considering Studies in the Review

Studies were included if they met the following criteria: (1) assessed an eMental healthcare technology for treating or preventing anxiety or depression; (2) the technology under investigation involved children or adolescents (<18 years), or

their parents or healthcare providers. Studies that included both adolescents <18 and young adults were included if the mean age of the study sample was  $\leq 19$  years to ensure that the results largely reflected implementation with children and adolescents; (3) the technology needed to be an internet-, computer-, tablet-, or mobile-based program or mobile app; (4) the technology was used within the primary or secondary healthcare system (as opposed to the school system); (5) reported on an implementation outcome as a primary or secondary measure. The 8 outcomes of interest were drawn from Proctor and colleagues' implementation framework [31]. These constructs were defined as follows: *acceptability* (ie, a measure of satisfaction with a technology including attitudes, functionality, preferences, and user experience); *adoption* (ie, the intention, initial decision, or action to take up or utilize a technology); *appropriateness* (ie, the perceived fit, relevance, usefulness/helpfulness, or compatibility of a technology for a given practice setting or problem); *cost*, (ie, the financial impact of an implementation effort); *feasibility*, (ie, the extent to which a technology had utility and compatibility within the practice setting); *fidelity*, (ie, the degree to which a technology was implemented as it was intended); *penetration*, (ie, the spread and reach of a technology within a service setting and its subsystems); and *sustainability*, (ie, the extent to which a technology was maintained within standard operations) [31]. We excluded protocols, editorials, and studies assessing telehealth interventions, including telepsychiatry and videoconferencing.

### Screening for Eligibility

References were organized and screened using EndNote X7.2.1. Three reviewers (AS, NDG, and MO) independently screened the titles and abstracts in the EndNote library and calculated the interrater agreement with the kappa statistic for every 100 articles screened [32]. Once a sufficiently high kappa was reached ( $\geq 0.80$ ), the remaining references in the library were divided into 3 equally sized groups. Each reviewer was given 2 of the 3 groups, allowing each article to be assessed by 2 reviewers, and each reviewer screened the studies using the title and abstract. Three reviewers (AS, NDG, MO) independently reviewed the full-text of studies that were identified as potentially eligible using the review's inclusion and exclusion criteria. Any discrepancies were discussed among the reviewers and taken to a third party (ASN) if no agreement could be reached.

### Data Extraction

Data were extracted by one reviewer (AS, NDG, or MO), and reviewed for accuracy and completeness by another. After verifying all of the extracted data, discrepancies were resolved by discussion or adjudication by another party (ASN). Extracted data included information on study characteristics (eg, authors, date of publication, country, and design) and implementation objectives, characteristics of the technology, study population, study setting, and implementation results. We coded statistically significant favorable ratings on measurement scales as "positive results" (eg, healthcare providers rating an intervention as highly acceptable) and statistically significant unfavorable ratings on measurement scales as "negative results" (eg, parents did not

think the activities in the program were acceptable for their child's age). Those studies that reported both positive and negative findings were coded as having "mixed results" (eg, child and parents did not show the same level of satisfaction with the intervention).

### Quality Assessment

Methodological quality was assessed independently by 2 of the 3 assessors (AS, NDG, and MO). Disagreements were resolved through discussion. ASN participated when consensus could not be reached. The quality of studies was assessed using the Mixed Methods Appraisal Tool (MMAT) [33]. The scoring scale ranges from 0 (low quality) to 100 (high quality) and was pilot tested for reliability [34]. The MMAT consists of 2 screening questions applicable to all types of study designs and 3-4 questions applicable to specific study designs (eg, The questions relevant to each study design were scored with the number of 'yes' answers summed, divided by the total number of questions, and multiplied by 100 to give a final percentage score.) Qualitative studies were appraised for the relevance of data sources, processes used for data analyses, consideration of study context, and the researchers' potential influences. Randomized controlled trials (RCTs) were appraised for sequence generation, allocation concealment, the completeness of outcome data, and study attrition. All other quantitative studies were appraised for recruitment strategies and sample representativeness, outcome measurements, the completeness of outcome data and study response rates, and the comparability of comparison groups (when applicable). Mixed methods studies were assessed for the relevance of the design, integration of methods, and limitations to integration. We did not exclude any studies on the basis of low-quality assessment scores.

### Data Analysis

A codebook approach [35] was used to organize data extraction according to the 8 implementation outcome categories [31]. When no implementation data were available for a particular outcome in the included paper, the category remained empty. Four team members (NDG, MO, AS, and ASN) reviewed the assignments of the study outcome data to the implementation categories, and assignments were finalized after all team members were confident that the data were categorized accurately. Descriptive statistics (counts, frequencies) were used to summarize patterns across studies.

## Results

### Literature Search and Selection

The search strategy identified 6269 citations after removal of duplicates. Of these, 727 studies were considered potentially relevant based on their title and abstract (Figure 1). After full-text review, 46 studies (plus one erratum) articles met the inclusion criteria.

### Description of Included Studies

Table 1 outlines the format and delivery characteristics of the technologies assessed in the included studies. The implementation of eMental healthcare technologies for anxiety and depressive disorders in childhood or adolescence was

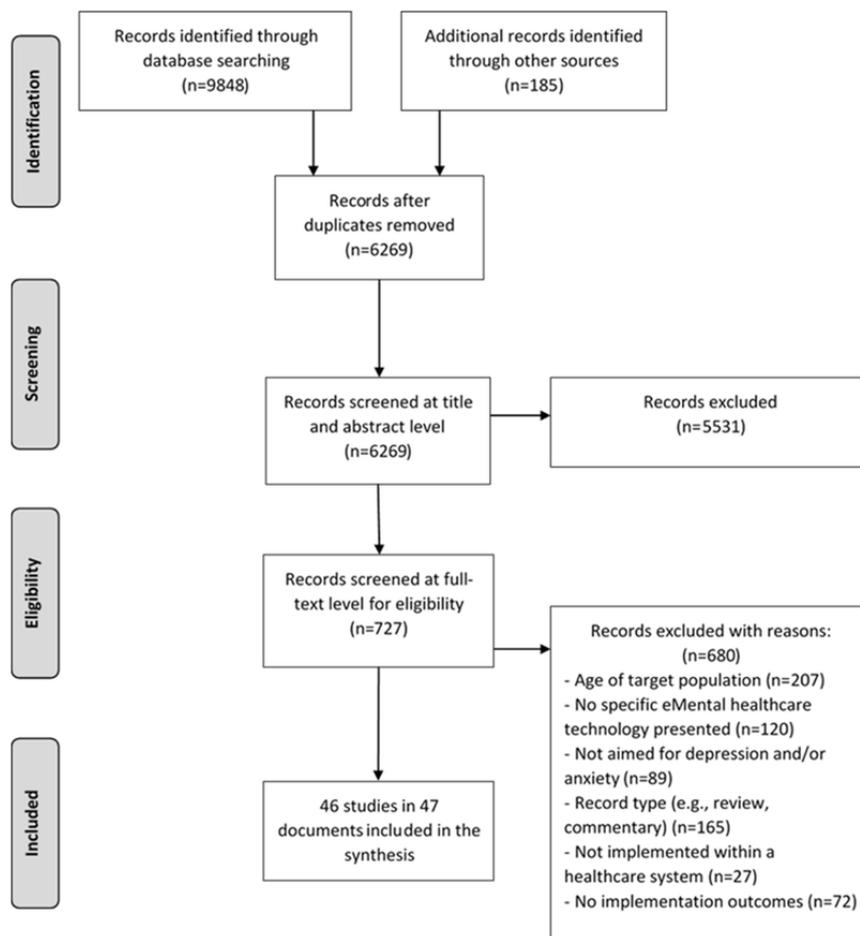
assessed in 23 and 18 studies, respectively. Five studies assessed a technology that targeted both anxiety and depression. The location of studies was restricted to economically developed countries with the United States (20 studies) and Australia (13 studies) being the most common locations. A total of 32 studies examined internet-based technologies, 11 examined computer-based technologies, and 3 examined smartphone-based (app/short message service, SMS, text message) technologies as part of treatment.

### Study Quality

Details on the quality of the studies are provided in [Multimedia Appendix 2](#). In total, 11 studies on eMental healthcare technologies for anxiety were of excellent quality with a score of 100 [37,46-50,52,55,78-80], 6 were of very good quality with a score of 75 [36,38,39,44,51,53], 4 were of moderate quality

with a score of 50 [42,43,45,54], and 2 were of poor quality with a MMAT score of 25 [40,41]. Studies on technologies for depression also varied in quality: 10 studies were of excellent quality [56,57,59,63-67,71,81], 2 were of very good quality [60,68], 4 were of moderate quality [58,61,69,72], and 2 were of low quality and received a score of 25 [62] and 0 [70]. Studies evaluating technologies applicable to both anxiety and depression were of excellent [75,77], very good [74], and moderate [73,76] quality. The most common factors impacting the quality scores for quantitative studies were the lack of description on how randomization sequences were generated and if/how allocation was concealed (ie, see MMAT items 2.1 and 2.2 in [Multimedia Appendix 2](#)). The common factor impacting quality scores for mixed-method studies was the lack of consideration of data triangulation (ie, see MMAT item 5.3 in [Multimedia Appendix 2](#)).

Figure 1. Literature search flow diagram.



**Table 1.** Reported format and delivery characteristics of eMental Health technologies for adolescents with anxiety and depression.

Technology/Program Name	Participants Target age (years)	Technology Details Parent involvement	Features (sessions)	Healthcare provider contact	
				Before program	During program
<b>Anxiety Programs</b>					
Cool Little Kids Online [36]	3-6	Yes	Internet-based (8 modules)	None	Phone
Camp-Cope-A-Lot [37-41]	7-13	Yes	Computer-based (12 sessions)	In-person	In-person <sup>a</sup>
DARE Program [42,79]	8-12	Yes	Internet-based (11 modules)	None	Phone, within program <sup>b</sup>
BiP OCD [78,80]	12-17	Yes	Internet-based (12 chapters)	None	Within program
BRAVE-ONLINE <sup>c</sup> [46-50]	7-18 <sup>d</sup>	Yes	Internet-based (10 sessions)	None	Email, within program
Cognitive bias modification [43]	10-15	Yes	Internet-based (8 sessions)	In-person <sup>e</sup>	None
Ricky and the Spider [51]	6-12	Yes	Internet-based (8 levels)	In-person	In-person
Cool Teens [44,52,53]	14-18	No	Computer-based (8 modules)	None	Phone
Self-help manual and treatment [54]	15-21	No	Internet-based (9 modules)	None	Within program
SmartCAT App [45]	9-14	No	Mobile-based app (Ad hoc; includes 5 main components)	None	In-person, within program
Virtual School Environment [55]	8-12	Yes	Computer-based (12 sessions)	In-person	In-person
<b>Depression Programs</b>					
Decision aid tool [56]	12-25	No	Internet-based (9 component webpage used during an appointment or in the waiting room)	None	In-person
Monitoring tool [57,58]	15-24	No	Internet/tablet-based (Depression assessments)	None	In-person <sup>f</sup>
Rebound (Australia) [59]	15-25	No	Internet-based (User can select from 56 sessions)	None	Within program
MAYA (Chile) [81]	12-18	No	Internet-based (1 session)	In-person	In-person
iDOVE (United States) [60]	13-17	No	Mobile-based (8 weeks of 2 way SMS <sup>g</sup> text messaging)	In-person	SMS text message
Technology-enhanced CBT <sup>h</sup> intervention (United States) [61]	12-17	No	Mobile/tablet-based (SMS text messaging)	None	In-person, SMS text message
Behavioral Activation (United States) [62]	12-17	No	Internet-based (Ad hoc)	None	None
CATCH-IT (United States) [63-70]	14-21	Yes	Internet-based (11-14 modules)	In-person	Phone
SPARX (Australia) [71]	12-19	No	Computer-based (7 modules)	None <sup>h</sup>	Phone
Depression Experience Journal (United States) [72]	8-19	Yes	Internet-based (Ad hoc)	In-person	None <sup>e</sup>
<b>Anxiety + Depression Programs</b>					
Multi-family group therapy (Canada) [73]	6-12	Yes	Internet-based (3 sessions)	None	Email

Technology/Program Name	Participants		Technology Details		
	Target age (years)	Parent involvement	Features (sessions)	Healthcare provider contact	
				Before program	During program
Treasure Hunt (Switzerland) [74]	9-13	No	Internet-based (6 levels)	None	In-person
SPARX (New Zealand) [75]	16-18	No	Computer-based (7 modules)	None	In-person
Problem-solving therapy (Netherlands) [76]	12-21	No	Internet-based (5 lessons)	None	Within program
RU-OK (United Kingdom) [77]	13-15	No	Internet-based (Ad hoc)	None	None <sup>e</sup>

<sup>a</sup>Sessions 1-6 were self-led, but conducted in the presence of a healthcare provider; sessions 7-12 were primarily led by a healthcare provider.

<sup>b</sup>Within program refers to communication self-contained within the program (internal email program). In this case, the user would have to login to see the communication that would not be delivered to their external email.

<sup>c</sup>Intervention has been modified for different age groups under slightly different names.

<sup>d</sup>BRAVE for children-ONLINE targets participants aged 7-14 years; BRAVE for teenagers-ONLINE targets participants aged 12-18 years.

<sup>e</sup>Intervention did not contain healthcare provider contact, but participants were referred by healthcare providers or were engaged with the healthcare system.

<sup>f</sup>Participants did not use the intervention for healthcare provider interaction; providers received data or email updates that were used in in-person sessions.

<sup>g</sup>SMS: short message service.

<sup>h</sup>CBT: cognitive behavioral therapy.

<sup>i</sup>SPARX was tested in different implementation contexts, some of which included no in-person contact and some with in-person contact.

## Trends in the Study of Implementation Among eMental Healthcare Technologies

Figure 2 displays the frequency by which implementation outcomes were studied for eMental healthcare technologies. Studies on eMental healthcare technologies for anxiety most commonly evaluated acceptability (78%), adoption (43%), and feasibility (43%) of the technologies, while studies on technologies for depression evaluated appropriateness (56%) and acceptability (50%). Studies testing technologies relevant to both anxiety and depression tended to evaluate acceptability (100%), adoption (40%), and appropriateness (40%). Across all studies, cost, fidelity, and penetration were the least measured implementation outcomes, and none of the studies evaluated technology sustainability in the healthcare service/system in which the technology was employed. While positive findings were reported 60% of the time or more in relation to measures of acceptability and costs across all included studies (Figure 3), mixed findings were reported more than 50% of the time in studies that measured adoption, feasibility, and fidelity outcomes.

## Implementation Findings for eMental Healthcare Technologies for Anxiety

Table 2 outlines the implementation findings among eMental healthcare technologies for anxiety. Both positive (61%) [36,38,39,41,43,45,50,54,55,78,80] and mixed (39%)

[37,40,42,46,48,49,79] findings were reported across 18 studies on technology acceptability. Positive results included high satisfaction and positive technology recommendations, with acceptability reported by parents [36,39,41,43,50], children [38,39,41,43,45,50,54,55,78,80], and healthcare providers [55]. Technology adoption was examined by 10 studies with studies reporting positive (60%) [42-44,47,50,53] and mixed (40%) [45,46,55,79] findings for technology compliance and adherence. Of the 6 studies that examined appropriateness, 4 described positive results (67%) [39,50,51,78] such as positive attitudes and perceived helpfulness of the technology among healthcare providers [39,51], while 2 studies [53,55] reported mixed results (33%) including moderate usefulness and helpfulness of the program for the youth [53]. Of the 23 studies on anxiety-directed technologies, only one examined cost, including initial implementation challenges such as startup costs, designated computers and clinic space, and technical assistance requirement [39]. Studies that examined the feasibility of anxiety technologies described more mixed (70%) [38-40,44,52,53,55] than positive (30%) [36,45,80] results, including barriers to participation such as finding time to complete tasks and ease of use. Only one study investigated technology penetration, reporting positive penetration with technology purchased by 56 child psychiatric institutions or practitioners within 1 year [51]. Studies examining eMental healthcare technologies for anxiety did not investigate or report on fidelity or sustainability.

Figure 2. Implementation outcomes measured according to the mental health condition targeted.

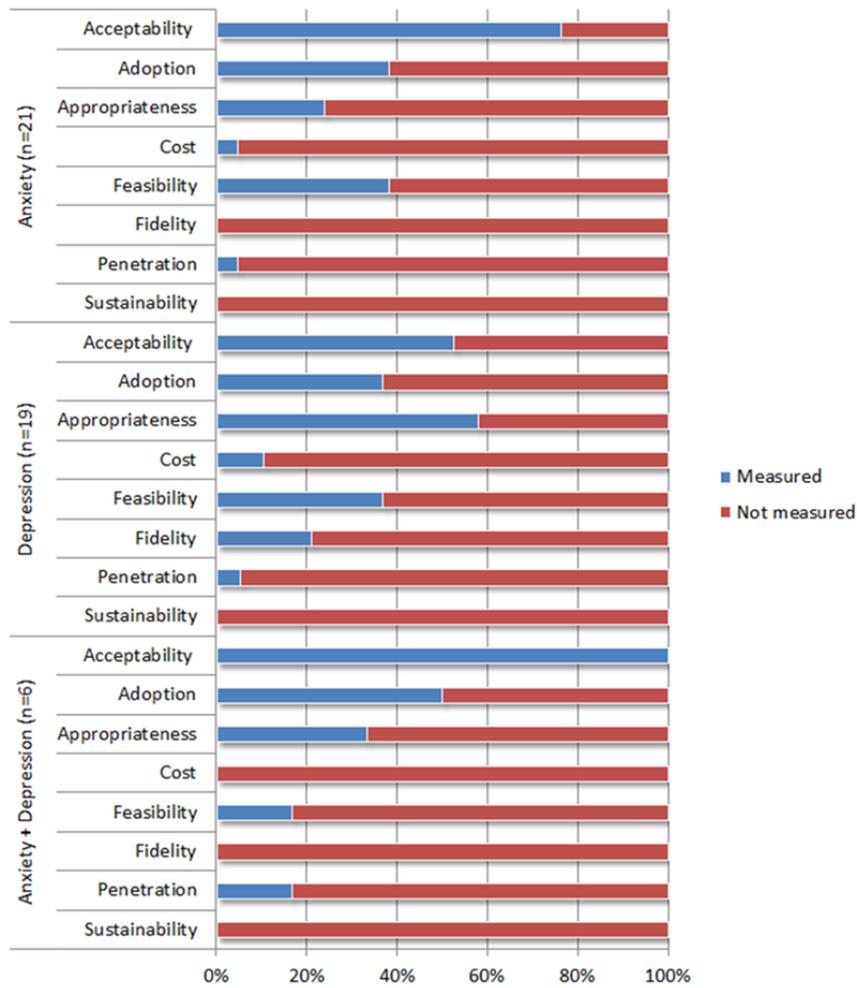
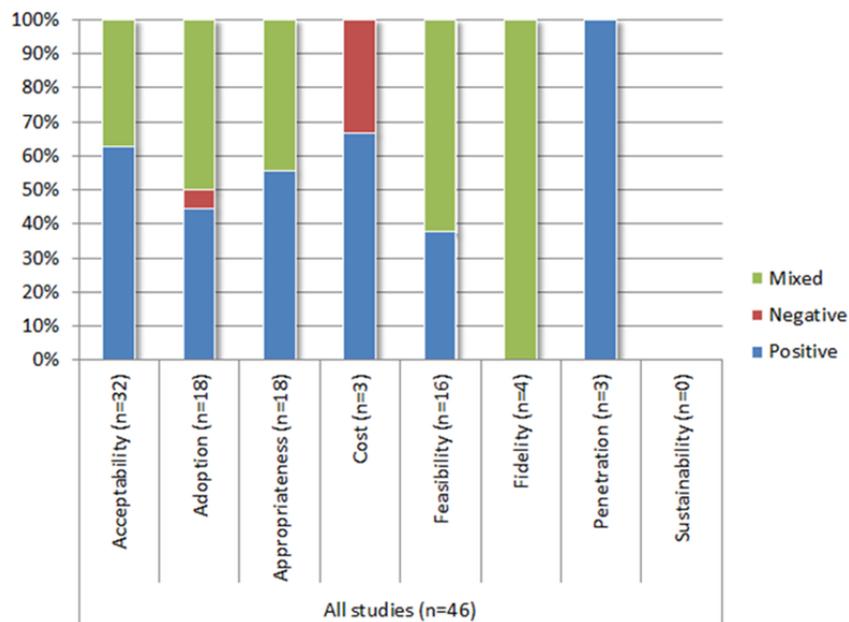


Figure 3. Conclusions reported by the authors for implementation outcomes.



**Table 2.** Implementation findings among eMental healthcare technologies for anxiety.

Program and study	Participants (n)	Implementation outcome (measure <sup>a</sup> ); findings <sup>b</sup>
<b>Cool Little Kids Online</b>		
Morgan et al [36]	<ul style="list-style-type: none"> <li>Parents of children aged 3-6 years with anxiety problems (n=51)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); P: +</li> <li>Feasibility (self-developed questionnaire); P: +</li> </ul>
<b>Camp-Cope-A-Lot</b>		
Salloum et al [40]	<ul style="list-style-type: none"> <li>Parents of children aged 7-13 years with an anxiety disorder (n=100)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); P: +/-</li> <li>Feasibility (published instrument); P: +/-</li> </ul>
Storch et al [41]	<ul style="list-style-type: none"> <li>Children aged 7-13 years with an anxiety disorder (n=49)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C: +</li> </ul>
Salloum et al [39]	<ul style="list-style-type: none"> <li>Children aged 7-13 years with an anxiety disorder (n=3) and their parents (n=7)</li> <li>Healthcare providers (n=3)</li> <li>Project coordinators (n=3)</li> <li>Administrators (n=3)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); P, C: +</li> <li>Appropriateness (self-developed interview); HCP: +</li> <li>Cost (self-developed interview); HCP, A: -</li> <li>Feasibility (published instrument &amp; self-developed interview); HCP, A, PC: +/-</li> </ul>
Crawford et al [37]	<ul style="list-style-type: none"> <li>Children aged 7-13 years with an anxiety disorder (n=17)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C: +/-</li> </ul>
Khanna and Kendall [38]	<ul style="list-style-type: none"> <li>Children aged 7-13 years with an anxiety disorder (n=16)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C: +</li> <li>Feasibility (self-developed questionnaire); C: +/-</li> </ul>
<b>DARE Program</b>		
Vigerland et al [42]	<ul style="list-style-type: none"> <li>Children (n=46) aged 8-12 years with an anxiety disorder and their parents (n=46)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); P, C: +/-</li> <li>Adoption (program utilization); P, C: +</li> </ul>
Vigerland et al [79]	<ul style="list-style-type: none"> <li>Children aged 8-12 years with social phobia (n=30) and their parents (n=57)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C: +</li> <li>Adoption (program utilization); C: +/-</li> </ul>
<b>BiP OCD<sup>c</sup></b>		
Lenhard et al [80]	<ul style="list-style-type: none"> <li>Adolescents aged 12-13 years with OCD (n=8)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed interview); C: +</li> <li>Feasibility (self-developed interview); C: +</li> </ul>
Lenhard et al [78]	<ul style="list-style-type: none"> <li>Adolescents aged 12-17 years with OCD (n=21)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> <li>Appropriateness (self-developed questionnaire); C: +</li> </ul>
<b>BRAVE ONLINE</b>		
Donovan and March [46]	<ul style="list-style-type: none"> <li>Children aged 3-6 with an anxiety disorder (n=23)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +/-</li> <li>Adoption (program utilization); C: +/-</li> </ul>
Anderson et al [47]	<ul style="list-style-type: none"> <li>Children and adolescents aged 7-18 years with an anxiety disorder (n=132) and their parents (n=NR<sup>d</sup>)</li> </ul>	<ul style="list-style-type: none"> <li>Adoption (program utilization); P, C: +</li> </ul>
Spence et al [48]	<ul style="list-style-type: none"> <li>Adolescents aged 12-18 years with clinical levels of anxiety (n=44)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (adapted questionnaire); C: +/-</li> </ul>
March et al [49]	<ul style="list-style-type: none"> <li>Children aged 7-12 years with an anxiety disorder (n=40) and their parents (n=NR)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); P, C: +/-</li> </ul>
Spence et al [50]	<ul style="list-style-type: none"> <li>Children and adolescents aged 7-14 years with clinical levels of anxiety (n=27) and their parents (n=NR)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); P, C: +</li> <li>Adoption (program utilization); P, C: +</li> <li>Appropriateness (self-developed questionnaire); P: +</li> </ul>
<b>Cognitive bias modification</b>		
Reuland and Teachman [43]	<ul style="list-style-type: none"> <li>Children and adolescents aged 10-15 years with social anxiety and their mothers (n=18 mother-child dyads)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed interview); P, C: +</li> <li>Adoption (program utilization); P, C: +</li> </ul>

Program and study	Participants (n)	Implementation outcome (measure <sup>a</sup> ); findings <sup>b</sup>
<b>Ricky and the Spider</b>		
Brezinka [51]	<ul style="list-style-type: none"> <li>Children and adolescents aged 6-13 years with OCD (n=18)</li> <li>Healthcare providers (n=13)</li> </ul>	<ul style="list-style-type: none"> <li>Appropriateness (self-developed questionnaire); HCP: +</li> <li>Penetration (uptake by practices); HCP: +</li> </ul>
<b>Cool Teens</b>		
Wuthrich et al [53]	<ul style="list-style-type: none"> <li>Adolescents aged 14-17 years with an anxiety disorder (n=24)</li> </ul>	<ul style="list-style-type: none"> <li>Adoption (program utilization); C: +</li> <li>Appropriateness (self-developed questionnaire); C: +/-</li> <li>Feasibility (self-developed questionnaire); C: +/-</li> </ul>
Cunningham et al [52]	<ul style="list-style-type: none"> <li>Adolescents aged 14-18 years with an anxiety disorder (n=22)</li> <li>Nonclinical adolescents (n=13)</li> </ul>	<ul style="list-style-type: none"> <li>Feasibility (self-developed questionnaire); C: +/-</li> </ul>
Cunningham and Wuthrich [44]	<ul style="list-style-type: none"> <li>Adolescents aged 14-16 years with an anxiety disorder (n=5)</li> </ul>	<ul style="list-style-type: none"> <li>Adoption (program utilization); C: +</li> <li>Feasibility (self-developed questionnaire); C: +/-</li> </ul>
<b>Virtual School Environment</b>		
Sarver et al [55]	<ul style="list-style-type: none"> <li>Children aged 8-12 years with a principal diagnosis of social anxiety disorder (n=17)</li> <li>Healthcare providers (n=NR)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C, HCP: +</li> <li>Adoption (program utilization); C: +/-</li> <li>Appropriateness (self-developed questionnaire); C: +/-</li> <li>Feasibility (successful use &amp; technical difficulties); C, HCP: +/-</li> </ul>
<b>SmartCAT App</b>		
Pramana et al [45]	<ul style="list-style-type: none"> <li>Children and adolescents aged 9-14 years with a diagnosis of GAD<sup>e</sup>, social or specific phobia, attention deficit hyperactivity disorder, oppositional defiant disorder, or social anxiety disorder (n=9)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> <li>Adoption (program utilization); C: +/-</li> <li>Feasibility (published instrument); C: +</li> </ul>
<b>Self-help</b>		
Tillfors et al [54]	<ul style="list-style-type: none"> <li>Adolescents aged 15-21 years with social anxiety disorder (n=10)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> </ul>

<sup>a</sup>Self-developed questionnaire/interview: bespoke questions or survey items created by the researcher; published instrument: validated tool with citation in text; program utilization/physician adherence: metrics of usage.

<sup>b</sup>C: child/adolescent/young adult report; HCP: healthcare provider report; P: parent report; +: high/positive findings; -: negative findings; +/- mixed findings.

<sup>c</sup>OCD: obsessive-compulsive disorder.

<sup>d</sup>NR: not reported.

<sup>e</sup>GAD: Generalized anxiety disorder.

**Table 3.** Implementation findings among eMental healthcare technologies for depression.

Program and study	Participants (n)	Implementation outcome (measure <sup>a</sup> ); findings <sup>b</sup>
<b>SPARX</b>		
Merry et al [71]	<ul style="list-style-type: none"> <li>Adolescents aged 12-19 years with depressive symptoms (n=94)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> </ul>
<b>Depression Experience Journal</b>		
Demaso et al [72]	<ul style="list-style-type: none"> <li>Primary caregivers (n=38) of hospitalized adolescents aged 8-19 years</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed interview); P: +</li> <li>Appropriateness (self-developed interview); P: +/-</li> </ul>
<b>Behavioral activation intervention</b>		
Davidson et al [62]	<ul style="list-style-type: none"> <li>Adolescents aged 12-17 years with clinical and subclinical depression (n=24)</li> </ul>	<ul style="list-style-type: none"> <li>Appropriateness (self-developed questionnaire); C: +</li> <li>Feasibility (voiced opinions); C: +</li> <li>Fidelity (voiced opinions); C: +/-</li> </ul>
<b>CBT<sup>c</sup></b>		
Kobak et al [61]	<ul style="list-style-type: none"> <li>Adolescents aged 12-17 years with clinical and subclinical depression (n=24)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C, HCP: +</li> <li>Appropriateness (self-developed questionnaire); HCP: +</li> </ul>
<b>Decision aid</b>		
Simmons et al [56]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 12-25 years with mild to moderate-severe depression (n=66)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C: +</li> <li>Adoption (program utilization); C: +/-</li> </ul>
<b>Monitoring tool</b>		
Hetrick et al [58]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-25 years diagnosed with depressive symptoms or a depressive disorder (n=101)</li> <li>FHealthcare providers (n=33)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C, HCP: +</li> <li>Appropriateness (self-developed questionnaire); C, HCP: +/-</li> </ul>
Hetrick et al [57]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 15-25 years diagnosed with major depressive disorder (n=15)</li> <li>FHealthcare providers (n=7)</li> </ul>	<ul style="list-style-type: none"> <li>Appropriateness (self-developed questionnaire &amp; interview); C, HCP: +</li> <li>Feasibility (self-developed interview); C, HCP: +/-</li> </ul>
<b>Rebound</b>		
Rice et al [59]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 15-24 years in partial or full remission of major depressive disorder (n=42)</li> </ul>	<ul style="list-style-type: none"> <li>Adoption (program utilization); C: +</li> </ul>
<b>MAYA</b>		
Carrasco [81]	<ul style="list-style-type: none"> <li>Female adolescents aged 12-18 years with symptoms of depression (n=15)</li> <li>Healthcare providers (n=5)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +/-</li> <li>Feasibility (self-developed questionnaire); C: +/-</li> </ul>
<b>iDOVE</b>		
Ranney et al [60]	<ul style="list-style-type: none"> <li>Adolescents aged 13-17 years at high risk for depression and with a past-year history of physical peer violence (n=16)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (adapted published instrument); C: +/-</li> <li>Adoption (program utilization); C: +/-</li> <li>Appropriateness (self-developed interview); C: +</li> <li>Feasibility (adapted published instrument); C: +</li> </ul>
<b>CATCH-IT</b>		
Gladstone et al [69]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-21 years with subthreshold depression (n=83)</li> </ul>	<ul style="list-style-type: none"> <li>Appropriateness (adapted questionnaire); C: +/-</li> <li>Feasibility (adapted questionnaire); C: +</li> </ul>
Ruby et al [67]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-21 years with subthreshold depression (n=83)</li> </ul>	<ul style="list-style-type: none"> <li>Cost (economic analysis); C: +</li> </ul>

Program and study	Participants (n)	Implementation outcome (measure <sup>a</sup> ); findings <sup>b</sup>
Eisen et al [70]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-21 years with subthreshold depression (n=83)</li> <li>Healthcare providers (n=63)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); HCP: +/-</li> <li>Appropriateness (self-developed questionnaire); HCP: +/-</li> <li>Feasibility (self-developed questionnaire); HCP: +/-</li> </ul>
Iloabachie et al [68]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-21 years with subthreshold depression (n=83)</li> </ul>	<ul style="list-style-type: none"> <li>Appropriateness (adapted questionnaire); C: +/-</li> </ul>
Van Voorhes et al [66]	<ul style="list-style-type: none"> <li>Adolescents with subthreshold depression (n=83)</li> <li>Primary healthcare providers (n=12)</li> <li>Healthcare settings (n=5)</li> </ul>	<ul style="list-style-type: none"> <li>Cost (marketing strategy success/cost reporting); HCP: +</li> <li>Penetration (uptake by practices); HCP: +</li> </ul>
Van Voorhes et al [63]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-21 years with subthreshold depression (n=83)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> <li>Adoption (program utilization); C: +/-</li> <li>Appropriateness (self-developed questionnaire); C: +/-</li> <li>Fidelity (physician adherence); HCP: +/-</li> </ul>
Van Voorhes et al [64,65]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 14-21 years with subthreshold depression (n=83)</li> </ul>	<ul style="list-style-type: none"> <li>Adoption (program utilization); C: +/-</li> <li>Fidelity (physician adherence); HCP: +/-</li> </ul>

<sup>a</sup>Self-developed questionnaire/interview: bespoke questions or survey items created by the researcher; published instrument: validated tool with citation in text; program utilization/physician adherence: metrics of usage.

<sup>b</sup>C: child/adolescent/young adult report; HCP: healthcare provider report; P: parent report; +: high/positive findings; -: negative findings; +/- mixed findings.

<sup>c</sup>CBT: cognitive behavioral therapy.

### Implementation Findings for eMental Healthcare Technologies for Depression

Table 3 displays the implementation findings among eMental healthcare technologies for depression. Most studies reported the technologies as acceptable (67%) with high satisfaction [56,61,63,72], recommendations for use [71], acceptability, and ease of use among children, parents, and healthcare providers [58]. The remainder (33%) reported mixed acceptability [60,70,81]. Of the 6 studies that examined adoption, one study (17%) described high usage [59], while the remaining studies (83%) described moderate or mixed adherence [56,63-65] and usage [60]. Appropriateness was the most commonly measured outcome among eMental healthcare technologies for depression, although results varied. Four studies (40%) reported high helpfulness [57,60-62], while 6 studies (60%) reported mixed outcomes [58,63,68-70,72]. Two studies examined cost outcomes [66,67] and described intervention implementation as economically viable. Of the 6 studies that investigated feasibility, 3 (50%) reported positive or high outcomes [60,62,69], while the other 3 (50%) described mixed ease of use [70,81] and attitudes [57]. Four studies examining fidelity reported mixed results [62-65], particularly healthcare provider adherence to the program. The CATCH-IT program was the only intervention that was examined for penetration [66]. Although penetration was successful, implementing the

technology successfully in 12 practices, several barriers to implementation were described, such as low levels of interest from healthcare providers and lack of established procedures and guidelines [66]. Studies examining eMental healthcare technologies for depression did not investigate or report on sustainability.

### Implementation Findings for eMental Healthcare Technologies for Anxiety and Depression

Table 4 shows the implementation findings among eMental healthcare technologies for both anxiety and depression. All 5 studies examined the acceptability of technologies aimed at treating anxiety and depression. Of these, 3 (60%) reported high satisfaction [73-75], with children and parents describing that they would not change any aspects of the program, and 2 studies (40%) reported moderate satisfaction [76,77]. Two studies examined adoption and reported low adherence to program sessions [75] and high website usage rates [77]. Of the 2 studies that examined appropriateness, both found positive attitudes and perceived helpfulness of the intervention from children and parents [73] and healthcare providers [74]. One study examined penetration of technology, reporting successful integration of the program into a practice of 2000 healthcare providers [74]. None of the 5 studies examined cost, feasibility, fidelity, or sustainability.

**Table 4.** Implementation findings among eMental healthcare technologies for both anxiety and depression.

Program and study	Participants (n)	Implementation outcome (measure <sup>a</sup> ); findings <sup>b</sup>
<b>Group therapy</b>		
Sapru et al [73]	<ul style="list-style-type: none"> <li>Children aged 6-12 years referred with a mood or anxiety disorder (n=16) and their parents (n=NR<sup>5</sup>)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C, P: +</li> <li>Appropriateness (open-ended feedback); C, P: +</li> </ul>
<b>Treasure Hunt</b>		
Brezinka [74]	<ul style="list-style-type: none"> <li>Children and adolescents aged 6-19 years with anxiety, depression, ODD<sup>c</sup>, or ADHD<sup>d</sup> (n=218)</li> <li>Healthcare providers (n=124)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> <li>Appropriateness (self-developed questionnaire); HCP: +</li> <li>Penetration (uptake by practices); HCP: +</li> </ul>
<b>SPARX</b>		
Bobier et al [75]	<ul style="list-style-type: none"> <li>Adolescents aged 16-18 years with severe psychiatric disorders (namely mood and anxiety disorders; n=20)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +</li> <li>Adoption (program utilization); C: –</li> </ul>
<b>Problem-solving therapy</b>		
Hoek et al [76]	<ul style="list-style-type: none"> <li>Adolescents and young adults aged 12-21 years with self-reported or parent-reported mild to moderate depressive or anxiety symptoms (n=22)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (published instrument); C: +/-</li> </ul>
<b>RU-OK</b>		
Ercan et al [77]	<ul style="list-style-type: none"> <li>Adolescents aged 13-15 years attending a hospital school for depression and anxiety (n=105)</li> </ul>	<ul style="list-style-type: none"> <li>Acceptability (self-developed questionnaire); C: +/-</li> <li>Adoption (program utilization); C: +</li> </ul>

<sup>a</sup>Self-developed questionnaire/interview: bespoke questions or survey items created by the researcher; published instrument: validated tool with citation in text; program utilization/physician adherence: metrics of usage.

<sup>b</sup>C: child/adolescent/young adult report; HCP: healthcare provider report; P: parent report; +: high/positive findings; – negative findings; +/- mixed findings.

<sup>c</sup>NR: not reported.

<sup>d</sup>ODD: oppositional defiant disorder.

<sup>e</sup>ADHD: attention deficit hyperactivity disorders.

## Discussion

### Principal Findings

Complimentary to recent reviews [12,82], this systematic review reports on how the implementation of eMental healthcare technologies for children and adolescents with anxiety or depression has been studied and reported. The majority of studies included in the review were RCTs, and the methodological quality of studies was scored as moderate to high in all but a few cases. Broadly synthesized using Proctor's [31] 8 dimensions of implementation, our review suggests that measures of acceptability, adoption, and appropriateness are more frequently reported than indicators of cost, fidelity, and sustainability. Further, the review highlights the lack of measurement precision around implementation constructs and the need to elucidate the relationship between implementation and effectiveness. Below, we highlight 5 key implications of our findings for advancing this emerging literature. Results derived from new lines of research can have significant practical value for decision-makers and administrators by providing the design of training, helping promote provider engagement, assisting in troubleshooting the obstacles that adolescents and parents encounter, and guiding projects that scale-up interventions in new contexts.

### Improving the Validity of Acceptability Measures

The vast majority of studies included in the review examined some dimension of acceptability, signifying that this construct is important as an indicator of effective implementation, but its measurement varied. Satisfaction, a frequent acceptability metric, was reported as high among participants (generally >70%), but was largely derived from self-reports of parents and adolescents taken at a single time-point (typically posttreatment). This means we still know little about satisfaction/dissatisfaction among those who fail to complete the treatment, or how early perceptions of satisfaction might impact effort and adherence during the later stages of treatment. More than half of the studies used nonvalidated measures of acceptability, which are problematic for assessing reliability and psychometric sensitivity. Given that almost all validated psychiatric patient satisfaction measures are validated for adults (not children and adolescents) and that developmental age affects perceptions of satisfaction with healthcare [83], our findings raise the possibility of overestimated satisfaction ratings within this literature. Low actual adherence rates reported in many studies, particularly those treating depression [84], suggest that we need to know more about the relationship among satisfaction, adherence, and clinical improvement. Most importantly, differences between those who do and do not respond to

inquiries about service satisfaction (ie, bias in nonresponse [85]) and the impact of novelty (ie, bias resulting from perceived “new” or “innovative” technology [86]) imply that satisfaction is a potentially tendentious implementation metric. Without psychometrically strong and developmentally appropriate measures of satisfaction and acceptability for eMental health, stakeholders run the risk of focusing on the wrong “pragmatic” attributes when determining if a given adolescent-focused intervention is worth long-term investment. As a metric frequently used to inform decision-making around service delivery, a more systematic approach to instrumentation around the acceptability construct is vital. Future research can use pragmatic trial designs and hybrid effectiveness-implementation designs that aim to elucidate mechanisms of action between acceptability and effectiveness.

### **Reframing Adoption as Process not Product**

While reporting on adoption (namely adherence) was fairly common in studies we reviewed, authors reported mixed findings. Moreover, none of the studies in our review formatively examined adolescent, parent, or clinician adoption in terms of readiness for eMental health, intent-to-use, or ongoing decision-making. All of these factors play a central role in behavior change associated with effective mental health treatments [87,88,89]. As adoption continues to be conceptualized in the literature primarily as a posthoc measure of “adherence,” our review suggests process-related measures of adoption could be a valuable new line of research. Most of the studies in our review reported on interventions involving multiple sessions (ie, anxiety interventions had a minimum of 8 sessions), requiring the youth to sustain and repeat interactions over time. Research from other fields, like adolescent online learning and gaming, could provide important insights here. For example, research has shown that young people’s internet self-efficacy, self-regulatory skills, and perceived quality of online learner-instructor interaction are important predictors of online engagement [90]. Rather than viewing adoption as a relatively stable end-product of individual effort, emphasis should be placed on understanding the situated, mutually constitutive relationship of a young person and the eMental healthcare environment. For example, use of modeling and path analysis techniques to identify the direct and indirect effects of provider (eg, therapeutic alliance, communication style) and technical (eg, persuasive system design components) or therapeutic (eg, comorbidity, treatment credibility) factors on adoption may provide valuable and practical insights. Improved knowledge of these processes could help administrators design training, promote provider engagement, and pre-emptively address obstacles for youth and their families.

### **Perceived Suitability of eMental Healthcare for Adolescents With Anxiety and Depression**

A little less than half of the studies testing depression interventions and a third of those focused on anxiety measured some dimension of “appropriateness,” with many reporting overall mixed results. Perceptions about the suitability of a given healthcare service in a particular setting, for a particular purpose, with a particular provider and clientele can be a function of organizational culture and climate, as well as a public opinion.

In practice, eMental healthcare is still considered outside standard practice by most youth mental health service providers [91]; yet, investments in eMental healthcare are rarely withdrawn because of purported safety risks or over concerns about the quality of care. This suggests that administrators, providers, and the general public feel that eMental healthcare is an appropriate treatment modality, but still continue to prioritize its use in some contexts over others. It may be because the treatment ideologies (ie, beliefs about the etiology of illness, the roles of the provider/patient, and the efficacy of various treatments) [92] held by clinicians, parents, and children/youth lead them to greater skepticism about whether eMental healthcare can deliver the same quality of care [93] as face-to-face services for children and adolescents. In particular, public opinion and clinician beliefs about depression-associated risks (eg, suicide, self-harm [94]), privacy [95], and the changes in provider-patient interaction via eHealthcare delivery [96]) could impact perceived appropriateness. This could be one explanation for the higher acceptability rates of anxiety-focused interventions than of depression-focused ones. Research on appropriateness would benefit from an exploration of how eMental healthcare treatment ideologies develop for different clinical contexts (ie, diagnosis, severity) and technological modalities (ie, teleconsultation, mobile apps, SMS text messaging) and assess their subsequent influence on other implementation factors. These lines of research could eventually assist providers in selecting eMental healthcare technologies to match the intensity of treatment with the complexity of the condition (ie, stepped care).

### **Disruption of Established Professional Roles, Responsibilities, and Working Styles**

Findings from this review also make an important contribution to expanding our understanding of feasibility. The feasibility results observed in our review were most frequently related to provider-level concerns (eg, issues of training, need for technical support). This suggests that the workflow impacts of eMental health services are a vital area for future implementation research. Given that most of the eMental healthcare technologies in our review included some form of healthcare provider interaction before or during the treatment, their role cannot be underappreciated. Many of the studies described atypical interactions for providers trained in traditional psychotherapy, including use of SMS text messages, frequent short emails, and bidirectional electronic exchanges, technical support, etc. Our review echoes recent calls to move beyond the simplistic analyses of barriers and facilitators to models of feasibility that allow researchers to test how eHealth modalities disrupt established professional roles, responsibilities, and working styles [97]. We recommend increased emphasis on underdeveloped implementation outcomes like feasibility, where few comprehensive and validated instruments exist [98]. Knowledge generated from this research could inform strategic targeting of resources and the tailoring of implementation strategies at an early stage to maximize opportunities for normalization of new eMental health workflows. Studies in our review were limited by small sample sizes and were mostly focused on measuring clinician attitudes with a lesser focus on quantifying actual clinician behaviors. Policy-focused research

involving clinical practice models for eMental health [99], effective training practices for eMental health, and guidelines for selecting safe and effective eMental health tools are needed to shape behaviors that will make eMental health feasible in routine care settings.

### **Toward Sustainable, Cost-Effective, Scalable eMental Health for Anxiety and Depression**

Finally, this review highlights persistent gaps in the measurement of fidelity, penetration, and sustainability constructs. These implementation facets are important macro-level determinants of policies and strategies for technology integration [100,101]. However, because these factors often require longer-term follow-up to adequately assess, they pose unique methodological challenges for researchers. For example, sustainability and penetration constructs typically require very large sample sizes that are hard to obtain [102] and there is concern that the current methodological approaches for eMental healthcare technology have a long lag-time from initiation, to publication of outcomes or implementation. While the promise of scalable, more cost-effective treatments is widely argued in eMental health planning, there are knowledge gaps pertaining to how these services are costed, billed, and supported in the long term. As implementation research matures in this area, it will be critical to apply research methodologies that optimize the ecological validity of constructs and address these practical, real-world implications [103]. The use of structured, theory-driven implementation methodologies would provide flexibility to allow interventions to be adapted for use in routine care settings [99,104].

### **Limitations**

Although this review was rigorous, carefully executed, and employed a robust methodological approach, it is not without limitations. Technologies being deployed in healthcare systems that have not been scientifically investigated and without reported implementation data were not available for our review. We did not search databases such as the NIH Reporter, which may have yielded additional eMental healthcare technology studies. While some of the studies in the NIH Reporter may

have been additionally registered in the clinicaltrials.gov registry after our search, some may not have been. Given that eMental healthcare technologies are constantly appearing and disappearing from the behavioral health service landscape, published accounts of the state of this field will likely always be slightly outdated. This is true for all eHealth-related research syntheses, and it only underscores the need to promote an “evergreen” mentality for research that acknowledges that the evidence base is always evolving. The inclusion of multiple study designs created a challenge for summarizing study features and generalizing study findings. Nonetheless, this approach allowed for the comparison of different kinds of evidences that shape real-world policy and service delivery. By not limiting our search based on study design, but rather reporting on quality via a validated appraisal tool, we established a starting point for broad critical appraisal. Finally, the inconsistent use of eHealth terminology [105-107] across the literature required us to make judgment calls regarding how to group implementation data across the 8 outcome categories. This could have resulted in the misclassification of some factors within the wrong outcome category [31].

### **Conclusions**

Acceptability of eMental healthcare technology appears to be high among users, and it is the most commonly investigated implementation outcome. Perceptions of the appropriateness of eMental healthcare technology for use in healthcare varied, as did the adoption of technologies in healthcare practice. These findings suggest that the implementation science of eMental health for adolescent anxiety and depression needs to mature. Validated implementation measures as well as research designs and analytic techniques that model complex interactions and implementation contexts should be pursued in earnest. Future studies should help bridge gaps in knowledge about the fidelity of eMental health interventions over time and how eMental health technologies spread through the healthcare system, direct and indirect costs, and sustainability models. Closing these knowledge gaps has the potential to make treatments more accessible and reduce the burden of anxiety and depression on affected children and adolescents.

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### **Authors' Contributions**

PJM conceptualized the project idea and all authors were involved in the design of this work. NDG, AS, and ASN were responsible for the screening, data extraction, and analysis. LW, NDG, and ASN were responsible for the initial drafting of the manuscript and PJM, KB, AH, LH, MPD, and AS provided comments and edits on it at all stages. All authors have read and approved the final version of the manuscript.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Search strategy for Epub ahead of print, in-process, & other non-indexed citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R).

[[PDF File \(Adobe PDF File\), 13KB - mental\\_v5i2e48\\_app1.pdf](#)]

## Multimedia Appendix 2

Study Quality according to Mixed Methods Appraisal Tool (MMAT).

[[PDF File \(Adobe PDF File\), 178KB - mental\\_v5i2e48\\_app2.pdf](#)]

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## Abbreviations

**MEDLINE:** Medical Literature Analysis and Retrieval System Online, or MEDLARS Online

**EMBASE:** Excerpta Medica dataBASE

**CINAHL:** Cumulative Index to Nursing and Allied Health Literature

**MMAT:** Mixed Methods Appraisal Tool

**RCT:** randomized controlled trials

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Original Paper

# Youth Mental Health Services Utilization Rates After a Large-Scale Social Media Campaign: Population-Based Interrupted Time-Series Analysis

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## Abstract

**Background:** Despite the uptake of mass media campaigns, their overall impact remains unclear. Since 2011, a Canadian telecommunications company has operated an annual, large-scale mental health advocacy campaign (Bell Let's Talk) focused on mental health awareness and stigma reduction. In February 2012, the campaign began to explicitly leverage the social media platform Twitter and incited participation from the public by promising donations of Can \$0.05 for each interaction with a campaign-specific username (@Bell\_LetsTalk).

**Objective:** The intent of the study was to examine the impact of this 2012 campaign on youth outpatient mental health services in the province of Ontario, Canada.

**Methods:** Monthly outpatient mental health visits (primary health care and psychiatric services) were obtained for the Ontario youth aged 10 to 24 years (approximately 5.66 million visits) from January 1, 2006 to December 31, 2015. Interrupted time series, autoregressive integrated moving average modeling was implemented to evaluate the impact of the campaign on rates of monthly outpatient mental health visits. A lagged intervention date of April 1, 2012 was selected to account for the delay required for a patient to schedule and attend a mental health-related physician visit.

**Results:** The inclusion of Twitter into the 2012 *Bell Let's Talk* campaign was temporally associated with an increase in outpatient mental health utilization for both males and females. Within primary health care environments, female adolescents aged 10 to 17 years experienced a monthly increase in the mental health visit rate from 10.2/1000 in April 2006 to 14.1/1000 in April 2015 (slope change of 0.094 following campaign,  $P < .001$ ), whereas males of the same age cohort experienced a monthly increase from 9.7/1000 to 9.8/1000 (slope change of 0.052 following campaign,  $P < .001$ ). Outpatient psychiatric services visit rates also increased for both male and female adolescents aged 10 to 17 years post campaign (slope change of 0.005,  $P = .02$ ; slope change of 0.003,  $P = .005$ , respectively). For young adults aged 18 to 24 years, females who used primary health care experienced the most significant increases in mental health visit rates from 26.5/1000 in April 2006 to 29.2/1000 in April 2015 (slope change of 0.17 following campaign,  $P < .001$ ).

**Conclusions:** The 2012 *Bell Let's Talk* campaign was temporally associated with an increase in the rate of mental health visits among Ontarian youth. Furthermore, there appears to be an upward trend of youth mental health utilization in the province of Ontario, especially noticeable in females who accessed primary health care services.

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**KEYWORDS**

mental health; youth; adolescent; social media; population health; mass media

## Introduction

### Background

Over the last decade, the growing use of social media technology has become an important method for many forms of societal communication. Given the broad reach of social media, it has been leveraged as a communication mechanism for a range of different health interventions, including smoking cessation [1], alcohol awareness [2], HIV prevention [3], childhood obesity [4], sexual health practices [5], and mental health awareness [6]. However, it is not certain whether these types of social media campaigns actually influence the behaviors of intended audiences [7,8] or the health care system in measurable ways [9]. Research completed to date provides an incomplete picture regarding the impact of social media used in health campaigns [10,11]. Currently, we know that traditional mass media health campaigns conveyed by television, radio, print advertisements, and outdoor media can generate reasonably effective results at the population level, especially when multiple media interventions are used to target an episodic situation (eg, vaccination) [9,12]. What remains unclear is whether large-scale health awareness campaigns underpinned primarily by social media messaging can also generate measurable behavior change at the population level, especially around sensitive topics such as mental illness and its related stigma.

In Canada, one mental health awareness campaign that has gained significant attention since 2011 is *Bell Let's Talk* [6,13]. First initiated in February 2011 and led by the Canadian telecommunications company Bell Canada, the *Bell Let's Talk* campaign has become a yearly event that draws significant volumes of social media traffic related to mental health and stigma awareness. The campaign is hosted by Clara Hughes, a prominent Canadian female athlete who medaled for Canada in both the summer and winter Olympics from 1996 to 2010. By recounting her struggles with depression, the campaign encourages the public to *start a dialogue* to break the silence around mental illness and to support mental health awareness across Canada [14]. To achieve this, the campaign encourages the public to interact with the campaign's various digital markers via social media on a predetermined day each year. Starting in 2012, the campaign began to leverage social media as a primary mechanism to encourage engagement with the public. During the February 8, 2012 event, the company promised to donate Can \$0.05 to mental health research and programming for every retweet of the @Bell\_LetsTalk campaign tweet (or in later years, any usage of the #BellLetsTalk hashtag on a variety of social media platforms) in addition to any call or SMS text message (short message service, SMS) sent on the Bell Canada network [15] (see [Multimedia Appendix 1](#) for tweet examples from February 8, 2012). The primary goal of the 2012 campaign was to invite Canadians to talk about mental health in an effort to break down stigma that "keeps too many people from seeking the help they need [16]." By the end of the 2012 campaign day, 78,520,284 interactions had been generated, resulting in a donation of Can \$3.92 million by Bell Canada to Canadian

mental health programs [17]. In more recent years, other events and activities related to the campaign have been held, including a 110 day cross-Canada bike ride by Clara Hughes in 2014 and the expansion of a community fund that provided financial grants to Canadian-registered charities and non-for-profit organizations to support mental health community-based programs and services. The most recent 2017 Bell Let's Talk campaign event (January 25, 2017) resulted in almost 132 million social media and network interactions (raising Can \$6.59 million) [18] and represents what is likely the most widely distributed campaign using elements of social media to broadcast mental health or stigma-reduction messaging in Canada.

Despite the success of *Bell Let's Talk* and other similar mental health or antistigma campaigns [9,19,20], limited research has focused on evaluating the impact on behavior change. Instead, previous research has focused on evaluating campaign awareness by the public and resulting attitude changes and knowledge uptake [19-23]. Recent evaluation of *Bell Let's Talk* by Harris/Decima has suggested that the campaign was successful at decreasing stigma and increasing personal awareness in a random telephone survey of Canadian adults (N=1007) over a 5-year period (2011-2015) [24]; however, no examination of the campaign's influence on behavior change at population level has been undertaken. To our knowledge, population-level behavior change of people in response to a mass media mental health campaign has only been addressed in one study [9], and no known studies exist where social media was used as a primary mechanism of intervention dissemination.

### The Study

Due to the increasing rates of mental illness, especially in youth populations [25-28] who are also heavy users of social media technology [29,30], our population-level analysis sought to evaluate the potential effects of the *Bell Let's Talk* on adolescent (aged 10-17 years) and young adult populations (aged 10-24 years). We hypothesized that the 2012 *Bell Let's Talk* campaign would stimulate an increase in mental health service utilization by youth, particularly for females, because of the use of a popular, female athlete role model (ie, Clara Hughes) as the primary campaign spokesperson. Therefore, our primary objectives were to (1) Investigate whether the occurrence of the 2012 *Bell Let's Talk* campaign was temporally associated with changes in mental health system use by youth aged 10 to 24 years and (2) Examine secular trends in mental health system use by youth over a 10-year period. To our knowledge, social media-enabled mental health awareness campaigns of this size and scale have never been fully examined using population-based methods.

## Methods

### Study Design and Setting

We conducted a cross-sectional time series analysis of all youth aged 10 to 24 years who accessed outpatient mental health services from January 1, 2006 to December 31, 2015 in the

province of Ontario, Canada. Residents of Ontario access universal health care, including hospital, diagnostic, and physician services. Research ethics board approval was obtained from Sunnybrook Health Sciences Centre, Toronto. Participant informed consent was not required. This report adheres to the REporting of studies Conducted by using the Observational Routinely-collected health Data statement [31].

### Data Sources

All Ontario residents have access to universally funded health care services and are identifiable through health care administrative records held by the Institute for Clinical Evaluative Sciences (ICES). Within the ICES environment, individual-level health service utilization can be anonymously tracked, linked, and analyzed for research purposes. A unique, encoded identifier permits linkage across several administrative databases. We used the Registered Persons Database (RPDB) to identify all youth aged 10 to 24 years who received outpatient mental health services during the study period. Demographic data and vital status were also obtained from the RPDB. The fee-for-service billings managed by the Ontario Health Insurance Plan (OHIP) were used to identify outpatient mental health visits to (1) Primary health care (family or general practitioners) and (2) Psychiatric services (psychiatrists). Diagnostic codes derived from the International Classification of Diseases, 9th Revision were used to identify all mental health visit diagnoses. Definitions of variables and administrative codes used in this study are detailed in [Multimedia Appendices 1-5](#).

### Study Population

Primary health care mental health and outpatient psychiatric service billings were identified for all youth aged 10 to 24 years from January 1, 2006 to December 31, 2015. Billing records were excluded if they had an invalid provincial health card number; were missing key demographic variables, including age and sex; or were billed to individuals not residing in the province of Ontario. As physicians can bill multiple billing codes for a visit, we collapsed multiple billings by the same physician for the same patient on a single day into one visit. In each month of our 10-year study period (January 1, 2006-December 31, 2015), we identified all youth (adolescents aged 10-17 years and young adults aged 18-24 years, separately) who received outpatient mental health services. Participants were included if they met the age inclusion and had a valid OHIP status. Youth who were missing key demographic variables, including age and sex, or those not residing in the province of Ontario, were excluded from analysis.

### Outcome Measures

Our primary outcomes of interest were the rate of outpatient mental health visits to (1) Primary health care or (2) Psychiatric services, ascertained on a monthly basis and stratified by sex (males and females) and youth groups (adolescents [aged 10-17 years]; young adults [aged 18-24 years]). Eligible outpatient visits for mental health were defined using OHIP billing codes with a mental health diagnosis. Diagnostic codes were selected according to a modified Steele et al [25,32] algorithm for diagnostic, fee, and assessment codes indicative of a mental health system visit ([Multimedia Appendices 2 and 3](#)). Secondary

outcomes included *new* mental health visits to (1) Primary health care or (2) Psychiatric services. A visit was defined as a *new* visit if the youth did not experience any mental health visit in the previous 12 months. All outcomes are presented as rates, calculated as the total number of visits per month divided by the corresponding youth and sex group population estimates derived from intercensal and postcensal estimates of the Ontario population (Ontario Ministry of Health and Long-Term Care: IntelliHEALTH) [33].

### Population Characteristics

We identified the following patient characteristics: age, sex, neighborhood-based socioeconomic status (neighborhood income quintiles), rurality status based on location of residence, comorbidity status, hospitalizations in the previous year, and diagnosis subgroup for their mental health visit. Income quintiles were based on a neighborhood measure of average household income, determined from their residential postal code and Statistics Canada Census data [34]. Previous hospitalizations were captured from the Discharge Abstract Database, whereas diagnostic subgroups were defined using the diagnosis codes associated with the OHIP databases billings for the mental health visits. Derived diagnostic groupings categorized outpatient diagnoses as either arising from a psychotic disorder, addictions and substance abuse, nonpsychotic disorder, or social problems [25,32] ([Multimedia Appendices 2-4](#)). Comorbidity status was defined using the Charlson Comorbidity Index [35]; an index that quantifies comorbidity based on prior hospital admissions. Previous health system use captured the number of outpatient mental health visits in the 12 months before the index mental health visit.

### Statistical Analysis

The study cohort was summarized using descriptive statistics, which included using proportions for categorical data and mean with SD or median with interquartile range for continuous data. Population characteristics were compared at three predefined time points: (1) preintervention, April 2008; (2) peri-intervention, April 2011; and (3) postintervention, April 2014. The three predefined time points were selected a priori to identify any potential demographic variability or nonstable health system utilization patterns of the population. Differences between time periods were assessed using the chi-square test for categorical data and one-way analysis of variance for continuous data. Interrupted time series analysis was performed to examine the impact of the 2012 *Bell Let's Talk* campaign (February 8, 2012) on each of our primary and secondary outcomes of interest, by sex groups (males and females). The models quantify both a level and slope change following the intervention, while accounting for the autocorrelation of observations. The 2012 campaign was selected as the intervention, as it was the first year that social media was officially leveraged and promoted. The onset date for the intervention was lagged nearly 2 months (until April 1, 2012) to account for the delay that would be required for a patient to schedule and attend a mental health-related physician visit. Analyses were performed at the visit level, and each year was divided into monthly intervals, spanning a total of 120 months during the study period (2006-2015). Autoregressive integrated

moving average models were used to adjust for residual autocorrelation. All analyses were performed at the Institute for Clinical Evaluative Sciences using SAS (SAS Institute) statistical software (SAS version 9.3 and SAS EG 6.1) using a Type 1 error rate of 0.05 as the threshold for statistical significance.

### Sensitivity Analysis

A sensitivity analysis was completed using a tracer variable of upper respiratory tract infections (Multimedia Appendix 5), which would not have been influenced by the campaign. This was done to assess whether any observable differences or biases existed within the cohort related to nonmental health system interaction or the presence of billing coding changes in the administrative data record between genders.

## Results

### Participants

In Ontario, the estimated number of youth aged 10 to 24 years during the study time period ranged from 2,576,630 (2006) to 2,564,097 (2015). Two age cohorts were selected for specific examination: (1) adolescents aged 10 to 17 years and (2) young adults aged 18 to 24 years.

### Adolescents

Over the entire study period, a total of 256,295 males and 277,599 females in the age group of 10 and 17 years made visits

to primary health care services for mental health reasons, accounting for a total of 696,301 and 782,507 visits for males and females, respectively. Outpatient psychiatric services were accessed over the study period by a total of 77,916 males and 49,801 females, accounting for 201,673 and 148,261 visits, respectively (Figure 1).

### Young Adults

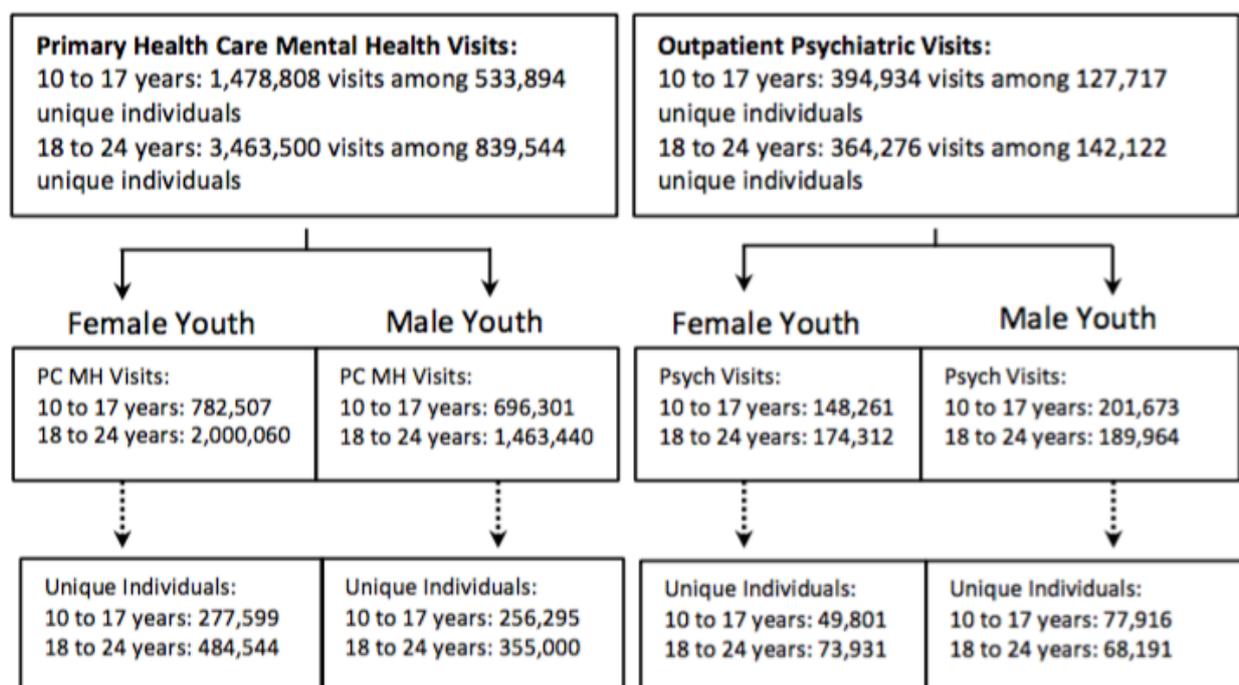
A total of 355,000 males and 484,544 females in the age group of 18 to 24 years made visits to primary health care services for mental health reasons, accounting for a total of 1,463,440 and 2,000,060 visits for males and females, respectively. Outpatient psychiatric services were accessed over the study period by a total of 68,191 males and 73,931 females, accounting for 189,964 and 174,312 visits, respectively (Figure 1).

### Outcomes

#### Adolescents

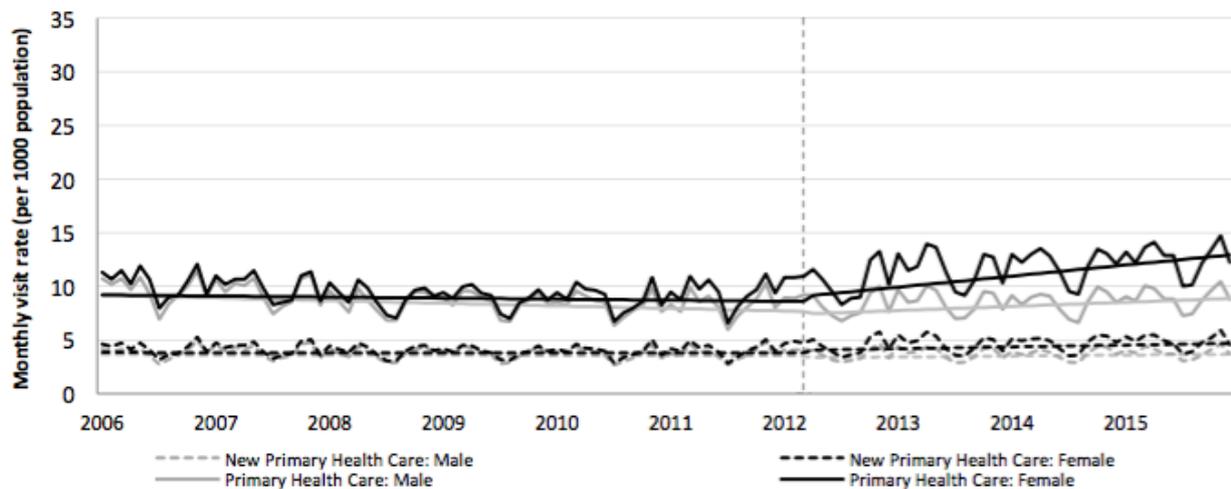
The monthly mental health visit rate to primary health care for females increased from 10.2/1000 in April 2006 to 14.1/1000 in April 2015, whereas male adolescents exhibited a moderate change from 9.7/1000 to 9.8/1000 (Figure 2). The monthly mental health visit rate to psychiatric services for female and male youth over the same two time points increased from 1.5/1000 to 3.1/1000 and 2.5/1000 to 3.4/1000, respectively (Figure 3). The monthly rate of new visits to psychiatric services also increased for females (0.42/1000 to 0.71/1000) and males (0.74/1000 to 0.99/1000) over the same time points (Figure 3).

**Figure 1.** Flowchart detailing mental health visits for primary health care psychiatric services by Ontario youth aged 10 to 17 years and 18 to 24 years from 2006 to 2015. Primary health care mental health and outpatient psychiatric service billings were identified for all youth aged 10 to 24 years from January 1, 2006 to December 31, 2015. Billing records were excluded if they had an invalid provincial health card number; were missing key demographic variables, including age and sex; or were billed to individuals not residing in the province of Ontario. Billings were restricted to one record per patient per day to define a health care visit.

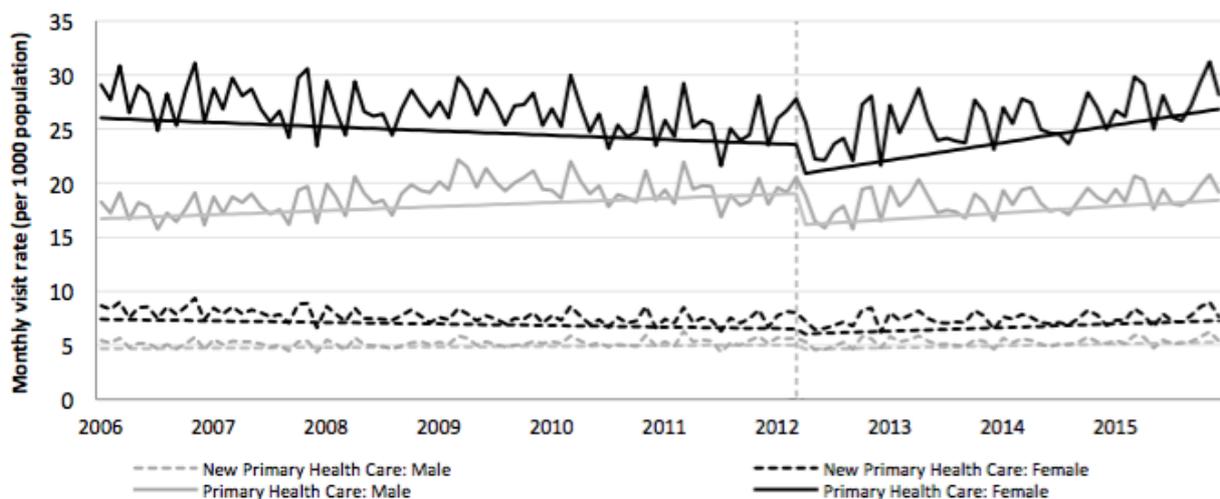


**Figure 2.** Monthly rate of outpatient mental health visits to primary health care and new mental health visits to primary health care for male and female: (1) adolescents (aged 10-17 years; top panel) and (2) young adults (aged 18-24 years; bottom panel) from 2006 to 2015. Trend lines show slope change after lagged intervention date. Vertical dash line shows lagged intervention date of April 1, 2012.

### Adolescents (10 to 17 years)



### Young adults (18 to 24 years)



After adjusting for seasonality and correlation between time periods, the campaign was associated with a statistically significant increase in the slope (visit rate) for all four outcomes among both sexes (Figure 2; Table 1). Females exhibited a nearly two-fold change in slope for both mental health visits and *new* mental health visits to primary health care when compared with their male counterparts (females: 0.094,  $P < .001$  vs males: 0.052,  $P < .001$  and females: 0.02,  $P = .004$  vs males: 0.009,  $P = .03$ , respectively). No statistically significant changes in the levels (magnitude) of the visit rates were observed immediately following the campaign.

#### Young Adults

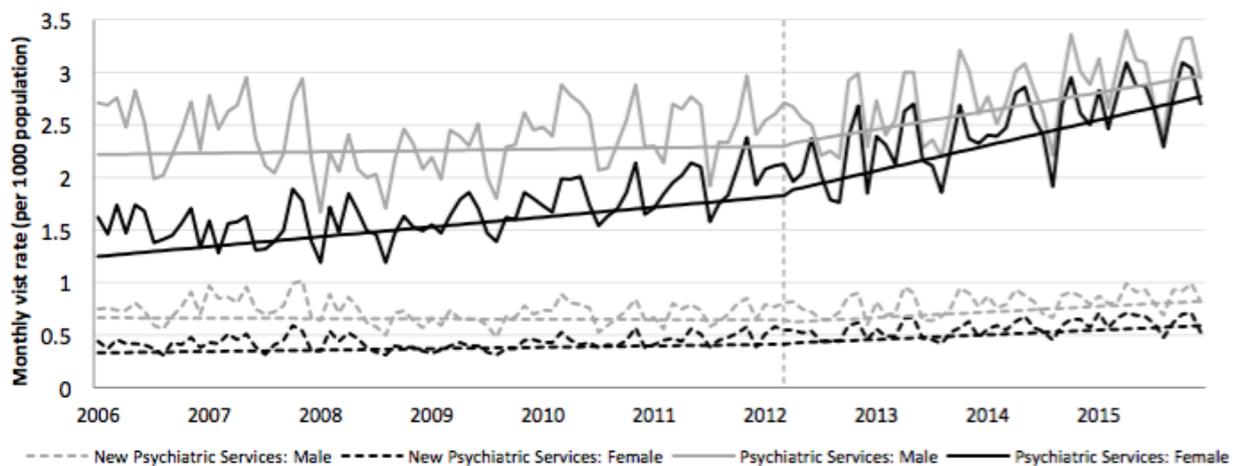
Among females, the mental visit rate to primary health care increased from 26.5/1000 to 29.2/1000 over the 10-year period. Males also experienced increases from 16.6/1000 to 20.3/1000 over study (Figure 2). The monthly mental health visit rate to psychiatric services for males and females over the same two

times points also increased from 2.1/1000 to 2.3/1000 and 1.95/1000 to 2.5/1000 for females and males, respectively (Figure 3). Furthermore, the monthly rate of new visits to psychiatric services increased for females from 0.28/1000 to 0.41/1000 and males from 0.34/1000 to 0.4/1000 (Figure 3).

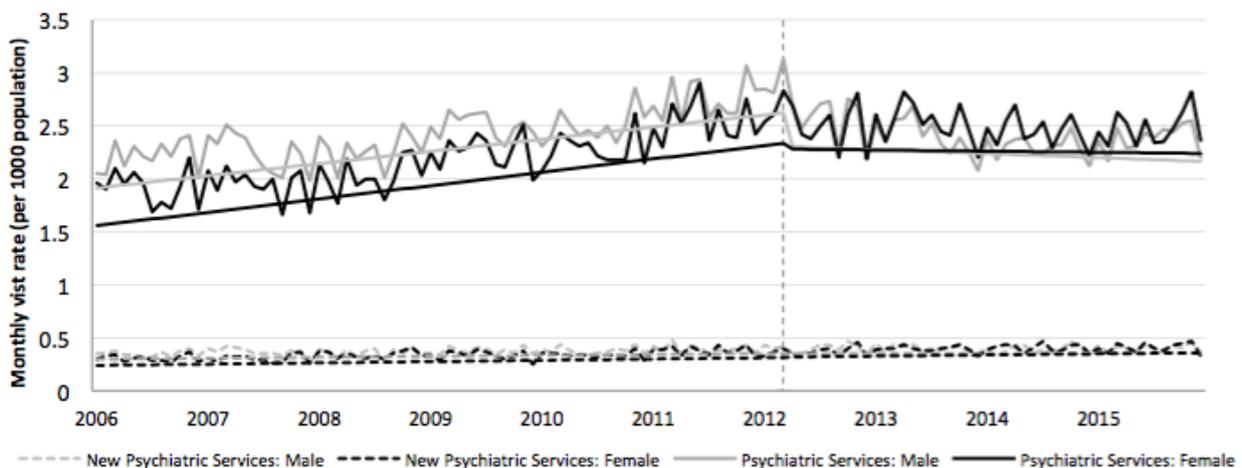
In young adults, a statistically significant increase in the slope of the primary health care visit rates in females (0.17,  $P < .001$ ), but not males, was observed (Figure 2; Table 1), whereas both exhibited a significant immediate drop in the rates (magnitude change) of primary health care mental health visits following the campaign (males:  $-2.9/1000$  and females:  $-2.8/1000$ ). This pattern was similar among new primary health care visits. Although the change in slope of new psychiatric services visits remained unchanged for both sexes, both male and female young adults experienced a decrease in the slope, to a plateau, of all psychiatric service visits after April 2012. A significant immediate drop in the rate of psychiatric service visits was observed for males, but not females.

**Figure 3.** Monthly rate of outpatient mental health visits to psychiatric services and new mental health visits to psychiatric services for male and female: (1) adolescents (aged 10-17 years; top panel) and (2) young adults (aged 18-24 years; bottom panel) from 2006 to 2015. Trend lines show slope change after lagged intervention date. Vertical dash line shows lagged intervention date of April 1, 2012.

### Adolescents (10 to 17 years)



### Young adults (18 to 24 years)



### Tracer

To understand whether our findings may be influenced by other cohort effects, we repeated the analysis using visit rates for upper respiratory tract infections ([Multimedia Appendix 5](#)). After adjusting for seasonality and correlation between time periods, no significant differences were observed; either the level or slope changes.

### Descriptive Data

Demographic characteristics for male and female adolescents and young adults who accessed primary health care for mental health purposes are presented in [Tables 2](#) and [3](#). These demographic characteristics were defined for three a priori-selected time periods: April 2008 (preintervention), April 2011 (peri-intervention), and April 2014 (postintervention).

### Adolescents

Among adolescents, the mean age of females was higher than that for males for all three time periods; a larger proportion of females were in the age range of 14 to 17 years compared with males (April 2014: 5655/7088, 79.78% vs 3387/5386, 62.88%, respectively). No considerable differences were noted between females and males with regards to the distribution across neighborhood income quintiles. More males had no hospitalizations in the previous 5 years, compared with females. For both males and females, the diagnoses most commonly noted were mood or behavioral complexion (ie, nonpsychotic disorders), followed by social problems, psychotic disorders, and substance use disorders. The median number of mental health visits per month for each of the three monthly intervals was consistently two visits for both males and females ([Table 2](#)).

**Table 1.** Interrupted time series parameter estimates for visit rate per 1000 people by visit type (ages 10-17 years; 18-24 years) from January 1, 2006 to December 31, 2015. Visit types were modeled separately for females and males. The campaign level parameter estimate measures the change in the visits from January 1, 2006 to December 31, 2015. The campaign trend estimate measures the change in rate of visit rate between the two time periods.

Visit type	Campaign level estimate (magnitude change)	<i>P</i> value	Campaign trend estimate (slope change)	<i>P</i> value
<b>Primary health care visits, age (years)</b>				
<b>10-17</b>				
Female	0.47	.30	0.09	<.001
Male	-0.24	.38	0.05	<.001
<b>18-24</b>				
Female	-2.80	<.001	0.17	<.001
Male	-2.90	<.001	0.02	.28
<b>New primary health care visits, age (years)</b>				
<b>10-17</b>				
Female	0.28	.06	0.02	.004
Male	-0.16	.16	0.01	.03
<b>18-24</b>				
Female	-0.49	.02	0.04	<.001
Male	-0.41	.003	0.01	.03
<b>Psychiatric services, age (years)</b>				
<b>10-17</b>				
Female	0.04	.60	0.01	<.001
Male	0.02	.88	0.01	<.001
<b>18-24</b>				
Female	-0.05	.40	-0.01	<.001
Male	-0.32	.002	-0.01	.003
<b>New psychiatric services, age (years)</b>				
<b>10-17</b>				
Female	0.01	.75	.003	.005
Male	-0.02	.65	0.005	.02
<b>18-24</b>				
Female	0.005	.64	0.00	.76
Male	-0.01	.71	0.00	.23

### Young Adults

For youth in the older cohort, males and females were equally matched in terms of average age. Furthermore, in both males and females, the 22- to 24-year old strata represented the age range where the majority of the mental health-related primary health care interactions occurred (eg, females aged 22-24 years

in April 2014 used 48.08%, or 3408 out of 7088 total visits experienced by those aged 18-24 years). No considerable differences were noted between females and males with regards to the distribution across neighborhood income quintiles. For both genders, mood or behavioral disorders (nonpsychotic) were most commonly diagnosed, followed by social, psychotic, and substance use disorders, respectively (Table 3).

**Table 2.** Characteristics of Ontario adolescents aged 10 to 17 years who had a primary health care mental health visit in the months of April 2008, 2011, and 2014, separated by males and females. Population characteristics are presented for three predefined time points: (1) preintervention, April 2008; (2) peri-intervention, April 2011; and (3) postintervention, April 2014. The three predefined time points were used to identify any potential demographic variability or nonstable health system utilization patterns of the population.

Demographics	Male (10-17 years)			P value	Female (10-17 years)			P value
	Preintervention, April 2008 (N=6132)	Peri-intervention, April 2011 (N=5243)	Postintervention, April 2014 (N=5386)		Preintervention, April 2008 (N=6023)	Peri-intervention, April 2011 (N=5439)	Postintervention, April 2014 (N=7088)	
<b>Age at index date</b>				<.001				<.001
Mean (SD)	13.85 (2.33)	14.18 (2.30)	14.18 (2.34)		14.76 (2.09)	14.87 (2.00)	14.96 (1.92)	
Median (interquartile range, IQR)	14 (12-16)	15 (12-16)	15 (12-16)		15 (14-16)	15 (14-17)	15 (14-17)	
<b>Categories (years), n (%)</b>				<.001				<.001
10-11	1315 (21.44)	942 (18.0)	977 (18.1)		668 (11.1)	492 (9.0)	524 (7.4)	
12-13	1333 (21.74)	969 (18.5)	1022 (18.98)		821 (13.6)	747 (13.7)	909 (12.8)	
14-15	1566 (25.54)	1398 (26.67)	1339 (24.86)		1785 (29.64)	1655 (30.43)	2247 (31.70)	
16-17	1918 (31.28)	1934 (36.89)	2048 (38.02)		2749 (45.64)	2545 (46.79)	3408 (48.08)	
<b>Income-based socioeconomic status, n (%)</b>				.58				.05
Quintile 1 (low)	1151 (18.77)	982 (18.7)	988 (18.3)		1115 (18.51)	965 (17.7)	1239 (17.48)	
Quintile 2	1190 (19.41)	946 (18.0)	955 (17.7)		1178 (19.56)	1052 (19.34)	1302 (18.37)	
Quintile 3	1219 (19.88)	1065 (20.31)	1110 (20.61)		1194 (19.82)	1117 (20.54)	1381 (19.48)	
Quintile 4	1275 (20.79)	1140 (21.74)	1150 (21.35)		1231 (20.44)	1166 (21.44)	1555 (21.94)	
Quintile 5 (high)	1277 (20.83)	1094 (20.87)	1165 (21.63)		1281 (21.27)	1128 (20.74)	1591 (22.45)	
Missing	20 (0.3)	16 (0.3)	18 (0.3)		24 (0.4)	11 (0.2)	20 (0.3)	
Rural location <sup>a</sup> , n (%)	831 (13.6)	692 (13.2)	724 (13.4)	.84	752 (12.5)	618 (11.4)	929 (13.1)	.23
<b>Health care system utilization</b>				<.001				<.001
<b>Charlson comorbidity score, n (%)</b>								
0	576 (9.4)	520 (9.9)	549 (10.2)		758 (12.6)	707 (13.0)	1132 (15.97)	
1+	61 (1)	38 (0.7)	49 (0.9)		66 (1)	54 (1)	64 (0.9)	
No hospitalizations, n (%)	5495 (89.61)	4685 (89.36)	4789 (88.92)		5199 (86.32)	4678 (86.01)	5892 (83.13)	
Previous mental health visit in the past 12 months, n (%)	3119 (50.86)	2651 (50.56)	2774 (51.50)	.61	2924 (48.55)	2747 (50.51)	4010 (56.57)	<.001
<b>Number of mental health visits during monthly interval</b>				.05				<.001
Mean (SD)	2.31 (0.88)	2.24 (0.60)	2.19 (0.53)		2.52 (1.33)	2.28 (0.71)	2.21 (0.51)	
Median (IQR)	2 (2-2)	2 (2-2)	2 (2-2)		2 (2-2)	2 (2-2)	2 (2-2)	
<b>Diagnosis group</b>				<.001				<.001
<b>Diagnosis groups, n (%)</b>								
Psychotic	168 (2.7)	160 (3.1)	176 (3.3)		101 (1.7)	98 (2)	148 (2.1)	
Substance	150 (2.4)	105 (2.0)	69 (1)		91 (2)	77 (1)	51 (0.7)	
Nonpsychotic	5420 (88.39)	4711 (89.85)	4907 (91.11)		5557 (92.26)	5050 (92.85)	6713 (94.71)	
Social	394 (6.4)	267 (5.1)	234 (4.3)		274 (4.5)	214 (3.9)	176 (2.5)	

<sup>a</sup>Rural location defined as residential areas outside the commuting zone of a city with a population  $\geq 10,000$ . Missing data on fewer than 0.1% per year.

**Table 3.** Characteristics of Ontario young adults aged 18 to 24 years who had a primary health care mental health visit in the months of April 2008, 2011, and 2014, separated by males and females. Population characteristics are presented for three predefined time points: (1) preintervention, April 2008, (2) peri-intervention, April 2011, and (3) postintervention, April 2014. The three predefined time points were used to identify any potential demographic variability or nonstable health system utilization patterns of the population.

Demographics	Male (18-24 years)			P value	Female (18-24 years)			P value
	Preintervention, April 2008 (N=9226)	Peri-intervention, April 2011 (N=9492)	Postintervention, April 2014 (N=10,810)		Preintervention, April 2008 (N=13,946)	Peri-intervention, April 2011 (N=12,818)	Postintervention, April 2014 (N=14,830)	
<b>Age at index date</b>				<.001				<.001
Mean (SD)	21.23 (1.96)	21.12 (1.96)	21.10 (1.97)		21.22 (1.96)	21.13 (1.97)	21.03 (1.96)	
Median (interquartile range, IQR)	21 (20-23)	21 (19-23)	21 (19-23)		21 (20-23)	21 (19-23)	21 (19-23)	
<b>Categories (years), n (%)</b>				<.001				<.001
18-19	2197 (23.81)	2383 (25.11)	2870 (26.55)		3357 (24.07)	3285 (25.63)	4014 (27.07)	
20-21	2635 (28.56)	2896 (30.51)	3118 (28.84)		3996 (28.65)	3733 (29.12)	4428 (29.86)	
22-24	4394 (47.63)	4213 (44.38)	4822 (44.61)		6593 (47.28)	5800 (45.25)	6388 (43.07)	
<b>Income-based socioeconomic status, n (%)</b>				<.001				<.001
Quintile 1 (low)	2094 (22.70)	2058 (21.68)	2198 (20.33)		3250 (23.30)	2915 (22.74)	3171 (21.38)	
Quintile 2	1946 (21.09)	1786 (18.82)	2029 (18.77)		2836 (20.33)	2525 (19.70)	2748 (18.53)	
Quintile 3	1674 (18.14)	1765 (18.59)	2035 (18.83)		2603 (18.66)	2315 (18.06)	2866 (19.33)	
Quintile 4	1714 (18.58)	1826 (19.24)	2208 (20.43)		2488 (17.84)	2506 (19.55)	2968 (20.01)	
Quintile 5 (high)	1756 (19.03)	2010 (21.18)	2300 (21.28)		2711 (19.44)	2503 (19.53)	3014 (20.32)	
Missing	42 (0.5)	47 (0.5)	40 (0.4)		58 (0.4)	54 (0.4)	63 (0.4)	
Rural location <sup>a</sup> , n (%)	881 (9.5)	867 (9.1)	993 (9.2)	.39	1335 (9.57)	1118 (8.72)	1342 (9.05)	.13
<b>Health care system utilization</b>				<.001				<.001
<b>Charlson comorbidity score, n (%)</b>								
0	1295 (14.04)	1094 (11.53)	1158 (10.71)		3525 (25.28)	2857 (22.29)	2970 (20.03)	
1+	99 (1)	92 (1)	94 (0.9)		162 (1.1)	156 (1.3)	196 (1.3)	
No hospitalizations, n (%)	7832 (84.89)	8306 (87.51)	9558 (88.42)		10258 (73.56)	9805 (76.49)	11664 (78.65)	
Previous mental health visit in the past 12 months, n (%)	5634 (61.03)	6023 (63.45)	7084 (65.53)	<.001	8793 (63.05)	8289 (64.67)	9856 (66.46)	<.001
<b>Number of mental health visits during monthly interval</b>				<.001				<.001
Mean (SD)	3.04 (1.68)	2.92 (1.58)	2.50 (1.09)		2.71 (1.35)	2.63 (1.22)	2.39 (0.86)	
Median (IQR)	2 (2-4)	2 (2-3)	2 (2-3)		2 (2-3)	2 (2-3)	2 (2-2)	
<b>Diagnosis group</b>				<.001				<.001
<b>Diagnosis groups, n (%)</b>								
Psychotic	497 (5.4)	509 (5.4)	658 (6.1)		341 (2.4)	350 (2.7)	447 (3.0)	
Substance	1342 (14.55)	1156 (12.18)	791 (7.3)		960 (6.9)	795 (6.2)	548 (3.7)	
Nonpsychotic	7152 (77.52)	7579 (79.85)	9112 (84.29)		12235 (87.73)	11354 (88.58)	13509 (91.09)	
Social	235 (2.5)	248 (2.6)	249 (2.3)		410 (2.9)	319 (2.5)	326 (2.2)	

<sup>a</sup>Rural location defined as residential areas outside the commuting zone of a city with a population  $\geq 10,000$ . Missing data on fewer than 0.1% per year.

## Discussion

### Principal Findings

From 2006 to 2015, the rates of outpatient mental health use by youth aged 10 to 24 years in the province of Ontario increased for both males and females. The 2012 *Bell Let's Talk* was temporarily associated with increases in the trends of outpatient mental health visits, especially within the adolescent female cohort. Although no discernable difference in the immediate change in the rate of mental health visits was observed among the adolescent groups, young adults exhibited a slight drop in most outpatient mental health visits, followed by a moderate increase or plateauing of rates.

### Comparison With Prior Work

Although we were unable to directly measure aspects related to the public's awareness of the *Bell Let's Talk* campaign or their reactions to its messaging in this study, indirect evidence of the campaign's penetration was captured by a 2015 Harris/Decima study [24]. A majority of participants in this random telephone survey of Canadian adults (N=1007) reported that they believed the campaign was successful at decreasing stigma (57% agreement, 574/1007), increasing personal awareness (81% agreement, 816/1007), and positively changed attitudes toward mental health (70% agreement, 704/1007) over a 5-year period [24]. Although there appears to be preliminary evidence of the campaign's penetration, immediate reaction to the campaign was not observed within health care administrative data. As the *Bell Let's Talk* campaign was primarily designed to generate awareness surrounding mental health and stigma, the lack of a substantive step change in health care utilization from normal levels is not surprising. Other research exploring the effects of mental health campaigns using social media discovered that changes related to campaign awareness, perceptions of stigma, and behavior intention toward future mental health-related situations were the only measurable variables reactive to the Web-based messaging [36-39]. As the findings of this study demonstrated trend increases related to outpatient mental health visits (slope changes pre- and postintervention), this suggests that the 2012 *Bell Let's Talk* campaign generated awareness related to a gradual change in behavior, rather than immediately triggering individuals with latent mental health concerns to seek formal mental health services. Therefore, although we hypothesized that the campaign would encourage individuals to seek mental health services, the real outcomes of this campaign were likely more related to societal awareness, rather than discrete outpatient mental health system utilization.

Consistent with other research, there appears to be an upward trend toward mental health services use in youth populations in Ontario [25,28,40], especially noticeable in females who accessed primary health care services. Previous research exploring gender differences related to youth accessing mental health have identified females as possessing greater willingness to seek help [41]. This alone does not provide sufficient explanation related to the further increased mental health visit rate trend observed in females compared with males. Given the growing public literacy related to mental illness [42] and the

increasing use of social media for all forms of communication (including discussion related mental health) [20,43], a range of extraneous variables not specifically measured in this study may offer explanatory insights related to the observed increasing mental health utilization slopes. One such promising extraneous factor was the increasing diversity of social media technology that emerged during the latter years of the study. Previous research has demonstrated that usage of certain social media technologies by youth populations can significantly influence body image conception and psychological or mental health well-being [44-48]. With the increasing variety of social media platforms available over the last 5 years (ie, Instagram, Vine, Snapchat, Tinder, and Grindr), further exploration of these forms of technology and their potential influence on youth mental health well-being should be examined.

Currently, we are unaware of any other studies that have utilized population-level data to examine the impact of a mental awareness and stigma campaign propagated largely through social media. Cheng and colleagues' [9] examination of the impact of a 2-month long, mass media mental health campaign (ie, *Transforming Lives*) on psychiatric emergency department utilization serves as the closest comparator with this study. Although their study focused on psychiatric emergency department visits associated with a mass media mental health campaign, differences in the structure and underpinning of the respective campaigns should be noted. The 2-month mass media campaign (ie, radio, website, newspaper, and Toronto public transportation advertising) examined by Cheng and colleagues [9] was executed by a Toronto-based (Ontario, Canada) hospital organization and did not possess an explicit promise of financial donation for interaction with the campaign; the day-long 2012 *Bell Let's Talk* campaign was operated nationally by a large Canadian telecommunication company and encouraged participation through Can \$0.05 donations for interactions with a campaign-specific social media metadata tag. These salient differences between the respective complexion and scale of campaigns should be kept in mind when comparing findings between the two interventions. Furthermore, although utilizing similar time series methods, Cheng and colleagues' [9] study was more specific in sampling than this current examination of the *Bell Let's Talk* campaign. Cheng and colleagues [9] examined visit rates at seven hospitals in the Greater Toronto area (Ontario, Canada) and reported that the *Transforming Lives* mass media campaign was significantly associated with an increased trend in the utilization of the psychiatric emergency department. Our study complements Cheng and colleagues' [9] findings, suggesting that mass media campaigns such as *Bell Let's Talk* can have potential influential effects on the use of mental health services at population levels. Further refinement will need to be undertaken to determine whether specific youth cohorts within the province of Ontario were influenced differently by the *Bell Let's Talk* campaign and how the growing presence of antistigma and mental health awareness in society may be influencing rates of mental health system utilization.

### Limitations

With any ecological study, there are several limitations that need to be explicitly delineated. First, we assessed all outpatient mental health use in this study using administrative data. Due

to the nature of the data, it was impossible to measure illness severity for individual interactions with the health system. This limitation prevented deeper analysis of youths' individual presentations and their usage of outpatient mental health services. Second, emergency department utilization for mental health services was not included in this study. Although emergency departments are an important point of contact for mental health services, only outpatient mental health visits were examined in this study to focus on planned or scheduled interactions that would be better representative of purposeful behavior change in reaction to the *Bell Let's Talk* campaign messaging. Third, given the broad inclusion criteria used in cohort development (ie, all youth eligible for universal health care), it was not possible to determine the influence of the 2012 *Bell Let's Talk* campaign on specific population subsets. Further research using smaller, specific, homogenous population cohorts (ie, depression and eating disorders) will be important to determine if there are any epidemiological signals that more wholesomely associate with the campaign. Finally, although the 2012 *Bell Let's Talk* campaign was associated with an increase in the trends of outpatient mental health visits, other population, environment, and societal extraneous variables may have also influenced the observed changes. Furthermore, given the growing size, scale, and social media embeddedness of the *Bell Let's Talk* campaign each subsequent year since 2012 [24], the potential cumulative influence of the campaign and its related events and activities (ie, cross-Canada bike ride event;

Community Fund) on people over time was not considered in this analysis and should be explored in a future examination.

## Conclusions

This study is one of the first population-level analyses of mental health utilization associated with a large-scale social media campaign targeting mental health awareness and antistigma. The use of health care administrative data allowed examination of mental health system utilization by those aged 10 to 24 years in the province of Ontario over a decade long period. Due to this uniqueness, the study provides important methodological implications for researchers wishing to ascertain the efficacy of social media and other digitally enabled media campaigns operated at population level. With the growing recognition of the communicative power of social media, further research is required to generate more precise modeling techniques to better understand their effects on population and public health [49]. Furthermore, through subgroup analyses sensitive to gender and age, we uncovered that trends in youth mental health utilization (especially for both female age cohorts who used primary health care for mental health services) have significantly increased since 2012. We are unclear of the mechanism related to this sharp trend increase for females, but feel this emergent finding requires immediate focus. Given recent emphasis on gender and sex within health sciences research [50,51], exploration of the relation to mental health system utilization is important for both practice and policy.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Tweet examples from February 8, 2012, including the initiation Bell Let's Talk tweet (top tweet) prompting Twitter users to retweet elements of the @Bell\_LetsTalk message and account to generate 5 cent donations.

[[PDF File \(Adobe PDF File\), 90KB - mental\\_v5i2e27\\_app1.pdf](#) ]

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## Multimedia Appendix 2

Selected OHIP fee codes for assessments, consultations, and clinical specialities that indicate possible mental health system interaction. OHIP: Ontario Health Insurance Plan.

[[PDF File \(Adobe PDF File\), 26KB - mental\\_v5i2e27\\_app2.pdf](#) ]

### Multimedia Appendix 3

Selected ICD-9 codes in the OHIP database that indicate possible mental health system interaction. Modified from the Steele et al algorithm. OHIP: Ontario Health Insurance Plan.

[[PDF File \(Adobe PDF File\), 28KB - mental\\_v5i2e27\\_app3.pdf](#)]

### Multimedia Appendix 4

Source and description of patient variables.

[[PDF File \(Adobe PDF File\), 25KB - mental\\_v5i2e27\\_app4.pdf](#)]

### Multimedia Appendix 5

Upper respiratory infection (URI) tracer, to assess for any observable differences or biases within the cohort related to nonmental health system interaction or the presence of billing coding changes in the administrative data record between genders.

[[PDF File \(Adobe PDF File\), 39KB - mental\\_v5i2e27\\_app5.pdf](#)]

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## Abbreviations

**ICES:** Institute for Clinical Evaluative Sciences

**OHIP:** Ontario Health Insurance Plan

**RPDB:** Registered Persons Database

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Original Paper

# Implementing Internet-Based Self-Care Programs in Primary Care: Qualitative Analysis of Determinants of Practice for Patients and Providers

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## Abstract

**Background:** Access to evidence-based interventions for common mental health conditions is limited due to geographic distance, scheduling, stigma, and provider availability. Internet-based self-care programs may mitigate these barriers. However, little is known about internet-based self-care program implementation in US health care systems.

**Objective:** The objective of this study was to identify determinants of practice for internet-based self-care program use in primary care by eliciting provider and administrator perspectives on internet-based self-care program implementation.

**Methods:** The objective was explored through qualitative analysis of semistructured interviews with primary care providers and administrators from the Veterans Health Administration. Participants were identified using a reputation-based snowball design. Interviews focused on identifying determinants of practice for the use of internet-based self-care programs at the point of care in Veterans Health Administration primary care. Qualitative analysis of transcripts was performed using thematic coding.

**Results:** A total of 20 physicians, psychologists, social workers, and nurses participated in interviews. Among this group, internet-based self-care program use was relatively low, but support for the platform was assessed as relatively high. Themes were organized into determinants active at patient and provider levels. Perceived patient-level determinants included literacy, age, internet access, patient expectations, internet-based self-care program fit with patient experiences, interest and motivation, and face-to-face human contact. Perceived provider-level determinants included familiarity with internet-based self-care programs, changes to traditional care delivery, face-to-face human contact, competing demands, and age.

**Conclusions:** This exploration of perspectives on internet-based self-care program implementation among Veterans Health Administration providers and administrators revealed key determinants of practice, which can be used to develop comprehensive strategies for the implementation of internet-based self-care programs in primary care settings.

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**KEYWORDS**

cognitive behavioral therapy; internet-based therapy; health information technology; behavioral intervention technology; internet; Veterans

## Introduction

**Background**

Internet-based self-care programs (ISPs) belong to a category of health information technology, which consist of personalized,

self-guided interventions delivered electronically to improve knowledge, awareness, or behavior change for mental or behavioral health conditions [1]. ISPs present interactive therapeutic material in rich formats such as audio, video, and text. Participants use ISPs at a pace and in a setting of their choosing, while being provided varying levels of support [2,3].

Evidence-based ISPs have shown efficacy for the treatment of many common conditions including depression, anxiety, substance use, and insomnia [4,5].

The potential health service benefits of ISPs are pronounced, as they may mitigate chronic and systemic problems associated with access to mental health services [6]. Access to services is a challenge even for integrated health care systems such as Veterans Health Administration (VHA), which are accountable to provide a coordinated range of services to a defined population [7,8]. One solution may lie in the implementation of ISPs, the benefits of which include reduced travel barriers, improved access to evidence-based therapies, and reduced stigma [9]. ISPs may also increase self-care and add to health care system productivity [10,11]. Within the VHA, ISPs may especially benefit patients where travel time and distance to VHA facilities or the lack of trained providers are limiting factors [12].

Despite the advantages of ISPs and evidence of general acceptability, ISP use in US health care systems, including the VHA, is not well documented and presumed low [13,14]. Although ISP use in the United Kingdom, Europe, and Australia is more routine and to some extent institutionalized in policy, there have been notable difficulties with ISP implementation at the point of care with patient and providers in the primary care settings [15-17]. For instance, a recent major pragmatic trial implementing ISPs for depression in primary care sites across the United Kingdom resulted in relatively low use of the programs by patients [18].

The lack of ISP use in US health care settings and the relative difficulty of implementation in other countries suggest the need for comprehensive strategies to address ISP implementation. Such strategies are dependent on the determinants of practice for a given setting—defined as the human and system factors, which determine to what extent and manner interventions are used. Determinants of practice have been referred to elsewhere by alternative terms such as barriers, obstacles, enablers, and facilitators [19]. For instance, in a study implementing evidence-based practices for the treatment of chronic diseases in primary care, the use of checklists by providers and self-management among patients were identified as important determinants of practice [20]. However, unlike other interventions, determinants of practice for ISPs rely on the acceptance and use of both technology and self-care by patients, providers, staff, and administrators [21].

## Objective

The identification of determinants of practice for ISP use will be a key step in the development of effective strategies for ISP implementation [22]. The objective of this study was to identify determinants of practice for ISP implementation perceived by VHA primary care and integrated mental health care providers and administrators. The identification of determinants will aid in the development of comprehensive strategies for ISP implementation.

## Methods

### Study Design

VHA primary care provider and administrator perspectives on ISP implementation were explored through qualitative analysis of semistructured interviews. The institutional review board of the VA Connecticut Healthcare System preapproved this study.

### Sample

To identify determinants encountered in care, participants were primary care providers, primary care mental health providers, clinic/facility administrators, and VHA system administrators who were known to be using or have used ISPs in patient care, interested in using ISP in primary care settings, or otherwise knowledgeable on the subject of ISP use. VHA does not systematically track or record patient or provider use of ISPs, and as yet, there is no validated way to search VHA electronic health records for evidence of use. Therefore, a provider sampling strategy based on in-depth investigator knowledge of the VHA system was used. Investigators identified an initial group of VHA key informants in ISP use. This group was expanded by asking interviewees for referrals to additional key informants. Recruitment was through e-mail contact that included a project description. Physicians, psychologists, nurse practitioners, nurse administrators, and social workers with both clinical and administrative responsibilities were recruited. A total of 20 interviews were conducted; 100% of those approached agreed to participate.

### Data Gathering

The principal investigator (EH) conducted semistructured interviews using a guide that first defined ISPs, giving examples of VHA-developed ISPs and other programs if needed, such as Moving Forward, PTSD Coach, and Sleep Healthy Using the Internet [23-25]. Determinants were then explored using 9 core question areas, with subquestions to explore specific topics that emerged. Question areas were derived from constructs (performance expectancy, effort expectancy, social influence, and facilitating conditions) from the Unified Theory of Acceptance and Use of Technology, a theory that describes factors associated with technology use [21]. Interviews were audio recorded and conducted over the phone, lasting between 45 and 90 min.

### Data Analysis

Interviews were transcribed verbatim. Thematic analysis, a foundational approach to the analysis of in-depth interviews, was used to analyze interview content through a 5-step group process: (1) familiarization with transcribed data; (2) generation of initial codes; (3) collating codes into themes; (4) reviewing, discussing, and modifying themes in relation to interview extracts; and (5) defining and developing a typology of themes [26]. Codes were first generated by individual investigators, and then discussed as a group, referencing the interview content to develop a final set of codes. Discrepancies in coding were addressed through group discussions led by the principal investigator (EH). Similarly, themes were then developed from codes using a group discussion process. Codes within themes were reviewed using the entire dataset to identify examples and

counterfactuals. Authors EH, LB, and EP participated in steps 1 through 3, whereas all authors participated in steps 4 and 5. Themes were organized according to socio-ecological levels within the integrated health care system: patients, providers, and the organization [27]. This manuscript describes patient- and provider-level themes associated with determinants of practice for ISP use at the point of care. Determinants active at the VHA organizational level will be described in future work. Data were managed and analyzed using Atlas.ti. version 4.2 software (ATLAS.ti Scientific Software Development GmbH).

## Results

### Interviewee Characteristics

Of the 20 individuals participating, more males than females were interviewed, while the training, background, and primary work locations of interviewees were relatively balanced (Table 1). Interviews began with questions concerning interviewees' and their colleagues' experience with using ISPs in clinical practice. ISP use among interviewees was relatively low. Although 16 (80%, 16/20) interviewees had used an ISP or discussed ISPs with patients at some point in practice, only 6 (30%, 6/20) were currently using them. One primary care provider stated:

*I have [used ISPs], but not typically, this isn't something that's kind of a normal or typical thing for me to do.*

Despite this level of use, all 20 interviewees (100%, 20/20) made statements in support of ISP use in primary care. One primary care provider stated:

*I'm all for it. I think that it's a great modality to utilize especially as we are getting...a lot more of the younger guys...who are much more computer tech savvy.*

### Perceived Determinants Associated With Patients

#### Attitude Toward Treatment

A total of 10 interviewees (50%, 10/20) identified patient interest in, motivation for, or willingness to engage in ISPs or mental health treatment in general as a determinant of ISP use. Interest in ISPs was generally described as high, but variable. One primary care provider with administrative responsibilities said most patients are using the internet for health information already:

*A lot of them...do a lot of exploration of their problems and try things out.*

Interviewees also discussed how patients must adjust to the idea of self-care and are variably motivated to engage in self-care. Consequently, providers assess patient interest and motivation before recommending ISP use. One provider in primary care mental health said:

*I meet with the patient and I pull up the course and we go through some of it and I get a sense of whether or not they have the interest in continuing to do it on their own.*

Another said:

*Motivation is a big one for everything. The big barrier is if they're not really motivated to do whatever, then they're likely not going to do it.*

**Table 1.** Characteristics of interviewees.

Characteristic	Interviewees (N=20), n (%)
<b>Gender</b>	
Male	13 (65)
Female	7 (35)
<b>Training</b>	
Doctor of Philosophy	9 (45)
Medical Doctor	6 (30)
Registered Nurse	3 (15)
Social work	2 (10)
<b>Primary work location</b>	
Primary care	8 (40)
Primary care mental health	8 (40)
ISP implementation research <sup>a</sup>	4 (20)
<b>Primary duty<sup>b</sup></b>	
Patient care	12 (60)
Administration	8 (40)

<sup>a</sup>Interviewees with direct experience with VA patients and providers in VA primary care and primary care mental health settings as part of ISP research.

<sup>b</sup>All interviewees had both clinical and administrative duties. This category identifies their primary duty activity.

## Literacy

Low technology and reading literacy were discussed in 8 interviews (40%, 8/20), especially in older Veterans. As a clinic administrator stated:

*I think that [the use of] technology-based care for sure is going to be based upon the age of the individual and their experience with technology.*

Two other interviewees, who were primary care providers, said reading literacy was a barrier, as most programs require participants to read and understand written language on screens. However, as a counterfactual, one mental health provider noted that oversimplifying ISP content might alienate literate individuals:

*Any time you are trying to get accessible language that most people understand, you risk inadvertently alienating folks who feel they are being talked down to.*

## Access to the Internet

In 6 interviews (30%, 6/20), patients' lack of reliable home or community Wi-Fi or hard-wired internet connections were discussed. Where such connections were available, internet speeds may be too slow to support ISP use. Lack of access also included limited bandwidth on cellular phone connections. Interviewees explained that reduced access was influenced by age, personal finance, and locations where cable, cellular, or public networks were not available. One primary care mental health provider said:

*For certain members of the older population, lack of consistent, decent access to the internet [is a problem]. I've got some guys who are homeless.*

## Internet-Based Self-Care Program Compatibility With Patient Experience

A total of 5 interviewees (25%, 5/20) identified compatibility between patients' experience of their mental health condition and ISP program content as a determinant of ISP use. Many ISPs deliver versions of manualized therapies, utilizing structured and sequenced formats to teach content and skills for common issues. However, ISPs may not be able to address unique patient experiences. Consequently, some patients may find that ISPs do not align with their specific mental health complaints. A primary care mental health provider shared the following issue:

*Sometimes [the patient's reaction is] like, "Hey, what I'm experiencing doesn't really fit to this framework."...I think that sometimes we risk alienating people who feel like we are not appealing to people at their level.*

## Patient Expectations

A total of 4 interviewees (20%, 4/20) discussed unrealistic expectations among patients about the time and effort required for ISP engagement, the application of content to their lives, and symptom improvement. One provider with administrator responsibilities said:

*The expectation when you're on line or using your phone is that things happen quickly. Learning how to relax still takes time. Actually being able to practice and incorporate the techniques still takes time.*

## Perceived Determinants Associated With Providers

### Familiarity With Internet-Based Self-Care Programs

A total of 18 interviewees (90%, 18/20) identified providers' familiarity with ISPs as a factor influencing use in clinical practice. Familiarity with ISPs ranges from awareness of available programs to regular and judicious use by providers of effective programs for the right patients. Moreover, 10 interviewees stated that they or other providers had limited awareness of any ISPs. One provider with VHA-wide administrative responsibilities stated:

*I don't even think that local staff know what internet-based self-help options out there are.*

In addition, 3 interviewees stated that they were aware of programs but were not familiar with their content or had not tried them. One administrator believed that providers must know about all aspects of ISPs to refer patients to them:

*As we move forward, the skill of front-line clinical providers is going to be just as much to know the potential benefits, risks, side-effects, value, [and] impact of digital health tools, as they currently know about pharmaceuticals.*

For another primary care provider, improving the "findability" of ISPs was key, described as the ability to access the right ISP at the right time for a specific patient.

### Changes to the Traditional Delivery of Care

A total of 11 interviewees (55%, 11/20) discussed how ISPs could improve current models of care delivery by increasing self-care, providing more patient-generated data, and affording different modes of communication. Interviewees indicated that some providers are reluctant for patients to take part in self-care or treatment outside the traditional provider-patient dyad. One provider who was also an ISP researcher stated:

*Some clinicians are reluctant to allow things to happen inside the black box...if the clinician isn't entirely comfortable with what the rules are, what's happening inside the app...they're not going to use it.*

Providers were also concerned about how a patient's clinical status would be monitored and how workload credit for a provider's time to support ISP use would be tracked. Other interviewees discussed the shift to using patient-generated health data in encounters:

*There is a culture shift that needs to happen with providers to help them recognize that patient generated health data has equal value to healthcare system-generated data.*

Others focused on possible changes to provider-patient communication, using secure messaging as an example:

*Secure messaging impacted their practice. The fear from the provider side was now the Veterans could have an unfiltered access to me and I'm going to spend all day filtering through these e-mails.*

### **Competing Demands and Lack of Time**

A total of 8 interviewees (40%, 8/20), chiefly primary care and primary care mental health providers, said that competing demands and a lack of time during patient appointments were barriers to ISP use. One said:

*It's just one of many, many things you're trying to do in the clinic.*

Another one said:

*I think there would be concern about extra time, like one more thing. More and more keeps getting added on.*

Still another provider stated:

*Clinicians are not necessarily going to have time to sit there with the patient and show 'em how the thing works, and kinda guide them through it.*

### **Perceived Determinants Associated With Patients and Providers**

#### **Human Contact**

A total of 10 interviewees (50%, 10/20) discussed human contact as critical for ISP use in primary care settings. One provider who was also an ISP researcher said:

*My overall impression is that these are materials that cannot be used without some sort of provider support...I don't think that sending people to the course or having people download the app is sufficient for those to have any kind of clinical utility.*

Interviewees made several points regarding the need to introduce ISPs to patients, elicit interest, assess willingness to engage, and match patients to specific programs. Interviewees also highlighted human contact to support patient progress. One mental health provider said:

*I routinely ask, when they come in, "Hey, were you able to use that? What was your experience?" If they didn't, I try to find out why.*

Four interviewees with a range of duties made suggestions about individuals, other than providers, who could support ISP use as a clinical intermediary, such as peer specialists, nurses, care managers, and masters-level clinicians.

#### **Age**

Age was discussed as a moderator of ISP use for patients in 6 interviews (30%, 6/20) and providers in 3 interviews (15%, 3/20). For patients, interviewees stated that age influences access to the internet, technology literacy, and preference for face-to-face care. One clinic administrator referenced the relatively low use of VHA's MyHealtheVet website by older Veterans [28]:

*I welcome those programs [but] I think it's challenging. A lot of our Veterans, it's such an older*

*population, I don't see a majority of them turning to the internet. I know some will. For example, MyHealtheVet, we thought we'd get a higher population of enrollment for that.*

Regarding provider age, interviewees said that the use of technology other than phones for communicating with patients could be a barrier for older providers.

## **Discussion**

### **Study Objective**

The aim of this study was to explore primary care provider and administrator perspectives on ISP implementation to identify important perceived determinants of practice for ISP use. We identified 10 themes for determinants of practice at both patient and provider levels. An understanding of these determinants is vital to the development of strategies for ISP implementation in primary care. Comprehensive implementation strategies for ISPs have yet to be clearly defined or rigorously tested. Our investigation of determinants suggests functions for such an ISP implementation strategy, which we feel can be performed by a clinical intermediary (Table 2).

### **Internet-Based Self-Care Program Use in Practice**

There is little information on rates of ISP use among US providers or within US health care institutions, and we presume this use to be low. Thus, the relatively infrequent use of ISPs reported by this group of interviewees is not too surprising. Nonetheless, interviewees were generally supportive of ISP use, in spite of identifying a number of determinants of practice that can be considered barriers to ISP use. The support for ISPs identified in this study is consistent with the general acceptance of and support for health information technology among providers and patients [13,29]. Support for ISPs relative to actual use may suggest an emerging tipping point for the increased use of ISPs in the United States, as has occurred in other countries. For example, a 2008 survey of mental health providers in the United Kingdom revealed that 99% used ISPs in care and 39% had been trained to use them [30]. At a minimum, our findings indicate that provider and patient attitudes toward ISPs are not strong barriers to implementation.

### **Patient-Level Determinants**

Perceived patient-level determinants of ISP use including literacy, internet access, and age are well documented, as in a recent analysis of interviews with VHA service users who stopped using an ISP for insomnia before program completion [31-34]. However, conflicting evidence suggests that internet use and the acceptability of ISPs among VHA service users are on par with those of the general population [35,36]. Given these differences and the relative difficulty of modifying the above determinants, compared with other patient-level determinants identified here and in similar studies (ie, interest/motivation, patient expectations, and ISP compatibility with patients), other determinants may be more amenable to mitigation and suitable for incorporation into strategies used to implement ISPs (see discussion below and Table 2) [37].

**Table 2.** Description of how a clinical intermediary can function in an internet-based self-care program implementation strategy to address key determinants of practice.

Determinant of practice	Action of clinical intermediary
<b>Determinants associated with providers</b>	
Provider familiarity	Provide recurring education to providers on ISP <sup>a</sup> availability and content
Changes to the traditional delivery of care	Provide supported self-care by mediating communication between the patient and provider regarding clinical questions about the program and progress in the program
Time/competing demands	Relieve provider workload by sharing responsibility with the provider for case identification, patient education, and program support
<b>Determinants associated with patients</b>	
Patient technology literacy	Perform basic education on program access and navigation such as website location and login. Provide human contact for technical assistance
Internet access	Identify community internet access points. Develop and maintain clinical internet access points within the health care facility
Interest/motivation	Supplement the provider in assessing interest in and motivation to engage in behavioral treatment through ISPs using motivational interviewing
Patient expectations	Supplement provider education about ISPs to ensure realistic expectations on the effort required and time course of symptom improvement
Patient experience of ISP fit	Provide insight on how program content may fit with an individual's experience and assist providers in identifying individuals who are failing ISPs or require a higher level of care
<b>Determinants associated with both patients and providers</b>	
Human contact	Meet patients individually or in groups to provide face-to-face support

<sup>a</sup>ISP: internet-based self-care program.

### Provider-Level Determinants

Two themes at the provider level—familiarity with available programs and change to the traditional delivery of care—stand out as key in this study and the few others that have evaluated provider perspectives on ISP use [38,39]. ISP familiarity as a determinant of practice suggests that educating providers about available ISPs and having them experience the platform should be a component of a comprehensive ISP implementation approach. Educational strategies to implement ISPs in health care settings must be flexible to account for varying levels of baseline ISP familiarity among providers. The likely downstream effects of increased provider familiarity with ISPs are the changes more ISP use could bring to the traditional delivery of care [40]. Providers must become more comfortable recommending not only technology use but also self-care to patients. Similarly, a system of stepped care must be in place so that patients who are not appropriate for or fail initial attempts at ISP treatment are identified and referred to other forms of care (eg, more provider interactions) [16].

### A Strategy for Internet-Based Self-Care Program Implementation

The determinants of practice identified here and those from other studies of ISP use outside of primary care, mental health, and VHA settings suggest the need for comprehensive strategies for ISP implementation [31,38,39]. Given the current level of support for ISPs identified among providers in this study, the function of such a strategy should not rely solely on educating providers about ISPs to gain support. Rather, key strategy functions should be more nuanced and include increasing

provider familiarity with specific programs, addressing competing demands, providing internet access, and modulating patient expectations, among others (Table 2). Also identified among these determinants is the need for human contact during ISP use. Such contact has already shown evidence for improving adoption and outcomes of ISPs. Support from a human may help address many of the other ISP implementation strategy functions identified here [41,42]. We propose that a clinical intermediary, an individual different from the primary provider, can deliver this human contact. As suggested by interviewees in this study, such a clinical role could be performed by peer specialists, nurses, care managers, and other clinicians trained to facilitate ISP use by engaging in the important implementation strategy functions described in Table 2. Future research should test the use of a clinical intermediary and identify the content, timing, and other specifics of these strategy functions as well as the training needed for this role. In addition, the materials needed to train a clinical intermediary could be spread health system-wide as part of future ISP dissemination efforts.

### Study Limitations

This study has several limitations. Interviews involved a relatively small group of individuals, and the frequency of ISP use within this group was low despite our objective to recruit ISP users. As such, these findings may represent only an initial indication of the important perceived determinants of practice for ISP use, and may be strengthened by a larger sample size or the inclusion of more VHA providers who regularly use ISP in care if they exist. In addition, the purposeful inclusion of individuals who have chosen not to use ISPs in care may reveal yet more critical determinants of practice. Moreover, it must

also be noted that determinants were developed from the *perspectives* of VHA providers and administrators. We did not verify these determinants using quantifiable means. However, interviewees had a breadth of relevant backgrounds and adequately represented ISP stakeholders within VHA. They, in turn, discussed a range of determinants of practice that influence ISP use. In addition, interviews with health care consumers may reveal yet more determinants. Organizational-level determinants of practice that might suggest enterprise-wide dissemination and implementation strategies or policy changes were not discussed but will be examined in future work. Finally, the VHA is a unique, integrated, and nationwide health care system that provides care for US Veterans. Thus, our results may not be representative of providers or patients in other health care systems.

## Conclusions

Developing and testing implementation strategies to facilitate the use of ISPs in primary care is a critical area in need of investigation. As an initial step, this study identified patient- and provider-level determinants of practice for the use of ISPs in the context of outpatient primary care settings in the VHA. An ISP implementation strategy that addresses the determinants identified here, including the use of a clinical intermediary to support both patients and providers, may be an effective way forward. These findings, as well as those from similar studies, can be used to inform the development of ISP implementation strategies, which can be further described and tested in future work.

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## Conflicts of Interest

None declared.

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## Abbreviations

**ISP:** internet-based self-care program

**VHA:** Veterans Health Administration

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Original Paper

# Expert Consensus Survey on Digital Health Tools for Patients With Serious Mental Illness: Optimizing for User Characteristics and User Support

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## Abstract

**Background:** Digital technology is increasingly being used to enhance health care in various areas of medicine. In the area of serious mental illness, it is important to understand the special characteristics of target users that may influence motivation and competence to use digital health tools, as well as the resources and training necessary for these patients to facilitate the use of this technology.

**Objective:** The aim of this study was to conduct a quantitative expert consensus survey to identify key characteristics of target users (patients and health care professionals), barriers and facilitators for appropriate use, and resources needed to optimize the use of digital health tools in patients with serious mental illness.

**Methods:** A panel of 40 experts in digital behavioral health who met the participation criteria completed a 19-question survey, rating predefined responses on a 9-point Likert scale. Consensus was determined using a chi-square test of score distributions across three ranges (1-3, 4-6, 7-9). Categorical ratings of first, second, or third line were designated based on the lowest category into which the CI of the mean ratings fell, with a boundary >6.5 for first line. Here, we report experts' responses to nine questions (265 options) that focused on (1) user characteristics that would promote or hinder the use of digital health tools, (2) potential benefits or motivators and barriers or unintended consequences of digital health tool use, and (3) support and training for patients and health care professionals.

**Results:** Among patient characteristics most likely to promote use of digital health tools, experts endorsed interest in using state-of-the-art technology, availability of necessary resources, good occupational functioning, and perception of the tool as beneficial. Certain disease-associated signs and symptoms (eg, more severe symptoms, substance abuse problems, and a chaotic living situation) were considered likely to make it difficult for patients to use digital health tools. Enthusiasm among health care professionals for digital health tools and availability of staff and equipment to support their use were identified as variables to enable health care professionals to successfully incorporate digital health tools into their practices. The experts identified a number of potential benefits of and barriers to use of digital health tools by patients and health care professionals. Experts agreed that both health care professionals and patients would need to be trained in the use of these new technologies.

**Conclusions:** These results provide guidance to the mental health field on how to optimize the development and deployment of digital health tools for patients with serious mental illness.

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**KEYWORDS**

biomedical technology; patient engagement; severe mental disorders

## Introduction

### The Potential of Digital Health Tools for Psychiatric Practice

The provision of acute and ongoing mental health care around the world continues to face challenges ranging from cost, access, and scalability to stigma-related concerns resulting in insufficient and inefficient treatment for many individuals with serious mental illness (SMI) [1]. Digital health is a rapidly advancing field that presents opportunities to significantly enhance health and health care. Digital health encompasses categories such as mobile health (mHealth), health information technology, wearable devices, telehealth or telemedicine, and personalized medicine [2]. Digital health tools have the potential to empower patients, improve access to care, enhance communication between patients and providers, improve health outcomes, and make health care processes and decisions more efficient and cost-effective [2-5]. Digital health tools are increasingly being adopted for use independently or in the context of traditional care and have been effective for monitoring and improving physical health in patients with a variety of conditions such as diabetes [6-8]. Interest in applying digital technologies to psychiatric practice has been increasing since the early 2000s, and recommendations for future research in this area were issued in 2013 by a technical expert panel convened by the Agency for Healthcare Research and Quality and the National Institute of Mental Health [9-11]. Examples of interventions that have used digital health tools in patients with SMI include mobile-based assessments and interventions

[12-15], computerized psychotherapies [16], cognitive remediation [17,18], family psychoeducation interventions [19], and interventions specifically targeting medication adherence [20].

Although digital health tools hold significant promise for the improvement of various elements of behavioral health intervention, and surveys have indicated that people with SMI are enthusiastic about using technology [21,22], adoption has been slow, testing of outcomes from acceptability to effectiveness has been limited, and codified development and deployment strategies have been lacking [23-30]. These preliminary efforts need to be undertaken before their effectiveness can be tested and verified so that the resulting findings can be incorporated into the redesign and reconfiguration of digital health tools to provide an optimal solution.

Moreover, it is clear that advances in the digital health tool field depend on the identification of the right patients, providers, and settings or conditions to maximize clinical effects and minimize risks. As the field is emerging, these considerations are yet to be fully studied and elucidated. However, practical guidance to facilitate the selection and use of these tools, which must include empirically derived guidance on appropriate user selection and clinical settings, as well as education and resource requirements for patients, may encourage adoption among all target users. In addition, consideration of implementation strategies and education about unintended consequences and known risks associated with the use of digital health tools, as well as mitigation strategies for each, will also be important.

Figure 1. Survey structure. Results from highlighted sections and questions are reported in this paper. HCP: health care professional.

#### PART A

##### SECTION I: User Characteristics

	Patients	HCPs	Caregivers
Competence	Q 1	Q 2	Q 3
Motivation	Q 4	Q 6	Q 8
Barriers or unintended consequences	Q 5	Q 7	Q 9

#### PART B

##### SECTION II: Product Characteristics

Initial engagement	Q 10
Sustained engagement	Q 11
Mitigating patient deficits	Q 12
Goal setting or reinforcement rewards	Q 13-15

##### SECTION III: User Support or Training

HCPs (Q 16)	Patients (Q 17)	Caregivers (Q 18)
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##### SECTION IV: Outcomes in Psychotherapy or Psychosocial Interventions

Patients (Q 19)
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Ideally, these considerations will be defined with empirical data; however, until these data emerge, academic clinicians with expertise in the field of behavioral health technology can provide valuable feedback on these issues. Results from the survey described here can be used to develop recommendations for physicians and other allied health care professionals (HCPs; eg, psychologists, case managers, and social workers) concerning the use of digital health tools in clinical practice.

## Rationale for the Use of the Expert Consensus Methodology

The expert consensus survey methodology was developed as a means of providing quantitative and reliable data on which to base best practice recommendations for clinical areas that are not well covered by definitive research [31]. Since 1996, this method has been applied to 26 areas of clinical practice, including schizophrenia, bipolar disorder, depressive disorders, attention-deficit hyperactivity disorder, obsessive-compulsive disorder, and dementia, with data presented in more than 75 publications since 1996 [32-34]. Given the limited empirical research concerning the use of digital health tools in psychiatry, the expert consensus survey methodology was used to develop recommendations for this emerging field.

The overall goals of this expert consensus survey were to assess expert opinion on target user characteristics, product features, and user support (training or resources) to facilitate adoption of and successful engagement with digital health tools by patients with SMI (Figure 1). This report describes results from subsections of the survey that focused on user characteristics (patients and HCPs) and user support. Results from this survey can provide guidance to optimize the development and use of digital health tools in clinical psychiatry.

## Methods

### Expert Panel

Experts were identified based on authorship on published articles and congress abstracts and the following criteria: work involving the design, development, validation, optimization, evaluation, implementation, and dissemination of assessment or technology-assisted treatment interventions in psychiatry. Of the 82 experts invited to participate in the survey via email, 17 did not respond, and 13 declined to participate. Of the remaining 52 experts who received the survey, 40 (77%) completed part A of the survey, and 39 (75%) completed parts A and B. This study was exempt from review by an institutional review board; it involved only the use of survey procedures, did not involve children, and the data were anonymized such that responses could not be linked to an individual respondent.

The respondents had an average of 16 years of experience in clinical practice, 20.5 years in clinical research, and 5 years in basic research. They reported currently spending approximately 15% of their professional time on average in clinical work, with 28% (11/40) spending 25% or more of their time in clinical work and 73% (29/40) spending less than 25% of their time. Of the 40 respondents, 63% (25/40), 45% (18/40), and 60% (24/40) reported extensive experience working with patients with schizophrenia, bipolar disorder, and major depressive

disorder (MDD), respectively; 55% (22/40), 38% (15/40), and 55% (22/40) had experience with developing or implementing digital health tools in patients with schizophrenia, bipolar disorder, and MDD, respectively. Most of the experts worked in an academic clinical or research setting, although some also worked in the public sector or in private practice. All the 40 experts had participated in a research project using mHealth or behavioral assessment tools, ambulatory monitoring, ecological momentary assessment, or experience sampling techniques (30/40, 75%); had participated in a research project using mobile mental health treatment tools or ecological momentary intervention techniques (25/40, 63%); or had prescribed or recommended a computerized treatment or mobile app to a patient (26/40, 65%). Moreover, 33% (13/40) and 38% (15/40) of experts had performed all three or two of the above, respectively. The expert panel had the most experience with mobile apps, computerized treatment programs, and websites.

### Creating the Survey

On the basis of their experience, as well as review of current literature in the field of digital health tools, the authors participated in multiple iterative group discussions to arrive at the survey structure and questions. This survey used the expert consensus methodology [31]. The developers created a 19-question survey with 540 options using Adobe Forms software (Adobe Systems Incorporated, San Jose, CA). The survey was divided into two parts (A and B) and took participants approximately 2 hours to complete either online or as a PDF document. The respondents were paid a fee for participating. In responding to the survey, the experts were instructed to assume that the patient has schizophrenia, bipolar disorder, or MDD. The term “*health care professional*” was used to refer to any professional who provides health care services to patients with  $\geq 1$  of these three disorders (eg, psychiatrists, psychologists, nurses, clinical social workers, or case managers). Although the survey covered a number of issues related to the use of digital health tools in patients with psychiatric disorders (Figure 1), this report focuses on questions regarding patients and HCPs that covered the following three main areas: (1) characteristics of the most appropriate users of digital health tools related to their ability to engage with and use a digital health tool (target user *competence*: questions 1, 2, and 19), (2) potential benefits of and barriers to use of digital health tools (target user *motivation*: questions 4-7), and (3) training resources needed to optimize use of digital health tools (training resources: questions 16 and 17). Graphic and tabular results for these 9 questions are presented in [Multimedia Appendix 1](#). The experts were asked to rate the options based on their experiences using the technology with which they were most familiar in patients with psychiatric illness in clinical research and practice settings and based on their best understanding of the current literature.

The experts rated 529 of the survey options using a rating scale slightly modified from a format developed by the RAND Corporation [35]. The scale ranged from 1 to 9 (eg, 1=not at all likely to motivate and 9=extremely likely to motivate, or 1=not important at all to 9=extremely important; to avoid confusion, for all questions rated with the 9-point scale, a score of 9 was used to indicate the most positive options and a score of 1 the

most negative options. For example, as shown in [Multimedia Appendix 1](#), in question 1, a score of 9 was used to indicate patient characteristics that were extremely likely to promote engagement and ability to use a digital health tool, whereas in question 5, a score of 1 was used to indicate a characteristic that had significant potential to be a barrier or an unintended consequence when using a digital health tool). For the other 11 options, respondents were asked to write in a response.

### Data Analysis

For each option scored on the rating scale, the presence of consensus was defined as a distribution unlikely to occur by chance by performing a chi-square test ( $P=.05$ ) of the distribution of scores across the three ranges of scores (1-3, 4-6, 7-9). The mean and 95% CI were calculated for the ratings. Categorical ratings of first, second, or third line were designated based on the lowest category in which the CI fell, with a boundary  $>6.5$  for first line and 3.5 to 6.5 for second-line options. Although significance of differences among options was not statistically evaluated, if the CIs do not overlap, that generally indicates a significant difference between options by  $t$  test, with a wider gap indicating a more significant difference (ie, a smaller  $P$  value).

## Results

### Graphic and Tabular Results

Graphic and tabular results of responses for all 9 questions are presented in [Multimedia Appendices 1](#) and [2](#), respectively. For an explanation of how to interpret the graphic results, refer to [Figure 2](#). Options on which consensus was not achieved are shown in the graphic results by an unshaded box and do not represent experts' consensus recommendations. The tabular results show the full range of responses to these questions.

### Patients

#### *Characteristics of Patients Likely to Influence Ability to Use Digital Health Tools*

To optimize the use of digital health tools in patients with SMI, it is essential to identify patients who are most likely to adopt digital technologies. The experts were asked to rate how certain characteristics affect patients' ability to successfully engage with and use a digital health tool. The responses are shown in [Figure 2](#) (and question 1a in [Multimedia Appendix 1](#)). A patient's interest in using state-of-the-art technology received a first-line rating from 90% (35/39) of experts, followed by access to necessary resources (eg, Wi-Fi and hardware), positive expectations about use of the digital health tool, ownership and use of a smartphone or computer or tablet, and positive social support. Patients with a serious level of chaos or disorganization in their lives, low literacy, or low motivation were considered the least likely candidates to use digital health tools.

The experts were next asked about the extent to which patients' diagnoses and the signs and symptoms of their illness are likely

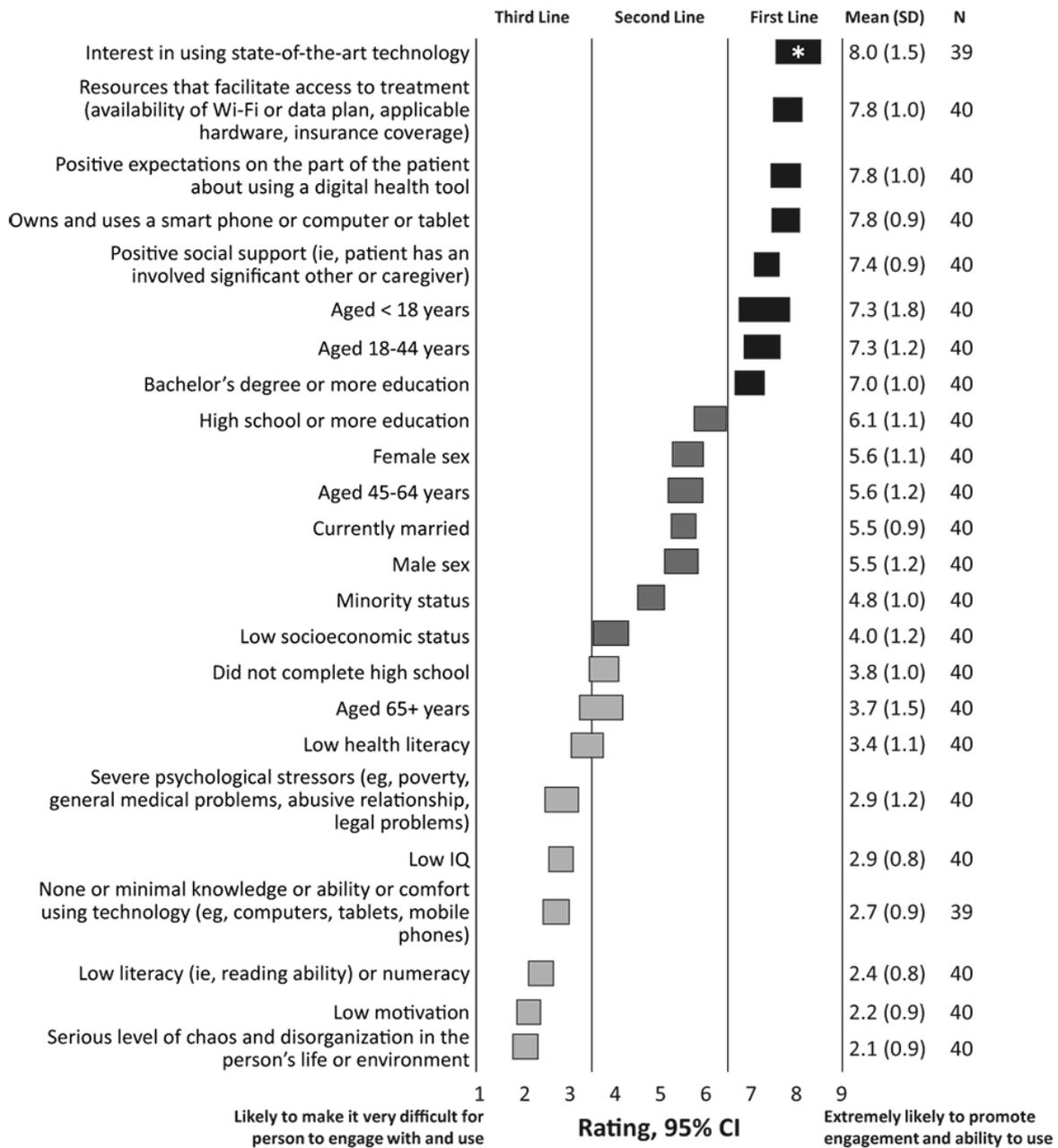
to influence their ability to successfully engage with and use digital health tools. The responses are summarized in [Figure 3](#) (and question 1b in [Multimedia Appendix 1](#)). Good occupational functioning was the only option rated first line (ie, most likely to promote the use of digital health tools). Although diagnoses of schizophrenia, bipolar disorder, or MDD were not independently considered likely to influence the ability to use a digital health tool, a number of symptomatic presentations associated with these disorders were rated as likely to make it difficult for a person to engage with a digital health tool. These included more severe positive, negative, disorganized, and neurocognitive symptoms; acute substance abuse; agitation or aggression; and low energy or frustration or tolerance.

Among the appraisals and experiences likely to affect patients' ability to engage with and use a digital health tool (see question 1c in [Multimedia Appendix 1](#)), all respondents considered a perception by patients that the digital health tool is beneficial as most likely to promote successful engagement and ability to use the digital health tool (mean rating 8.2, SD 0.7). Other characteristics highly likely to promote patient use of digital health tools included the following: agreement with tasks and goals of digital treatment (mean 7.9, SD 0.8), self-efficacy beliefs about being able to use the device (mean 7.9, SD 0.9), a good therapeutic alliance (mean 7.7, SD 0.9), willingness to complete tasks or homework between treatment sessions (mean 7.7, SD 0.9), a history of good treatment adherence (mean 7.4, SD 0.9), and readiness to change (mean 7.3, SD 1.1). Negative past experience with treatment and limited insight into their illness were rated as likely to make it more difficult for patients to engage with or use digital health tools.

To assess how patient and disease characteristics affecting the use of digital health tools compare with those that affect psychotherapy or psychosocial interventions in general, the experts were asked to rate how the same patient characteristics (except those related to technology) affect the chances of achieving favorable outcomes in any psychotherapy or psychosocial intervention (see question 19 in [Multimedia Appendix 1](#)). The responses of the experts were similar to those obtained when they were asked about characteristics that would affect use of digital health tools. They considered that the patients who were most likely to achieve favorable outcomes were those patients who had positive expectations about the therapy (mean 7.8, SD 1.0), resources that facilitate access to treatment (mean 7.7, SD 0.9), positive social support (mean 7.5, SD 1.4), and good occupational functioning (mean 7.1, SD 0.8). Sex, age, marital status, socioeconomic status, and high school educational level were considered unlikely to influence outcomes (all received second-line ratings). Low motivation, a serious level of chaos or disorganization in patients' lives or environment, severe psychosocial stressors (eg, poverty and general medical problems), substance abuse problems, greater severity of symptoms, and greater severity of neurocognitive impairment were considered likely to have an adverse effect on outcomes.

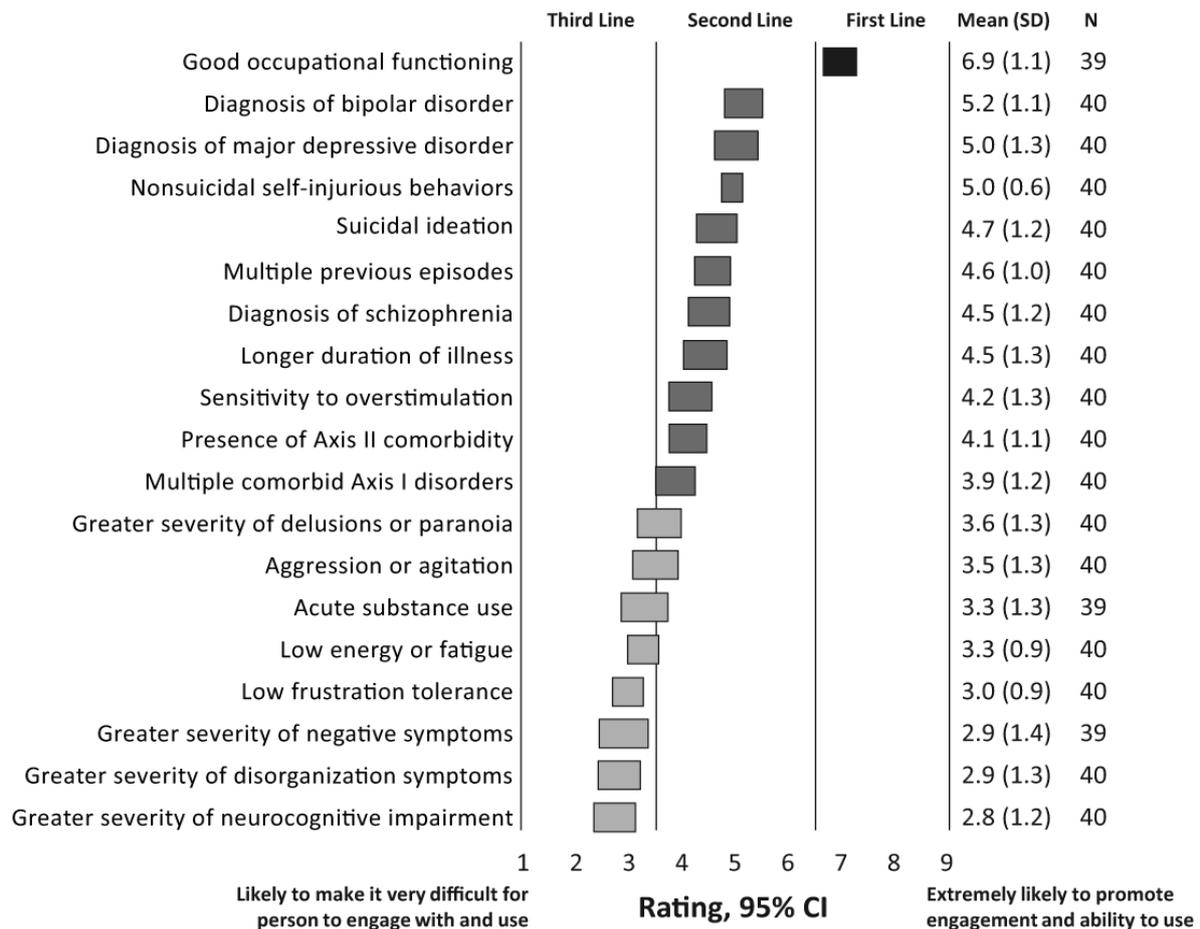
**Figure 2.** Patient characteristics that affect engagement with and use of a digital health tool. The CIs for each option are shown as horizontal bars; consensus is indicated by a shaded bar; the number of respondents, the mean rating, and SD are given in the column on the right. Note that some respondents did not rate some options; therefore, the number of respondents is 39 or 40 for the options in this survey question. The experts rated each item on a scale of 1 to 9, with 1=likely to make it very difficult for person to engage with and use, 5=not likely to influence the ability to engage with or use, and 9=extremely likely to promote engagement and ability to use. \*Highest rating of 9 given by ≥50% of experts.

**Q1a. How much do you believe the following patient characteristics affect the chances that a patient can successfully engage with and use a digital health tool?**



**Figure 3.** Disease-related characteristics that affect a patient’s ability to engage with and use a digital health tool. The CIs for each option are shown as horizontal bars; consensus is indicated by a shaded bar; the number of respondents, the mean rating, and SD are given in the column on the right. Note that some respondents did not rate some options; therefore, the number of respondents is 39 or 40 for the options in this survey question. The experts rated each item on a scale of 1 to 9, with 1=likely to make it very difficult for person to engage with and use, 5=not likely to influence the ability to engage with or use, and 9=extremely likely to promote engagement and ability to use.

**Q1b. How much do you believe the following patient characteristics affect the chances that a patient can successfully engage with and use a digital health tool?**



**Potential Benefits and Barriers or Unintended Consequences for Patients**

The experts were told to assume that certain benefits had been demonstrated to be benefits for digital health tools for SMI patients. They were then asked how likely these various potential benefits would be to motivate patients to use digital health tools (see question 4 in Multimedia Appendix 1). Table 1 lists benefits that were rated as highly likely to motivate patients (options rated first line that received a mean rating ≥7.0). The following two options were rated high second line and received mean ratings ≥7.0: (1) reduction in the number of hospitalizations and (2) increased social engagement enabled by technology. There was no consensus among experts on the potential of digital health tools to reduce health care costs as a motivating factor for patients.

The experts were asked to consider the average patient with SMI and rate how likely it was that various items would be a

potential barrier or lead to unintended consequences for patients using digital health tools (see question 5 in Multimedia Appendix 1). The items rated by the experts as having a substantial potential to be a barrier or unintended consequence of patients’ use of a digital health tool (third-line options with mean ratings ≤3.5) are listed in Table 1. No consensus was achieved concerning the following as potential barriers: increase in family conflict because of information provided by the digital health tool, depersonalization of patient care and potential damage to therapeutic relationship, patient’s use of the digital health tool in isolation leading to decreased face-to-face interaction with clinician or treatment team, and patient being disappointed by not receiving prompt response from the HCP. In addition, no consensus was achieved concerning the following two items specific to patients with psychosis: (1) possible exacerbation of paranoid symptoms related to being monitored or “controlled” and (2) patients’ misinterpretation of interactions with the digital health tool because of paranoid delusions.

**Table 1.** Potential motivators and barriers related to patients' use of digital health tools. For potential benefits, experts rated each item on a scale of 1 to 9, with 1=not at all likely to motivate, 5=somewhat likely to motivate, and 9=extremely likely to motivate. For potential barriers or unintended consequences, the experts rated each item from 1 to 9 with 1=significant potential, 5=some potential, and 9=minimal potential to be a barrier or unintended consequence.

Variable	Rating, mean (SD)
<b>Potential benefits or motivating factors<sup>a</sup></b>	
Improved functioning (eg, social and work functioning)	7.9 (1.3)
Reduced symptomatology	7.8 (1.2)
Receiving feedback or support from clinicians via the digital health system between face-to-face sessions	7.6 (1.1)
Ability to engage with health care professionals (HCPs) periodically after discharge from face-to-face sessions	7.5 (1.1)
Increased interaction with treatment team via digital health device in geographic areas where face-to-face access to HCPs is limited	7.4 (1.5)
Increased confidence or self-efficacy and hope related to his or her health care	7.4 (1.3)
Elimination or reduction of problems with transportation to treatment	7.0 (1.3)
More personalized or tailored treatment approach can be offered by technology	7.0 (1.3)
Receiving prompt helpful automated feedback in response to input or questions	7.0 (1.4)
<b>Potential barriers or unintended consequences<sup>b</sup></b>	
Patient does not believe that the intervention is well suited to his or her particular problem or problems	2.6 (1.8)
Patient finds it a burden to use the digital health tool	2.6 (1.9)
Patient does not understand how to use the digital health tool	2.8 (1.9)
Patient has concerns about being monitored or policed	3.1 (1.9)
Patient finds the digital health tool intrusive	3.2 (2.1)
Patient has concerns about privacy	3.4 (1.9)
Patient feels frustrated and discouraged with using the technology	3.5 (2.3)

<sup>a</sup>First-line mean ratings.

<sup>b</sup>Third-line mean ratings.

### ***Training and Resources to Facilitate Use of Digital Health Tools by Patients***

The experts rated the importance of HCPs providing different types of training and resources to help patients successfully engage with and use a digital health tool (see question 17a, [Multimedia Appendix 1](#)). A high rate of consensus was obtained on the importance of HCPs providing initial training to patients on the system, with 97% (38/39) of experts rating it first line (mean 8.4, SD 0.9). First-line ratings with a mean  $\geq 7.4$  were also given by  $>80\%$  of experts to the following: responding to technical problems identified by the patients as quickly as possible, identifying trends in digital data and responding immediately to critical clinical information, providing specific and clear feedback on the data gathered via the digital health tool during treatment sessions, reinforcing patients' continued engagement with the digital health tool within the first week of use and on an ongoing basis (independent of the clinical information reported or the outcomes), arranging for a member of the treatment team to provide ad hoc support for system use, helping patients set goals using the digital health tool, and developing reward systems for successful engagement and self-management. The experts also recommended providing follow-up and ongoing training on the system for patients (mean 7.1, SD 1.4), providing initial training on the system to families

or caregivers (mean 6.9, SD 1.8), and providing specific feedback between treatment sessions about data gathered from the digital health tool (mean 6.5, SD 1.7).

The experts indicated that they believed providing many of these types of training and resources to patients would be at least somewhat difficult for the average HCP (see question 17b in [Multimedia Appendix 1](#)). Although providing initial training was rated as the most important component in helping patients successfully engage with and use a digital health tool, 56% (22/39) of experts thought that it would be somewhat difficult for HCPs to train patients (mean 5.3, SD 1.8).

### **Health Care Professionals**

#### ***Characteristics of Health Care Professionals Likely to Influence Ability to Use Digital Health Tools***

The experts rated the probability that certain HCP characteristics and resources would be helpful in enabling HCPs to incorporate digital health tools in their practices (see question 2 in [Multimedia Appendix 1](#)). There was a high degree of consensus among experts (highest rating of 9 given by  $\geq 50\%$  of the respondents, mean rating  $\geq 8.2$ ) that HCPs should be enthusiastic about the tool and willing to work with patients using digital health tools, have availability of staff to support ongoing use of technology (eg, make follow-up calls and monitor progress),

and have availability of necessary equipment (eg, computers and broadband internet) for delivering patient treatment on a regular basis. First-line ratings (mean and SD) were also given to the availability of staff with technology skills to train patients (mean 8.1, SD 1.1), availability of necessary equipment for patient use in the HCP's office for training (mean 8.0, SD 1.0), HCP experience with technology (eg, computer and smartphone; mean 7.6, SD 1.0), availability of free trial versions of the tool (mean 7.5, SD 1.0), a digital health tool consistent with the HCP's theoretical orientation (mean 7.5, SD 1.2), and a 24/7 call center to provide technical support to HCPs and patients (mean 7.4, SD 1.5).

### **Potential Benefits and Barriers or Unintended Consequences for Health Care Professionals**

The experts rated potential benefits of and barriers to the use of digital health tools by HCPs who treat patients with psychiatric disorders (see questions 6 and 7 in [Multimedia Appendix 1](#)). With the assumption that the items had been demonstrated to provide benefits for HCPs, experts were asked to rate the likelihood of these items in motivating HCPs to use the tools. Reimbursement by payers for time spent training patients and family members about digital health tool and for time spent using or reviewing data from the digital health tool were the two options that received the highest rating of 9 from >60% of the experts (they were also rated first line by >90% of the experts). Improved patient functioning, reduced patient symptomatology, increased efficiency of care provision, and increased ability to deliver evidence-based treatment were among other options rated first line (all received mean rating >7.5). High second-line ratings with a mean of ≥6.8 were given

to the following options: ability of multiple HCPs involved in the patient's care to access the data (mean 7.0, SD 1.5), increased ability to tailor the treatment to a specific patient (mean 6.9, SD 1.5), 24-hour capability to assess and intervene with at-risk patients (mean 6.8, SD 2.0), and facilitation of patient disclosure about topics patients may be reluctant to share in face-to-face settings (mean 6.8, SD 1.4). No option received a third-line rating.

Drawing from the question 7 structure, using digital health tools may raise concerns for HCPs about (1) process and credibility of the intervention, (2) usability or feasibility, (3) liability and logistical issues, and (4) potential unintended consequences. Inadequate information on integrating the digital system with usual care was considered as the most significant concern regarding the process and credibility of the intervention (see [Multimedia Appendix 1](#), question 7). Among usability issues, patients' lack of access to and understanding of the required technology and a HCP's perception of the digital health tool as time-consuming were considered to be potentially significant barriers in use of digital health tools by HCPs. The potential for increased liability, as well as uncertainty about receiving reimbursement, and other logistical challenges including difficulty having the digital health tool approved by insurance, time disruption involved in integrating digital data into clinical practice, and availability of too much patient information to a time-constrained HCP were deemed to have significant potential to pose barriers to use of digital health tools by HCPs. The experts did not reach consensus on whether digital health tool use could lead to the unintended consequences of patients being distracted from therapy targets or discontinuing traditional face-to-face treatment in favor of self-management.

**Table 2.** Training and resources to support health care professionals' (HCPs') ability to prescribe and interact with digital health tools. The experts rated each item on a scale of 1 to 9, with 1=not at all important, 5=somewhat important, and 9=extremely important.

Training or resources considered important <sup>a</sup>	Rating, mean (SD)
Clear rationale provided to HCPs <sup>b</sup> about how using this device can improve outcomes <sup>c</sup>	8.3 (0.9) <sup>c</sup>
Provision of hands-on work with device or dashboard during training sessions	7.9 (1.2)
Inclusion of clinical examples and case materials as core elements of the training	7.9 (1.4)
Clear and concise tutorial provided in the digital device	7.7 (1.3)
Technical call center support	7.6 (1.1)
Prepared handouts to give to patients	7.4 (1.6)
In-person training sessions	7.4 (1.5)
Simple platform that can be learned with user guide and video demonstration without requiring in-person training	7.3 (1.8)
Having HCP use the digital system as a "patient" for a trial period to become familiar with its features	7.2 (1.7)
Complete protocol and user guide	7.2 (1.5)
Training provided in HCP's office (detailing approach)	7.2 (1.7)
Availability of follow-up training sessions (if needed)	7.2 (1.4)
Continuing medical education credit for completing training	7.2 (1.6)

<sup>a</sup>First-line mean ratings.

<sup>b</sup>HCP: health care professional.

<sup>c</sup>Indicates options that received highest rating of 9 by ≥50% of experts.

### ***Training and Resources to Facilitate Use of Digital Health Tools by Health Care Professionals***

Another goal of the survey was to elicit expert opinion on the different types of training and resources that HCPs would need to successfully implement use of digital health tools in their practices (see question 16a in [Multimedia Appendix 1](#)). The experts were asked to assume that the HCP would receive computerized reports with output from the digital health tool. [Table 2](#) shows the types of training and resources for HCPs that were considered very important (13 of the 20 listed options that were rated first line). Giving HCPs a clear rationale about how use of a digital health tool could improve outcomes was rated first line by 95% (37/39) of respondents. The types of training and resources that were considered somewhat important (high second-line ratings) included in-person training followed by Web-based video reinforcement, video-based online training modules, training webinars, frequently asked questions or user forums on a website, online chat support for questions or technical issues, and working with medical schools to provide training in digital health technology.

The experts were then asked to rate the likelihood that HCPs would participate in these types of training (see question 16b in [Multimedia Appendix 1](#)). Participation in individualized training in the HCP's office and a concise tutorial provided in the digital health tool were rated first line. The experts thought that HCPs were somewhat likely (high second-line ratings) to use technical call center support (mean 6.4, SD 1.9), training webinars (mean 6.0, SD 1.4), follow-up training sessions when needed (mean 6.0, SD 1.7), and in-person training sessions (mean 5.9, SD 1.9). Consensus was not reached on whether HCPs would be willing to use the digital system as a "patient" for a trial period to become familiar with its features.

## ***Discussion***

### **Overview**

Within the emerging field of technology in health care, a primary goal of this survey study was to provide guidance to mental health professionals (physicians and other allied HCPs such as psychologists, case managers, and social workers) on how to best integrate digital mental health tools into their practices. The presentation of the results in the preceding section was organized on the basis of target users, beginning first with considerations for patients' use of digital health tools, followed by considerations for HCPs' use of digital health tools. However, the following discussion is organized to show how these findings might best be applied in real-world clinical settings. The discussion will therefore begin with commentary on how to develop training and resources and how best to identify appropriate HCPs for digital health tool use, followed by a discussion of benefits that would motivate HCPs and patients, and potential barriers or unintended consequences for which one should be alert.

### **Resources and Training for Health Care Professionals and Patients**

Before HCPs can be asked to implement digital health tools in their practices, developers of these tools need to set up resources

and training: first, to inform HCPs about *why* they might want to use such tools (ie, potential benefits of using a digital health tool for HCPs) and second, to teach interested HCPs *how* to use these devices. The experts indicated that the first and most important step in interacting with HCPs is to provide them with a clear rationale about how using a digital health tool could improve outcomes for their patients, which was rated first line by 95% (37/39) of respondents. The specific types of training for HCPs that the experts thought would be most helpful and that HCPs would be most likely to actually participate in were individualized training in their offices and a clear and concise tutorial provided in the digital health tool itself. These results suggest that strategies that are most convenient and time-efficient, particularly given the ever increasing workload demands that HCPs encounter [36], are likely to be most feasible and effective for HCPs.

Adhering to user-centered design principles to guide the development of digital health tools that are user-friendly and easy to understand is foundational to a successful digital health tool design. In the field of mental health care, provision of human support has also been recognized to be important for effective engagement with digital interventions [26]. Accordingly, Mohr et al have emphasized the "service" or support component for users in their model for designing digital health tools for mental health care [26]. Expert opinion in this survey corroborated the need for training and support to effectively engage with a digital health tool. Once the HCP has decided to begin prescribing a digital health tool and has received initial training on the device, the next and most crucial step in enabling a patient to successfully engage with and use a digital health tool is to have the HCP provide initial training to the patient (rated first line by 97% [38/39] of the experts). Other strategies that the experts indicated would be most helpful for HCPs in promoting patient engagement with a digital health tool are quick response to technical problems identified by patients, as well as critical clinical information provided by the digital health tool, provision of initial and ongoing support and reinforcement to patients by both the HCP and other members of the treatment team, and helping patients set goals using the digital health tool. However, a significant number of experts indicated that they believed carrying out these activities would be somewhat difficult for many HCPs.

### **Identifying Appropriate Health Care Professionals, Motivating Them to Use Digital Health Tools, and Potential Barriers or Unintended Consequences**

#### ***Identifying Appropriate Health Care Professionals***

The experts were queried about characteristics of HCPs and resources that would increase the probability that they could successfully incorporate digital health tools in their practices. The three factors that received the highest rating from more than half of the experts and that were rated first line by  $\geq 95\%$  of the respondents were interest in and enthusiasm about using a digital health tool and availability of the necessary staff and equipment (eg, broadband internet if needed and mobile devices) to support use of such a tool. The experts also considered it very helpful if the HCP had experience with technology (eg, computers and smartphones).

### ***Motivating Health Care Professionals***

Not surprisingly, given the current insurance system in the United States, the experts rated reimbursement for time spent training patients and reviewing and using data from the digital health tool as the biggest potential motivators for HCPs to incorporate digital health tools in their practices (these options received the highest rating of 9 from >60% of the experts). The importance of addressing reimbursement and cost issues to facilitate digital health tools adoption among physicians was highlighted in a recent review by de Grood et al [24]. The experts also gave first-line ratings to many factors related to patient outcomes, including improved adherence to treatment and functioning, reduced symptomatology, more accurate data concerning adherence and symptoms on which to base clinical decision making, and a potential reduction in hospitalizations. Again, these results reinforce the importance of generating outcomes data and communicating this information to HCPs when providing initial training.

### ***Potential Barriers or Unintended Consequences for Health Care Professionals***

Given that digital health tools have only recently been introduced in the care of patients with SMI, we queried the experts about potential barriers to their use and about possible unintended consequences that might result from their use. The experts expressed concerns about a number of issues involving the process, usability, liability, and logistics associated with digital health tools. Data from the current survey corroborate findings of other research studies [24,37] and underscore the importance of collective industry efforts to address these issues. Not surprisingly, given the early stage of use of these technologies, the experts expressed uncertainty about a number of options that were rated as having “some” potential to be a barrier or unintended consequence but with no consensus on many of these options. It is important for HCPs in the field to remain vigilant to potential unintended consequences. Additionally, future research should examine how important these issues will actually prove to be in practice.

### **Identifying Appropriate Patients, Motivating Them to Use Digital Health Tools, and Potential Barriers or Unintended Consequences**

#### ***Identifying Appropriate Patients***

As would be expected based on the treatment adherence literature [38-41], the experts endorsed positive expectations about the potential benefits of treatment, a good therapeutic alliance with the HCP, good occupational and cognitive functioning, and a readiness to change among characteristics that are very likely to promote engagement with digital health tools. The survey responses suggested that many of the characteristics that promote favorable outcomes in any psychosocial intervention are similar to those that promote favorable outcomes when interventions are delivered via a digital health tool, except that patients will also need access to and the ability to use technology.

The experts endorsed higher educational level; younger age; and interest in, access to, and familiarity with digital technology as likely to make it easier for patients to engage with and use a

digital health tool, whereas sex and minority or socioeconomic status were not considered likely to affect a patient’s ability to use a digital health tool. These results correspond to those reported in studies that have investigated user characteristics related to digital health technologies. In a cross-sectional study of 100 patients with SMI, Borzekowski et al reported that sex and ethnicity did not affect the use of technology to access health information, although younger age and higher education level were associated with a greater use of the internet for this purpose [22]. More recently, Robotham et al surveyed 121 patients with psychosis and 120 with depression and found that older patients were less likely to use internet-enabled devices (eg, computers and mobile phones) [42]. In patients with psychosis, older age predicted reduced confidence in using and less access to mobile phones; in patients with depression, older age predicted reduced access to computers [42].

Although results of our survey suggest that the ability to use a digital health tool is likely independent of a specific patient diagnosis, the experts thought that specific symptomatic presentations such as poor cognitive functioning, severe symptoms, and acute substance abuse were likely to make it more difficult for patients to engage with technology. These data suggest that assessment of a patient’s clinical state and timing of a digital health tool prescription are important considerations in how clinicians employ their treatment armamentarium. A 2014 study by Gill et al, which used an automated internet-based tool to screen for depression in a sample of 45,142 individuals, reported that current depression status, previous treatment seeking for depression, and lower education level predicted lower rates of adherence with rescreening [43]. Survey results have shown that individuals who self-identify as having schizophrenia are more likely to use technologies (eg, computer, tablet, and mobile phone) when they are feeling well and not experiencing many symptoms [44]. Therefore, patients’ clinical state is an important consideration for successful use of digital health tools. Moreover, patient characteristics should be considered in the design of the digital health tool itself. For example, Rotondi and colleagues have made recommendations for mitigating the effects of cognitive dysfunction in patients with SMI [45,46].

#### ***Motivating Patients***

HCPs will need to educate patients about potential benefits of the digital health tool in their mental health care regimen. The experts who responded to our survey endorsed a number of potential benefits that they believed would motivate patients to use a digital health tool, including improved functioning; reduced symptomatology; increased access to, interaction with, and feedback from their physician and other treatment team members; and a reduction in number of hospitalizations. The benefit associated with use of digital health tools should be empirically demonstrated by the developers of these tools so that this information can be communicated to HCPs who can then share it with their patients when introducing the digital health tool.

There was also no consensus among the experts on whether use of digital health tools might reduce health care utilization and costs. Some evidence suggests that this may be the case in other

therapeutic areas. A systematic review of published literature demonstrated cost-effectiveness of mHealth interventions in areas focusing on outpatient clinic attendance, cardiovascular disease, and diabetes [47]. An ongoing randomized controlled trial aims to investigate the cost-effectiveness of an internet- and mobile-based intervention for preventing depression in individuals with chronic back pain [48]. Future research should address whether digital health tools are cost-effective in patients with SMI.

### ***Potential Barriers or Unintended Consequences for Patients***

Similar to the questions about potential barriers to and unintended consequences of use of digital health tools by HCPs, the experts rated a number of options as having potential to be barriers to or unintended consequences of use of digital health tools for patients (Table 1), while they also expressed uncertainty (no consensus) about many potential problems their patients might face. Future research should examine how important these issues will actually prove to be. In previous surveys of patients with schizophrenia or schizoaffective disorder, two of the most common barriers to using the internet were security concerns (46%) and lack of knowledge of technology (40%) [42].

### **Study Limitations**

This study had several limitations. First, the survey asked the participants to assume hypothetical use of the type of technology with which each expert had the most experience rather than asking about a specific tool or product. There is much variation in digital health tools, and the responses may have been different if the survey had specified a particular tool. Second, the expert panel represented individuals with a broad range of experience with different types of technological tools (eg, mobile phone apps, online therapy programs, and computerized cognitive remediation) and widely differing roles in treatment interventions in psychiatry. However, we achieved the goal of ensuring that the respondents were experts in the use of technology in this population. It should be noted, however, that the panel reported extensive experiences with Web or mobile or computer technologies but very little experience with sensor technologies. Third, the questions and response options specify tools that presuppose HCP involvement in digital health tool with patients. There are numerous examples of digital health tools that are consumer-facing and do not involve the HCP. Additionally, given that the experts were all developing, studying, and using technology interventions in this population, there may have been a bias to positively rate the digital health

tools to advocate for their use, although experts' own level of comfort with using technology was not assessed. Yet another limitation is that the experts' responses may not have been well informed by first-hand experiences with digital health tools in interacting with patients in real-world settings, as indicated by the respondents spending on average approximately 15% of their professional time in clinical work. There is a potential for discrepancy between expert ratings and ratings of mental HCPs in clinical practice. Furthermore, the experts provided their perspective on patient-related factors that might differ from those of actual patients. Demographics and other characteristics of patients treated by the clinicians in this expert panel were not collected. Finally, although the survey asked about many different factors, the experts were limited to responding to predefined options.

In alignment with the emphasis on user-centered design for developing digital health tools [49], in the future, it will be important to take patient perspectives also into account. Particularly in the field of mental health care, where patients can have unique needs in engaging with technology, results of this survey can guide the choice of appropriate patients who are likely to adopt digital health tools. As patients and HCPs gain increasing experience with the use of digital health tools, future research studies and surveys in the field should seek input from actual users to facilitate effective use of digital health tools. While appreciating the potential of digital technology to transform mental health care, it will be crucial to address barriers in implementation of digital health tools and focus on efforts to make digital health tools easy to access, use, and integrate into clinical care. Various frameworks have been put forth in efforts to standardize the design process [26,46,49]; however, frameworks to harmonize the implementation and integration of digital health tools in clinical care are also needed.

### **Conclusions**

The use of digital health tools in the provision of mental health care is an emerging field. There is an unmet need for guidance on how to optimize the use of digital health tools to achieve desired outcomes in this patient population. In this report, we presented the recommendations of a panel of experts in this field on how to identify the most appropriate patients and HCPs to facilitate initial adoption of and sustained engagement with digital health tools and on what training and resources these target users will need. The results of this survey can guide clinicians in optimizing the use of digital health tools in psychiatry.

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### **Conflicts of Interest**

AH and JPD were employees of Otsuka Pharmaceutical Development and Commercialization, Inc, at the time of this study and are currently employees of Otsuka America Pharmaceutical, Inc. RR and JEH served as consultants for Otsuka Pharmaceutical Development and Commercialization, Inc, and were reimbursed for their work on the survey and data analysis.

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### **Multimedia Appendix 1**

Graphical survey results.

[[PDF File \(Adobe PDF File\), 269KB - mental\\_v5i2e46\\_app1.pdf](#) ]

## Multimedia Appendix 2

Tabular survey results.

[[PDF File \(Adobe PDF File\), 155KB - mental\\_v5i2e46\\_app2.pdf](#)]

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## Abbreviations

**HCP:** health care professional  
**MDD:** major depressive disorder  
**mHealth:** mobile health  
**SMI:** serious mental illness

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Original Paper

# Open Notes in Swedish Psychiatric Care (Part 2): Survey Among Psychiatric Care Professionals

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## Abstract

**Background:** This is the second of two papers presenting the results from a study of the implementation of patient online access to their electronic health records (here referred to as Open Notes) in adult psychiatric care in Sweden. The study contributes an important understanding of both the expectations and concerns that existed among health care professionals before the introduction of the Open Notes Service in psychiatry and the perceived impact of the technology on their own work and patient behavior after the implementation. The results from the previously published baseline survey showed that psychiatric health care professionals generally thought that Open Notes would influence both the patients and their own practice negatively.

**Objective:** The objective of this study was to describe and discuss how health care professionals in adult psychiatric care in Region Skåne in southern Sweden experienced the influence of Open Notes on their patients and their own practice, and to compare the results with those of the baseline study.

**Methods:** We distributed a full population Web-based questionnaire to psychiatric care professionals in Region Skåne in the spring of 2017, which was one and a half years after the implementation of the service. The response rate was 27.73% (699/2521). Analyses showed that the respondents were representative of the staff as a whole. A statistical analysis examined the relationships between health professional groups and attitudes to the Open Notes Service.

**Results:** A total of 41.5% (285/687) of the health care professionals reported that none of their patients stated that they had read their Open Notes. Few health care professionals agreed with the statements about the potential benefits for patients from Open Notes. Slightly more of the health care professionals agreed with the statements about the potential risks. In addition, the results indicate that there was little impact on practice in terms of longer appointments or health care professionals having to address patients' questions outside of appointments. However, the results also indicate that changes had taken place in clinical documentation. Psychologists (39/63, 62%) and doctors (36/94, 38%) in particular stated that they were less candid in their documentation after the implementation of Open Notes. Nearly 40% of the health care professionals (239/650, 36.8%) reported that the Open Notes Service in psychiatry was a good idea.

**Conclusions:** Most health care professionals who responded to the postimplementation survey did not experience that patients in adult psychiatric care had become more involved in their care after the implementation of Open Notes. The results also indicate that the clinical documentation had changed after the implementation of Open Notes. Finally, the results indicate that it is important to prepare health care professionals before an implementation of Open Notes, especially in medical areas where the service is considered sensitive.

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**KEYWORDS**

electronic health records; eHealth; telemedicine; postimplementation survey; health care surveys; mental health; Open Notes; psychiatry; health professionals

## Introduction

### Background

This paper is the second of 2 that present the results from a study of the pre- and postimplementation of patient online access to their electronic health records (here referred to as Open Notes) in adult psychiatric care in Sweden. The study consisted of 2 surveys: 1 at baseline and 1 at postimplementation. In this paper, we present the results from the postimplementation survey and compare them with the results from the previously published baseline survey [1]. The study, as a whole, is unique and contributes an important understanding of the expectations and concerns that existed among Swedish health care professionals (HCPs) before the introduction of Open Notes in psychiatry and their perceptions of the impact of the technology on their own work and on patient behavior afterward. The study design also allowed us to compare expectations and experiences between different groups of HCPs.

### Open Notes in Sweden

The Open Notes Service was first launched for patients in nonpsychiatric care in Uppsala County in 2012. Today, all citizens in the country except adolescences between 13 and 16 years of age can read their Open Notes from nonpsychiatric settings online. In some counties, however, patients in psychiatric care can also read their notes online. Region Skåne, the site of our study, was the first county to add psychiatric care to the service [1]. Open Notes is an important civic eHealth service in Sweden and, as in other countries, the intention is to increase patient empowerment and participation [2]. Health care coverage in Sweden is universal, which means that all residents have access to publicly financed health care and, thus, the Open Notes Service. Sweden has 10 million citizens and, at the end of April 2018, approximately 1.8 million of them had read their Open Notes online. Swedish patients logged in to the service nearly 5.4 million times during the first 4 months of 2018, which is an average of almost 49,000 log-ins every day. Every day during these 4 months, 2500 patients used the service for the first time. However, the service is not seen as entirely positive among HCPs; results from qualitative studies in Sweden indicated that some doctors have a negative view of the service [3,4].

In part 1 of this study, carried out in 2015, we queried HCPs in Region Skåne in a baseline survey about how they expected Open Notes to affect their patients and their own practice before its implementation in adult psychiatric care [1]. We later followed up with a postimplementation survey to gain more knowledge about how the HCPs in adult psychiatric care in Region Skåne experienced the influence that Open Notes had on their patients and their own practice.

### Principal Findings From the Baseline Survey

The results from the full population baseline survey showed that psychiatric HCPs generally thought that Open Notes would influence both the patients and their own practice negatively. Doctors, psychologists, and medical secretaries were in many cases more negative than nurses and assistant nurses. Almost 60% of the HCPs believed that patients who read their Open

Notes would be more worried, and half of the respondents thought that these patients would find the notes more confusing than helpful. To our surprise, medical secretaries were as negative toward the service as the doctors were. In particular, their concerns were that patients would be offended by the entries and would disagree with the content in their records. However, the respondents also believed that Open Notes would benefit the patients. Approximately 40% anticipated that most of the patients would feel more in control of their care, and 30% believed that patients would be better prepared for appointments. One of the most notable results in the baseline study was that approximately 60% of both doctors and psychologists were worried that they would be less candid in their documentation after the implementation of Open Notes [1].

We sent out a second survey to investigate how the concerns listed above and other opinions of the HCPs had changed after the implementation of patient access to their Open Notes in psychiatry. We queried the HCPs about their experiences of the service one and a half years after the baseline survey and, thus, one and a half years after the implementation. The objective of this study was to describe and discuss how HCPs in adult psychiatric care in Region Skåne in southern Sweden experienced the influence that the Open Notes Service had on their patients and their own practice, and to compare the results with those from the previously published baseline survey study.

## Methods

### Survey Design

The material we present here is the result of a postimplementation survey in psychiatric care. Both this survey and the previous baseline survey were part of a larger research project (the eHealth Services' Impact on the Working Environment of Health Professionals [EPSA] Project, financed by AFA Insurance, Sweden) on how the work and work environment of HCPs are influenced by civic eHealth services such as Open Notes. The employees in adult psychiatry were not presented the results from the baseline survey until after they had completed the postimplementation survey in order to avoid biasing the respondents' opinions. We distributed the postimplementation survey one and a half years after the implementation of Open Notes. The reason for this decision was that we wanted both the staff and patients to have gained considerable experience from using the service before we sent the follow-up survey.

Both the baseline [1] and the postimplementation surveys were based on the surveys developed by the OpenNotes Project in the United States [5-8]. In both cases, the original surveys were translated and adjusted to fit the Swedish context. The questions were then translated into English for presentation in this paper. The postimplementation survey covers the following themes: benefits and risks for patients, changes in practice, changes in clinical documentation and work conditions, about me, and future development of Open Notes. Most of the questions from the baseline survey remained the same, but we changed the verb tense in many of them. We also changed the response options in some questions either because some professional groups would otherwise not have been able to answer the specific

question, or because we were interested in a more detailed answer than the response options from the baseline survey offered. In addition, because Open Notes in adult psychiatric care in Region Skåne has been implemented in the universal health care system, patients with many different diagnoses can read their records. A question posed in the discussion of the first paper was whether there was a difference in how the service influenced patient groups with various diagnoses. Did HCPs think that Open Notes could benefit any special group of patients or might the service be particularly problematic for other groups of patients in psychiatry [1]? We thus added this question to the postimplementation survey. The survey consisted of 44 fixed-choice questions and 20 open-ended questions. We designed the postimplementation survey so that the respondents could choose not to answer all the questions.

### Setting and Population

The Division of Psychiatric Care in Region Skåne consists of 3 subdivisions: adult, child and youth, and forensic. It employs roughly 3000 people. In 2017, there were over 575,000 appointments, of which almost one-fifth were with a doctor. The number of unique patients was over 56,000. Patients in adult psychiatry were offered online access to their Open Notes in October 2015, and the plan was that patients in forensic psychiatry and parents of patients in child and youth psychiatry should be offered the service from the fall of 2018.

We invited the entire population of HCPs ( $n=2521$ ) in adult psychiatry in Region Skåne who meet patients to participate in this postimplementation study. This included assistant nurses, doctors, medical secretaries, nurses, occupational therapists, physical therapists, psychologists, social workers, and unit managers. In the population, approximately two-thirds of the doctors were psychiatrists, and nearly half of the nurses were specialists in psychiatric care. We referred to these two professions as doctors and nurses in both questionnaires. The rationale for not taking a sample was that the employees are a heterogeneous population where some of the professional groups are large and others are small. Further, the study design required that it would be possible to compare the results from this survey with those from the previous full population baseline survey. The population of HCPs in this postimplementation study was smaller than in the baseline study [1]: approximately 500 fewer individuals. The main reason for this is that the list of institutional email addresses that we received from Region Skåne had been revised and updated in the meantime; the list no longer included summer employees, for instance.

### Survey Administration

We used the Web survey tool Sunet Survey (Artisan Global Media). The emails were sent from Lund University, Lund, Sweden. On March 14, 2017, we sent a prenotification email to the study population, and on March 16, we sent a cover letter with a link to the online survey to the institutional email addresses of the professionals. Both the prenotification email and cover letter informed the recipients that participation was voluntary, that the computer files with the results were confidential, that respondents could terminate their participation at any time, and that tracking of individual responses was not

possible. We did not offer any survey incentives. We sent 4 reminders, and the survey closed on April 22, 2017.

### Data Analysis

We present descriptive information for each fixed-choice question in the postimplementation survey and chi-square tests to examine the relationships between professionals and their attitudes to the Open Notes Service. Due to the small number of respondents, we grouped occupational therapists, physical therapists, social workers, unit managers, and those who selected “other” together for the chi-square tests. All reported  $P$  values were 2-sided. We considered  $P<.05$  as statistically significant. However, in this survey, we offered response options such as “not relevant” and “I do not know,” and due to this, we did not conduct chi-square tests on 25 of the questions. In some cases, though, we did consider the question results for specific professions despite the lack of a chi-square result so that we would be able to compare the results from certain professions in the baseline study with those in the postimplementation study. The survey data were imported into and analyzed in IBM SPSS, version 23 (IBM Corporation). We also present the results of 2 of the independent open-ended questions on how the service influenced patient groups with different diagnoses. We will present the rest of the free-text responses in a separate paper. The study consisted of 2 surveys, and one of the aims was to compare the answers between them. Thus, we compared the results from the 28 questions that were similar in both surveys on a group level, and we present an overview with descriptive data of the comparison between the expectations before the implementation and the experiences after. However, in some cases where the response options differed in the second survey, we present these options together with the comparison.

### Ethics

We followed the guidelines on research ethics issued by the Swedish Research Council [9]. This study did not cover any sensitive information and did not require ethical approval according to the Swedish regulations on research ethics. Potential respondents were provided with information about the survey and its purpose in the prenotification email and the cover letter, including that participation was voluntary.

## Results

### Survey Respondents

The response rate to the Web survey was 27.73% (699/2521). The distribution of the various professions corresponded well with the overall percentage of employees in each profession in the region. The questionnaire was distributed to both permanent and temporary employees, which may have influenced the response rate negatively. Table 1 presents the demographics of the survey respondents. For statements that evaluated attitudes and experiences, we combined the alternative responses “somewhat agree” and “agree,” indicating that the respondent agreed at some level.

### Open Notes' Influence on Patients

Among the respondents, 40.1% (276/689) estimated that 1% to 25% of their patients read their Open Notes; 37.7% (260/689)

could not estimate the proportion because very few of their patients ever mentioned it. The pattern was similar for the question about how often patients brought up and talked about something they had read in their Open Notes: 42.4% (291/687) of the respondents answered that this situation occurred less than monthly, and 41.5% (285/687) answered that none of their patients had talked about the content of their health record (data not shown).

**Table 2** presents the percentage of respondents who answered that they “somewhat agree” or “agree” with statements about how Open Notes influenced their patients. The first 7 statements are related to the potential benefits of Open Notes to patients, and the last 2 are related to the potential risks.

The HCPs who responded to the postimplementation survey generally thought that the expected benefits of Open Notes for patients were somewhat absent. Only 5.7% (37/651) answered that patients who read their Open Notes took better care of themselves, and 8.0% (52/650) answered that patients who read their Open Notes were more likely to take medication as prescribed. Approximately one-fourth (153/652, 23.5%) agreed to the statement that patients who read their Open Notes from psychiatry felt more in control of their health, and 14.2% (91/642) of the respondents experienced that patients who read their Open Notes trusted their HCPs more as professionals. At the same time, 24.6% (159/647) believed that patients who read their Open Notes found the notes more confusing than helpful, and 33.5% (217/648) thought that these patients worried more.

**Table 1.** Demographic characteristics of the respondents (n=699).

Characteristics	Responses, n (%)
<b>Professional affiliation (n=684)</b>	
Nurse	191 (27.9)
Assistant nurse	164 (24.0)
Doctor	97 (14.2)
Psychologist	63 (9.2)
Medical secretary	35 (5.1)
Social worker	45 (6.6)
Occupational therapist	18 (2.6)
Physical therapist	17 (2.5)
Unit manager	28 (4.1)
Other	26 (3.8)
<b>Sex (n=682)</b>	
Female	492 (72.1)
Male	154 (22.6)
Do not want to define	36 (5.3)

**Table 2.** Psychiatric professionals' views on how patient online access to the Open Notes Service in adult psychiatric care influenced their patients, in answer to the question stub “Generally, my patients who read their Open Notes from psychiatry online:”

Survey item	Responses, n (%) <sup>a</sup>
Understand their health and medical conditions better (n=657)	100 (15.2)
Remember the plan for their care better (n=649)	132 (20.3)
Take better care of themselves (n=651)	37 (5.7)
Are more likely to take medications as prescribed (n=650)	52 (8.0)
Feel more in control of their health care (n=652)	153 (23.5)
Are better prepared for appointments (n=246)	107 (16.6)
Trust me more as their care personnel (n=642)	91 (14.2)
Worry more (n=648)	217 (33.5)
Find the notes to be more confusing than helpful (n=647)	159 (24.6)

<sup>a</sup>Respondents who indicated “somewhat agree” or “agree” on a 4-point scale, with response options “disagree,” “somewhat disagree,” “somewhat agree,” and “agree.” There was also the option “I do not know.” We did not conduct a chi-square test on these questions due to the response options.

Of the 699 HCPs, 212 (30.3%) responded with free text to the question “For which patient groups or diagnoses in adult psychiatry may Open Notes be an asset?” There were many different responses to this open-ended question, and the most common ones were everyone (63/212, 29.7%), I do not know (26/212, 12.3%), and no one (21/212, 9.9%). Some respondents answered with examples of specific patient groups or diagnoses, and the most common answers were patients in general psychiatry (n=11), patients who need memory support (n=10), patients who understand that they are sick (n=9), and patients with depression (n=7).

Of the 699 HCPs, 276 (39.5%) responded with free text to the question “For which patient groups or diagnoses in adult psychiatry may Open Notes be particularly problematic?” The most common answers to this question were patients with a personality disorder (88/276, 31.9%), patients with psychosis (82/276, 31.1%), and patients with paranoia (47/276, 17.0%). Some respondents answered everyone (n=14), I do not know (n=13), or no one (n=11). Thus, the pattern of answers to the question about Open Notes being problematic differed from that about Open Notes being an asset.

### Changes in Practice

Table 3 shows how the respondents experienced that Open Notes influenced their practice. Generally, the results indicate that there was little impact on practice. Only 14.5% (86/594) answered that appointments took longer when patients had read their Open Notes, and 18.0% (106/588) answered that they spent significantly more time addressing patient questions outside of appointments when patients had read their notes online. Few HCPs (34/609, 5.6%) answered that Open Notes had replaced other types of communication such as letters or phone calls.

Almost one-fourth (180/671, 26.8%) of the HCPs encouraged patients to read their Open Notes, and 15.6% (105/671) of the respondents stated that they took the initiative to talk with a patient about something they were able to read in their Open Notes. Some HCPs (67/670, 10.0%) also actively used Open Notes in treatment.

The chi-square tests showed that experiences differed among the various groups of professionals. Medical secretaries (7/22, 32%) and doctors (19/86, 22%) stated more often than psychologists (6/55, 11%) and nurses (15/167, 9.0%) that appointments took significantly longer when the patient had read his or her Open Notes. The pattern was the same for the statement “I spend significantly more time addressing patient questions outside of appointments when patients have read their Open Notes.” Approximately one-third of the doctors (28/83, 34%) and 23% (5/22) of the medical secretaries answered yes to this question, compared with 15.4% (26/169) of the nurses and 14% (7/52) of the psychologists. Medical secretaries (5/26, 19%) answered more often than doctors (5/86, 6%) and nurses (4/168, 2.4%) that Open Notes had replaced other types of communication such as letters or phone calls.

### Changes in Clinical Documentation, Work Conditions, and Care Delivery

Table 4 shows the HCPs’ views on how the Open Notes Service influenced clinical documentation. Table 5 shows HCPs’

statements about how work conditions and care delivery in adult psychiatric care were influenced by this service, which is aimed at the patients. Approximately 20% of the respondents stated that they were less candid in their documentation (147/667, 22.0%) and spent more time editing notes (117/662, 17.7%) after the implementation of Open Notes. The Swedish Public Access to Information and Secrecy Act states that parts of the content in the health record may be withheld from a patient if it has been determined that the patient’s condition would deteriorate seriously if he or she were allowed to read the content. Content can also be withheld if another person (eg, a relative) is mentioned in the health record, and if that person could be endangered if the patient is allowed to read this entry. Thus, the health care provider has an obligation to carry out what is referred to here as a confidentiality check before the patient is allowed access to the information in his or her health record. Historically, this check was performed when a patient ordered a paper copy of the health record. However, the introduction of Open Notes has changed this procedure, and now all HCPs who enter documentation in health records need to carry out this confidentiality check each time they make an entry, since the patient has immediate access to the content. One-third (231/664, 34.8%) of the HCPs reported that they did a confidentiality check. At the same time, few HCPs (43/667, 6.4%) used the Specific Information template in Open Notes, which is where an HCP can enter content that is hidden from the patient online.

Due to the answer options, it was not possible to conduct a statistical analysis to examine the relationships between professionals and attitudes on the questions about clinical documentation. However, the psychologists (39/63, 62%) and doctors (36/94, 38%) responded that they were less candid in their documentation after the implementation of Open Notes. Most of the psychologists (39/62, 63%) and doctors (51/94, 54%) answered that they conducted a confidentiality check when writing in the health records, compared with 30.9% of the nurses (58/188) and 20.6% of the assistant nurses (33/160).

Table 5 presents the HCPs’ views on how Open Notes influenced work conditions and care delivery. Few HCPs (95/642, 14.8%) agreed that it changed the relationship between their profession and the patient. However, 22.8% (146/639) stated that it increased the risk for threats and violence. Only 13.2% of the HCPs (80/606) believed that patient satisfaction improved after the implementation of Open Notes, and 23.3% (141/606) believed that patient care was safer. Approximately one-third (226/668, 33.9%) of the HCPs agreed with the statement “In the future, patients should be able to write a divergent opinion that is stored in connection to the HCP’s note in the health record.” Nearly 40% of the HCPs (239/650, 36.8%) answered that Open Notes in psychiatry was a good idea.

Medical secretaries (8/26, 31%) believed that Open Notes changed the relationship between them and the patients to a larger degree than doctors (18/92, 20%) and nurses (20/181, 11.1%). Doctors (22/95, 23%) and psychologists (17/61, 28%) were less likely than assistant nurses (58/157, 37%) and nurses (74/185, 40%) to agree with the statement “Patient online access to their Open Notes in adult psychiatry is generally a good idea.”

**Table 3.** Psychiatric professionals' views on how patient online access to the Open Notes Service in adult psychiatric care influenced their practice and results of the chi-square test for some of these items.

Survey item	Responses, n (%)	P value
Appointments take significantly longer time when the patient has read their Open Notes. (n=594) <sup>a</sup>	86 (14.5)	.005
I spend significantly more time addressing patient questions outside of appointments when patients have read their Open Notes. (n=588) <sup>a</sup>	106 (18.0)	.001
Has Open Notes replaced other communication such as letters or phone calls? (n=609) <sup>a</sup>	34 (5.6)	.002
Has the ombudsman function in Open Notes replaced other communication with relatives? (n=589) <sup>a</sup>	43 (7.3)	.02
Have you taken the initiative to talk with any of your patients about something they have been able to read in their Open Notes? (n=671) <sup>b</sup>	105 (15.6)	N/A <sup>c</sup>
Have you encouraged the patient to read their Open Notes? (n=671) <sup>b</sup>	180 (26.8)	N/A
Have you used Open Notes actively in treatment? (n=670) <sup>b</sup>	67 (10.0)	N/A
Psychiatric patients who read their Open Notes are more involved in their care. (n=635) <sup>d</sup>	125 (19.7)	.31
How often do you meet patients who have read their health record on paper? (n=651) <sup>e</sup>	24 (3.7)	N/A
<b>How many of your patients who have read their Open Notes have been offended? (n=627)<sup>f</sup></b>		
No patients	340 (54.2)	N/A
1-3 patients	247 (39.4)	N/A
4-10 patients	33 (5.3)	N/A
11 or more patients	7 (1.1)	N/A
<b>How often do patients contact you or your department with questions about the contents of their Open Notes? (n=675)<sup>f</sup></b>		
I do not know any patients who have contacted me or my unit about this	316 (46.8)	N/A
Less than once a month	322 (47.7)	N/A
1-3 times a month	31 (4.6)	N/A
1-6 times a week	4 (0.6)	N/A
Daily	2 (0.3)	N/A
<b>How often are patients opposed to the contents of their Open Notes? (n=674)<sup>f</sup></b>		
I do not know any patients who have contacted me or my unit about this	325 (48.2)	N/A
Less than once a month	286 (42.4)	N/A
1-3 times a month	57 (8.5)	N/A
1-6 times a week	4 (0.6)	N/A
Daily	2 (0.3)	N/A
<b>How often do patients contact you or your department and demand that the contents of their Open Notes should be changed? (n=667)<sup>f</sup></b>		
I do not know any patients who have contacted me or my unit about this	398 (59.7)	N/A
Less than once a month	244 (36.6)	N/A
1-3 times a month	22 (3.3)	N/A
1-6 times a week	2 (0.3)	N/A
Daily	1 (0.1)	N/A
<b>How often do patients contact you or your department because they found significant errors in their EHR<sup>g</sup>? (n=675)<sup>f</sup></b>		
I do not know any patients who have contacted me or my unit about this	444 (65.8)	N/A
Less than once a month	210 (31.1)	N/A
1-3 times a month	18 (2.7)	N/A
1-6 times a week	3 (0.4)	N/A

Survey item	Responses, n (%)	P value
Daily	0	N/A

<sup>a</sup>Respondents indicating “yes.” It was also possible to answer “no.”

<sup>b</sup>Respondents indicating “yes.” It was also possible to answer “no” or “not relevant.” We did not conduct a chi-square test on these questions due to the answer options.

<sup>c</sup>N/A: not applicable.

<sup>d</sup>Respondents indicating “somewhat agree” or “agree” on a 4-point scale, with response options “disagree,” “somewhat disagree,” “somewhat agree,” and “agree.”

<sup>e</sup>Respondents indicating that they to “a large extent” or “a very large extent” agree. It was also possible to choose the options to “a little extent,” “not at all,” or “not relevant.” We did not conduct a chi-square test on this question due to the answer options.

<sup>f</sup>We did not conduct a chi-square test on this question due to the answer options.

<sup>g</sup>EHR: electronic health record.

**Table 4.** Psychiatric professionals’ views on how patient online access to the Open Notes Service in adult psychiatric care influenced clinical documentation.

Survey item	Responses, n (%)
I am less candid in my documentation after the implementation of Open Notes. (n=667) <sup>a</sup>	147 (22.0)
I spend significantly more time writing or dictating or editing notes after the implementation of Open Notes. (n=662) <sup>a</sup>	117 (17.7)
When I write in Open Notes, I am aware that I have to do a confidentiality check because the patient can immediately read what I have written. (n=664) <sup>a</sup>	231 (34.8)
Do you use the Specific Information template in the health record to write information that is hidden from the patient in their Open Notes? (n=667) <sup>a</sup>	43 (6.4)

<sup>a</sup>Respondents indicating “yes.” It was also possible to answer “no” and “not relevant.” We did not conduct a chi-square test on these questions due to the answer options.

## Open Notes in the Future

Considering the continuous development and changes in the technical prerequisites of the Open Notes Service in Sweden, we found it of interest to ask the HCPs about their views on the future development of Open Notes. Approximately one-third (245/668, 36.7%) disagreed with the statement “In the future, patients should be able to write a divergent opinion that is stored in connection to the HCP’s note in the health record.” Almost as many, 33.9% (226/668), of the respondents agreed with the statement, and 29.5% (197/668) reported that they did not have an opinion. Doctors (57/96, 59%) disagreed with the statement to a higher degree than the other professional groups. Furthermore, 79 of 699 HCPs (11.3%) responded with free text to the question “Do you have any suggestions to improve Open

Notes, to make the service more useful to patients and health care providers?” Here are some examples of the suggestions: HCPs should be able to sign a note in the health record with an identification number instead of name in order to feel safer; HCPs should be notified that a patient has read his or her Open Notes; HCPs should be able to decide when a note should be visible online. The HCPs also stated that there should be more education and information about the service for both the employees and the patients, and that it should be possible for patients and their relatives to write their views of problems in the health record. However, there were also respondents who suggested that the service should be shut down, and that the health record had primarily been a tool for the HCPs in their work in the past and that it should have remained that way.

**Table 5.** Psychiatric professionals' views on how patient online access to the Open Notes Service in adult psychiatric care influenced work conditions, and the results of the chi-square test for some of these items.

Survey item	Responses, n (%)	P value
Medical care is delivered more efficiently after the implementation of Open Notes. (n=616) <sup>a</sup>	74 (10.6)	.04
Patient satisfaction has improved after the implementation of Open Notes. (n=606) <sup>a</sup>	80 (13.2)	.02
Oral reporting between staff has increased since the implementation of OpenNotes. (n=641) <sup>a</sup>	72 (11.2)	.009
Patient care is safer after the implementation of Open Notes. (n=606) <sup>a</sup>	141 (23.3)	.86
Patient online access to their Open Notes contributes to health care on equal terms for all patients. (n=640) <sup>b</sup>	119 (18.6)	.71
Patient online access to their Open Notes in adult psychiatry influences the relationship between the different professions working there. (n=638) <sup>b</sup>	63 (9.9)	.48
Patient online access to their Open Notes in adult psychiatry influences the relationship between the patient and your profession. (n=642) <sup>b</sup>	95 (14.8)	<.001
Patient online access to their Open Notes in adult psychiatry influences the risk for me to be subjected to threat and violence. (n=639) <sup>c</sup>	146 (22.8)	N/A <sup>d</sup>
Patient online access to their Open Notes in adult psychiatry influences the risk for me to be reported to the Patients Advisory Committee. (n=635) <sup>c</sup>	145 (22.8)	N/A
Patient online access to their Open Notes in adult psychiatry influences the risk for me to be reported to the Health and Social Care Inspectorate. (n=631) <sup>c</sup>	103 (16.3)	N/A
In the future, patients should be able to write a divergent opinion that is stored in connection to the HCP's <sup>e</sup> note in the health record. (n=668) <sup>f</sup>	226 (33.9)	N/A
Patient online access to their Open Notes in adult psychiatry is generally a good idea. (n=650) <sup>g</sup>	239 (36.8)	.005

<sup>a</sup>Respondents indicating "yes". It was also possible to answer "no".

<sup>b</sup>Respondents indicating that agree to "a large extent" or "a very large extent." It was also possible to choose the options to "a little extent" or "not at all."

<sup>c</sup>Respondents indicating that "the risk will increase." It was also possible to answer "the risk will not change," "the risk will decrease," and "not relevant." We did not conduct a chi-square test on these questions due to the response options.

<sup>d</sup>N/A: not applicable.

<sup>e</sup>HCP: health care professional.

<sup>f</sup>Respondents who answered "somewhat agree" or "agree" on a 4-point scale, with response options "disagree," "somewhat disagree," "somewhat agree," and "agree." It was also possible to answer "no opinion."

<sup>g</sup>Respondents who answered "somewhat agree" or "agree" on a 4-point scale, with response options "disagree," "somewhat disagree," "somewhat agree," and "agree."

### Comparison Between Results From the Baseline Survey and the Postimplementation Survey

Table 6 presents an overview of the results from the 2 surveys that are comparable with each other. Part 1 of this report shows detailed information about the responses from the baseline survey [1], and this paper reports detailed information about the responses from the postimplementation survey above.

The general tendency in the comparisons is that approximately half as many respondents in some way agree with the statements in the postimplementation survey as in the baseline survey. However, there are some exceptions. The first 4 statements in the changes in practice section show that many respondents in the baseline survey expected that patients would be more active in different ways when they had read their Open Notes. The results from the second survey, however, show that very few

patients contacted the HCPs with questions, requested changes to the content, found significant errors, or opposed what was written in the notes. Another comparison that does not follow the general tendency is the statement about patients being offended. The results from the 2 surveys are almost the same, but it is important to note that it was unusual that the respondents met patients who were offended. The more detailed results in Table 3 show that most of these HCPs stated that they had met 1 to 3 patients who were offended. Another result that is almost the same in both surveys is that Open Notes contributed to health care on equal terms for all patients: respondents in both surveys agreed with this statement to the same extent. Yet another difference can be found in the last statement in Table 6 (Open Notes in adult psychiatry is generally a good idea), where the percentage was higher in the postimplementation survey than in the baseline survey.

**Table 6.** Comparison between results from the baseline survey and the postimplementation survey.

Survey item	Baseline <sup>a</sup> , %	Postimplementation, %
<b>Influence on patients</b>		
Patients will/did understand their health and medical conditions better.	30.1 <sup>b</sup>	15.2 <sup>b</sup>
Patients will/did remember the plan for their care better.	48.2 <sup>b</sup>	20.3 <sup>b</sup>
Patients will/did take better care of themselves.	11.2 <sup>b</sup>	5.7 <sup>b</sup>
Patients will be/are more likely to take medications as prescribed.	18.5 <sup>b</sup>	8.0 <sup>b</sup>
Patients will/did feel more in control of their health care.	44.4 <sup>b</sup>	23.5 <sup>b</sup>
Patients will be/are better prepared for visits.	31.1 <sup>b</sup>	16.6 <sup>b</sup>
Patients will/did trust me more as their caregiver.	27.4 <sup>b</sup>	14.2 <sup>b</sup>
Patients will/did worry more.	58.1 <sup>b</sup>	33.5 <sup>b</sup>
Patients will/did find the notes to be more confusing than helpful.	52.7 <sup>b</sup>	24.6 <sup>b</sup>
<b>Changes in practice</b>		
Patients will/did contact me or my practice with questions about their notes.	68.7 <sup>b</sup>	5.5 <sup>c</sup>
Patients will/did find significant errors in the notes.	41.9 <sup>b</sup>	3.1 <sup>c</sup>
Patients will/did oppose with what is written in their notes.	63.2 <sup>b</sup>	9.4 <sup>c</sup>
Patients will/did request changes to the content of notes.	52.4 <sup>b</sup>	3.7 <sup>c</sup>
Patients will be/are offended.	44.5 <sup>d</sup>	45.8 <sup>e</sup>
Visits will take/take longer.	35.1 <sup>d</sup>	14.5 <sup>f</sup>
I will spend/spend time addressing patient questions outside of visits.	40.6 <sup>d</sup>	18.0 <sup>f</sup>
<b>Changes in clinical documentation, work condition, and care delivery</b>		
I will be/am less candid in my documentation.	40.5 <sup>d</sup>	22.0 <sup>f</sup>
I will spend/spend more time writing/dictating/editing notes.	41.5 <sup>d</sup>	17.7 <sup>f</sup>
Medical care will be/is delivered more efficiently.	21.1 <sup>f</sup>	10.6 <sup>f</sup>
Patient satisfaction will/has improve(d).	29.5 <sup>f</sup>	13.2 <sup>f</sup>
Patient care will be/is safer.	36.3 <sup>f</sup>	23.3 <sup>f</sup>
Open Notes will contribute/contribute to health care on equal terms for all patients.	17.3 <sup>g</sup>	18.6 <sup>g</sup>
Open Notes will influence the relationship between professions.	20.6 <sup>g</sup>	9.9 <sup>g</sup>
Open Notes will influence the relationship between the patient and your profession.	35.6 <sup>g</sup>	14.8 <sup>g</sup>
Open Notes will influence the risk for me to be subjected to threat and violence.	45.6 <sup>h</sup>	22.8 <sup>h</sup>
Open Notes will influence the risk for me to be reported to the Patients Advisory Committee.	42.2 <sup>h</sup>	22.8 <sup>h</sup>
Open Notes will influence the risk for me to be reported to the Health and Social Care Inspection.	32.2 <sup>h</sup>	16.3 <sup>h</sup>
Open Notes in adult psychiatry is generally a good idea.	27.7 <sup>b</sup>	36.8 <sup>h</sup>

<sup>a</sup>Published previously in part 1 [1].

<sup>b</sup>Percentage of respondents who indicated “somewhat agree” or “agree.”

<sup>c</sup>Percentage of respondents who indicated “1-3 times a month,” “1-6 times a week” or “daily.”

<sup>d</sup>Percentage of respondents who indicated that they were “moderately concerned,” “very concerned,” or “so concerned that, I do not want Open Notes in psychiatric care at all.”

<sup>e</sup>Percentage of respondents who indicated “1-3 patients,” “4-10 patients,” or “11 or more patients.”

<sup>f</sup>Percentage of respondents who indicated “yes.”

<sup>g</sup>Percentage of respondents who indicated that they to “a large extent” or “a very large extent” agree.

<sup>h</sup>Percentage of respondents who indicated that “the risk will increase.”

## Discussion

### Principal Findings

To our knowledge, the previously published paper, with resulted from the preimplementation baseline survey [1], was the first of its kind to examine how HCPs working in adult psychiatric care in a universal health care setting anticipated how Open Notes would influence their work and their patients. Accordingly, our postimplementation survey is the first follow-up survey of its kind to examine how HCPs working in this setting experienced the influence of Open Notes on their patients, their work, and care delivery. The 2 surveys make it possible to compare and discuss the differences between the expectations and the experiences of the implementation of the Open Notes Service.

One of the main arguments for Open Notes is that the service will increase patient participation and, hence, patient empowerment. The rhetoric and expectations from politicians and key actors are, for example, that patients who read their notes will take better care of themselves, that they will feel more in control of their care, and that they will be better prepared for appointments [2]. Thus, in the 2 surveys, we asked the HCPs in adult psychiatric care about their expectations and experiences of both the benefits and risks for their patients. Comparison of the results (Table 6) shows that both hopes about benefits and worries about risks for patients were higher before the Open Notes implementation than after. Thus, Table 6 shows that the proportion of respondents who agreed with the statements about how Open Notes would influence patients in the postimplementation survey is approximately half as large as in the baseline survey [1]. There were other differences between the 2 surveys: doctors, psychologists, and medical secretaries were in many cases more negative toward the service than were nurses and assistant nurses in the baseline survey. In the postimplementation survey, though, there were fewer such differences in opinions between the various professional groups. The respondents in the postimplementation survey also stated that, in general, there had been little actual impact on their practice in terms of longer appointments or more questions from patients about the contents of their health records.

One explanation for these results may be that many patients in adult psychiatry in Region Skåne did not read their Open Notes. Almost one-third of the respondents in the baseline survey [1] thought that 50% or more of their patients would read them online. However, the results of the postimplementation survey show that very few HCPs met patients who mentioned they had read their Open Notes. One reason may be that little or no information had been given to patients in adult psychiatric care in Region Skåne about the service. This is different from other countries: patients in Sweden, for example, do not receive an email from their HCP notifying them that there is a new online note to read. Thus, Swedish patients in Region Skåne may not be aware that they are able to read notes from a psychiatry appointment online. Another explanation could be that some

patients had read their notes but neglected to mention it to the HCPs.

The introduction of Open Notes in Sweden is widespread. We wondered whether the Region Skåne HCPs in our postimplementation survey had any thoughts about how the service could influence different groups of patients in psychiatric care. We asked them whether they thought that Open Notes benefited any specific group or might be particularly problematic for others. The most common free-text answer about which patients would benefit was everyone, followed by I do not know and no one. They thus responded with general attitude statements about the service, rather than mentioning specific patient groups. This indicates that some respondents seemed to be either generally positive toward the Open Notes Service or generally negative toward it. This observation is strengthened by the fact that these free-text answers, which can be described as almost ideological statements, also appeared among the other free-text answers. However, research showed that employees who are dissatisfied are more likely to answer open-ended questions [10], and this should be taken into consideration. Still, such ideological standpoints may influence how professionals act in their daily work. However, the pattern was very different in the answers to the question about Open Notes being particularly problematic for some groups of patients. The 2 most common answers to this free-text question were “patients with a personality disorder” and “patients with psychosis;” “patients with paranoia” was the third most common answer. This result points out a delicate problem: all patients, regardless of diagnoses, have the same right to read their health records online. However, the answers from the HCPs indicate that the transparency could be more problematic for some patients than for others. These opinions could influence how HCPs who meet patients with these diagnoses act in their work. This can be connected to the results from both surveys, which indicate that Open Notes might change clinical documentation. We cannot but wonder whether the HCPs treating patients with the 3 diagnoses above were overrepresented in the group of HCPs who claimed that they became less candid in their documentation; further research is needed to clarify this question.

One of the most interesting results in the baseline survey was that approximately 60% of both doctors and psychologists were worried that they would be less candid in their documentation after the implementation of Open Notes. Findings from studies in the United States indicate the same concerns, with concerns that the increased transparency would “water down” the content in the records [11]. Mental health clinicians in the United States also claimed that they were more careful about what they wrote to protect themselves and their patients [12]. The results from the postimplementation survey indicate that there have been changes in clinical documentation: over 60% of the psychologists and nearly 40% of the doctors stated that they were less candid in their documentation after the implementation of Open Notes. This indicates that there may be a risk for watered down health records in adult psychiatry, and it is

important to gain a greater understanding of when these situations occur and why there are HCPs who changed their way of writing entries in the health record after the implementation of Open Notes. Yet another perspective is that less candid information in the health records could negatively influence both the work of the HCPs and the overall aim to have more informed and active patients. It may become more difficult for HCPs to deliver safe care with high quality if information is missing in the health records, and the vision of increased patient participation can be harder to fulfill if important information is withheld from a patient because of less candid documentation.

Furthermore, patient safety is an important part of care, and new ways of delivering care may influence patient safety in different ways. An overall and important intention in health care is to increase patient safety; hence, an interesting question is whether Open Notes does that. Table 6 shows that 36.3% of the HCPs in the baseline survey thought that implementation would increase patient safety. Among the respondents who answered the postimplementation survey, though, only 23.3% stated that patient safety increased after implementation. These results, together with the rest of the results, indicate that the enhanced transparency may influence patient safety in different ways. Thus, there is a need for more knowledge about the influence of the Open Notes Service on patient safety.

Finally, it is important to note that an implementation of such a service as Open Notes can never be described as completed. There will always be new patients and new employees who will have to learn to use the service, and the prerequisites of the technology will change due to new regulations and new, more up-to-date electronic health records. Consequently, there will always be old users who will have to learn to manage new technical prerequisites, and new users who will have to learn to manage the existing ones. In addition, there will always be patients who never read their Open Notes for different reasons. Being aware of all these circumstances, we decided that the second survey would be distributed one and a half years after the implementation of Open Notes in adult psychiatric care, so that the employees would have had considerable experience of both using the service and meeting patients who had read their records online. Still, many employees stated that they never met a patient who said that he or she had done so, but one important result from the postimplementation survey is that the employees acted as if the patients had read their notes online. Thus, Open Notes seems to have changed the clinical documentation irrespective of whether the patients were active.

### Limitations

This study has several limitations. First, we had no way of knowing whether the same individuals answered the baseline survey and the postimplementation survey. It was not possible to send the survey to the same individuals because this was a full population study, and during the one and a half years between the 2 surveys, new employees started working in adult psychiatric care and others left. Thus, it is possible to compare the results from the 2 surveys on a group level, but we do not know whether and how individual employees did or did not change their opinion about Open Notes. Second, the response

rate to the Web questionnaire was 27.73%. This is similar to the response rate in the baseline survey of 28.86% [1]. The explanations for the response rate may be the same as in the previous survey: some employees may have been absent during the time that it was possible to answer the survey, and the implementation of Open Notes may have been a sensitive topic that could have influenced the response rate negatively. A third limitation, unfortunately, is that there were no separate statistics for the log-ins by patients in psychiatric care. Fourth, we were not able to conduct chi-square tests on as many answers in the postimplementation survey as in the baseline survey. This was due to the answer options “not relevant” and “I do not know” for some of the questions. Thus, it was not possible to carry out statistical analyses to examine the relationships between professionals and their attitudes to the Open Notes Service to the same extent as in the first survey.

### Conclusions

Given the expansion of the use of Open Notes in psychiatry [13,14], there is a need for more knowledge about how the technology influences both patients and HCPs, since the technology, at least in Sweden, primarily was developed and deployed for nonpsychiatric settings. Consequently, some HCPs have worried that Open Notes in psychiatry would put both patients and themselves at risk [1,14]. Through the analysis and comparison of the baseline survey and the postimplementation survey, we have been able to both provide more knowledge to this important area and identify areas where even more is needed.

First, the results of this study show that most HCPs who answered the postimplementation survey did not experience that patients in adult psychiatric care were more involved in their care after the implementation of Open Notes. Thus, it would be interesting to study the patients' views of Open Notes and compare the results with those from this study.

Second, the postimplementation survey results also indicate that the clinical documentation changed after the implementation of Open Notes. This implies that a technical solution aimed at the patients may change documentation patterns in a way that neither increases care safety nor establishes good conditions for HCPs to deliver high-quality care. This might be particularly problematic, as doctors and psychologists were the 2 main groups that claimed that they became less candid in their documentation after the implementation of Open Notes. This also indicates a need for more knowledge about the actual influence of Open Notes in terms of changes in the content of health records.

Third, the results indicate that it may be important to prepare HCPs before an implementation of Open Notes, especially in medical areas where the service can be considered sensitive. This is an actual issue at the moment in Region Skåne, since the plan is that patients in forensic psychiatry, parents of patients in child and youth psychiatry who are younger than 13 years, and adolescents who are older than 16 years will be able to read health records from psychiatry online from the fall of 2018.

Fourth, further research is needed to investigate the influence of Open Notes in psychiatric settings over time, especially

regarding changes in clinical documentation. There is a need for studies that focus on how Open Notes influence patient safety in both psychiatric and nonpsychiatric settings. Research is also needed on how Swedish patients, especially in psychiatric care, use their Open Notes.

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## Conflicts of Interest

None declared.

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## Abbreviations

**EPSA:** eHealth Services' Impact on the Working Environment of Health Professionals  
**EHR:** electronic health record  
**HCP:** health care professional

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Original Paper

# Public Attitudes Toward Guided Internet-Based Therapies: Web-Based Survey Study

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## Abstract

**Background:** Internet interventions have been proposed to improve the accessibility and use of evidence-based psychological treatments. However, little is known about attitudes toward such treatments, which can be an important barrier to their use.

**Objective:** This study aimed to (1) determine attitudes toward guided internet interventions, (2) assess its acceptability compared with other internet-based formats, and (3) explore predictors of acceptance.

**Methods:** A convenience-sample Web-based survey (N=646) assessed attitudes toward guided internet therapies (ie, perceived usefulness and helpfulness, and advantage relative to face-to-face therapy), preferences for delivery modes (ie, e-preference: guided internet interventions, unguided internet interventions, or videoconferencing psychotherapy), and potential predictors of attitudes and preferences: sociodemographics, help-seeking-related variables, attachment style, and perceived stress.

**Results:** Although most participants perceived internet interventions as useful or helpful (426/646, 65.9%), a few indicated their advantage relative to face-to-face therapy (56/646, 8.7%). Most participants preferred guided internet interventions (252/646, 39.0%) over videoconferencing psychotherapy (147/646, 22.8%), unguided internet interventions (124/646, 19.2%), and not using internet interventions (121/646, 18.8%; missing data: 1/646, 0.2%). Attachment avoidance and stress were related to e-preference (all  $P < .05$ ). Moreover, preference for therapist-guided internet interventions was higher for individuals who were aware of internet-based treatment ( $\chi^2_6 = 12.8$ ;  $P = .046$ ).

**Conclusions:** Participants assessed therapist-guided internet interventions as helpful, but not equivalent to face-to-face therapies. The vast majority (523/646, 81.0%) of the participants were potentially willing to use internet-based approaches. In lieu of providing patients with only one specific low-intensity treatment, implementation concepts should offer several options, including guided internet interventions, but not limited to them. Conversely, our results also indicate that efforts should focus on increasing public knowledge about internet interventions, including information about their effectiveness, to promote acceptance and uptake.

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**KEYWORDS**

mental health; eHealth; attitude to computers; patient preference; cognitive therapy; acceptability of health care; stress, psychological; object attachment

## Introduction

### Background

With 12-month prevalences ranging across countries from 9.8% to 19.1% [1], mental health disorders are widespread. Mental health disorders constitute one of the leading causes of disability [2] and are associated with low quality of life, increased risk of developing chronic physical conditions and related mortality [3,4], and an immense economic burden leading to productivity losses and substantial societal costs [5,6]. Yet fewer than half of individuals affected by mental health disorders are detected and receive professional treatment [7]. Untreated mental illness is estimated to account for 13% of the total global burden of disease [8]. Structural barriers such as limited access to treatment have been named as a reason for the insufficient uptake of individuals with mental health disorders [7]. Additionally, attitudinal barriers, such as personal stigma [9] or preferring to solve problems on one's own, may be decisive in explaining insufficient treatment rates [10].

Using the internet as a delivery mode for self-help treatments has thus been discussed as a promising chance to inform the dissemination of professional treatment, as electronic mental health services (eMHSs) allow for mass deliverance of anonymous, low-threshold treatment options that may reach individuals for whom traditional face-to-face approaches are not an option [11,12]. In recent years, a large number of randomized controlled trials have shown that internet interventions can effectively treat various mental health disorders, such as depression [13,14], anxiety [15-17], insomnia [18], alcohol use disorder [19], comorbid mental health problems in chronic somatic diseases [20,21], and psychosomatic disorders [22]. The largest evidence base exists for the effectiveness of guided interventions [22,23], and research has shown that such approaches can be effective when delivered under routine care conditions [24-26]. In addition to guided or unguided internet interventions, videoconferencing psychotherapy (VCP) is considered as a further option to overcome regional barriers for a variety of patient populations [27]. However, the poor adoption of eMHSs worldwide indicates that low acceptability and intention to use might constitute a barrier in reaching the full potential of internet-based approaches (cf, [28-32]).

### Public Acceptance Indicators for E-Mental Health Services

Determinants of intentions to use eMHSs are not well understood [28,29]. Yet there are indicators commonly discussed as influential for help-seeking intentions and acceptance of eMHSs, such as attitudes [33-35] and "e-preferences" [28].

#### Attitudes

Positive public attitudes could be an indicator of acceptance and adoption of internet interventions. Generally, attitudes can be characterized as an aggregate of subjective assessments about an object, ranging, for example, from harmful to helpful [36].

The theory of planned behavior [37] proposes that attitudes, among other factors, shape individuals' intentions, which then lead to a certain behavior. Individuals' personal expectancies are assumed to shape such attitudes and to thereby influence

behavioral intentions [37]. In accordance with the unified theory of acceptance and use of technology [38], performance expectancy (ie, how useful an individual perceives an intervention to be for reaching a specific goal) might thus play an important role in the adoption and acceptance of internet interventions [39,40] and provide a guideline in overcoming the limitations in the acceptability of eMHSs [34,39,41,42].

#### E-Preference

Technology acceptance of eMHS can be operationalized by intentions to use these services [39], which can be affected by the individual preference for a specific delivery mode [28]. Treatment preference means to choose a treatment in favor of an alternative option. Research evidence suggests that considering patients' preferences for a psychological treatment is associated with improved clinical outcomes [43]. However, little is known about preferences for specific delivery modes, such as therapist-guided treatment, unguided internet interventions, and VCP, and their impact on the willingness to use eMHSs. Some studies identified a preference for traditional (face-to-face) over internet-based treatment (eg, [28,29,31,44-47]) and for therapist-guided over unguided eMHSs (eg, [28,29,33]).

#### Determinants of Attitudes Toward and Preferences for Internet-Based Therapies

Potential determinants of attitudes and preferences for eMHS include sociodemographics such as age, region [45], or professional background [48-50]. Regarding health-related and help-seeking variables, using the internet for mental health information [45,51], previous use of eMHSs [31], a history of mental illness and help-seeking experience such as undergoing psychotherapy [29], knowledge about eMHSs or awareness of electronic therapies ("e-awareness") [33,41,42], personality traits [28], and perceived stress [42,52] have been reported as predictors. Regarding the role of symptom severity, a recent study [12] illustrated a help-seeking behavior paradox in students, where individuals' readiness to seek help from face-to-face services declined with increased perceived stress. In contrast, the same study also demonstrated a positive association between distress and seeking help online.

Attachment style may be a further predictor of eMHS uptake [52], since attachment theory [53] has been applied to predict intentions to use face-to-face help services (eg, [54]). Based on early infant-caregiver interactions, relatively stable internal working models of the self and others in terms of mental representations of close relationships are built. These implicit expectations regarding self-efficacy and reliance on significant others in stressful situations are manifested in adulthood [53]. Adult attachment style can play a role in preferences and attitudes toward seeking help in the context of emotionally relevant relationships, such as in mental health care [52,54]. While a secure attachment style (low attachment anxiety and avoidance; ie, positive models of the self and others) is associated with functional coping strategies, insecure attachment styles were identified as a global vulnerability factor for mental health [55,56] and are related to altered stress responses, symptom reporting, and less use of health care resources [57,58]. However, the role of attachment styles in the readiness to use

eMHSs remains unclear [52], especially concerning different delivery modes of internet interventions that vary in the degree of human support.

Taken together, the identification of determinants of attitudes toward and preferences for eMHSs is at an early stage [34]. This study addressed this research gap.

## Objective

The purpose of this study was to (1) explore attitudes toward guided internet interventions and to (2) assess the acceptability of guided internet interventions compared with other formats of internet-based delivery (ie, e-preference: unguided self-help interventions and VCP vs not using eMHSs in case of emotional problems). Another goal was to (3) identify determinants of the public acceptability of eMHSs by exploring associations between attitudes toward guided internet interventions, preferences for a specific delivery mode of eMHSs, and participant characteristics (ie, sociodemographics, help-seeking-related variables, attachment style, and perceived stress).

## Methods

### Study Design and Participants

We conducted a cross-sectional Web-based survey using a quasi-experimental study design. Data were collected between November 2015 and June 2016 using Unipark software (Enterprise Feedback Suite survey, version 10.6, Questback). We obtained a convenience sample (N=646) via the virtual laboratory and Moodle of the University of Hagen, Hagen, Germany, and social media websites (Facebook, Facebook Inc; and Xing, Xing AG). No ethical approval was required. Inclusion criteria were self-reported age over 18 years and written informed consent. Psychology students could receive credits for their participation.

**Textbox 1.** Preference for internet therapies illustrated by case vignettes. Options 1-3: internet therapies differentiated by the degree of professional support. The instruction was adapted and translated from German.

Internet-based psychotherapies include a broad spectrum of types of treatments for relatively well treatable, mild to moderate forms of depression and anxiety disorders. The following 3 examples illustrate distinct types of internet therapies:

1. Unguided internet-based self-help treatment programs: The patient follows a Web-based, structured self-help treatment program, including problem-specific tasks, exercises, and tutorials, via mobile phone or computer for several weeks without individual feedback.
2. Therapist-guided internet-based self-help treatment programs: The patient follows a Web-based, structured self-help treatment program with therapist guidance. Communication with the therapist consists of text-based feedback via email or chat provided on demand.
3. Videoconferencing psychotherapy: The communication is mediated by a webcam. As with face-to-face psychotherapy, the treatment takes place within specified sessions with immediate verbal and nonverbal feedback.

In case of emotional problems, which of the described interventions would you most likely personally use? Please choose the internet therapy form you prefer most based on your current expectations.

1. Unguided internet-based self-help treatment
2. Therapist-guided internet-based self-help treatment
3. Videoconferencing psychotherapy
4. I would not use any internet therapy at all

## Measures

### Attitudes Toward Guided Internet Interventions

We used a modified 17-item version of an e-therapy attitudes measure (ETAM) [42] containing statements about typically cited benefits of internet therapy and its comparability with face-to-face psychotherapy, as well as subjective beliefs (eg, about data security). Participants were asked to rate their agreement with each statement on a 5-point rating scale ranging from 0 (“strongly disagree”) to 4 (“strongly agree”). To ensure comparability, participants were instructed to rate items regarding guided internet interventions (see [Textbox 1](#)). Based on previous exploratory factor analysis, we identified two factors, which we termed perceived usefulness and helpfulness, and advantage relative to face-to-face therapy. [Multimedia Appendix 1](#) provides detailed information about the exploratory factor analysis. For classification of attitudes, we used predefined cutoffs in line with previous work using the ETAM [41,42]: mean scores <1.5 (a median score of 0 or 1) were defined as negative, values between 1.5 and 2.49 (median score of 2) as neutral, and scores ≥2.5 (median scores of 3 or 4) as positive attitudes toward guided internet interventions. Cronbach alpha was excellent in this survey (alpha=.92).

### Preference for Internet Interventions (E-Preference)

We operationalized preference (see [Textbox 1](#)) by assessing help-seeking intentions for different delivery modes of internet interventions (e-preference, options 1-3) in contrast to the disinclination to use internet interventions in case of emotional problems (non-e-preference, option 4).

### Determinants of Attitudes Toward and Preferences for Internet Interventions

#### Sociodemographics and Help-Seeking-Related Variables

Sociodemographic characteristics were sex, age, marital status, native language, region, country of residence, educational level, employment status, and work in health care or the social sector.

We investigated participants' awareness of electronic therapy (e-awareness) by asking them whether they had ever heard or read about internet-based therapies. We also asked participants to assess their subjective health status, experiences with online counseling or conventional inpatient or outpatient psychotherapy, and their frequency of seeking health information online.

### Attachment Style

We considered attachment style as a potential determinant of the acceptance of guided internet interventions, since previous work indicated a connection between individual needs for interpersonal proximity versus distance in case of emotional problems and help-seeking intentions (cf, [54]). We measured adult attachment using the Experiences in Close Relationships-Relationship Structures questionnaire [59] 9-item global version to assess attachment anxiety and avoidance [60]. Participants were asked to rate the extent to which they believed each statement best described their feelings about close relationships on a 7-point Likert scale ranging from 1 ("strongly disagree") to 7 ("strongly agree"). The intercorrelation of dimensions ( $\rho_{(646)}=.272, P<.001$ ) was comparable with other studies [61]. Cronbach alpha was good for attachment avoidance ( $\alpha=.88$ ) and excellent for attachment anxiety ( $\alpha=.91$ ).

### Assessment of Stress Perceptions

#### Current Stress Level

We used a visual analog scale [62] to assess current perceived stress level on a scale with 2 end points: 0 ("not at all") and 10 ("maximum").

#### Perceived Stress (Past Month)

To measure stress perceptions during the past 4 weeks, we used the Perceived Stress Questionnaire 20-item short version (PSQ-20) [63]. Participants were asked to indicate how often statements applied to themselves on a 4-point Likert scale ranging from 1 ("almost never") to 4 ("usually"). Cronbach alpha was poor ( $\alpha=.55$ ).

### Procedure

After entering the Web-based survey, participants were provided with the study information and consent form. Next, they were asked sociodemographic and help-seeking questions. Then, preference for specific forms of internet interventions, attitudes toward guided internet interventions, stress perceptions, and attachment style were assessed. The average completion time ranged from 10 to 15 minutes.

### Statistical Analysis

We considered only completed surveys for data analyses. To ensure data quality, data validation checks were performed independently by 2 researchers prior to the statistical analyses. Descriptive analyses were used to classify attitudes toward and preference for a specific delivery mode of internet therapies. Regarding predictors of attitudes, we explored differences in variance (analysis of variance) in attitudes (overall mean score) based on sociodemographics, health variables, and e-preference. Due to the scarce theory base and questionable multivariate normal distribution, we used Spearman rank correlation ( $\rho$

coefficient) instead of multiple regression analysis to identify associations between attitudes, attachment style, and stress perceptions. Moreover, we explored differences using 1-way analysis of variance and Pearson chi-square tests in preferences based on the same predictors as for attitudes. Pairwise comparisons (post hoc tests) to examine mean differences ( $M_{diff}$ ) were conducted using Bonferroni adjustments in case of variance homogeneity (Levene test,  $P>.05$ ) or Dunnett *C* test in case of variance heterogeneity. Statistical tests for significance (2-tailed hypotheses with alpha level of .05) were performed using IBM SPSS version 24 (IBM Analytics).

## Results

### Descriptive Analyses

Of 1300 respondents who accessed the platform, 778 provided informed consent, with 1 person declining and thus being excluded. We consequently analyzed the responses of 646 respondents who completed the survey. Tables 1 and 2 summarize the sample's characteristics.

### Attitudes Toward Guided Internet Interventions

Analysis of attitudes toward guided internet interventions indicated an overall moderate acceptance (ETAM overall mean score, Table 3). As Table 4 shows, descriptive analyses further showed that, although most participants (426/646, 65.9%) perceived internet approaches as useful or helpful, only a few participants (56/646, 8.7%) also indicated that guided internet-based approaches had a relative advantage over or comparability with conventional face-to-face approaches.

Overall, participants agreed with 7 of the 17 positive statements about internet interventions made in ETAM items (Table 3). Those positively attributed beliefs about internet therapies involved modernity (item 1), compatibility with everyday life (item 3), accessibility (item 5), coverage of costs by health insurance providers (item 6), helpfulness (item 12), anonymity (item 14), and a chance to get help earlier (item 15).

Furthermore, 7 of the 17 items were classified as negative. Participants rather disagreed with the possibility of replacing face-to-face therapies (item 2), the equivalence of delivery modes (item 4), comparability of effectiveness (item 7) and therapeutic relationships (item 8), preference for internet therapy over face-to-face therapy (item 11), data security (item 13) and suitability for diverse populations (item 17).

Participants classified 3 items as neutral or undecided. These statements addressed internet therapies as an alternative to face-to-face therapies (item 9), willingness to use internet therapies (item 10), and the occurrence of misunderstandings (item 16).

### Preference for Different Delivery Modes

As Figure 1 shows, most respondents indicated that they preferred guided internet interventions (252/646, 39.0%) over VCP (147/646, 22.8%), unguided internet interventions (124/646, 19.2%), or no Web-based treatment (121/646, 18.8%; missing data: 1/646, 0.2%). Thus, the vast majority were "e-preferers" (523/646, 81.0%).

**Table 1.** Sociodemographic characteristics (N=646).

Variables	Data
<b>Age (years)</b>	
Mean (SD)	31.18 (10.08)
Range (median)	18-64 (29)
<b>Sex, n (%)</b>	
Female	493 (76.3)
Male	147 (22.8)
Other	3 (0.5)
Missing data	3 (0.5)
<b>Native language, n (%)</b>	
German	568 (87.9)
Bilingual including German	40 (6.2)
Other than German	37 (5.7)
Missing data	1 (0.2)
<b>Marital status, n (%)</b>	
Single	327 (50.6)
Married or living in a close relationship	288 (44.6)
Divorced or living separated	26 (4.0)
Other	3 (0.5)
Missing data	2 (0.3)
<b>Employment status<sup>a</sup>, n (%)</b>	
Employed	177 (27.4)
University student, part-time or full-time	345 (53.4)
Employee in training <sup>b</sup>	14 (2.2)
Self-employed	46 (7.1)
Unemployed	11 (1.7)
Parental leave	15 (2.3)
Retired	8 (1.2)
Current work incapability	3 (0.5)
Other employment (commentary section)	27 (4.2)
<b>Employment in health care or social sector, n (%)</b>	
No	493 (76.3)
Yes, in a therapeutic field	57 (8.8)
Yes, in a nontherapeutic field	96 (14.9)
<b>Education level attained, n (%)</b>	
No school certificate	3 (0.5)
Basic school qualification <sup>c</sup>	10 (1.5)
Secondary school ( <i>Mittlere Reife</i> ) <sup>d</sup>	57 (8.8)
German <i>Abitur</i> or <i>Fachabitur</i> <sup>e</sup>	329 (50.9)
University degree (Bachelor level)	86 (13.3)
University degree (Masters level)	143 (22.1)
Postgraduate or postdoctoral degree	9 (1.4)

Variables	Data
Other degree (commentary section)	9 (1.4)
<b>Country of residence, n (%)</b>	
Germany	585 (90.6)
Other country <sup>f</sup>	60 (9.3)
Missing data	1 (0.2)
<b>Region of residence, n (%)</b>	
Village or small town, with <5000 inhabitants	100 (15.5)
Provincial town, with 5000-19,999 inhabitants	99 (15.3)
Medium-sized city, with 20,000-100,000 inhabitants	124 (19.2)
Big city or metropolis, with >100,000 inhabitants	322 (49.8)
Missing data	1 (0.2)

<sup>a</sup>The main employment was requested (if respondents had multiple roles, they were asked to choose in which role they spent most of their working time at the time of participation in this survey).

<sup>b</sup>German dual system: occupational trainee or pupil (secondary education).

<sup>c</sup>Basic school qualification with usually 9 school years of education in Germany (German *Hauptschule*).

<sup>d</sup>Secondary school (German *Mittlere Reife*), or 10 years of education in Germany.

<sup>e</sup>German *Abitur* or *Fachabitur* with 12-13 years of education in Germany. This education is necessary to get access to a college or university.

<sup>f</sup>Most of the subgroup of non-Germany residents indicated they lived in Austria (35/646, 5.5%).

## Determinants of Attitudes

### Sociodemographic Variables

Attitudes and age were significantly and positively correlated ( $\rho_{(643)}=.079$ ,  $P=.045$ ), with older participants displaying more favorable attitudes than younger participants toward internet-based guided self-help. Unemployed participants (mean 2.30, SD 0.69) showed more positive attitudes than employees in training (mean 1.37, SD 0.37,  $M_{diff}$  0.93, SE 0.288, 95% CI 0.003-1.85). We found no significant differences in attitudes for sex, marital status, region, native language, education level, or work in the health care or social sector (all  $P>.05$ ).

### Help-Seeking-Related Variables

Frequency of seeking health information online was associated with differences in internet intervention attitudes ( $F_{4,641}=6.675$ ;  $P<.001$ ,  $\eta_p^2=.040$ ), with more positive attitudes reported by individuals who sought information weekly (mean 2.01, SD 0.61,  $M_{diff}$  -0.36, SE 0.112, 95% CI -0.67 to -0.04), several times a month (mean 2.11, SD 0.78,  $M_{diff}$  -0.45, SE 0.097, 95% CI -0.72 to -0.18), or rarely (mean 1.91, SD=0.59,  $M_{diff}$  -0.26, SE 0.080, 95% CI -0.48 to -0.04; all  $P<.05$ ) than by those who never did (mean 1.66, SD 0.59). This was not the case for participants who reported seeking information daily (mean 1.46, SD 0.99); both groups (never, daily) expressed rather negative attitudes. There was a significant positive correlation between attitudes toward guided internet interventions and perceived stress on the PSQ-20 ( $\rho_{(643)}=.092$ ,  $P=.020$ ). No significant differences in attitudes were identified for any of the other

help-seeking-related variables (eg, e-awareness, attachment style, all  $P>.05$ ).

## Determinants of E-Preference

### Sociodemographic Variables

We found no significant differences in e-preferences (preference for guided or unguided internet interventions and VCP) based on age, sex, marital status, region, native language, education level, employment status, or work in the health care or social sector (all  $P>.05$ ).

### Help-Seeking-Related Variables

E-awareness significantly predicted a preference for different forms of internet-based therapy ( $\chi^2_6=12.8$ ;  $P=.046$ ). Individuals who were aware of internet therapies (97/214, 45.5%) or not sure (40/87, 46.0%) were more likely to prefer guided internet interventions than were those who were not aware (115/343, 33.5%).

We found differences in e-preference based on experience with online counseling ( $\chi^2_3=13.8$ ;  $P=.003$ ); persons with experience were less likely to prefer unguided interventions (7/68, 10.6%) than were those without (117/578, 20.2%).

Experience with psychotherapy also predicted e-preference ( $\chi^2_9=21.6$ ;  $P=.01$ ). A preference for guided internet interventions was most common among persons without experience who were currently seeking a therapist (20/35, 57.1%) and persons with experience with psychotherapy (99/228, 43.4%). All subgroups were nonetheless most likely to prefer guided internet interventions.

**Table 2.** Sample characteristics (N=646).

Help-seeking-related variables	Data
<b>Subjective health status, n (%)</b>	
Healthy or relatively healthy	492 (76.2)
Acute illness	39 (6.0)
Chronic illness	83 (12.8)
Other (commentary section)	30 (4.6)
Missing data	2 (0.3)
<b>Experience with online counseling, n (%)</b>	
No, no experience with online counseling	578 (89.6)
Yes, experience with online counseling	67 (10.4)
Missing data	1 (0.2)
<b>Experience with psychotherapy<sup>a</sup>, n (%)</b>	
No, I have no experience and I have also no need for psychotherapeutic help	303 (46.9)
No, I have no experience, but I am seeking psychotherapeutic help from a therapist	35 (5.4)
Yes, I am in therapy	79 (12.2)
Yes, in the past (experience with psychotherapy)	228 (35.3)
Missing data	1 (0.2)
<b>Web-based health information use (frequency), n (%)</b>	
Daily	15 (2.3)
Several times a week	49 (7.6)
Several times a month	146 (22.6)
Rarely or occasionally	369 (57.1)
Very rare or never	67 (10.4)
<b>E-awareness (awareness of the existence of electronic therapies), n (%)</b>	
No (not aware)	343 (53.1)
Yes (aware)	214 (33.1)
Not sure	87 (13.8)
Missing data	2 (0.4)
<b>Attachment style (ECR-RS<sup>b</sup>), mean (SD), median, range</b>	
Attachment avoidance	3.61 (1.38), 3.50 (1.00-7.17)
Attachment anxiety	3.46 (1.77), 3.33 (0.00-7.00)
<b>Stress perceptions, mean (SD), median (range)</b>	
Current stress (visual analog scale)	5.67 (2.96), 6.0 (0-10)
Perceived stress (Perceived Stress Questionnaire 20-item short version)	47.00 (19.60), 46.67 (3.33-95.00)

<sup>a</sup>Experience with psychotherapy or current need or demand for professional psychological help.

<sup>b</sup>ECR-RS: Experiences in Close Relationships-Relationships Structures questionnaire.

**Table 3.** Summary of attitude assessment results with the e-therapy attitudes measure<sup>a</sup> (ETAM; N=646).

ETAM		Mean (SD)	Median	Range
Overall score attitude assessment (ETAM mean score)		1.93 (0.72)	1.94	0-4
Perceived usefulness and helpfulness (PU) scale		2.72 (0.79)	2.86	0-4
Relative advantage and comparability (RA) scale		1.37 (0.78)	1.33	0-4
<b>Scale item<sup>b</sup></b>				
1./PU	Internet-based therapies are modern and in line with our modern times.	2.84 (1.04)	3.0	0-4
2./RA	Internet-based therapies will replace conventional face-to-face psychotherapy in the future.	0.94 (0.93)	1.0	0-4
3./PU	Internet-based therapy is more compatible with work and private life than conventional face-to-face therapy.	2.73 (1.05)	3.0	0-4
4./RA	It makes no difference to me whether psychotherapy is conducted through the internet or in a psychotherapy practice in a clinic.	0.69 (0.96)	0.0	0-4
5./PU	Internet-based therapies will reach more individuals with mental health problems.	2.77 (1.09)	3.0	0-4
6./PU	Health insurance companies should cover the costs for internet-based therapies.	2.77 (1.16)	3.0	0-4
7./RA	Internet-based therapy programs are as effective as conventional face-to-face psychotherapies.	1.39 (0.99)	1.0	0-4
8./RA	Trust in a therapist can be just as easily built on the internet as in conventional face-to-face psychotherapy.	1.39 (1.14)	1.0	0-4
9./RA	Internet-based therapies are an appropriate alternative to conventional face-to-face psychotherapy.	1.82 (1.10)	2.0	0-4
10./RA	In case of mental health problems, I would attend an internet-based therapy.	1.70 (1.34)	2.0	0-4
11./RA	I would prefer an internet-based therapy to a conventional face-to-face psychotherapy.	1.03 (1.16)	1.0	0-4
12./PU	Internet-based therapies will reach more patients and help them.	2.55 (1.10)	3.0	0-4
13./RA	I'm not particularly worried about data security in internet therapies.	1.29 (1.33)	1.0	0-4
14./PU	The anonymity in internet therapies decreases the threshold to speak openly and honestly about important issues.	2.69 (1.19)	3.0	0-4
15./PU	Through the dissemination of internet therapies, persons will get professional help earlier.	2.75 (1.04)	3.0	0-4
16./RA	Misunderstandings occur in internet therapies as often as in conventional psychotherapies.	1.96 (1.23)	2.0	0-4
17./RA	Internet therapies are suitable for most patients, regardless of their personal background (age, sex, education, etc).	1.54 (1.18)	1.0	0-4

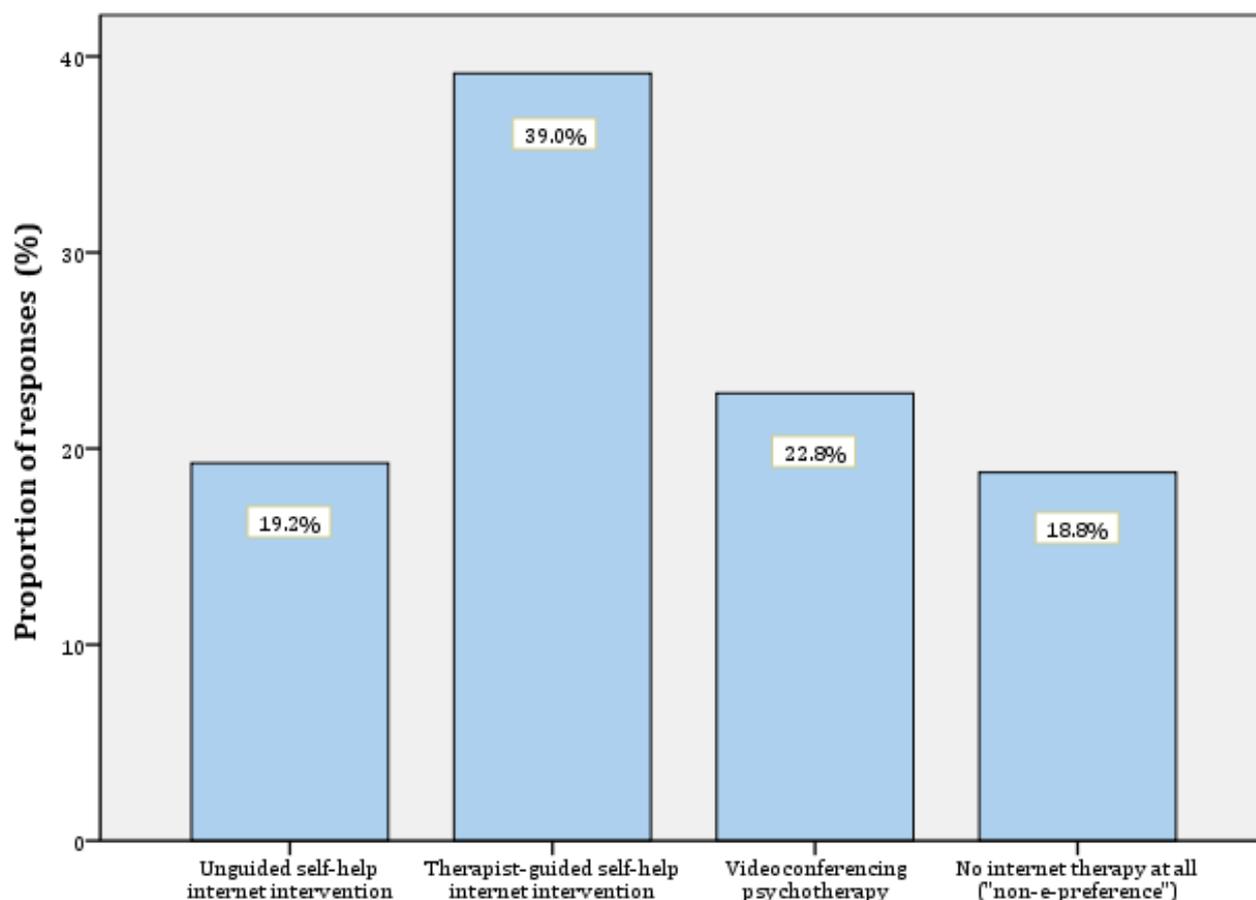
<sup>a</sup>The ETAM rating scale ranged from 0 ("strongly disagree") to 4 ("strongly agree").

<sup>b</sup>All items were translated from German to English. Item 1 refers to expectations and can be interpreted best in connection to other attitudinal items (compared with the previous version with 14 items, items 1-12 remained and items 13-17 are novel items of the 17-item version).

**Table 4.** Classification of attitudes toward guided internet interventions assessed by the e-therapy attitudes measure (ETAM; N=646).

ETAM	Classification of ETAM scores <sup>a</sup>		
	Low acceptance, negative attitude, n (%)	Moderate acceptance, neutral attitude, n (%)	High acceptance, positive attitude, n (%)
Overall mean score (attitudes)	168 (26.0)	324 (50.2)	124 (23.8)
Perceived usefulness and helpfulness	44 (6.8)	175 (27.1)	426 (65.9)
Relative advantage and comparability	364 (56.3)	226 (35.0)	56 (8.7)

<sup>a</sup>Low acceptance, negative attitude: scale mean score range 0-1.49; moderate acceptance, neutral attitude: scale mean score range 1.5-2.49; high acceptance, positive attitude: scale mean score range 2.5-4.0.

**Figure 1.** Participants' stated preference for a specific delivery mode of internet interventions (N=646).

### Attachment Style

Attachment avoidance significantly predicted e-preference ( $F_{3,640}=6.315$ ;  $P<.001$ ,  $\eta_p^2=.029$ ). Participants with higher attachment avoidance were less likely to prefer VCP than other formats (unguided internet interventions:  $M_{diff} -0.579$ , SE 0.166, 95% CI  $-1.020$  to  $-0.139$ ; guided internet interventions:  $M_{diff} -0.426$ , SE 0.142, 95% CI  $-0.801$  to  $-0.051$ ; non-e-preference:  $M_{diff} -0.651$ , SE 0.166, 95% CI  $-1.095$  to  $-0.208$ ). There was no significant association between preference and attachment anxiety ( $F_{3,640}=2.247$ ;  $P=.08$ ).

### Perceived Stress

Current perceived stress was associated with e-preference (visual analog scale:  $F_{3,640}=3.855$ ;  $P=.009$ ,  $\eta_p^2=.018$ ), with participants who experienced higher stress being more likely to prefer guided interventions than VCP ( $M_{diff} 0.86$ , SE 0.277, 95% CI 0.13-1.60). Scores for current stress were lowest in non-e-preferers (mean 5.26, SD 2.80) and highest in those who preferred guided internet intervention (mean 5.90, SD 2.60). Another significant difference between the preference groups was shown for perceived stress in the past month (PSQ-20:  $F_{3,638}=2.943$ ;  $P=.03$ ,  $\eta_p^2=.014$ ). Pairwise comparisons were not significant. PSQ-20 scores were lowest for non-e-preference (mean 44.39, SD 20.81) and highest for therapist-guided intervention preference (mean 49.67, SD=19.14).

The other help-seeking-related variables were not associated with significant differences in preferences (all  $P>.05$ ).

## Discussion

### Principal Findings

#### Attitudes Toward Guided Internet Interventions

This study identified an overall moderate public acceptance, or moderately positive attitudes, toward guided internet interventions in a German sample. This tendency is in line with another study on a psychoeducational intervention using an adapted ETAM version [41]. Participants supported health care insurance coverage of costs for guided internet-based therapies and endorsed the helpfulness of such approaches, their perceived anonymity, and the chance to receive help earlier compared with traditional health care. At the same time, participants disagreed with the supposed comparability of guided internet interventions with face-to-face psychotherapy, for example, with regard to their effectiveness and possibility to develop a good therapeutic relationship. Our findings are, furthermore, consistent with earlier research with respect to a general preference for face-to-face therapies over internet interventions [28,29,44], data security concerns [64,65], and perceived higher compatibility of internet interventions with everyday life [11,29].

We found no relevant differences for sociodemographics as predictors of attitudes toward internet-based guided self-help. Interestingly, neither education level nor sex was associated

with attitudes. These results are in line with a study on the acceptance of internet-based interventions in chronic pain [66]. Replication of this finding might indicate that the often-reported overrepresentation of woman and highly educated participants in randomized controlled trials evaluating internet interventions [13,67-72] might not be due to lower acceptance of digital health interventions in general, but due to other relevant barriers such as lower willingness to seek help. Future research should try to shed light on low utilization rates among persons with low education and men.

Moreover, participants with higher levels of perceived stress in the past month tended to express a more positive attitude toward internet interventions, which is consistent with a prior study using the same instrument to assess attitudes [42]. This might point to improved acceptance of such guided internet interventions among participants in a stressful situation with an actual need for support.

### ***Preference for Specific Delivery Formats***

This study identified a clear preference for guided over unguided internet interventions, which only few studies have investigated before [34]. Interestingly, guided internet interventions were also preferred over VCP. Approximately four-fifths of the participants were willing to use internet-based approaches for emotional problems, indicating a broad applicability of internet interventions for mental health care.

High e-awareness was associated with a preference for guided internet interventions. Overall, e-awareness in our sample was low (33.1%), which could be, for instance, seen in context of the early stage of implementation of eMHSs in Germany [50,73] and might rise further in the future. This is supported by previous German surveys reporting even lower rates of e-awareness (14.0%-27.3%; [42,52,64]), including a representative socioeconomic panel (SOEP-Innovation Modules 2016, N=4802) showing 24.4% e-awareness (D Richter, written communication, May 2017). Experience with seeking psychological help formats was also a determinant of preferences, which is consistent with other studies [29,31]. Results also suggest that attachment avoidance was associated with a higher preference for guided and unguided self-help via internet interventions, and very low preference for VCP. This finding contributes to research on links between attachment styles and face-to-face health care use readiness [52,57,58] and might indicate that internet-based (guided) self-help approaches could help to reach individuals for whom attitudinal and other psychological barriers such as attachment avoidance might be a drawback for use of an intervention [74].

Furthermore, participants with higher levels of perceived stress showed a higher preference for internet-based guided self-help than for VCP. This might indicate that individuals with stressful lives have problems adhering to fixed synchronous therapy sessions, and that providing asynchronous treatments might help them to get access to psychological treatments, which they would otherwise not use. Such an assumption is supported by studies that found high proportions of first-time help seekers in internet-based stress management programs [75-79]. However, future research is needed to confirm such an assumption.

### **Implications**

This study provides several important implications for research and practice.

#### ***Providing Asynchronous Treatment Formats to Increase Health Care Utilization***

First, results indicate that, although internet-based approaches are not an option for some individuals, a large proportion of participants in this study were potentially inclined to use eMHSs for treatment. However, e-preference rates were lowest for VCP, which, as a synchronous delivery format, is the most similar to conventional face-to-face psychotherapy [27]. Results also indicated that individuals with high attachment avoidance were least inclined to use this synchronous format to seek help, but were more willing to use asynchronous internet-based interventions. Perceived stigma and a preference for managing mental health problems on one's own are known barriers to seeking synchronous treatment [10], and personal characteristics such as attachment style may contribute [57,58]. This suggests that provision of asynchronous treatment options, such as guided or unguided internet interventions, could be a feasible way to reach larger proportions of the general population, especially individuals who would not use synchronous options such as face-to-face psychotherapy or VCP. Matched-care models have been proposed before (cf, [80]), allocating internet-based or face-to-face treatment based on symptom severity; findings in this study, however, pointed out that various asynchronous as well as synchronous treatment formats should be provided simultaneously to reach as many individuals affected by mental health problems as possible.

Second, these results also suggested that offering guidance alongside internet-based self-help internet interventions in routine care could, from a public health perspective, have a major influence on their effects on a population level. Whether to offer guided or unguided interventions in routine care has been debated in the literature since internet-based self-help has emerged. This discussion has since predominately focused on potential differences in adherence, effects, and costs [22,81-83]. Meta-analytic findings clearly indicate that stand-alone guided self-help interventions can be effective in the prevention and treatment of a range of mental health problems, including depression [68], anxiety [72], and stress [77]. However, although more patients could potentially be treated for the same costs using unguided self-help, a basic prerequisite to exploiting the potential of any effective treatment is that affected individuals are willing to use it [84]. This study showed that approximately twice as many participants preferred guided interventions over unguided interventions. Thus, with evidence showing guided interventions to be comparable with face-to-face psychotherapy, for example for depression and anxiety [17,85], and with large effect sizes of guided formats when delivered under routine care conditions [25,86-88], preference should be given at the moment, whenever possible, to guided self-help in routine care. However, it should also be acknowledged that almost 20% of participants preferred unguided self-help; hence, future studies should clarify whether offering both guided and unguided interventions could lead to greater effects on a population level

due to higher overall utilization rates, compared with offering only one of the two options.

### ***Raising E-Awareness and Knowledge***

Awareness about internet-based treatment was rather low in this sample, but was positively associated with higher preference for guided internet interventions. Furthermore, participants did not find internet interventions to be equal in effectiveness and therapeutic relationship to face-to-face therapies. Previous research, however, has shown that the effects of guided internet interventions are comparable with face-to-face therapies [17,85] and that therapeutic relationships are of the same quality as in conventional treatment [1-4]. This finding points to the importance of developing measures to increase awareness of and knowledge about the efficacy of internet-based treatment in the public to raise its acceptance. Acceptance-facilitating interventions using brief, highly scalable educational videos have been shown to be a valid strategy to enhance the acceptability of internet interventions in clinical practice [66,71,84]. As acceptance-facilitating interventions may be easily disseminated through official health care information channels, they might be an auspicious approach to increase e-awareness and knowledge concerning internet interventions, and thus raise their public acceptance.

### **Limitations**

First, the early stage of validation of the ETAM and the application of a heuristic rule to classify attitudes are a limitation that might have biased results regarding the categorization of attitudes with mainly neutral or undecided views. Future efforts should try to develop data-based cutoff values using representative samples. Second, the prior presentation of the case vignette regarding e-preferences might have led to more positive attitudes toward internet interventions, considering that

a previous study using the ETAM without this case vignette revealed overall negative views [42]. Hence, these results might only be generalizable to situations in which potential participants receive minimal information about internet interventions. Third, we investigated determinants of attitudes toward and preferences for internet therapies based on self-reports, with most respondents (492/646, 75.2%) rating themselves as relatively healthy. It may be the case that attitudes toward digital mental health approaches change with current symptomatology, help-seeking wishes, and the availability of other formats for preferable treatments in routine care. Since the study was conducted in Germany, results may only be applicable to countries with similar economies or health care systems. Fourth, e-preferences were operationalized only regarding preferences for a specific treatment, and we do not know whether patients were nevertheless willing to use an alternative treatment format, if their preference would not be available in routine care, which should be tested in future studies. Moreover, with regard to non-e-preferers, we only assessed whether somebody would not prefer guided and unguided self-help or VCP, but we did not assess preference for face-to-face psychotherapy and pharmacotherapy, which should also be tested in subsequent studies.

### **Conclusions**

This study revealed moderately positive attitudes toward guided internet interventions and a clear public preference for guided over unguided internet-based treatment and VCP. Results of this survey indicated that increasing awareness about the existence of effective internet-based treatment options should be a key priority to raise their acceptability, and that guided internet-based programs should be implemented in routine care along with conventional face-to-face treatment to account for different patient preferences and help-seeking characteristics.

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### **Conflicts of Interest**

None declared.

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### **Multimedia Appendix 1**

Exploratory factor analysis for the e-therapy attitudes measure (including pattern and structure matrices).

[PDF File (Adobe PDF File), 65KB - [mental\\_v5i2e10735\\_app1.pdf](#) ]

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## Abbreviations

- ECR-RS:** Experiences in Close Relationships-Relationships Structures questionnaire  
**eMHS:** electronic mental health service  
**ETAM:** e-therapy attitudes measure

**M<sub>diff</sub>**: mean difference

**PSQ-20**: Perceived Stress Questionnaire 20-item short version

**PU**: perceived usefulness and helpfulness

**RA**: relative advantage and comparability

**SOEP**: socioeconomic panel

**VCP**: videoconferencing psychotherapy

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Original Paper

# Engagement With a Trauma Recovery Internet Intervention Explained With the Health Action Process Approach (HAPA): Longitudinal Study

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## Abstract

**Background:** There has been a growing trend in the delivery of mental health treatment via technology (ie, electronic health, eHealth). However, engagement with eHealth interventions is a concern, and theoretically based research in this area is sparse. Factors that influence engagement are poorly understood, especially in trauma survivors with symptoms of posttraumatic stress.

**Objective:** The aim of this study was to examine engagement with a trauma recovery eHealth intervention using the Health Action Process Approach theoretical model. Outcome expectancy, perceived need, pretreatment self-efficacy, and trauma symptoms influence the formation of intentions (motivational phase), followed by planning, which mediates the translation of intentions into engagement (volitional phase). We hypothesized the mediational effect of planning would be moderated by level of treatment self-efficacy.

**Methods:** Trauma survivors from around the United States used the eHealth intervention for 2 weeks. We collected baseline demographic, social cognitive predictors, and distress symptoms and measured engagement subjectively and objectively throughout the intervention.

**Results:** The motivational phase model explained 48% of the variance, and outcome expectations (beta=.36), perceived need (beta=.32), pretreatment self-efficacy (beta=.13), and trauma symptoms (beta=.21) were significant predictors of intention (N=440). In the volitional phase, results of the moderated mediation model indicated for low levels of treatment self-efficacy, planning mediated the effects of intention on levels of engagement (B=0.89, 95% CI 0.143-2.605; N=115).

**Conclusions:** Though many factors can affect engagement, these results offer a theoretical framework for understanding engagement with an eHealth intervention. This study highlighted the importance of perceived need, outcome expectations, self-efficacy, and baseline distress symptoms in the formation of intentions to use the intervention. For those low in treatment self-efficacy, planning may play an important role in the translation of intentions into engagement. Results of this study may help bring some clarification to the question of what makes eHealth interventions work.

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**KEYWORDS**

electronic health (eHealth); engagement; trauma; stress disorders, post-traumatic; PTSD; Health Action Process Approach (HAPA); outcome expectations; internet; digital health intervention

## Introduction

### Background

There has been a growing trend in the delivery of mental health treatment over the internet [1]. Results of a recent survey found that 87% of American adults now use the internet, and of those users, over 80% look online for health-related material [2]. Likewise, the numbers of online psychotherapeutic interventions (ie, electronic health, eHealth) have also increased [3]. This increase may be because of several advantages offered by eHealth interventions, such as reduced stigma, costs, and increased autonomy, anonymity, and accessibility [4]. However, engagement with eHealth interventions is a concern. Theoretically based research in this area is sparse [5] despite consistent evidence suggesting engagement is essential for optimizing outcomes [6]. This study examined engagement with a trauma recovery eHealth intervention using a theoretical model explaining how and why people engage.

Exposure to potentially traumatic events in adult US populations is widespread [7]. A significant number of those exposed will develop posttraumatic stress disorder (PTSD) along with depression, anxiety, and substance use disorders [8]. Finding ways to treat traumatized populations to reduce the associated medical, psychological, and social costs is essential [9]. There is a growing concern that those with more persistent mental health issues following trauma are reluctant to seek treatment [10]. Significant barriers to treatment include logistical, geographical, financial, stigma, and other attitudinal challenges [11]. One promising approach to overcoming these barriers is the provision of mental health services via technology that can be readily standardized for broad dissemination of evidence-based care.

Ample research has shown eHealth interventions are effective in decreasing distress symptoms in trauma survivors [12-15]. However, limited participation and high attrition rates are common [16,17]. As the amount of exposure to an intervention is strongly linked to behavioral outcomes [18], understanding the factors that influence engagement is a major step in improving their effectiveness [19].

### Study Aim

Our study aimed to examine the utility of using a single theoretical model, the Health Action Process Approach (HAPA) [20], to evaluate differential predictors of eHealth engagement for trauma recovery. The HAPA examines stages of behavior change and considers psychological factors and self-regulatory strategies to model both direct and indirect pathways of engagement, irrespective of the technological features of the intervention.

### Electronic Health and Engagement

The term engagement has been used in a variety of ways, making it challenging to synthesize consistent models and measures. Generally, engagement is described as efforts by a user to start and continue with an intervention and encapsulates objective and subjective experiences [21]. However, this definition of engagement is not consistently observed across the literature. For the purposes of our study, we define

engagement objectively and subjectively as a measure of how participants interact with the eHealth intervention, including how long and how often the intervention is used. This definition of engagement is sometimes referred to as the micro level of engagement [21]. Engagement is different from adherence, which refers to using the intervention as intended. Attrition occurs when an individual drops out of the intervention before completion (ie, nonadherence). Attrition from open access nontracked websites can be very high, with as few as 1% of users completing a full course of online therapy [22]. Attrition from traumatic stress-related interventions can be especially problematic [23]. Studies have found attrition rates ranging from 36% to 78% [24,25]. As a result, the degree of engagement (or lack thereof) can have a significant effect on key outcomes and impact on quality of life.

Predictors of engagement with eHealth interventions more generally and trauma programs more specifically have not been studied in a systematic, theoretically based way [6]. Previous a-theoretical approaches have investigated potential predictors of engagement with mixed findings. These studies focused on how user characteristics such as demographics [26], health problems, and social factors [27] affect engagement. However, meta-analytic findings suggested limited evidence for any specific individual characteristic that may influence engagement with eHealth interventions [28].

Other researchers have focused on effects of the technical design aspects on engagement [29]. These components include varying levels of interactivity [30], gamification [31], tailoring [32], modality (mobile vs Web), and software sophistication [33]. These ever-evolving features can be combined in countless ways, making engagement research difficult to generalize across interventions.

Researchers from areas beyond trauma (eg, health and illness issues) have applied theoretical frameworks to explain eHealth engagement. The Technology and Acceptance Model has been used to explore intentions to engage with information and communication technologies among health care providers [34]. This model examined perceived usefulness and ease of use but failed to consider perceptions of need, self-efficacy, and symptom severity. Other approaches combined multiple theoretical models to address different components of eHealth engagement separately, such as health service utilization and technology acceptance theories [35], but do not consider all components simultaneously. Mâsse [36] used the theory of planned behavior and self-determination theory to examine engagement with an eHealth obesity intervention and found intentions did not directly predict engagement. One possible explanation may be that, unlike the HAPA, these theories did not consider indirect pathways through which intentions are translated into engagement. Recently, Kok [19] examined nonadherence to phobia interventions and suggested that patient expectations and baseline symptom severity could affect adherence to eHealth interventions.

### Health Action Process Approach Model

The HAPA [20] is an approach developed to predict engagement in health behavior. The model has good predictive validity across a variety of preventative health behaviors, including

physical exercise [37,38], nutrition [39], and cancer screening [40]. Our study is a novel application of the HAPA (Figure 1) to investigate engagement with a trauma recovery eHealth intervention. HAPA addresses both motivational and volitional processes, with different patterns of social-cognitive predictors emerging in respective phases. These patterns, as they relate to eHealth engagement with a trauma recovery intervention, were explored in this study.

**Motivational Phase**

The HAPA motivational phase is typically characterized by awareness of risk, outcome expectancies, and perceived task self-efficacy (ie, pretreatment self-efficacy). For our eHealth intervention, positive outcome expectancies may refer to the ability to cope with posttraumatic distress. Pretreatment self-efficacy reflects beliefs about the ability to initiate eHealth engagement [41]. Individuals high in pretreatment self-efficacy imagine success and are more likely to adopt a new behavior [39].

Besides self-efficacy and outcome expectations, the role of other motivational variables such as perceived need and posttraumatic symptoms may be considered in the motivational phase of the HAPA. Perceived need [39] is defined as one’s perception of needing an intervention for trauma-related symptoms such as anxiety, depression, and other PTSD symptoms. Perceived need may lead to deliberations about behavior change [42]. The construct of perceived need for a coping support intervention may be considered conceptually similar to a construct of perceived risk [20]. Furthermore, the degree of distress or PTSD symptoms [43] may affect the perceived capability to manage distress or utilize available resources following a traumatic event [44]. Research found baseline PTSD symptoms positively related to engagement [27]. However, the relationship between baseline mental health symptoms and treatment engagement indicators such as attrition is unclear, where higher attrition is

associated with higher symptoms in some studies [45,46] vs lower baseline PTSD symptoms in others [47]. It is possible that baseline symptom severity can serve as an index of perceived need or as a barrier to participation.

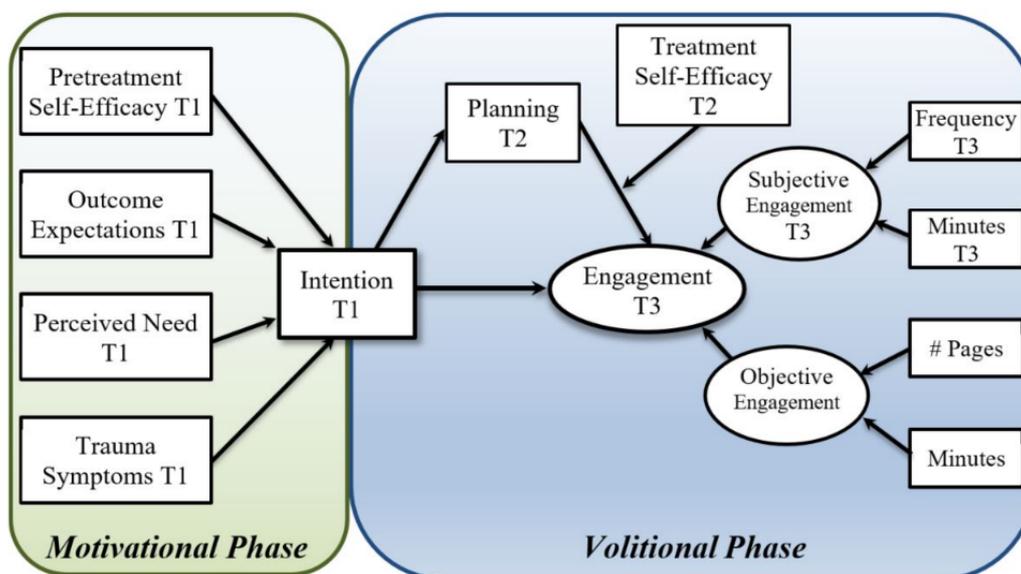
**Volitional Phase**

After intention has been formed in the motivational stage of the HAPA, an individual enters the volitional stage where self-regulation skills such as planning and treatment self-efficacy prompt behavior enactment [20,48]. Planning specifies when, where, and how a behavior will be implemented [49]. Planning may refer to emerging barriers that would prevent one from acting as planned [50]. Treatment self-efficacy refers to the perceived ability to maintain a new behavior and cope with arising barriers. Adhering to a trauma recovery eHealth intervention may turn out to be far more challenging than expected, but a self-efficacious person should respond confidently and develop better strategies for responding to arising difficulties [40].

**Engagement**

The primary outcome of this study was engagement with a trauma recovery eHealth intervention. A major challenge in the study of engagement is the lack of a shared definition and conceptualization of user engagement [21]. Historically, behavior-based metrics such as page views and time online have been used as indicators of engagement [51]. As Danaher [52] noted, “a key ingredient in determining the impact of any Web-based behavior change program is the extent to which participants are exposed to the program.” However, intervention exposure alone fails to capture the experiential aspects of engagement. A recent systematic review concluded that a valid and reliable conceptualization of engagement needs to consider objective and subjective measures that include behavioral and experiential dimensions of eHealth intervention interactions [53].

**Figure 1.** Longitudinal revised Health Action Process Approach (HAPA) research model. In the motivational phase, pretreatment self-efficacy, outcome expectations, perceived need, and trauma symptoms are predicted to have a significant positive effect on the formation of intentions. In the volitional phase, intentions are translated into engagement, mediated by planning and moderated by levels of treatment self-efficacy. Engagement is a latent construct consisting of both subjective (estimated frequency and duration) and objective measures. Objective engagement is continuously measured by the electronic health (eHealth) intervention.



High quality, objectively measurable information on engagement can be acquired from page logs, time on site, and other indicators of treatment exposure. These objectively measurable metrics were included in our study. Our study also included self-report measures of engagement to capture subjective perceptions of usage.

### Study Hypotheses

Using the HAPA as a model guiding the relationships between the study variables (Figure 1), we hypothesized time 1 (T1) pretreatment self-efficacy, outcome expectancy, perceived need, and PTSD symptoms would be positively related to the formation of intentions to engage at T1 (the motivational hypothesis). Once intentions were formed, time 2 (T2) planning was hypothesized to mediate the translation of T1 intentions into eHealth intervention engagement at time 3 (T3), moderated by the level of T2 treatment self-efficacy (the volitional hypothesis).

## Methods

### Participants

To increase external validity, participants were recruited from the Trauma, Health, and Hazards Center trauma registry (15/440, 3.4%), national domestic violence advocate and rape crisis center registries (64/440, 14.5%), the national development and research institute list servers (56/440, 12.7%), social media (19/440, 4.3%), and the University of Colorado at Colorado Springs (UCCS) student population (286/440, 65.0%) from May 2015 to October 2016. All participants included in the study had directly experienced one or more traumatic events as measured by the Life Events Checklist [54], were 18 years or older, had a private area to access the internet, and spoke English. Table 1 displays the demographic information. Of the 626 who completed the T1 survey, 440 participants qualified for the study (mean age 25.57 years; SD 11.02; 337/440, 76.6% female; 66/440, 15% Hispanic). Of those who qualified, 186 created an account on the website, 161 participated in the T2 survey (mean age 28.11 years; SD 13.31; 128/161, 79.5% female), and 115 participated in the T3 survey (mean age 28.49 years; SD 12.98; 94/115, 81.7% female). Those failing to access the intervention (ie, nonuse attrition) were not considered for T3 analyses.

All participants who met criteria at T1 (N=440) reported that they were directly exposed to one or more traumatic events either through experiencing or witnessing the event, including physical assault (248/440, 56.4%), transportation accidents (300/440, 68.3%), unwanted sexual contact (219/440, 49.9%), sexual assault (158/440, 35.9%), life-threatening illness or injury (225/440, 51.1%), fire or explosion (167/440, 38%), natural disasters (175/440, 39.7%), sudden violent death of someone close (109/440, 24.9%), serious accidents (150/440, 34.2%), severe human suffering (136/440, 30.9%), toxic exposure (68/440, 15.5%), military combat (37/440, 8.5%), and other traumatic events (258/440, 58.6%). Participants experienced the same traumatic event with varying frequency, ranging from

56.4% (248/440) who experienced the event once, to 9.1% (40/440) who experienced the event at least 14 times.

### Procedure and Study Design

The UCCS Institutional Review Board approved the study. UCCS psychology students signed up for this study via the Sona online system, and nonstudents were contacted via email or a flyer. All participants were provided a brief statement explaining the procedure and purpose of the study along with a link to the T1 survey on Qualtrics. Figure 2 illustrates the participant flowchart. After participants read the online informed consent form and clicked the “I accept” button, they completed the T1 questionnaire. Participants who completed the T1 survey and met the inclusion criteria were given access to the eHealth intervention via email. The email provided participants with the website address and instructions on how to create a user account, log in to the site, and directed them to use the site as much as they would like over the next 2 weeks.

One week after qualifying for the study, participants were sent an email asking them to complete the short T2 survey. One week after finishing the T2 survey, participants were prompted by email to take the T3 survey on Qualtrics. After finishing the final survey, participants were debriefed, and UCCS psychology students received additional extra credit. Nonpsychology students were entered into a raffle for one of four US \$25.00 gift cards. Local and national mental health resources were provided to all participants after the study.

### Measures

The following measures incorporated variables in the motivation and volitional phases of the HAPA model (see Figure 1). The motivational components were available at T1 and included pretreatment self-efficacy, outcome expectations, perceived need, trauma symptoms, and intention. The volitional phase components were assessed at T2 and T3 and included planning, treatment self-efficacy, and subjective engagement. Objective engagement levels were tracked and recorded automatically by the intervention throughout the study.

In addition to the HAPA variables, participant website satisfaction was also measured. All measures except trauma symptoms were developed for this study, as there were no measures available to assess these constructs. Their psychometric properties are shown in Table 2.

### Motivation Model Measures

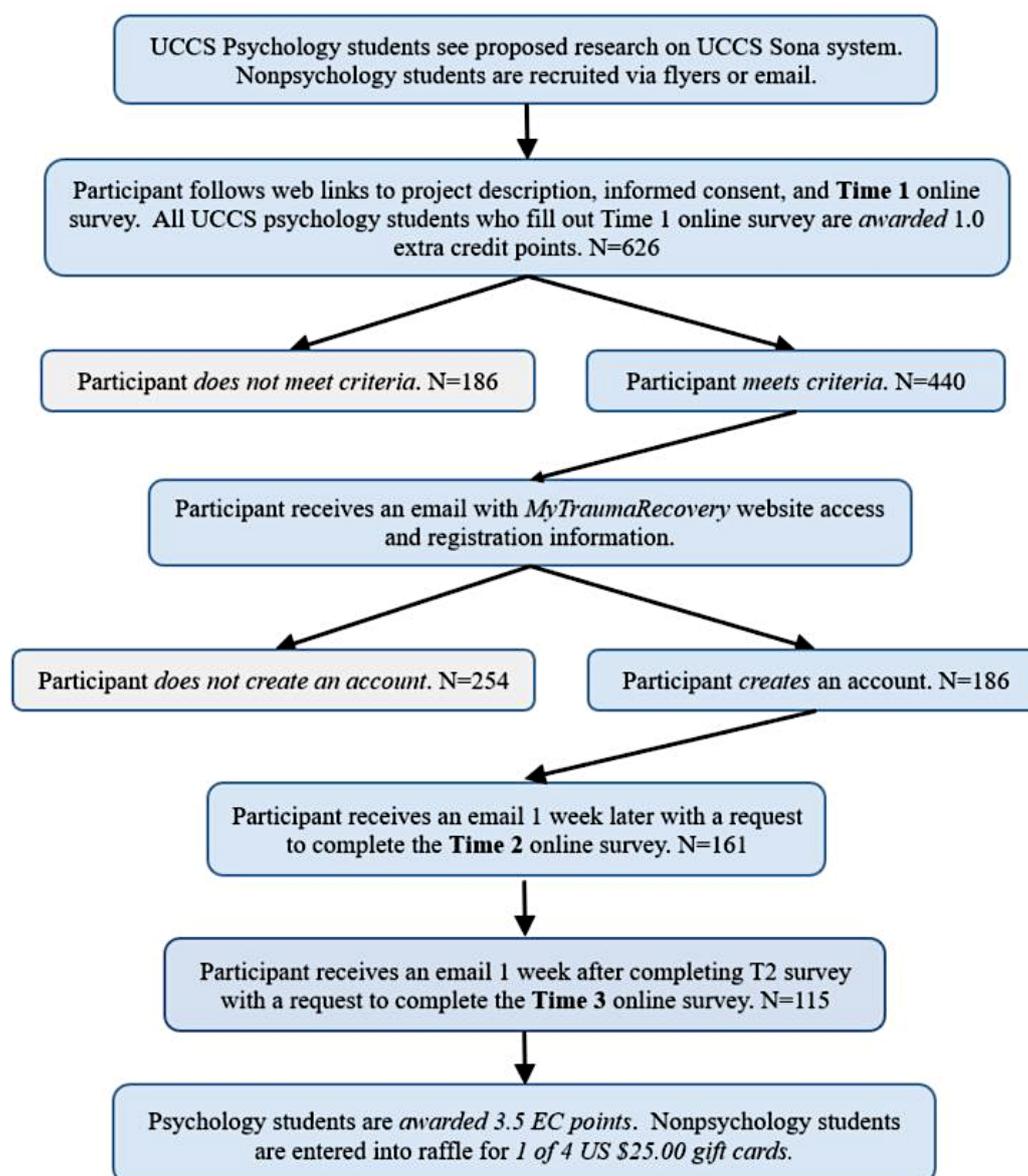
#### Pretreatment Self-Efficacy (Time 1)

Pretreatment self-efficacy was measured by eight questions that began with the sentence stem “I am confident that I can start using an eHealth intervention in the next two weeks...” The sentence stem was followed by items representing technological and coping related barriers such as “even if I am uncomfortable using the internet” or “even if I am having difficulty handling all the things I have to do.” Participants responded on a 5-point scale ranging from not at all confident to very confident.

**Table 1.** Descriptive statistics for demographics for time 1 (baseline), time 2 (one week after baseline), and time 3 (two weeks after baseline). Some percentages do not add up to 100% because of missing data.

Measure	Time 1 (N=440)	Time 2 (N=161)	Time 3 (N=115)
Mean age in years (SD)	25.57 (11.02)	28.11 (13.31)	28.49 (12.98)
Age range in years	18-80	18-80	18-78
<b>Gender, n (%)</b>			
Female	337 (76.6)	128 (79.5)	94 (81.7)
Male	101 (23.0)	33 (20.5)	21 (18.3)
Other	2 (0.5)	0 (0.0)	0 (0.0)
<b>Intimate relationship, n (%)</b>			
Single <sup>a</sup>	192 (43.6)	38 (39.2)	43 (37.4)
Committed <sup>b</sup>	213 (48.4)	50 (51.5)	60 (52.2)
Other	35 (8.0)	9 (9.3)	12 (10.4)
<b>Highest education, n (%)</b>			
High school	280 (63.3)	43 (44.3)	60 (52.2)
Associates degree	95 (21.6)	24 (24.7)	30 (26.1)
Bachelor's degree	45 (10.2)	20 (20.6)	18 (15.7)
Graduate degree	18 (4.1)	10 (10.3)	07 (6.1)
<b>Employment, n (%)</b>			
None	117 (26.6)	22 (22.7)	24 (20.9)
Part-time	196 (44.5)	34 (35.1)	52 (45.2)
Full-time	116 (26.4)	33 (34.0)	34 (29.6)
Retired	10 (2.3)	8 (8.2)	05 (4.3)
<b>Income (USD), n (%)</b>			
\$0-\$25,000	186 (42.3)	42 (43.3)	46 (40.0)
\$25,001-\$70,000	143 (32.5)	34 (35.1)	42 (36.5)
\$70,001-\$100,000	58 (13.2)	10 (10.3)	13 (11.3)
>\$100,000	50 (11.4)	10 (10.3)	12 (10.4)
<b>Mental health, n (%)</b>			
Treatment (current)	71 (16.1)	17 (17.5)	22 (19.1)
Treatment (past year)	32 (7.3)	9 (9.3)	7 (6.1)
Treatment (lifetime)	183 (41.6)	51 (52.6)	57 (49.6)
<b>Frequency of traumatic event, n (%)</b>			
1 time	248 (56.4)	80 (49.7)	53 (46.1)
2-13 times	129 (29.3)	51 (31.7)	36 (31.3)
>14 times	40 (9.1)	20 (12.4)	17 (14.8)

<sup>a</sup>Includes widowed or divorced.<sup>b</sup>Includes married couples and couples in a committed relationship.

**Figure 2.** Participant flowchart.**Table 2.** Number of items, scoring range, and Cronbach alpha for time 1 (N=440), time 2 (N=161), and time 3 (N=115) measures. PCL-5: Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

Scale	Number of items	Scoring range	Cronbach alpha T1	Cronbach alpha T2	Cronbach alpha T3
1. PCL-5	20	0-80	.95	— <sup>a</sup>	.95
2. Outcome expectations	10	10-50	.85	.83	.85
3. Pretreatment self- efficacy	8	8-40	.95	—	—
4. Perceived need	6	6-30	.92	—	—
5. Intention	5	5-25	.88	—	—
6. Treatment self-efficacy	8	8-40	—	.96	.94
7. Planning	4	4-20	—	.80	.79
8. Engagement (subjective)	10	—	—	—	.86

<sup>a</sup>Not measured at respective time point.

### **Outcome Expectancies (Time 1, Time 2, and Time 3)**

Both positive (pros) and negative (cons) outcome expectancies were assessed with 10 questions that started with the sentence stem “If I use the eHealth intervention on a regular basis I expect that...” followed by the items measuring possible pros and cons. Example pros and cons include “it will help me to relax more” or “it will not make any difference in how I feel.” Cons were reverse scored, and the total score was computed by adding the answers to all items.

### **Perceived Need (Time 1)**

Perceived need was measured with six responses to the following statement: “Please indicate your perception of how much you believe you need an intervention for the following issues.” Issues pertain to dealing with the trauma such as “to feel normal again?” and “to be able to manage distressing dreams or images about the traumatic experience.” Participants responded on a 5-point scale ranging from strongly disagree to strongly agree.

### **Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (Time 1 and Time 3)**

The PTSD Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; PCL-5) was used to measure the distress symptoms associated with trauma. The PCL-5 is a 20-item self-report measure that assesses the 20 DSM-5 symptoms of PTSD [55]. PCL-5 has shown strong internal consistency ( $\alpha=.94$ ) and test-retest reliability ( $r=.82$ ) [56]. The PCL-5 was scored using a total symptom severity score (range, 0-80) by summing the scores for each of the 20 items.

### **Intention (Time 1)**

Behavioral intentions are the perceived likelihood to act in a certain way, and for this study, they comprised a person’s motivation toward using an eHealth intervention. Intention to perform a behavior should be measured the same way as assessing the behavior itself [50]. Intention to use the eHealth intervention was measured by five questions that began with the sentence stem “During the next two weeks I intend to use the eHealth intervention to help me...” Example questions include “to learn relaxation skills” or “fight negative thinking.” Responses ranged from strongly disagree to strongly agree.

### **Volitional Model Measures**

#### **Treatment Self-Efficacy (Time 2 and Time 3)**

Treatment self-efficacy was measured by eight questions that began with the sentence stem “I am confident I could continue to use an eHealth intervention over the next two weeks...” followed by items measuring treatment self-efficacy related technology and trauma coping self-efficacy. Example items include “even if I do not like it initially” and “even if it brings up difficult memories.” Participants responded on a 5-point scale ranging from not at all confident to very confident.

#### **Planning (Time 2 and Time 3)**

Individuals were asked if they had made a plan or schedule for using the eHealth intervention. For those who planned, details

of their plan were measured by four questions that began with the sentence stem “My plan included...” followed by questions regarding when, where, what, and how often they would use the intervention. Example questions include “how often I would use the eHealth intervention” and “what modules of the eHealth intervention I would use.” Responses ranged from strongly disagree to strongly agree.

### **Engagement (Time 3)**

Engagement was measured both subjectively and objectively. Subjective measures included questions regarding frequency and duration assessed at T3. Frequency was assessed with five questions that began with the sentence stem “How often did you use the following eHealth intervention modules...” followed by a list of five modules (unhelpful ways of coping, relaxation, social support, self-talk, trauma triggers, and memories). Answers were rated on a 6-point scale ranging from 1 (“never”) to 6 (“more than once a day”). Duration was measured by the total estimated usage (in minutes) of the five modules. Objective measures consisted of automatically recorded data that quantified the frequency (number of pages visited) and duration (total number of minutes logged in) of intervention usage [18,52]. Inactive minutes were not included in the objective duration calculation. Participants were deemed inactive when their login time exceeded 15 min without any corresponding page activity. Subjective and objective variables were combined as observed variables loading a respective latent variable to represent overall engagement (see Figure 1).

### **Electronic Health Intervention—My Trauma Recovery**

My Trauma Recovery (MTR) is a self-guided, theoretically based, interactive internet application with no interaction with a therapist. MTR is based mainly on social cognitive theory [57], where individuals are viewed as proactive agents who can choose their environments, find beneficial social networks, and engage in self-management behaviors that allow them to both initiate and maintain long-term recovery [13].

The intervention focuses on increasing an individual’s ability to cope with trauma via six self-directed modules: (1) unhelpful ways of coping, (2) relaxation, (3) social support, (4) self-talk, (5) trauma triggers and memories, and (6) seeking professional help. The first five modules were included in the subjective engagement measure. A self-test provides users the opportunity to gain feedback on their current emotional distress and provides graphs that depict their assessment results. Throughout the six modules, the site utilizes mastery experiences, vicarious success modeling, verbal persuasion, and tools to monitor and regulate internal distress to increase coping self-efficacy through interactive, tailored experiences. Individuals can use any of modules as often as needed and can assess their progress over time. On the basis of their assessments, suggestions are made to maximize trauma coping self-efficacy gains. Completing all the MTR modules requires approximately 2 hours. However, users generally do not finish all the modules in a single sitting. Additionally, the interactive components of the website offer opportunity to revisit the different modules over time (eg, triggers management or relaxation). Therefore, we allowed participants access to the intervention for 2 weeks to provide ample opportunity to explore all components of MTR.

MTR has received initial support for its effectiveness in reducing symptoms in two separate randomized clinical trials [58,59]. The first randomized clinical trial with disaster survivors following hurricane Ike demonstrated that the MTR website participants improved significantly on worry with little change for the comparison information only or waitlist groups. A marginal effect for depression was also identified [58]. The website was also evaluated in a randomized clinical trial with two populations in China where significant positive effects were also found [59]. Benight and colleagues [13] describe how the website utilizes interactive components (eg, video and audio modeling), question and answer segments, verbal persuasion, and mastery to promote engagement and empowerment.

### Statistical Analysis

Due to the small sample size at T3 (N=115) compared with T1 (N=440), separate analyses were run for the motivational (T1) and volitional (T2, T3) phases. The motivational hypothesis was analyzed with the T1 sample (N=440), and the volitional hypothesis was analyzed with completers only (N=115; see Figure 1). Two participants completed T3 but did not complete T1 or T2. Therefore, they were removed from the final dataset. Additionally, there were two duplicate instances of a participant (did the survey twice) in which case the first instance was used. Data were assessed for outliers, normality, and collinearity. The collinearity tolerance statistic was below .20, and there was no correlation between variables above .90. Therefore, there was no indication of multicollinearity.

The motivational phase hypothesis (Figure 1) was tested via structural equation modeling (SEM) using IBM SPSS Amos v24.0 (IBM Corporation, Armonk, NY, USA) with maximum likelihood estimation. Model fit was examined using the chi-square goodness of fit test, as well as the comparative fit index (CFI) [60], Tucker-Lewis index (TLI) [61], and root mean square error of approximation (RMSEA) [62]. Cutoff points used for the fit indices were CFI >0.96, TLI >0.95, and RMSEA <0.06.

A moderated mediation analysis was performed using Mplus version 7.4 (Muthén & Muthén, Los Angeles, CA, USA) (Figure 1) to test volitional phase hypothesis. This analysis estimates the indirect effect coefficient for each indirect pathway between the independent variable (intention at T1) and the dependent variable (engagement at T3), accounting for the mediator (planning at T2) and moderator (treatment self-efficacy at T2). In this model, treatment self-efficacy was hypothesized to moderate the translation of plans into action. Engagement was modeled as a latent variable consisting of observed objective and subjective measures.

The bootstrapping method was used to test inferences about the significance of mediation effects when treatment self-efficacy

was high (1 SD above the mean) and low (1 SD below the mean), with 5000 bootstrap samples. Bootstrap CIs not including zero indicate a significant indirect effect. The bootstrap approach is considered superior to normal theory-based Sobel test for the significance of the mediation [63]. Results of the analysis are presented as standardized coefficients for each parameter.

## Results

### Preliminary Analysis

The descriptive statistics for the demographic variables are shown in Table 1. Attrition analysis revealed that there were no significant differences between T1 and T3 in sex,  $\chi^2_1(N=440)=2.7$ ,  $P=.10$ , and education,  $t_{431}=0.792$ ,  $P=.31$ . However, there was a significant difference between T1 and T3 groups in age,  $t_{438}=-3.34$ ,  $P<.001$ ; baseline PTSD symptoms,  $t_{438}=-2.79$ ,  $P=.02$ ; and trauma frequency,  $t_{415}=-3.15$ ,  $P=.005$ ; where those who completed T3 were older, had greater symptom severity, and had experienced a greater frequency of trauma. Table 2 shows the internal consistency of each of the measures used in the analyses, indicating that all measures had good to excellent reliability.

Table 3 displays bivariate correlation coefficients, means, and SDs for the HAPA study variables of the motivational and volitional phases. The correlations among motivational phase predictors (T1) for all who met the inclusion criteria (N=440) revealed significant positive correlations among intention and PCL-5 scores, outcome expectations, pretreatment self-efficacy, and perceived need. Correlations for the motivational predictors of those who created an account (N=115; shown below the diagonal line) showed similar patterns except for pretreatment self-efficacy, which no longer showed a significant correlation with intention.

The correlations between the volitional phase predictors (T1, T2, and T3) revealed that intention was significantly positively correlated with planning, treatment self-efficacy, and subjective engagement. Notably, treatment self-efficacy exhibited significant positive medium-sized correlations with all the motivational predictors and most of the volitional phase predictors. Interestingly, only the subjective measures of engagement showed significant positive correlations with intention.

Importantly, paired samples  $t$  tests indicated a clinically significant decrease in PTSD symptoms [59] for completers with at least subthreshold baseline levels of PTSD symptoms (PCL-5 >20; N=66) between T1 (mean 38, SD 13.11) and T3 (mean 25.56, SD 14.33),  $t_{65}=8.48$ ,  $P<.001$ ,  $d=0.48$ . In addition, outcome expectations significantly increased from T1 (mean 34.68, SD 5.07) to T3 (mean 39.29, SD 5.71),  $t_{65}=-6.62$ ,  $P<.001$ .

**Table 3.** Correlations, means, and SDs of Health Action Process Approach (HAPA) variables for time 1 (N=440), time 2 (N=161), and time 3 (N=115). Correlations in the upper diagonal region for time 1 show values for all participants who met criteria at time 1 (N=440). Correlations in the lower diagonal region for time 1 show values of participants who created an account (N=115). Time 1 was assessed at baseline, time 2 was assessed one week after baseline, and time 3 was two weeks after baseline. PCL-5: Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

HAPA variables	Time 1					Time 2		Time 3			
	1	2	3	4	5	6	7	8	9	10	11
1. PCL-5	1.00	.07	.10 <sup>a</sup>	.52 <sup>c</sup>	.41 <sup>c</sup>	.27 <sup>b</sup>	.25 <sup>b</sup>	.34 <sup>b</sup>	.33 <sup>b</sup>	.16	.12
2. Outcome expectations	.11	1.00	.34 <sup>c</sup>	.37 <sup>c</sup>	.54 <sup>c</sup>	.12	.36 <sup>c</sup>	.15	.15	-.10	.01
3. Pretreatment self-efficacy	.06	.19 <sup>a</sup>	1.00	.17 <sup>c</sup>	.32 <sup>c</sup>	.31 <sup>c</sup>	.38 <sup>c</sup>	.01	.09	.15	.12
4. Perceived need	.55 <sup>b</sup>	.44 <sup>b</sup>	-.05	1.00	.58 <sup>c</sup>	.33 <sup>c</sup>	.33 <sup>c</sup>	.41 <sup>c</sup>	.21	.14	.13
5. Intention	.54 <sup>c</sup>	.56 <sup>c</sup>	.02	.59 <sup>c</sup>	1.00	.31 <sup>c</sup>	.39 <sup>c</sup>	.38 <sup>c</sup>	.23 <sup>a</sup>	.02	.11
6. Planning						1.00	.40 <sup>c</sup>	.41 <sup>c</sup>	.15	.35 <sup>b</sup>	.20 <sup>a</sup>
7. Treatment self-efficacy							1.00	.39 <sup>c</sup>	.27 <sup>b</sup>	.16	.10
8. Subjective engagement frequency								1.00	.37 <sup>c</sup>	.33 <sup>b</sup>	.19
9. Subjective engagement minutes									1.00	.05	.15
10. Objective engagement pages										1.00	.55 <sup>b</sup>
11. Objective engagement minutes											1.00
Mean (SD)	24.83 (19.05)	32.67 (5.75)	28.54 (8.56)	17.67 (6.42)	17.51 (4.78)	32.54 (3.50)	24.53 (8.39)	7.85 (4.01)	75.61 (91.60)	81.77 (70.59)	54.16 (83.79)

<sup>a</sup> $P < .05$ .

<sup>b</sup> $P < .01$ .

<sup>c</sup> $P < .001$ .

### Motivational Phase Model

To test the motivational phase, an SEM was analyzed using T1 participants (N=440). Missing data for all items were 0.05% for T1, 1.24% for T2, and 1.39% for T3. Missing data were imputed with maximum likelihood procedure using AMOS v.24. Additionally, we performed a Little's missing completely at random (MCAR) test, a stricter criterion than missing at random. A Little's MCAR test with sex and employment as reference variables showed missing data were MCAR for pretreatment self-efficacy items,  $\chi^2_7=6.6$ ,  $P=.48$ , and perceived need items,  $\chi^2_{15}=10.9$ ,  $P=.76$ . Items were not MCAR for PCL-5,  $\chi^2_{55}=76.6$ ,  $P=.03$ ; outcome expectations,  $\chi^2_9=28.2$ ,  $P=.001$ ; or intention,  $\chi^2_4=10.0$ ,  $P=.04$ . However, for each of these measures, less than 0.06% of the items were missing, so all items were imputed together.

The original independence SEM yielded a poor fit with  $\chi^2_6(N=440)=245.1$ ,  $P<.001$ , CFI=0.526, TLI=0.210, and RMSEA=0.315 (90% CI 0.282-0.349). Modification indices suggested that correlating the measurement variables of PCL-5 scores and perceived need, outcome expectations and perceived need, and outcome expectations and pretreatment self-efficacy would improve overall model fit. These correlated errors were included in the final motivational SEM, producing an excellent fit,  $\chi^2_2(N=440)=5.0$ ,  $P=.08$ , CFI=0.995, TLI=0.974, RMSEA=0.058 (90% CI 0.000-0.124) that explained 48% of

the variance. Figure 1 shows the T1 motivational model. In this model, pretreatment self-efficacy (beta=.13,  $P<.001$ ), outcome expectations (beta=.36,  $P<.001$ ), perceived need (beta=.32,  $P<.001$ ), and PCL-5 (beta=.21,  $P<.001$ ) were significant predictors of intention and indicated support for the motivational model hypotheses.

### Volitional Phase Model

A moderated mediation analysis was performed to test the volitional phase with completers (N=115). We handled missing data using the full information maximum likelihood method. The assumption of full information maximum likelihood estimation is that missing data must be at least missing at random to have reliable outcomes. A Little's MCAR test with sex and employment status as reference points showed that missing data were MCAR,  $\chi^2_{13}=5.6$ ,  $P=.96$ . The bootstrap CIs revealed a conditional mediation effect of T2 planning on T3 engagement moderated by T2 treatment self-efficacy at low levels of treatment self-efficacy (-1 SD; B=0.89; 95% CI, 0.143-2.605). The conditional indirect effect was nonsignificant at high levels of treatment self-efficacy (+1 SD; B=0.49; 95% CI, -0.020 to 2.099). In the overall model, the direct effect of intention on planning (beta=.21,  $P=.008$ ) was significant, and the direct effect of planning on engagement (beta=.45,  $P=.06$ ) was approaching significance. The direct effect of intention on engagement (beta=.26,  $P=.11$ ) and the interaction effect between planning and treatment self-efficacy on engagement (beta=-.15,  $P=.37$ ) were not significant. These results suggest that for those

with lower treatment self-efficacy, T2 planning increased as T1 intention increased, which further enhanced T3 engagement.

Next, to examine whether the variables that were significantly different between the completers of T3 and dropouts affected the results, these variables were included in the model. The baseline PTSD was included in the motivational phase; thus, we did not include it in this analysis. Age and trauma frequency were entered in the model as covariates for engagement. Results were consistent with the results without the covariates. The conditional indirect effect was significant at low levels of treatment self-efficacy ( $-1$  SD;  $B=0.90$ ; 95% CI, 0.124-2.330). The conditional indirect effect was not significant at high levels of treatment self-efficacy ( $+1$  SD;  $B=0.47$ ; 95% CI,  $-0.043$  to 1.751).

## Discussion

### Principal Findings

The aim of this study was to examine the associations between motivational and volitional predictors of engagement with an eHealth intervention for trauma recovery. Previous engagement research focused primarily on a-theoretical approaches such as user characteristics and interventions features. These approaches are heavily tied to individual attributes or unique aspects of the eHealth intervention, and few offer general theoretical frameworks for understanding the process of engagement. Thus, no clear model exists to explain what factors influence engagement in eHealth interventions. To the best of our knowledge, this is the first study to focus on the psychological process of eHealth intervention engagement using the theoretical frameworks of social cognitive theory and the HAPA.

### Motivational Model

The motivational component of the HAPA model indicates individual intention to utilize an eHealth intervention for trauma is significantly related to outcome expectations, pretreatment self-efficacy, perceived need, and PTSD symptom severity. As hypothesized, higher baseline levels of pretreatment self-efficacy ( $\beta=-.13$ ) and outcome expectancy ( $\beta=.36$ ) predict greater intention to engage. These results support the findings of previous studies that used the HAPA model for predicting engagement with other health behaviors such as physical activity [38], breast self-examination, and rehabilitation participation [40,64].

In line with previous mental health research [42], this study indicates that higher baseline levels of perceived need are important in predicting greater intention ( $\beta=.32$ ). This study measured the perceived need for a coping support intervention, whereas previous HAPA studies measured a related construct of perceived risk of developing a disease or disorder [64]. Perception of need rather than risk proved to be an important consideration when examining intervention vs prevention behaviors.

Higher baseline PTSD symptoms also predicted greater intention ( $\beta=.21$ ). Research suggests that PTSD symptomatology is one of the determinants of the intention to seek help [27]. However, the original HAPA model [20] did not include symptoms as a predictor of intention. This is likely because of

the original model being used to explain physical health behaviors rather than mental health-related behaviors. This also highlights the potential differences in motivational factors between prevention programs and coping support (or symptom relief) interventions. Future studies should examine the differences in the motivational HAPA predictors for symptom-targeted interventions vs prevention programs.

Our results extend the HAPA motivational model suggesting that symptom severity (eg, PTSD) may be an important factor in understanding intention to utilize an eHealth program. These findings indicate that models such as HAPA may need to consider symptoms of physical or mental illness in understanding motivational factors related to intention. Though higher symptoms predicted greater intention to use the intervention, previous studies found higher baseline symptoms associated with lower usage [47]. This may suggest a nonlinear relationship between baseline symptoms and eHealth usage (ie, curvilinear). However, this has yet to be investigated.

### Volitional Model

The volitional section of the HAPA model suggests that the role of intention on engagement was differential relative to the individual perceptions of treatment self-efficacy. High intentions are associated with higher levels of planning, yet this relationship is relative to the level of perceived treatment self-efficacy. Planning promoted greater engagement only for individuals with low treatment self-efficacy ( $B=0.89$ ). Consistent with Schwarzer [50], intenders are motivated to change but often do not act because they may lack the right skills to translate their intention into action. In support of this, our study suggests that those intenders who do not have high confidence in their ability to continue to use a trauma recovery eHealth intervention employ self-regulatory strategies such as planning to facilitate engagement with the intervention. This has important implications for eHealth intervention utilization and treatment development.

### Clinical Implications

Improving engagement with therapy, whether in-person or online, can potentially lead to improved therapeutic outcomes. By understanding the impact of phase-specific self-efficacy, perceived need, and outcome expectations, interventions can be designed to enhance these perceptions, which in turn could lead to improved engagement. Specifically, these results suggest that communicating the expected outcomes of an intervention could have a significant impact on initial engagement. For those who have low perceived need and high PTSD symptoms, motivational enhancement to increase perceived need before treatment may lead to improved engagement [65]. Furthermore, for some individuals, including planning in intervention strategies may also improve treatment engagement. These, in turn, can potentially lead to decreased distress symptoms as intervention engagement is one of the most consistent predictors of positive outcomes [66].

Collectively our findings provide a new way to approach our understanding of engagement with eHealth interventions for trauma and eHealth more generally. Future studies should examine additional mediators and moderators to engagement.

For example, recent HAPA related research has found perceived social support and self-regulation (ie, motivation and willpower) to also mediate the intention-behavioral gap for physical activity uptake [37].

### Limitations

Although the motivational phase has a high amount of explained variance (48%), it might be because of the cross-sectional analysis. Future studies should examine this phase longitudinally. Whereas our 2-week study examined the pretreatment and treatment phases of the behavioral change process, the HAPA model typically is also applied to the maintenance and recovery phases of health behavior change. These phases may not apply to engaging in an eHealth intervention to manage psychological distress. However, it might be interesting to conceptualize the processes that would bring a person back to an eHealth intervention following an upsurge in symptoms. Individual perceptions of optimism or self-efficacy in managing these challenges, including returning to an eHealth program, are important to consider. This is akin to optimistic beliefs about one's ability to deal with barriers that arise while maintaining the behavioral change and recovery self-efficacy associated with one's conviction to get back on track after being derailed [40]. Additionally, our study investigated action planning (eg, when, where, and how) and did not consider coping planning (ie, how one will cope with obstacles). Past research has revealed differential effects of the two planning processes on the translation of intention to action [38]. Future studies should consider additional phases and examine these planning processes separately.

It should be noted that our research design did not allow us to compare the interaction of the HAPA model factors with important aspects of different eHealth trauma interventions (ie, active comparison group). Future studies will need to focus on deconstructing critical intervention components for different eHealth approaches in relation to the HAPA factors (eg, outcome expectations and perceived treatment self-efficacy).

Another limitation of this study was the high dropout attrition rate over the course of the three measurements. Of the 440 who met criteria for the study, only 115 completed the T3 survey. This attrition rate of almost 73.9% was not unusual for eHealth interventions [22] but did affect the quantitative methods used to test the overall HAPA model. Instead of looking at the model as a whole, two separate analyses were performed for the motivational and volitional phases, an approach that is clearly not optimal. A single analysis would require imputing 73.9% of the missing data. We argue this would compromise the accuracy of the results [67]. Thus, we decided to run two separate analyses. These separate models eliminated the possibility of examining the effects of the motivational predictors on the volitional phase of engagement. A further investigation into the relationship between demographic, mental health histories, and social cognitive predictors for

noncompleters vs completers may reveal valuable engagement related information as well.

Finally, and perhaps most importantly, the conceptualization of engagement needs further examination. Our measures of engagement focused on frequency and duration. Additional measures of engagement (sometimes referred to as measures of adherence) can include number of log-ins, number of exercises completed, and the number of days used [68]. Interestingly, the subjective measures rather than the objective measures were correlated with the HAPA predictors. This lends support to other research that found engagement to be a complex, multi-faceted experience that cannot be reduced to the patient's interactions with the intervention [53,69]. Our engagement conceptualization did not take into consideration potency, uptake, and user experience [70]. Adherence and dose, which are often defined in terms of predefined expected intensity of usage [45], require in-depth usage analysis of the eHealth intervention and associated outcomes to understand how much usage is needed for effectiveness. A recent study found more than a quarter of their participants used the intervention once (ie, "one-hit-wonder") because they could get the help they needed, suggesting intervention dosage must be considered when evaluating engagement [71]. Though we included a subjective measure of usage, other perceptions such as affect, attention, and interest were not measured [53,69]. Usability metrics that assess user satisfaction with the aesthetics of an eHealth intervention in terms of its layout, navigation, and content can also influence total engagement [72]. Future studies should evaluate other constructs related to engagement including affect, interest, dosage, and usability metrics. Finally, our study did not consider missing objective engagement data (those who failed to create an account). This type of missingness is not a random, and failure to consider it can lead to biased results [73].

### Conclusions

In conclusion, this study found support for the utilization of the HAPA model for understanding predictors of engagement with an eHealth intervention for trauma recovery. Results of this study help to clarify what makes eHealth interventions work [5]. This novel theoretical approach to eHealth intervention engagement research can be applied to other types of interventions in a variety of domains. The results of this study extended the HAPA model for health behaviors to include additional predictors of engagement. Perceived need, outcome expectations, pretreatment self-efficacy, and PTSD symptoms were all found to be significant positive predictors of intention; and planning mediated the translation of intention into engagement for those with low treatment self-efficacy. This study offers preliminary information suggesting possible differences in social cognitive predictors for coping support programs vs preventive interventions. Future research applying the extended HAPA model of engagement with other eHealth trauma interventions including mobile apps may offer a generalization of our findings.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CFI:** comparative fit index

**DSM-5:** Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

**HAPA:** health action process approach

**MCAR:** missing completely at random

**MTR:** My Trauma Recovery

**PCL-5:** Posttraumatic Stress Disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

**PTSD:** posttraumatic stress disorder

**RMSEA:** root mean square error of approximation

**SEM:** structural equation model

**T:** time

**TLI:** Tucker-Lewis index

**UCCS:** University of Colorado at Colorado Springs

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Original Paper

# Veterans' Perspectives on Fitbit Use in Treatment for Post-Traumatic Stress Disorder: An Interview Study

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## Abstract

**Background:** The increase in availability of patient data through consumer health wearable devices and mobile phone sensors provides opportunities for mental health treatment beyond traditional self-report measurements. Previous studies have suggested that wearables can be effectively used to benefit the physical health of people with mental health issues, but little research has explored the integration of wearable devices into mental health care. As such, early research is still necessary to address factors that might impact integration including patients' motivations to use wearables and their subsequent data.

**Objective:** The aim of this study was to gain an understanding of patients' motivations to use or not to use wearables devices during an intensive treatment program for post-traumatic stress disorder (PTSD). During this treatment, they received a complementary Fitbit. We investigated the following research questions: How did the veterans in the intensive treatment program use their Fitbit? What are contributing motivators for the use and nonuse of the Fitbit?

**Methods:** We conducted semistructured interviews with 13 veterans who completed an intensive treatment program for PTSD. We transcribed and analyzed interviews using thematic analysis.

**Results:** We identified three major motivations for veterans to use the Fitbit during their time in the program: increase self-awareness, support social interactions, and give back to other veterans. We also identified three major reasons certain features of the Fitbit were not used: lack of clarity around the purpose of the Fitbit, lack of meaning in the Fitbit data, and challenges in the veteran-provider relationship.

**Conclusions:** To integrate wearable data into mental health treatment programs, it is important to understand the patient's perspectives and motivations in using wearables. We also discuss how the military culture and PTSD may have contributed to our participants' behaviors and attitudes toward Fitbit usage. We conclude with possible approaches for integrating patient-generated data into mental health treatment settings that may address the challenges we identified.

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**KEYWORDS**

fitness trackers; patient generated health data; consumer health informatics; stress disorders, post-traumatic; PTSD; mental health; veterans

## Introduction

### Study Motivation

Approximately one in five adults in the United States will experience a mental health disorder each year amounting to 43.4 million adults with a diagnosable mental illness [1]. About 41% of these individuals will receive treatment in a variety of different formats and settings [2]. Across treatment formats and settings when measurement occurs, it typically consists of self-report measures. Traditionally, these measurements use methods such as paper questionnaires and self-tracking journals. However, increasingly, new avenues for collecting data are becoming available through wearable devices such as Fitbits [3] and mobile phone sensors. These devices could contribute to an understanding of a patient's daily experience and provide some indication of their behavioral and mental health [4,5]. The data from these devices are commonly referred to as patient-generated data (PGD) or patient-generated health data [6,7]. Unlike traditional clinical data, patients, not providers, are responsible for capturing and sharing PGD with health care providers (HCPs). As the penetration of wearable devices and mobile phones increases in the general population, there is an increasing interest in integrating such technologies with mental health treatment [8-10] and leveraging the potential of PGD to transform treatment practices and inform treatment evaluation. However, if such devices and data are going to improve clinical care, it is imperative to understand how they can be integrated with existing care practices to facilitate and enhance treatment.

Mental health issues are particularly prevalent in veteran populations. The rates of post-traumatic stress disorder (PTSD) are much higher for veterans than in the civilian population [11]. Consequently, a variety of approaches are being used to deliver mental health services to veterans [12-15]. One such approach is intensive outpatient programs (IOPs). In these programs, veterans stay at or near the treatment facility for a period of time to receive intensive mental health therapy and, in some cases, wellness interventions. These programs also provide a particularly interesting setting in which to study the integration of PGD into the care process. Specifically, these settings present unique challenges to the integration of PGD compared with other settings such as primary care [16,17] because of the exposure to other patients, frequency of interactions and access to clinicians, as well as environmental differences. Although there is a growing body of research on the use of PGD in primary care settings [18-20], there have been few studies that have examined the challenges of implementing PGD technologies in specialty mental health settings.

In particular, we have little understanding about how wearables and PGD could be integrated into intensive mental health treatment. To address this research gap, we conducted an interview-based study with veterans who had participated in a 3-week IOP. The IOP focused on veterans with PTSD. Participants in this program were given a complementary Fitbit. Because veterans were given minimal instructions on its use within the program, we were able to explore a broad range of motivations without a particular goal of their use in mind. The objective of this study was to understand how patients used

their Fitbit and their motivations for either using or not using the Fitbit. This user-focused study is the first step in identifying approaches to meaningfully integrate the Fitbit into mental health treatment.

The paper is organized as follows. In the next section, we present relevant background research related to PGD, veterans, and PTSD. In the Methods section, we present our research questions and describe our methodology. Next, in Results, we identify and describe key motivations that veterans had for using or not using the Fitbits during their IOP stay. We then discuss some key issues we learned about the integration of PGD in mental health treatment in the Discussion section. We conclude with some thoughts on future research directions.

### Background

#### *Use of Patient-Generated Data in Mental Health Care*

Previous studies on self-tracking in physical health conditions have shown that self-tracking can help patients improve self-management practices [21], motivate behavior change [22] such as increasing physical activity (PA) [23], and identify patterns in health and behavior [24]. Wearable consumer health tracking devices that record PGD are designed with the user as the primary stakeholder; yet increasingly, data from these devices are finding its way into clinical settings in multiple ways [6,7]. For example, such data might enter the clinical setting indirectly through the patient introducing it himself or herself to a provider or directly through application programming interfaces that could integrate the data into traditional clinical practices. Patients may share PGD with their HCPs for a variety of reasons including a desire for a personalized care plan, assistance in making sense of the data, and emotional support. However, there are a number of barriers to fulfilling these expectations [25]. Some of these barriers include a lack of time to review or discuss the data, few HCPs who are qualified to engage with the data, and insufficient mechanisms with which to transfer the data [16].

Although much of the current research on PGD use within the clinical environment has been in the context of physical health treatment such as irritable bowel syndrome [16], diabetes [26], and heart failure [27], there is a growing focus on the role of PGD in mental health treatment. The early work exploring the integration of wearables into mental health treatment largely centered on their use for the adjunctive goal of weight loss [28,29]. The goal of this research was to determine if wearable devices designed to promote PA would be acceptable and feasible in populations in high-risk and challenging populations. As such, these studies focused on individuals with serious mental illness (SMI; ie, bipolar disorder, psychosis, and severe depression). In general, it was found that people with SMI found the devices easy to use and useful for motivation, goal setting, facilitating social connection, and self-monitoring [28]. Indeed, integrating such devices into a lifestyle intervention for individuals with SMI was found to be able to significantly reduce weight below baseline levels [29].

More recent work has focused on using wearables to reinforce mental health treatments. In this work, researchers have focused on the mental health targets that could be reasonably assessed

or targeted through such devices. For example, PA has been used in several psychosocial treatments including behavioral activation [30] and exercise indicated for its mental health benefits [31]. A few studies have explored the potential of wearable devices to increase PA as a complement to existing mental health treatments. For instance, one pilot study explored the use of a fitness tracker in the context of group behavioral activation for the treatment of depression [8]. Overall, patients felt positive about the trackers and found that they increased awareness, provided peer motivation, provided opportunities to set and track goals, and provided reinforcement. However, they also noted some challenges, particularly in misrepresentation of information such as stairs climbed. Another pilot study of a lifestyle physical activation intervention for depressed women with alcohol dependence used a fitness tracker to support goal setting and self-monitoring in the intervention [10]. Participants in this study reported high levels of satisfaction with the intervention and with the tracker and reported higher use of PA to cope with cravings or reduce negative emotions. This research suggests that wearables and the data associated with them could potentially benefit mental health treatment.

### ***Post-Traumatic Stress Disorder***

PTSD is a debilitating condition that can develop after exposure to a traumatic event, that is, an event in which the individual experienced or witnessed actual or threatened, death, serious injury, or sexual violence. The core features of the disorder include re-experiencing symptoms in which the individual has unwanted and intrusive recollections of the event (eg, memories and nightmares), avoidance symptoms in which the individual purposely avoids reminders of the event, cognitive and mood symptoms including persistently low mood and distorted beliefs about the event (eg, inappropriate self-blame), and hyperarousal symptoms in which the individual is on alert (eg, scanning the environment) and on edge (eg, irritability and sleep disruption) [32]. PTSD is also associated with a number of other consequences including withdrawal, isolation, substance use, and suicidality [33,34]. There are several evidence-based treatments that have been shown to be effective for PTSD, including Prolonged Exposure (PE) and Cognitive Processing Therapy (CPT) [35]. These treatments typically involve 10 to 12 weekly 60-min sessions. More recently, evidence suggests that wellness interventions such as mindfulness and yoga may also have positive benefits in the treatment of PTSD [36,37].

Rates of PTSD in military personnel are higher than in civilian samples, with a recent meta-analysis indicating that 23% of veterans returning from Operation Enduring Freedom and Operation Iraqi Freedom suffer from PTSD [38]. However, uptake of evidence-based treatment among veterans and military service members is poor. For example, one study found that only 4% to 14% of veterans received any sessions of an evidence-based psychotherapy during the first 6 months of treatment at a Veterans Affairs specialty PTSD clinic [39]. Moreover, among those that do initiate treatment, evidence suggests that almost 40% terminate before receiving therapeutic benefit [40]. Poor accessibility and avoidance appear to be key barriers to PTSD treatment for veterans [41-43], indicating that novel treatment approaches are needed that can overcome these issues. An increasingly popular approach is to deliver

evidence-based PTSD treatment intensively, that is, daily treatment over several weeks with patients living at or near the treatment site, with the goal of reducing external distractions and practical barriers to treatment and providing less opportunity for avoidance [44]. These treatments also allow for the integration of multiple treatment modalities, including wellness interventions, to support treatment adherence and enhance treatment outcomes.

### ***Potential of Patient-Generated Data in Post-Traumatic Stress Disorder Treatment***

There are several reasons that the integration of wearable devices into the treatment process might help to promote the successful treatment of PTSD. First, a meta-analysis evaluating four randomized controlled trials (N=200) showed that PA was significantly more effective than control conditions in reducing PTSD symptoms [45]. A recent study by Powers and colleagues [46] showed that the addition of exercise to PE significantly augmented treatment outcomes relative to PE alone. The exercise augmentation group also showed enhanced brain-derived neurotrophic factor relative to the PE alone group, suggesting that the benefits of exercise may be because of an enhanced capacity for learning and memory.

Second, in addition to the capacity to support PA, other functions of wearable devices might also help to support treatment success. Sleep disruption is one of the most common and distressing symptoms of PTSD [47,48]. Yet, evidence suggests that front-line treatments for PTSD do a poor job of improving sleep [49-51]. Largely, clinicians rely on self-reported sleep disruption, which is known to be flawed and is often mistrusted by providers [52]. Thus, better understanding of a patient's sleep patterns and sleep quality using wearable device data could help to inform clinical decision making in the context of PTSD treatment, including the use of adjunctive sleep interventions.

Finally, beyond the specific functionality of wearable devices, it is also possible that the integration of PGD into the treatment setting could help to build rapport between the patient and provider [25]. Therapeutic alliance has been shown to be an important predictor of treatment outcome for PTSD [53].

### ***Summary***

As highlighted in this section, there is growing interest in the role of wearables and PGD in mental health treatment. In particular, although the use of PGD in PTSD treatment holds promise, more research is needed to investigate how PGD can be integrated into an intensive outpatient care setting for the treatment of PTSD. We were able to take advantage of the opportunity to address these two questions through interviews with veterans who attended a 3-week IOP for PTSD in which Fitbit devices were routinely deployed. Consequently, for this study, we had the following two research questions:

Research question 1: How did the veterans in the intensive treatment program use their Fitbit?

Research question 2: What are contributing motivators for the use and nonuse of the Fitbit?

Driven by the sociotechnical perspective [54] in which the meaningful use of a technological system is highly dependent on its interactions with people and processes, our study explores how the device was used in the program and how veterans perceived the opportunities and barriers to its potential usefulness and integration.

## Methods

### Setting

Participants were recruited from a database of veterans who had completed the IOP for PTSD at the Road Home Program located at Rush University Medical Center. The IOP consisted of a 3-week, daily treatment program that provided evidence-based treatment for PTSD. Each cohort of patients consists of 10 to 13 veterans.

Treatment at the IOP was multifaceted: the core elements of the program included daily individual and group CPT [55], as well as group mindfulness and yoga. Veterans also received a number of secondary intervention components including fitness, nutrition, psychoeducation on relevant topics, medication management (as needed), case management, art therapy, and acupuncture (optional). For assessment purposes, veterans were asked to complete four clinical survey assessments regularly to track their symptoms of PTSD (PTSD Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, PCL-5) [56,57], depression (Patient Health Questionnaire-9) [58], negative cognitions (Post-traumatic Cognitions Inventory) [59], and guilt (Trauma-Related Guilt Inventory) [60].

As part of the treatment program, veterans received a complimentary Fitbit Charge HR during their first day of treatment. The Fitbit Charge HR has passive activity tracking and sleep tracking capabilities including step counting, heart rate monitoring, and sleep monitoring. The companion Fitbit mobile app allows for manual input of weight, food, and water intake, as well as the review of all logged data. The use of the Fitbit was completely voluntary.

In a 15-min session, research assistants distributed Fitbits to the veterans and assisted with device set-up including syncing with a mobile phone if the veteran had one. Veterans were informed that the Fitbits were being provided because the IOP was interested in learning how health and activity levels changed over the course of treatment and after patients returned home. Veterans were also given a brief tutorial regarding the functionality of the Fitbit and were told that they can raise any questions about their Fitbit in their nutrition class the following morning. Veterans were also given the option of sharing their data for future quality improvement initiatives aimed at determining the value of the Fitbit data. If they agreed, they provided their Fitbit account log-in information to Road Home Program staff, who downloaded the information from their account at the end of the 3-week stay. In total, they were able to download Fitbit data for 73.8% (93/126) of patients who attended the IOP and received Fitbits.

### Recruitment and Participants

The program staff emailed recruitment messages to veterans that completed the IOP within 12 months before the study and had agreed to have the program store their Fitbit data. The first author also conducted in-person recruiting at the IOP for the ongoing cohort at the time. We interviewed a total of 13 participants (Table 1). Due to the in-person recruiting efforts, 5 of 13 (38%) of our participants came from the ongoing cohort. The longest a participant had been out of the IOP was 9 months. Our participant sample represents approximately 13% (13/96) of all veterans that completed the IOP in the 9 months before the interviews.

The participants consented once online and also over the phone before the interview. They did not receive compensation. This study received institutional review board approval from the authors' home institutions.

An overwhelming majority of the study participants were men (11/13, 85%). Their ages ranged from 30 to 61 years with a mean of 41 years (SD 10). The majority of study participants (9/13, 69%) entered the program with a PCL-5 score that classified their PTSD symptoms as "severe," and the remaining participants had a symptom classification of "moderate."

### Data Collection

In August and September 2017, we conducted 13 semistructured interviews with veterans and service members (hereafter referred to as "veterans") who had previously completed the IOP at the Road Home Program. Each interview lasted approximately 60 min. We employed a semistructured interview guide to allow for consistency across participants yet flexibility to further explore topics as they arose during the interviews. The phone interviews were conducted to ease travel burden on participants and allow for recruitment of veterans who did not live in the local area. All interviews were audio-recorded and transcribed by a member of the research team or by a company independent of the research team. Coding was conducted based on these transcripts. Data collection continued until data saturation was reached and interviews no longer revealed new or surprising information [61,62].

The interview guide was organized around our two research questions. For our first research question (research question 1: How did the veterans in the intensive treatment program use their Fitbit?), we asked participants about their experiences with self-tracking, both Fitbit and non-Fitbit, before and during their time in the program. For our second research question (research question 2: What are contributing motivators for the use and nonuse of the Fitbit?), we asked participants about their motivations and desired outcomes from using the Fitbit. For participants that used the Fitbit for self-tracking, we also asked what they did with their self-tracked data, including their data sharing practices and the actual outcome of tracking. Finally, we asked the participants about their attitudes toward self-tracking and additional envisioned uses of the Fitbit within the IOP. The full script for the semistructured interview guide is available in [Multimedia Appendix 1](#).

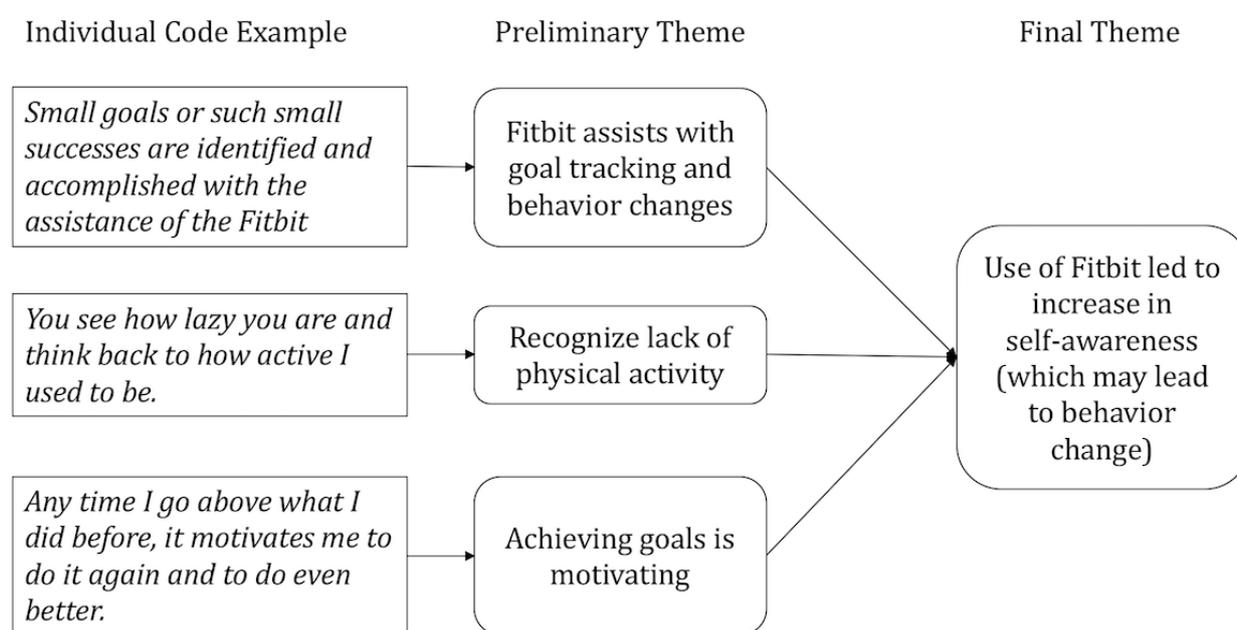
**Table 1.** Participant demographics.

ID	Age, years	Sex	Race	Number of months between IOP <sup>a</sup> completion and interview	Branch	PTSD <sup>b</sup> severity at baseline <sup>c</sup>
P1	41	Male	African American	3	Army	Severe
P2	57	Female	White	2	Army	Moderate
P3	52	Male	African American	4	Marine	Severe
P4	34	Male	White	6	Army	Severe
P5	41	Male	Other	4	Navy	Severe
P6	61	Female	African American	4	Army	Moderate
P7	38	Male	White	6	Army	Severe
P8	37	Male	White	9	Army	Moderate
P9	30	Male	White	0	Army	Severe
P10	36	Male	African American	0	Marine	Severe
P11	34	Male	White	0	Army	Severe
P12	34	Male	White	0	Army	Moderate
P13	42	Male	White	0	Army	Severe

<sup>a</sup>IOP: intensive outpatient program.

<sup>b</sup>PTSD: post-traumatic stress disorder.

<sup>c</sup>PTSD severity at baseline based on PTSD Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (PCL-5) scores. Scores of 37 to 49 correspond to moderate and 50 to 80 correspond to severe.

**Figure 1.** Example interview coding process.

## Data Analysis

The transcribed interviews resulted in 360 pages of electronic transcription data. For our data analysis, we used a thematic analysis approach [63]. This approach involves becoming familiar with the data, systematically identifying individual codes, and organizing these codes into broader themes (Figure 1). We used a single coder approach in which the first author iteratively identified individual codes during and after data collection, refining themes throughout the study. Single coder

approaches are methodologically sound when they include checks on validity and reliability. For our purposes, validity and reliability were promoted using a peer-checking process in which the first author iteratively reviewed a selection of code definitions and raw text with the second and final authors. This process is commonly used in qualitative research [64,65].

To outline our approach more specifically, the first author began analysis by systematically reviewing each transcript multiple times. Individual codes were created each time a participant

mentioned use or nonuse of the Fitbit (eg, participant says he identifies small goals and the Fitbit helps him reach them). Codes were also created when participants mentioned contexts surrounding use of the Fitbit (not pictured in Figure 1; eg, a veteran talking to the director of the program about Fitbit data). Individual codes were then grouped into preliminary themes based on similarities (eg, Fitbit assists with goal tracking and behavior changes). Memos were used to keep track of emerging common themes or developing codes. Finally, the preliminary themes were grouped into broader final themes (eg, use of Fitbit led to increase in self-awareness (which may lead to behavior change). The themes identified were grounded in the data itself as opposed to existing theories as per the thematic analysis approach. This approach allowed us to openly explore the individual contexts and motivations through which participants chose to engage or disengage with their Fitbit.

## Results

### Motivations for Use

In this section, we describe three major motivations for veterans to voluntarily use the Fitbit during the IOP: increased self-awareness, its contribution to supporting social interactions, and a desire to give back. In these findings, a recurring influencer of these motivations was the intensive treatment context in which patients were provided and used the Fitbits. Relatedly, veterans' motivations to use the Fitbit emerged only after receiving the complementary device and may differ from motivations of users who purposefully purchased a device on their own.

#### Increase Self-Awareness

The Fitbit's ability to track a variety of physical data increased the self-awareness of some of the veterans about their activities. In turn, this increased self-awareness provided veterans a mechanism to better understand their unhealthy behaviors. For instance, one veteran noted that the Fitbit helped him better understand his sleep patterns. He stated the following:

*[The Fitbit] really showed me how much sleep I was getting because I really didn't think it was that bad until I got the Fitbit. [P3]*

The Fitbit data provided the veteran with "concrete" evidence of previously unknown problems.

Another effect of increased self-awareness is that participants started to formulate goals and change their behaviors to meet those goals. One veteran (P3) stated the following:

*...When I got the Fitbit and I started putting 10,000 steps down as my goal, the first couple of times I didn't get it and I said "Well maybe I should change" or I said "No maybe I need to step up to the challenge" so that was how it started. [P3]*

For this veteran, becoming aware of his current state of physical fitness when he failed to reach his step count goals led him to adopt new habits such as walking between class and the dormitory and taking the stairs instead of the elevator.

Although increased self-awareness led mostly to positive behavior change, it is important to note that there were instances

where this was not the case. For instance, one veteran (P12) reported that a rising heart rate often accompanied anxiety that occurred while being in a crowd. So, he would review his heart rate data and attempt to recall the context around when his heart rate is elevated. He stated the following:

*Basically yeah just try to figure out "Hey the pulse was getting high—was I doing this or going there?" It might be because of anxiety or whatnot so I would just try and figure things out before I go back to that place again or whatnot. [P12]*

Thus, although the Fitbit aided him in being able to associate changes in heart rate with potential cues such as specific activities or his surroundings, P12 used this increased awareness to avoid situations that led to an increase in his anxiety. Avoidance is viewed as counterproductive to treating anxiety [66]. So, in this case, the increased self-awareness actually led to a negative behavior change from a treatment perspective. However, this association could be used in P12's therapy to help address the why his anxiety increased near those settings.

#### Supporting Social Interactions

During their 3-week stay, veterans interacted with their peers and clinicians daily. Consequently, one of their motivations for using the Fitbit was that it supported a variety of social interactions including competition, support, and conversation.

One of the many ways that veterans interacted with each other was through competition. Many of the participants stated that as veterans, they were trained to be competitive, and that is how they often interacted with each other in the military. During the IOP, this often took the form of a step-count competition, as illustrated in the following quote:

*People in the military always like to make everything into a little competition so it was just kind of one of those, you know, over the weekend or something like that, it'd be like "Oh well how much have you been walking?" and kind of pick on each other and just kind of using it as a I don't even know what the word is...kind of give us something to joke around about, you know. To kind of help break the mood up every once in a while you know, or kind of just take our attention off of what was going on. [P4]*

Increasing daily PA was a shared goal among many veterans. Therefore, they created online communities on the Fitbit platform for their cohort where the veterans could participate in step count challenges. These communities had leaderboards to highlight who took the highest number of steps in the day or week.

Second, the Fitbit also promoted supportive interactions between veterans and between veterans and their clinicians. For example, other veterans supported P2 who had a personal goal of taking one more step than she took the previous day in an effort to increase her PA, as illustrated in the following quote:

*What I try to do is I try to do one more step the next day but then sometimes I get depressed and I'm like "Oh I'm fat, what difference does it make?" but I have a couple of the ladies from the program and you*

*know they'll say "Okay we're going to do this together this week" and then I'm like "Oh okay" and then I'll try to get back into it. [P2]*

In this example, she tracked her steps using the step count feature on the Fitbit and shared the results with her peers. They used this data to encourage her in her progress toward her goal.

Although the Fitbit and its data were not formally integrated into the IOP program, veterans did use their Fitbit data in their interactions with clinicians. For instance, a participant was able to retrieve the number of hours he actually slept instead of just relying on his recall when his clinician asked him about his sleep, as illustrated in the following quote:

*I have the data. It says I haven't slept a lot versus I slept 4 hours and 28 minutes on average this week. In the medical field people are like hey 7-8 or 6-8 hours is the normal. You know, to be more specific. I bet if I went through my doctor or something like that they can be like 'Huh we need to look into it' hopefully. [P10]*

The Fitbit could allow P10 to more accurately provide specific data to the clinician. This could make his conversation with the clinician more meaningful to him.

Once the Fitbit made the veterans more aware of their issues, some of them would initiate dialogue with their therapy team about these problems. In one example, a participant who had been wearing his Fitbit described how he started a conversation about emotion management by reviewing his heart rate data with the nurse on staff and his clinician. He was ultimately able to tackle some issues through the mindfulness training he received, and this reinforced the usefulness of the Fitbit for him. He stated the following:

*...so that's how it all came full circle and why I continue to wear that app, or this Fitbit is...these are the things that it's just multifaceted and if we didn't have all those different programs all together at the Road Home, then I don't think the lightbulb would have clicked. [P7]*

For P7, discussing his Fitbit data with the different clinicians gave him a better understanding of how his physical health impacted his mental health. The notion of physical and mental connectedness is further examined in the Discussion section.

### **Giving Back**

Several participants stated that they hoped their Fitbit data would benefit future veterans, move research forward in the treatment of PTSD, and support the development of the IOP. One participant described his contribution of data in the following way:

*By sharing the data, it makes me feel like I'm helping contribute to other people's health. By helping to get them better by allowing them to look back and see what worked and didn't work and how well it's affected me. [P13]*

Other participants stated that they were particularly interested in research that could improve PTSD interventions for veterans, as illustrated in the following quote:

*...I hope that using our information that they're keeping track of helps the program down the road and help really kind of link some of the things between PTSD and physical wellbeing and things like that to kind of help guide physicians and dieticians and things like that to kind of what would be better for the veterans instead of kind of going off of I guess what I would call the standard type thing of "Oh hey you need to cut back on red meats. You need to start eating more vegetables." [P4]*

This example also highlights the potential relationship between physical and mental health that participants frequently mentioned during the interviews.

Participants also reported using the Fitbit to express gratitude for having the opportunity to participate in the program. One participant emailed a screen capture showing the number of steps he took that day to the director of the program. He stated the following:

*I wanted them to know that I was taking the program seriously. Like what you gave me—the resources you gave me—I used them. That's big with me...I wanted them to know that physically, I'm doing this thing as well as mentally. [P3]*

P3 and a few other participants believed that taking the program "seriously" (fully engaging) meant not only putting in effort to pay attention in therapy and do homework but also wearing the Fitbit.

### **Motivations for Nonuse**

In the previous section, we described motivations for using the Fitbit. However, not all participants used the Fitbit. In this section, we identify three major reasons that the veterans did not use the Fitbit or certain features of the Fitbit.

#### **Lack of Clarity About Purpose**

Participants who did not use their Fitbits questioned the benefits of tracking for their self-improvement or as part of their therapy. Because there was little direction from the IOP about the role of the Fitbit in the program, many veterans did not understand its purpose. One participant who described himself to be in good physical shape abandoned use of his Fitbit after the first week at the program. He stated the following:

*I was the only active duty person in the class and some of them were...some of my peers were overweight and some of them had injuries so for me, at my age, I go off of our physical fitness test and our height and weight standards and that's how I gauge myself so I mean I can't compare myself to somebody that's not either required to exercise or has an injury. [P5]*

P5 primarily thought of the Fitbit as providing him information about his physical status. It was not made clear to him how the Fitbit could support the broader goals of the program.

The IOP's approach to treatment was holistic and incorporated trauma-focused therapy with physical wellness activities, but many veterans did not see this link, which affected their use of the Fitbit. When one participant (P13) was asked why he did

not discuss his Fitbit data with his clinician, he explained that his priority was therapy. Therefore, he wanted to focus on the homework assigned by his individual therapist that he believed would more directly address his mental health concerns. He stated the following:

*Yeah the therapy is what we were there for versus the physical. I mean, this is for PTSD and I know my physical injuries were a lot but we were talking more about mental so that was what I was focused on. I think the little bit of physical stuff we got is a big help but I don't think that being in that program we were worrying about the physical aspect. I know they were trying to teach us stuff and that was good but we were so wrapped up on the mental that the little bit of physical stuff we were doing was second and I think that's where we needed to be. [P13]*

The belief that physical and mental wellness were connected varied between participants. Some participants saw them as disparate components of health, but others believed they were intertwined. P7 describes how providers at the IOP taught him how physical and mental health were connected, as illustrated in the following quote:

*...I was always just thought like okay physical activity means physical health but there they spent the time to explain that physical activity does mean physical health but it could also mean mental health for a lot of different reasons and so that really struck a chord with me. [P7]*

Not all participants left the program with the same belief as P7, and the extent to which veterans believed that physical fitness influenced their mental wellness was a motivator to engage with the Fitbit or a reason to disengage.

### **Lack of Meaningful Data**

The veterans were not given any formal training on how to use the Fitbit or interpret the data, and this inability to derive meaning from the data discouraged some participants from using the Fitbit. For instance, P1 was unable to decipher how the Fitbit tracked his sleep and did not understand the data as it was presented in the mobile app. Consequently, he abandoned the sleep tracking feature:

*Tell me a little bit more about sleep because it's interesting that you kept a sleep journal for a little bit but you didn't track sleep with your Fitbit from what I understand [Interviewer]*

*No I did not. I tried to a couple of times. Honestly maybe because I didn't understand it. How can it tell when I wake up or if I was asleep or?...I didn't get any detail out of it...I didn't look at it in detail to see how it really tracks my sleep like how accurate is it? So I chose not to. [P1]*

As the example highlights, Fitbits may reduce the burden from manual tracking, but if veterans do not understand or trust the data, it could be difficult for them to be motivated to use it.

However, even when participants know how to use it, the Fitbit may not capture the issues that they want to better understand.

In the following example, P4 discusses how the Fitbit's measures for sleep does not reflect the fact that he experiences night terrors, which is common in patients with PTSD [67].

*I mean they were useful but not at kind of what I was hoping for as far as trying to show how restless I was, you know, or my...hope...trying to think how...like kind of help try to track my heart rate or anything like that because it was tracking just movement during sleep and not really heart rate or anything like that. [P4]*

*So it wasn't quite useful for sleep because it was only tracking movement and not heart rate so you're saying if it did track heart rate during sleep that would have been more telling? [Interviewer]*

*I would think so, you know or some way to kind of show, you know something other than just movement because I have, with my night terrors, I don't know what it's called right now pretty much I would be sweating really bad even though...like I'd be wrapped up in a blanket feeling cold but sweating at the same time. [P4]*

The Fitbit did not have the mechanisms to detect night terrors, and therefore, tracking sleep using the Fitbit was not perceived to be valuable. For these participants, tracking a particular behavior could have proved to be meaningful to them; however, the Fitbit itself was unable to meet the user's aims.

### **Challenges in the Veteran-Provider Relationship**

The rapport between a therapist and patient is critical for effective therapy [53], yet several participants mentioned that veterans have an inherent distrust of HCPs, which made it difficult for them to share information including Fitbit data. P8 explains how veterans may be hesitant to disclose information to clinicians to avoid feeling "judged" by someone who has not experienced war, as illustrated in the following quote:

*I really upset some therapists when I told them I could get more out of a soldier at a smoke pit saying you can get from an office...They [therapists] weren't there. They didn't experience any of it. They may have secondary PTSD from hearing everybody else's stories but it's that first-person understanding that helps. [P8]*

When asked for his thoughts on veterans initiating a conversation regarding the Fitbit data with clinicians at the IOP, he viewed the relationship in a more adversarial way, which prevented him from wanting to share information. He stated the following:

*"They're not telling us what's happening. How can we help these guys if they don't open up to us?" It's a battle that a lot of these therapists are having with us. I don't really understand how we could initiate something like that because I've been actively trying to combat PTSD for the last nine years in October. [P8]*

Other participants with a similar hesitation suggested that it's best if clinicians initiate a conversation regarding the Fitbit data.

A few mentioned that they would openly share their data if they were directly asked, as illustrated in the following quote:

*Who would I share it with? Nobody ever asked. If they had asked I would have shared it. But they didn't ask. I mean even when they ask for the blood tests and stuff, they had some people that had a hard time taking blood but even then they said "No no, keep trying" ...and I don't know what information they need or who it is. I would have shared it with them. [P2]*

The motivations surrounding how a veteran could use the Fitbit data in their sessions with clinicians are complicated. However, before this data can even be used, there has to be a level of trust built between the veteran and therapist.

## Discussion

### Principal Findings

This study contributes to a growing body of research on PGD use in mental health care. Although our investigation took place in a single setting in which Fitbit Charge HR devices were distributed, many of our findings were consistent with findings from studies exploring people engaging in self-tracking in other settings, as well as tracking enthusiasts often referred to as “quantified-selfers.” For example, self-awareness is a common motivation that is not unique to our veteran population [68,69]. Previous studies on individuals that track health information, financial information, or other life information found that tracking plays an important role in how people learn about themselves and use that information to change their behavior [24,68]. Similarly, we found that veterans who were motivated to use the Fitbit often used it to learn about their current health status, and in some cases this led them to change their behaviors. However, because this was the first study to explore motivations of individuals undergoing mental health treatment, we also identified some unique issues in this study. For instance, in previous studies of PGD, patients were often eager to share their data with clinicians [25]. However, in this study, some veterans had difficulty sharing data with their clinicians because of their concerns that the clinicians could not understand them because of the clinician’s lack of experience in the military. This hesitancy resulting from different backgrounds was not found in other studies. Furthermore, although this research reaffirms findings of PGD research in other settings [16,17], it also expands it into a domain that has not been studied before—veterans who engaged in an intensive mental health treatment to help them manage their PTSD.

In the rest of the discussion, we turn our attention to the military culture, PTSD and Fitbit use, the integration of PGD into mental health treatment settings, and the transformative opportunities that are possible with PGD.

### Military Culture, Post-Traumatic Stress Disorder, and Fitbit Use

Veterans have a shared experience of military life and culture that differentiates them from the general population [70]. Military life is more interdependent than civilian life, with military personnel undergoing training that emphasizes a commitment to each other and service to their country. It also

has ranks and promotions that makes a social hierarchy clearly visible. Participants commonly identified features of the Fitbit that could be tied to military values or could leverage characteristics of “military people.” For example, many participants noted that challenges such as the step competition appealed to the competitive nature that is common among individuals who had served in the military. Furthermore, the close camaraderie that is part of the military is reflected in the participants’ willingness to use the Fitbit to benefit future veterans of the program. These differences between military and civilian life have led to calls to tailor health care specifically to this population in what is deemed veteran-centric care [70]. This model mostly focuses on acknowledging issues that might affect behavior such as complex deployment and reintegration needs or understanding of common issues facing veterans including PTSD, traumatic brain injuries, depression and suicide, or amputations and rehabilitation care. Fitbits could play an important role in this model because of the physiological data it could provide clinicians about the veterans that could be used to better understand their problems. Our findings highlight some of the motivations that are drawn from the military culture that affected how veterans were motivated in using the Fitbit.

The interdependent nature of military culture might have been accentuated by aspects of the IOP program. Participants in this program come from around the country to spend 3 weeks receiving treatment for PTSD, leaving their lives, and sometimes their families behind. Although this experience may be familiar to military personnel, it is still different from many other health care treatment settings that treat mental health issues such as PTSD. Many IOP participants described a sense of camaraderie with peers from their cohort. This camaraderie could be leveraged to encourage them to use the Fitbit and be attentive to the data. Furthermore, this camaraderie could also help increase veterans’ awareness of each other that could be used for behavior change in the same way that participants described self-awareness for behavior change. For example, if veterans became more attuned to how others were sleeping, it might increase empathy for peers when going through a day’s treatment after a poor night’s sleep or make the individuals more attuned to cues linked with poor sleep (eg, emotion regulation, attention, and focus). Facilitating awareness of others might contribute to a culture of discussion around links between insights gleaned from one’s data and emotional and physical health, which could in turn also facilitate sharing and use in their treatment.

Our findings indicate some promising future considerations for PGD and its contribution to helping address mental health issues such as PTSD. First, veterans were motivated to use the Fitbit to increase their self-awareness that could ultimately lead to behavior change. Self-monitoring is a common treatment element used in a variety of effective mental health treatments with the goal of promoting self-awareness [71]. PGD could support current practices of self-monitoring or even open up new opportunities for self-awareness. Second, PGD might be able to better quantify aspects of mental health conditions by providing a more “objective” history of this information than patients could provide. As participants indicated, they could discuss physiological avoidance with the example of heart rate

data or could potentially more accurately report their sleep quality or quantity on a given night. Finally, mental health treatments might have benefits that extend beyond mental health symptoms alone. In efforts to reduce assessment burden, clinicians and researchers are often limited as to the number and breadth of questions they can ask patients. PGD could help clinicians better understand the broader impact of treatment and help clinicians better tie treatment activities to meaningful changes in a patient's life.

### **Integrating Patient-Generated Data Into Mental Health Treatment**

There are a number challenges that we must address as we consider the best approaches for integrating PGD into care settings for mental health treatment. We have to consider issues related to processes, policies, and technologies. Furthermore, we need to better understand the issues related to the growing focus on combining physical and mental health treatments [72,73].

#### ***Processes, Policies, and Technologies***

Researchers have identified a variety of organizational [74] and individual factors [75] that affect the implementation and use of new technologies. These issues include designing policies and processes to support the use of the technology along with developing training and implementation strategies for the technology [76].

First, before any technology such as Fitbits are implemented in a care setting, there has to be clear policies in place to handle issues such as privacy and sharing of data. This is particularly important when dealing with wearable devices that continually collect data about the individual [77]. The concerns about privacy were raised by the veterans, who were unsure about whether clinicians were allowed to look at or discuss the Fitbit data because of privacy rules. Therefore, in a setting such as the IOP, it is important to develop clear policies about privacy-related issues such as who can see the PGD, how can patients change their privacy preferences, and who owns the data.

Second, it is important to ensure that the technology is integrated into the workflow of the organization. Researchers have identified a variety of challenges that arise when technologies are not properly integrated. These challenges include resistance to adoption, development of workarounds, and lack of use [78]. One of the primary challenges to effectively utilizing the Fitbit was the lack of any process to integrating it into the IOP workflow. Besides a short training session on how to use the Fitbit, the veterans were not provided with any details about how the Fitbits could be used in their care process during their 3-week stay. Furthermore, there was no formal process to share the data with the clinicians. The lack of processes for incorporating the Fitbits into the treatment plan for the veterans was a major barrier for use. As our findings noted, one major disincentive was the lack of a clear purpose. This lack of purpose led to the lack of clear processes in the IOP.

Finally, the successful implementation of any technology requires a well-designed implementation and user training plan [76]. When this does not happen, technologies often fail, or the

adoption of these technologies are much slower than what was anticipated [79]. In the IOP, the veterans were provided with minimal training on how to use the Fitbit. Furthermore, the lack of an implementation plan for incorporating the Fitbit into the IOP led to confusion about its benefits. As one veteran noted, he did not see the need to use the Fitbit because he was not dealing with physical issues but rather mental ones. Because of a lack of training, it was not clear to the veteran how the Fitbit fit into the broader treatment plan. The lack of a clear implementation plan and effective user training increased the barriers to using the technology.

### ***Building Connections Between Physical and Mental Health***

The use of self-tracking devices for mental health represents both a growing interest in technology for mental health [80] and trends in health care generally to combine physical and mental health treatment in integrated behavioral health models [81]. Indeed, our findings suggest that a key aspect of facilitating this connection is to increase patients' awareness of how using these devices to track physical data can actually support mental health care. Participants who did not see this connection were unmotivated to use the Fitbits because of their views that they were in the program to work on their PTSD as opposed to physical health concerns. This could have been mitigated through more direct instructions as to how to use the Fitbit and data gained from it in this clinical context. In some cases, although there were no clear instructions, participants spontaneously made these connections, finding relationships between things such as heart rate and anxiety, sleep and type of therapy received (eg, sleep better on days with art therapy), and PA and mood. However, many of the veterans did not see the connection, which led to underutilization of the Fitbit. Consequently, organizations who want to utilize self-tracking tools such as the Fitbit must more clearly connect the relationship between physical and mental health.

### **Transformative Opportunities With Patient-Generated Data**

PGD has the potential to create new opportunities and new conversations in mental health treatment. Our theme of veteran-provider relationship is an important finding because the relationship between patient and provider is a critical determinant of successful mental health treatment [82] and has been found to predict improvement in exposure-based treatments for PTSD [83,84]. Along these lines, PGD could benefit this relationship by providing concrete examples that providers could use to tailor their treatments and thus, allow providers to more effectively treat veterans. Additionally, sharing PGD could start conversations that build trust and understanding between patient and provider by allowing the provider an additional window into a patient's life. However, the use of such data and devices in clinical practice and clinical research does raise a host of ethical questions [85]. Yet, dealing with these questions is likely a necessity given the increased attempts toward using this data in the health space.

PGD also represents a different type of information entering the clinical context for mental health treatment. As mentioned earlier, mental health assessment is largely based on self-report,

reflective measurements, and questions. Many providers open their sessions by asking patients about what has happened since the last time they met. PGD might facilitate a different type of interaction—one that explores patterns or specific values in data collected outside the session and in real-world contexts. In light of this, it would be useful to think about how PGD can expand or change thinking toward clinical data rather than viewing it as an unobtrusive and passive method for replacing that data. As such, future work should start from the viewpoint of what PGD can offer by itself, and interview studies, such as this one, are valuable tools to guide such work.

### Limitations and Future Work

Given the dearth of research in this area, this study was an important step forward. However, as an early step into a new research area, the study had several limitations that could be addressed in future work. Our sample was self-selected in several ways, including only using veterans who agreed to have Road Home download and store their Fitbit data. As such, our results might be oriented toward those who might be more interested in using the Fitbit rather than the average veteran. However, we do note that overall 73.8% (93/126) of those receiving Fitbits opted to provide their data, so this still represents a large proportion of veterans treated in this program. Furthermore, as an initial study, our participant screening process included any veteran that completed the IOP to reach a broad understanding of device usage in our study context. Future studies could use a purposive sampling method to select veterans with specific use patterns, which could provide a deeper understanding of what drives those specific patterns and ensure that veterans with disparate use patterns were included in the data collection. Additionally, we only interviewed veterans at a single time point—after they finished the IOP program. Motivations to use the Fitbit and use of the Fitbit itself may change over time. Depending on what is tracked, the motivation to start tracking and maintain tracking may be different. It is also possible that motivations might be tied to different stages on a veteran's journey or the stage of PTSD treatment. Future studies could investigate how wearables are used at different stages of treatment and post treatment.

Although our data did not show that gender impacted interview responses, given that the majority of our participants were male (11/13, 85% male; 2/13, 15% female), our study may not fully reflect the experience of female veterans in the program. Given that women comprised 9.4% of the total veteran population in the United States in 2015, and this is projected to steadily increase over the next 30 years, research on female veterans

may become increasingly relevant [86]. Future work on the use of wearables by specifically women veterans may reveal whether there are gender-based influences on motivations for use.

We interviewed patients for their motivations and uses of the Fitbit, but clinicians may have a different set of motivations and uses for the Fitbit data. Patients generate data through wearables, but providers determine what to integrate and how to integrate into their care practice. A future study on the provider's perspective on PGD may answer these questions and highlight opportunities and obstacles to the use of PGD in treatment. Future research could also investigate how PGD can improve therapeutic relationships and facilitate new exchanges between patient and provider.

Finally, in this study, we focused on data from the Fitbit device, as well as its mobile app, but clinical survey measures or worksheets may also be considered a form of self-logging data. Some definitions of PGD dictate that to be considered PGD, tracking must be patient-initiated as opposed to clinician-initiated, whereas others refrain from making this distinction. As the definition of PGD is only starting to be applied in the field of mental health, questions arise such as whether symptom tracking through surveys is within the realm of PGD or if it is considered a clinical tool. Further work is needed within the field of mental health on how to define PGD.

### Conclusions

Our study identified several reasons veterans undergoing intensive treatment for PTSD decided to use or not use Fitbits provided to them by the treatment program. We found that the participants of our study were motivated to use the Fitbit to increase their self-awareness, interact with fellow veterans and HCPs, and as a means of giving back to other veterans. We also found that participants of the study stopped using the Fitbit for reasons including lack of clarity of the purpose of tracking, the inability to track behaviors of interest, and challenges in the veteran-provider relationship.

As researchers continue to investigate the effectiveness of mental health treatments that integrate wearables, it is important to develop an understanding of the users of these tools. This study is one of the first to explore the patient perspective of using wearables in mental health treatment. Engaging patients will be critical to realizing the potentials of wearables and PGD in mental health treatment. We hope our research will help in future design and implementation of sociotechnical systems that integrate wearable data with clinical data.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Semistructured interview protocol.

[[PDF File \(Adobe PDF File\), 305KB - mental\\_v5i2e10415\\_app1.pdf](#)]

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## Abbreviations

**CPT:** Cognitive Processing Therapy

**HCP:** health care provider

**IOP:** intensive outpatient program

**PA:** physical activity

**PCL-5:** PTSD Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

**PE:** Prolonged Exposure

**PGD:** patient-generated data

**PTSD:** post-traumatic stress disorder

**SMI:** serious mental illness

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Original Paper

# Improvement of Attention-Deficit/Hyperactivity Disorder Symptoms in School-Aged Children, Adolescents, and Young Adults With Autism via a Digital Smartglasses-Based Socioemotional Coaching Aid: Short-Term, Uncontrolled Pilot Study

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## Abstract

**Background:** People with autism spectrum disorder (ASD) commonly experience symptoms related to attention-deficit/hyperactivity disorder (ADHD), including hyperactivity, inattention, and impulsivity. One-third of ASD cases may be complicated by the presence of ADHD. Individuals with dual diagnoses face greater barriers to accessing treatment for ADHD and respond less positively to primary pharmacologic interventions. Nonpharmacologic technology-aided tools for hyperactivity and inattention in people with ASD are being developed, although research into their efficacy and safety remains limited.

**Objective:** The objective of this preliminary study was to describe the changes in ADHD-related symptoms in children, adolescents, and young adults with ASD immediately after use of the Empowered Brain system, a behavioral and social communication aid for ASD running on augmented reality smartglasses.

**Methods:** We recruited 8 children, adolescents, and young adults with ASD (male to female ratio of 7:1, mean age 15 years, range 11.7-20.5 years) through a Web-based research signup form. The baseline score on the hyperactivity subscale of the Aberrant Behavioral Checklist (ABC-H), a measure of hyperactivity, inattention, and impulsivity, determined their classification into a high ADHD-related symptom group (n=4, ABC-H $\geq$ 13) and a low ADHD-related symptom group (n=4, ABC-H<13). All participants received an intervention with Empowered Brain, where they used smartglasses-based social communication and behavioral modules while interacting with their caregiver. We then calculated caregiver-reported ABC-H scores at 24 and 48 hours after the session.

**Results:** All 8 participants were able to complete the intervention session. Postintervention ABC-H scores were lower for most participants at 24 hours (n=6, 75%) and for all participants at 48 hours (n=8, 100%). At 24 hours after the session, average participant ABC-H scores decreased by 54.9% in the high ADHD symptom group and by 20% in the low ADHD symptom group. At 48 hours after the session, ABC-H scores compared with baseline decreased by 56.4% in the high ADHD symptom group and by 66.3% in the low ADHD symptom group.

**Conclusions:** This study provides initial evidence for the possible potential of the Empowered Brain system to reduce ADHD-related symptoms, such as hyperactivity, inattention, and impulsivity, in school-aged children, adolescents, and young adults with ASD. This digital smartglasses intervention can potentially be targeted at a broader array of mental health conditions that exhibit transdiagnostic attentional and social communication deficits, including schizophrenia and bipolar disorder. Further research is required to understand the clinical importance of these observed changes and to conduct longitudinal studies on this intervention with control groups and larger sample sizes.

**KEYWORDS**

autism spectrum disorder; Asperger syndrome; augmented reality; virtual reality; artificial intelligence; affective computing; patient education as a topic; ADHD; attention deficit disorder with hyperactivity; attention; smartglasses

## **Introduction**

Autism spectrum disorder (ASD) is a lifelong developmental disorder characterized by challenges in social communication and the presence of repetitive behaviors or restricted interests. Many people with ASD experience symptoms of inattention and hyperactivity, and approximately one-third of people with ASD have diagnosable attention-deficit/hyperactivity disorder (ADHD) [1,2]. There are considerable gaps in knowledge in how to provide optimal assessment and management of this group of patients [3]. Early diagnosis and intervention are beneficial for both ASD [4] and ADHD [5]. Evidence from genetic, cognitive, and behavioral research suggests that when ADHD and ASD co-occur, they may be considered a separate overarching condition [6-8], and a variety of ASD-ADHD developmental subtypes have already been proposed [9].

The combination of ASD and ADHD has been linked to greater cognitive impairment [10,11], general psychopathology [12,13], emotional processing impairment [14], and to significantly higher rates of some hyperactivity and impulsivity symptoms than in individuals with ADHD alone [15]. Furthermore, the co-occurrence of ADHD and ASD is associated with a greater risk of developing other psychiatric disorders, such as schizophrenia, bipolar disorder, and anxiety disorder, than in controls and individuals with either condition alone [16]. The pervasive nature of impairments in social communication and attention across psychiatric disorders may suggest that these deficits should be investigated transdiagnostically, an approach advocated by the US National Institute of Mental Health Research Domain Criteria framework [17]. Attentional and social communication deficits have been identified in many disorders of brain function, including schizophrenia [18,19], bipolar disorder [20,21], anxiety disorders [22], and traumatic brain injury [23,24]. Therefore, the study of individuals with combined ASD and ADHD can help elucidate the basis of a wide variety of disorders of the brain.

It is therefore important to address ADHD. While the leading approach has been psychopharmacologic medication, people with co-occurring ASD and ADHD have been found to be less likely to receive appropriate treatment for their ADHD [15] and appear to respond less favorably to treatment than do individuals with ADHD alone [25]. Additional concerns about ADHD treatment, in particular stimulant medication, focus on their long-term effectiveness [26], side effects [27], and parental reservation about their use [28]. Yet evidence also shows that leaving individuals with untreated ADHD may lead to considerable negative social and behavioral sequelae, including greater risk of academic failure [29], alcohol and drug use [30], and contact with the criminal justice system.

There has been growing interest in the use of cognitive training in ADHD, a nonpharmacologic approach that may use neurofeedback or novel digital approaches, or both. Recent studies have shown promise [31,32], although historic interventions have raised questions regarding their effectiveness [33]. There is also concern that technology may actually prove to be distracting and reduce learners' attentiveness to educational tasks [34-36].

Little research has described the impact of digital interventions on people with ASD who demonstrate ADHD symptoms [37]. Some preliminary research has shown the utility of augmented reality interventions in ASD samples [38-40]. Intervention based on augmented reality has also been shown to help to improve ADHD symptoms in people with ASD, with improvements in both selective and sustained attention in children with ASD [38]. We have previously described the delivery of social communication coaching on augmented reality smartglasses via Empowered Brain (previously the Brain Power Autism System; Brain Power LLC) [41]. Our early pilot report on 2 boys with ASD demonstrated short-term improvements in the hyperactivity subscale of the Aberrant Behavioral Checklist (ABC-H) [41], a validated instrument that assesses hyperactivity, impulsivity, attention, and noncompliance [42]. The ABC-H has previously been used as a key outcome measure in ADHD treatment studies in children with ASD [43-47].

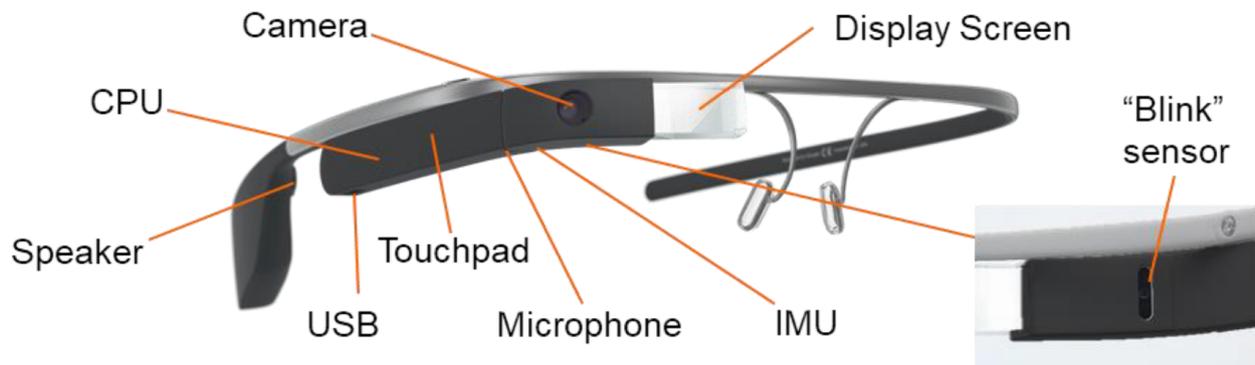
## **Objectives**

In this pilot study, we explored the short-term effect of an Empowered Brain intervention on ADHD symptoms in a group of 8 children, adolescents, and young adults with ASD. We documented caregiver-reported ADHD symptoms as measured by the ABC-H. Further, we discuss the implications of these results on future research in the field.

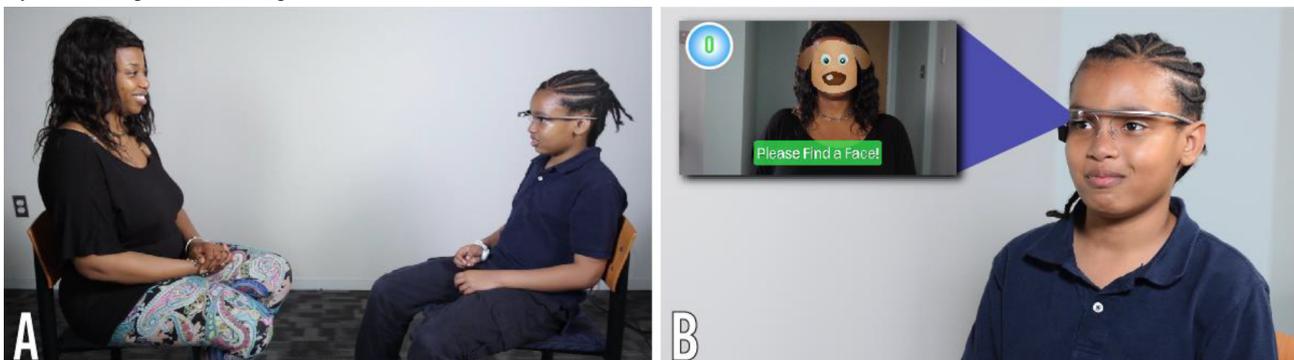
## **The Empowered Brain System**

Empowered Brain is a combination of modern smartglasses and educational modules targeting socioemotional and behavioral management skills [41,48]. Smartglasses are lightweight head-worn computers with a small transparent display that can provide guidance to users through both visual and audio cues (Figure 1 [49]). Empowered Brain can collect a wide variety of user data through an in-built sensor array that includes a camera, microphone, touchpad, "blink" sensor, gyroscope, and accelerometer. Empowered Brain includes modules that use these sensors to deliver social communication and cognitive skills coaching. This digital approach may be particularly valuable to both people with ASD [50] and people with ADHD [51,52].

**Figure 1.** Google Glass prototypical head-worn smartglasses with in-built sensors, as well as a small screen and a bone conduction speaker to provide a private audiovisual experience. Empowered Brain integrates Google Glass with a range of assistive and educational modules. User-centered design is a critical part of producing assistive technology for autistic children [49]. The modules were developed through an iterative, user-centered design and evaluation process in conjunction with behavioral specialists and families with autistic children. CPU: central processing unit; IMU: inertial measurement unit; USB: universal serial bus.



**Figure 2.** Demonstration of the use of the Empowered Brain system. (A) Child and partner sitting opposite one another with child wearing smartglasses. (B) Close-up view of the child wearing the smartglasses. The child can see the in-game view, displayed on the left side of the insert, through the optical display of the computerized smartglasses.



For example, Empowered Brain incorporates the Face2Face module, software that helps guide users to pay attention to socially salient visual stimuli (human faces; Figure 2 and Figure 3). The ability to pay attention to important social stimuli, and to direct gaze toward the most socially salient features of the face, has been identified as a key challenge in ASD [53]. When the Face2Face module is running, Empowered Brain is able to identify the presence of human faces within its visual field and helps direct users toward the human faces through engaging visual cartoonlike images and guidance arrows. As the user pays more visual attention to the human face, they earn points and other in-game rewards. The points stop accumulating after a short period of time to avoid coaching users to stare. Figure 2 displays the relative positioning of the user and partner when using the Face2Face module.

Using a similar approach, Empowered Brain can detect not only human faces, but also human facial emotions when running the Emotion Charades module (Figure 4). In Emotion Charades, users have a gamelike experience in which they identify the emotions of another person. Empowered Brain rewards correct answers with in-game rewards or provides guidance when needed.

Additionally, the system incorporates mechanisms to alter the difficulty associated with using each gamified app. One method is to alter the attentional challenge by displaying virtual elements

that will either help to enhance attention or act as distractors to the social stimuli that the user is tasked to interact with. These virtual elements are overlaid over the user's real-world view and include both dynamic real-time positional cues based on user movement and physiology, and reward-based virtual elements that provide feedback on the user's in-app performance.

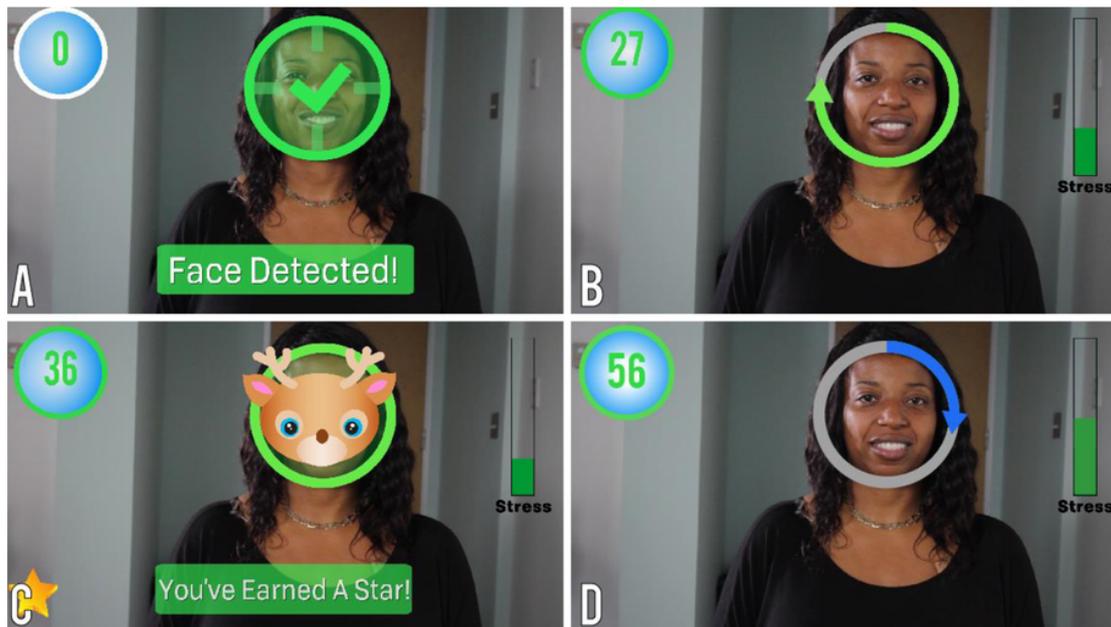
A series of research studies have investigated the use of Empowered Brain in ASD samples. The feasibility of using Empowered Brain in ASD was established during testing with 2 boys with ASD, both of whom demonstrated improvements in ASD symptoms as measured by the ABC [41]. Empowered Brain was safely used with no reported serious negative effects in 18 children and adults with ASD [54]. A separate report of 21 users with ASD found that Empowered Brain was well tolerated, with 91% of participants demonstrating tolerability across 3 separate measures [48]. The same study also found that 94% of participants reported the use of Empowered Brain to be comfortable. Additionally, the form factor of the computerized smartglasses of Empowered Brain has been described as desirable for school use by children with ASD [55]. Exploratory studies into the longitudinal use of Empowered Brain in school settings as a facilitative socioemotional learning tool have been reported by multiple educators as having a positive impact on student learning and social communication [56]. Empowered Brain has also been found to improve social communication as

measured by longitudinal educator and parental scores on the Social Responsiveness Scale, Second Edition, a reference standard validated measure of social communication functioning in ASD [57].

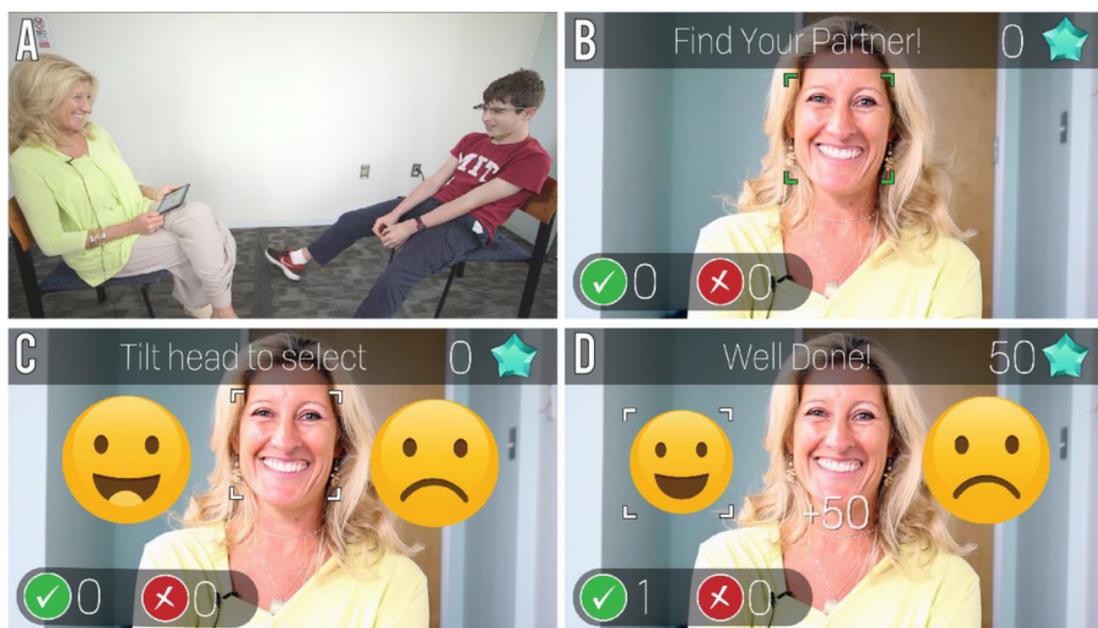
The facial affective analytics component of Empowered Brain was developed in partnership with Affectiva, an emotion artificial intelligence company. The Empowered Brain also uses

experimental artificial intelligence technologies developed by Amazon. This work was also made possible by Google, Inc, now known as Alphabet, Inc, who provided substantial hardware and guidance in engineering. Brain Power, the company that developed Empowered Brain, has been a long-term Glass partner in the Glass Enterprise Partnership Program at X, a company of Alphabet, Inc.

**Figure 3.** Empowered Brain’s Face2Face module. Face2Face is a 2-player game that encourages face-directed gaze during social interactions. (A) Child’s view on smartglasses: Face2Face detects the face in the field of view. (B) As the child maintains gaze toward the partner’s face, the progress circle fills up and the child continues to earn points (upper left). (C) When the progress circle is full, the child earns a star (lower left) and a mask is displayed as a reward. (D) Another progress circle fills up as the child demonstrates continued gaze toward the partner’s face.



**Figure 4.** Empowered Brain’s Emotion Charades module. (A) Emotion Charades is a 2-player game. The child, wearing smartglasses, sits across from his partner, whose app directs her to display an emotion. (B) Emotion Charades detects the partner’s face. (C) The partner displays an emotion (happy), which is detected by the system. The smartglasses show the child 2 emotions. (D) The child tilts his head to select the emotion that matches the partner’s expression, earning points for correct responses (upper right).



## Methods

### Institutional Review Board Approval

The methods and procedures of this study were approved by Acentral, Inc, Institutional Review Board (Newburyport, MA, USA), an affiliate of the Commonwealth of Massachusetts Department of Public Health.

### Participants

We recruited participants through a Web-based research interest form. Written consent was provided by the legal guardians of children and by cognitively abled adults. Participants between 7 and 17 years old provided written assent, when they were able to.

We questioned all caregivers of participants as to whether they had a history of ADHD and whether they were currently receiving treatment for ADHD. Additionally, all participants had a baseline ABC-H and Social Communication Questionnaire (SCQ) [58].

### Measures

The ABC-H is a subscale of the ABC and measures key ADHD symptoms such as inattention, impulsivity, and hyperactivity. The ABC has been extensively used in the developmentally disabled population, and the ABC-H has been used as an outcome measure of studies that have investigated the treatment of ADHD in populations with concurrent ASD [43-47]. In the assessment of ADHD symptoms in ASD, the ABC has shown itself to have superior psychometric properties, in particular validity [59] and reliability [60], compared with other rating scales of ADHD symptoms in children with developmental disorders (such as ASD). The ABC-H includes items that rate key ADHD symptoms. Specifically, the ABC-H assesses inattention and impulsivity through items that require the rater to assess whether their client is “easily distractible,” “does not pay attention to instructions,” “pays no attention when spoken to” or is “impulsive.”

Following these baseline assessments, we stratified the participants into high and low ADHD symptom groups based on their baseline ABC-H score. For the high ADHD group, we chose cutoff scores of 13 for male participants and 8 for female participants. These scores were determined by prior research that recorded the ABC scores for a sample of 666 people with developmental disorders, and found a mean ABC-H score of 13.38 for males and 8.12 for females [61].

Accordingly, we considered males with a score of 13 or higher and females with a score of 8 or higher to have high ADHD symptoms, and those with a lower score, to have low ADHD symptoms. Despite a history of ADHD diagnosis, we used the ABC-H as a stratification method, as it provided a numerical measure of recent (baseline) ADHD symptom burden. This numerical subscale allows for a more quantitative measure of change in rated items. While we obtained a clinical history of ADHD for the participants, the clinical diagnosis of ADHD in ASD is challenging [62], and it was only with the release of the *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition) (DSM-5) [63] that it became possible to diagnose

ADHD in an individual with ASD. Prior to the release of the DSM-5, the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition, Text Revision) specifically excluded a diagnosis of ADHD being made when an individual had a diagnosis of ASD. Therefore, while background information regarding ADHD history is important, we felt the ABC-H to be a more accurate measure of ADHD symptom load to determine the stratification into low and high ADHD symptom groups.

All participants had a baseline SCQ [58] as a validated measure of their ASD symptoms.

### Procedure

All participants were accompanied by a caregiver to the testing session. We oriented the participants and their caregivers to Empowered Brain and Google Glass and measured their ability to tolerate wearing the smartglasses. Once the participants showed they were able to wear the smartglasses for at least one minute, the participants were able to use Empowered Brain social communication modules and had a series of gamified experiences while interacting with their caregiver, including using Empowered Brain modules such as Face2Face and Emotion Charades (Figure 2, Figure 3). Empowered Brain modules help users to recognize and direct their attention toward socially salient stimuli such as human faces (in particular, the central part of the face, including eye regions), emotional facial expressions, and changes in the social environment. Participants and caregivers were able to verbalize any concerns or difficulties in using Empowered Brain both during and immediately after the session. We obtained an ABC-H score at 24 hours and at 48 hours after the session through the caregiver's report. A clinically significant change in ABC-H was determined by a 25% or more change in the score, a standard that has previously been used in combination with another scale to determine responders to ADHD treatment in an ASD population [43].

Individuals who had expressed interest via the website signup but who had a known history of epilepsy or seizure disorder were not enrolled in this study. Users who had any uncontrolled or severe medical or mental health condition that would make participation in the study predictably hazardous were also not eligible for enrollment. We obtained information regarding potential exclusions to this study directly from the caregivers of the participants.

## Results

A total of 8 children, adolescents, and young adults with ASD signed up to take part in this research (average age 15 years, range 11.7-20.5; 7 male and 1 female participants). Table 1 and Table 2 summarize participant demographics. Half of the participants had a history of ADHD (n=4, 50%), 3 of whom were receiving active treatment at the time of testing. Of note, based on their ABC-H scores, 2 participants who had a previous diagnosis of ADHD were categorized in the low ADHD symptom group, while the remaining 2 were categorized into the high ADHD symptom group. The SCQ score demonstrated that participants represented a wide range of social communication abilities, from 11 to 28 points (mean score 18).

All participants were able to use smartglasses and complete the coaching session. The high ADHD-related symptom group had a similar ASD severity to the low ADHD-related symptom group (SCQ score 18.5 vs 17.6, respectively), but consisted of younger participants (12.5 vs 17.6 years, respectively). Postintervention ABC-H scores were lower for most participants at 24 hours (n=6, 75%) and for all participants at 48 hours (n=8, 100%). At 24 hours after the session, average ABC-H scores decreased by 54.9% in the high ADHD symptom group and by 20.0% in the low ADHD symptom group. At 48 hours after the session, ABC-H scores compared with baseline decreased by 56.4% in the high ADHD symptom group (Table 3) and by 66.3% in the low ADHD symptom group (Table 4).

The high ADHD-related symptom group consisted of 4 participants who had an average ABC-H score of 25.75 at the start of the study (Table 3). The low ADHD-related symptom group consisted of 4 participants who had an average ABC-H score of 5.5 at the start of the study (Table 4). Figure 5 presents the ABC-H scores of the participants graphically.

We noted that, while the participants in the high ADHD-related symptoms group were younger, they had a similar ASD symptom severity as measured by the SCQ to the low ADHD-related symptom group. It is perhaps not a surprise to find that the high symptom group was younger, given that the ABC-H subscale is weighted toward hyperactivity, and hyperactivity is an ADHD symptom that improves with age [64].

**Table 1.** Individual participant demographics (n=8).

Participant identifier	Age (years)	Sex	SCQ <sup>a</sup>	ADHD <sup>b</sup> diagnosis	ADHD treatment
1	12.6	Male	22	No	No
2	11.7	Male	11	Yes	Yes
3	12.4	Male	23	No	No
4	13.4	Female	18	Yes	Yes
5	16.9	Male	16	Yes	No
6	20.5	Male	28	No	No
7	19.4	Male	15	Yes	Yes
8	13.4	Male	12	No	No

<sup>a</sup>SCQ: Social Communication Questionnaire.

<sup>b</sup>ADHD: attention-deficit/hyperactivity disorder.

**Table 2.** Overall participant demographics (n=8).

Characteristic	Data
<b>Age (years)</b>	
Mean (SD)	15 (3.4)
Range	11.7-20.5
<b>Sex, n (%)</b>	
Male	7 (87.5)
Female	1 (12.5)
<b>Prior ADHD<sup>a</sup> diagnosis, n (%)</b>	
Yes	4 (50)
No	4 (50)
<b>ADHD treatment during study, n</b>	
Yes	3
No	5
<b>Social Communication Questionnaire score</b>	
Mean (SD)	18.1 (5.8)
Range	11-28

<sup>a</sup>ADHD: attention-deficit/hyperactivity disorder.

**Table 3.** High ADHD<sup>a</sup>-related symptom groups: ABC-H<sup>b</sup> scores and percentage change relative to baseline (n=4).

Participant identifier	Baseline score	24-hour score	24-hour % change	48-hour score	48-hour % change
1	17	1	-94.1	1	-94.1
2	48	40	-16.7	42	-12.5
3	24	3	-87.5	4	-83.3
4	14	11	-21.4	9	-35.7
Score, mean (median)	25.75 (20.5)	13.75 (7)	N/A <sup>c</sup>	14 (6.5)	N/A
Participant % change, mean (median)	N/A	N/A	-54.9 (-52.4)	N/A	-56.4 (-57.5)

<sup>a</sup>ADHD: attention-deficit/hyperactivity disorder.

<sup>b</sup>ABC-H: hyperactivity subscale of the Aberrant Behavioral Checklist.

<sup>c</sup>N/A: not applicable.

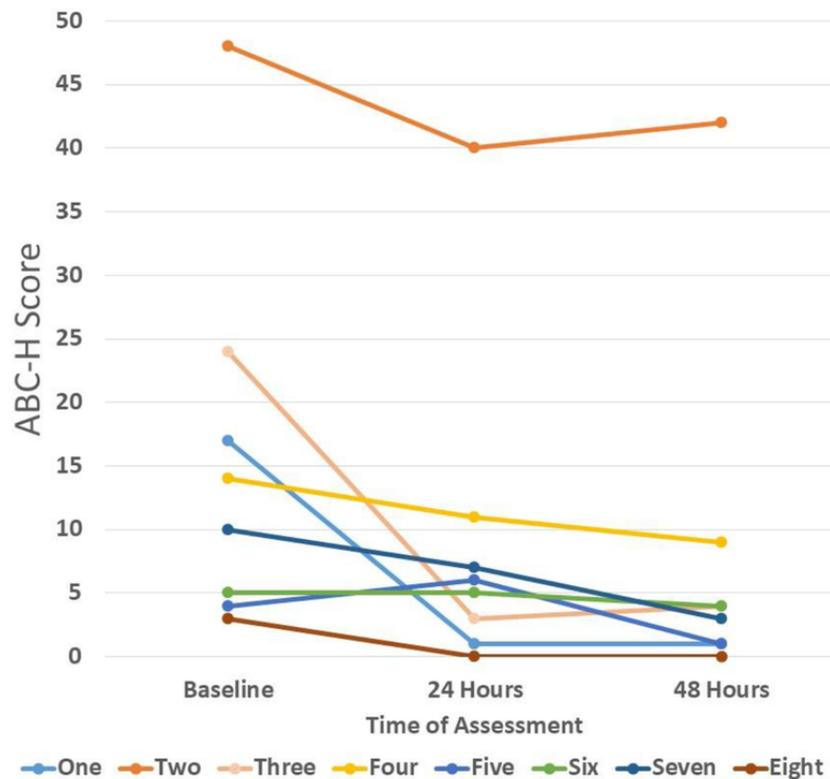
**Table 4.** Low ADHD<sup>a</sup>-related symptom groups: ABC-H<sup>b</sup> scores and percentage change relative to baseline (n=4).

Participant identifier	Baseline score	24-hour score	24-hour % change	48-hour score	48-hour % change
5	4	6	50	1	-75
6	5	5	0	4	-20
7	10	7	-30	3	-70
8	3	0	-100	0	-100
Score, mean (median)	5.5 (4.5)	4.5 (5.5)	N/A <sup>c</sup>	2 (2)	N/A
Participant % change, mean (median)	N/A	N/A	-20 (-15)	N/A	-66.3 (-72.5)

<sup>a</sup>ADHD: attention-deficit/hyperactivity disorder.

<sup>b</sup>ABC-H: hyperactivity subscale of the Aberrant Behavioral Checklist.

<sup>c</sup>N/A: not applicable.

**Figure 5.** Change in score on the hyperactivity subscale of the Aberrant Behavioral Checklist (ABC-H) by participant identifier from baseline to 48 hours after the intervention.

## Discussion

### Principal Findings

While many people with ASD struggle with symptoms of ADHD, including hyperactivity, impulsivity, and inattention, considerable gaps in knowledge remain in regard to their optimum assessment and management [3]. The combination of ADHD and ASD has been linked not only to greater impairment [10,11] and psychopathology [12,13], but also reduced access and response to psychopharmacologic treatment for ADHD [15,25]. These are important considerations given the substantial negative sequelae of untreated ADHD [29,30]. There has been increasing interest in developing digital interventions to address the symptoms of ASD or ADHD, but few technological interventions have been studied for people with ASD and ADHD symptoms. This population may potentially benefit from such approaches.

All participants in this study managed to complete the Empowered Brain intervention session without any reported negative effects, and all participants tolerated using smartglasses for the duration of the testing session. This is important, as a major limiting factor in the use of and continued engagement with assistive technologies is their usability, tolerability, and associated negative effects.

Most participants improved their ADHD-related symptoms following the intervention at both 24 hours (n=6, 75%) and 48 hours (n=8, 100%) after the session. We noted that 1 participant in the high symptom group had a greater reduction at 24 hours than at 48 hours, and that 1 participant in the low symptom group had an increase in ADHD-related symptoms at 24 hours followed by a large decrease from baseline at 48 hours.

Mean participant ABC-H percentage changes showed a significant response in the high ADHD-related symptom group (>25% improvement in ABC-H score) at both 24 (54.9% reduction) and 48 hours (56.4% reduction). The low ADHD-related symptom group appeared to show a response at 48 hours (66.3% reduction), but not at 24 hours (20.0% reduction). While the response of the low ADHD-related symptom group appeared to be of greater magnitude, we, who include subspecialist clinicians, advise caution in assessing the low ADHD-related symptom group, given the low baseline and small absolute score changes. Such results may render the findings in this group as not being as clinically significant as the outcomes associated with the high ADHD-related symptom group. An alternative explanation may also be put forward, and that is that the technology is especially impactful for individuals with a milder ADHD symptom burden. Future larger studies would allow for more robust statistical analysis and conclusions to be made.

### Limitations

There are several important limitations to this work that deserve mention. There was no control group, and the number of participants in this pilot study was relatively small (N=8), although this is a sizeable sample relative to other research on novel technologies in ASD, especially in regard to other smartglasses research [41,48]. While quantitative approaches

using validated scales are very useful, future research efforts would also benefit from the use of qualitative approaches, and some early results of such methods have been reported [56].

We should certainly consider the potential for an expectancy effect [65] in using this technology, especially given that the testing session was a novel experience for both the participant and the caregiver. However, the potential for this effect should also be tempered by our knowledge that transitions or new experiences have been associated with extreme distress in people with ASD, so much so that it is a characteristic part of diagnosis [63]. We noted that none of the participants encountered any noticeable distress or problems with using the smartglasses.

It would be useful for future research to incorporate a larger sample size, with more female participants. One can also see the benefit of age-matched neurotypical and ADHD-only controls. While the ABC-H is a very useful scale to use in this context, the use of broader ADHD-related measures would also provide for further insights. Despite our findings, the broader generalizability of our results to the wider ASD population will remain limited until further research is undertaken.

### Future Research

We hope that this study can pave the way for more funding and interest to study the potential application of this emerging technology to not just dually diagnosed ADHD and ASD samples, but more broadly to other categorical psychiatric diagnoses that are also associated with both attentional and social communication impairments. Such diagnoses include schizophrenia, bipolar disorder, and anxiety disorder. While deficits in social communication occur across many psychiatric disorders, most digital social communication interventions have been studied in ASD alone [66]. Therefore, research and development of an intervention that can target transdiagnostic symptoms could be valuable in both clinical scenarios and in research using the Research Domain Criteria framework.

Smartglasses may have a particularly unique role in this respect, as they also contain a variety of quantitative sensors that are located more closely than any other wearable technology to the main perceptual apparatus of the brain. These sensors can collect and help analyze sensor data to help classify human behavior. This digital phenotyping approach aims to detect changes in affective and behavioral states associated with both improvements and deteriorations in psychiatric disorders, and to help to identify new methods to subtype disorders [67].

Empowered Brain is being developed as a tool that can be used by caregivers, therapists, and educators to deliver socioemotional interventions to users with ASD. It is designed as a tool that can be used on a daily basis for 10 to 20 minutes per intervention. While this study reports on the impact of Empowered Brain on ADHD symptoms after a single intervention, further research is required to understand how the longitudinal use of this technology may affect ADHD symptoms in people with ASD. This technology also has the potential to address the attentional and social communication deficits that are transdiagnostically present across psychiatric disorders. Data collection via sensors that are proximally situated to the principal human perceptual organs may result in a more ecologically

valid digital phenotyping approach. This digital phenotyping approach may aid the research of proposed developmental subtypes of a distinct ASD-ADHD combination disorder and, more broadly, psychiatric and brain injury-related disorders.

## Conclusion

Empowered Brain is a smartglasses-based social communication intervention that has been previously shown to improve social communication functioning in ASD. This study provides early

evidence for the possible potential of Empowered Brain to reduce ADHD symptoms, such as hyperactivity, inattention, and impulsivity, in school-aged children, adolescents, and young adults with ASD. Our results also suggest that, despite concerns about increased distraction and reduced attentiveness, the Empowered Brain did not result in any increased ADHD symptoms in any of the participants at 48 hours after the intervention.

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## Conflicts of Interest

NTS is the inventor of the Empowered Brain system. All of the authors have affiliations at Brain Power, a neurotechnology company that supported this report. Brain Power receives funding support from US Federal and Congressional sources.

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## Abbreviations

- ABC-H:** hyperactivity subscale of the Aberrant Behavioral Checklist  
**ADHD:** attention-deficit/hyperactivity disorder  
**ASD:** autism spectrum disorder  
**DSM-5:** Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)  
**SCQ:** Social Communication Questionnaire

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Original Paper

# Computerized Cognitive Training in Children With Autism and Intellectual Disabilities: Feasibility and Satisfaction Study

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## Abstract

**Background:** Researchers are increasingly interested in testing and developing computerized cognitive training interventions for individuals with autism spectrum disorder due to the limited accessibility of treatments for this disorder. Understanding the feasibility of testing cognitive interventions for this population is critical, especially for individuals with ASD who have low to moderate intellectual ability.

**Objective:** The aim of the study was to evaluate the feasibility of computerized cognitive training as measured by attrition rate and a parent satisfaction survey.

**Methods:** A total of 26 participants aged 8-17 years with an autism spectrum disorder diagnosis and significant intellectual impairment were enrolled (mean age 11.1 years). They were instructed to complete 25 sessions of Cogmed Working Memory Training in 5 to 6 weeks with coach assistance. Attrition rate and parent satisfaction surveys were measured after the completion of training.

**Results:** Most participants (96%, 25/26) completed the training and indicated high satisfaction (>88%). However, among the participants who completed the training, 5 participants (19%) were unable to finish in 6 weeks, the recommended training period by Cogmed. Parents noted various positive (eg, voice-overs) and negative (eg, particular graphic and sounds associated with a stimulus) features of the game that they thought affected their child's response.

**Conclusions:** Children with autism spectrum disorder and intellectual impairments can successfully participate in computerized cognitive training interventions but may require additional weeks to complete the training beyond the time needed for children without intellectual impairments. The overall completion rate, with extended time to complete the training, was high. Developers of cognitive training programs for this population should take into account potential issues regarding the noise level of stimuli and characteristics of the visual graphics.

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**KEYWORDS**

autism; training; working memory; intellectual disability; treatment adherence; satisfaction

## Introduction

### Developing Novel Interventions for Treating Autism

Autistic spectrum disorder (ASD) is a common neurodevelopmental disorder, with an overall prevalence of 1.47% of children in the United States [1]. Traditionally, interventions for ASD have relied on models of individual training with a therapist or small group therapy with a therapist or caregiver [2]. There are inherent limitations in this model, however, due to the limited access to trained professionals and a relatively high cost of service delivery. With concerns about the rising prevalence of ASD [1], there is an urgent need for additional and supplemental interventions to address deficits associated with ASD. Increasingly, interventions using computer technology are being considered to fill this gap [3,4]. A critical step before implementing a technological intervention for persons with ASD is assessing whether its use is feasible and acceptable to caregivers. Moving new potential interventions rapidly into the community requires partnerships with the stakeholders, in which they can give feedback on their experience [5]. As noted by Kelley and colleagues [5], ongoing input from the perspective of the stakeholders (in this case, parents) is key throughout the translational phase as a potential intervention moves from inception, discovery to delivery. Input and feedback from stakeholders can then be used to develop new interventions and refine those in the pipeline. The funding agency for this project, the Department of Defense (Autism Research Program), through a Pilot Award, also recognized the need to first test the feasibility of a potential therapy before it would be tested in a full-scale, randomized control trial. Findings from feasibility studies on recruitment, retention, and satisfaction with the intervention are important to determine how and if a full-scale study should be implemented [6]. As such, this paper focuses on the feasibility and acceptability of computer technology in children with ASD who have moderate to low intellectual functioning. A future paper will present data on the efficacy of the intervention from these participants.

### Working Memory Impairments in Autism

ASD is characterized by impairments in communication skills and reciprocal social interactions, and restricted, repetitive, and stereotyped patterns of behavior and interests [7]. In addition, executive function, which is responsible for organizing and regulating behaviors [8-10], has been emphasized as a core dysfunction of ASD [10-13]. One important component of executive functioning is working memory (WM), which is involved in maintaining and manipulating incoming information during planning and executing cognitive tasks [14,15]. WM performance is highly predictive of individual differences in verbal and visuospatial memory span and reasoning [16], general fluid intelligence [17], reading comprehension difficulties [18-21], mathematical difficulties [22-24], and attention deficit hyperactivity disorder (ADHD) symptoms [25,26]. Andersen et al [27] showed that verbal WM ability in children with high-functioning ASD does not demonstrate the typical developmental increases in capacity expected over a 2-year time period [27] found in children with ADHD or typically developing (TD) children. In other studies, children with ASD

had lower spatial working memory training (WMT) abilities than TD children [28,29].

Although WM capacity was previously assumed to be a stable trait [30,31], more recent studies have suggested that WM capacity can be increased through targeted training [32-35]. WMT has been shown to be beneficial in many populations, including individuals within ADHD [36-40], Down syndrome [41,42], and fetal alcohol disorders [43]. However, the efficacy of WMT is currently debated. For example, a number of reviews and meta-analyses identified limitations of the research in WMT [34,44,45], such as the lack of methodological consistency between studies [34] and inconsistency in generalization of benefits to other cognitive domains [36,44,45].

Few studies have examined the effects of computerized WMT in children with ASD [3,46]. de Vries and colleagues [3] concluded that WMT is not feasible for children with ASD, based on their sample (8-12 years of age; IQ>80) as evinced by a high attrition rate (26%) and marginal improvement on near-transfer WM and ADHD behavior. However, the findings were limited by the absence of assessment of motivation. Because high motivation and a positive attitude are critical components to successful training [32,44], it is possible that the high attrition rate may have been due to low motivation.

### Addressing Gaps in Working Memory Training in Autism

Another limitation in the existing cognitive training literature is the lack of research on children with ASD and intellectual disability (ID), which is crucial considering that over a third of individuals with ASD also have ID [1]. The aforementioned de Vries study [3] included children with intellectual functioning of greater than 80. Understanding feasibility of training is valuable for exploring the viability of translating computerized interventions, such as WMT, into clinical practice. To this end, this study assessed a computerized cognitive training program for feasibility, as measured by attrition rate and parent responses, in children with ASD with low to moderate intellectual ability.

## Methods

### Participants

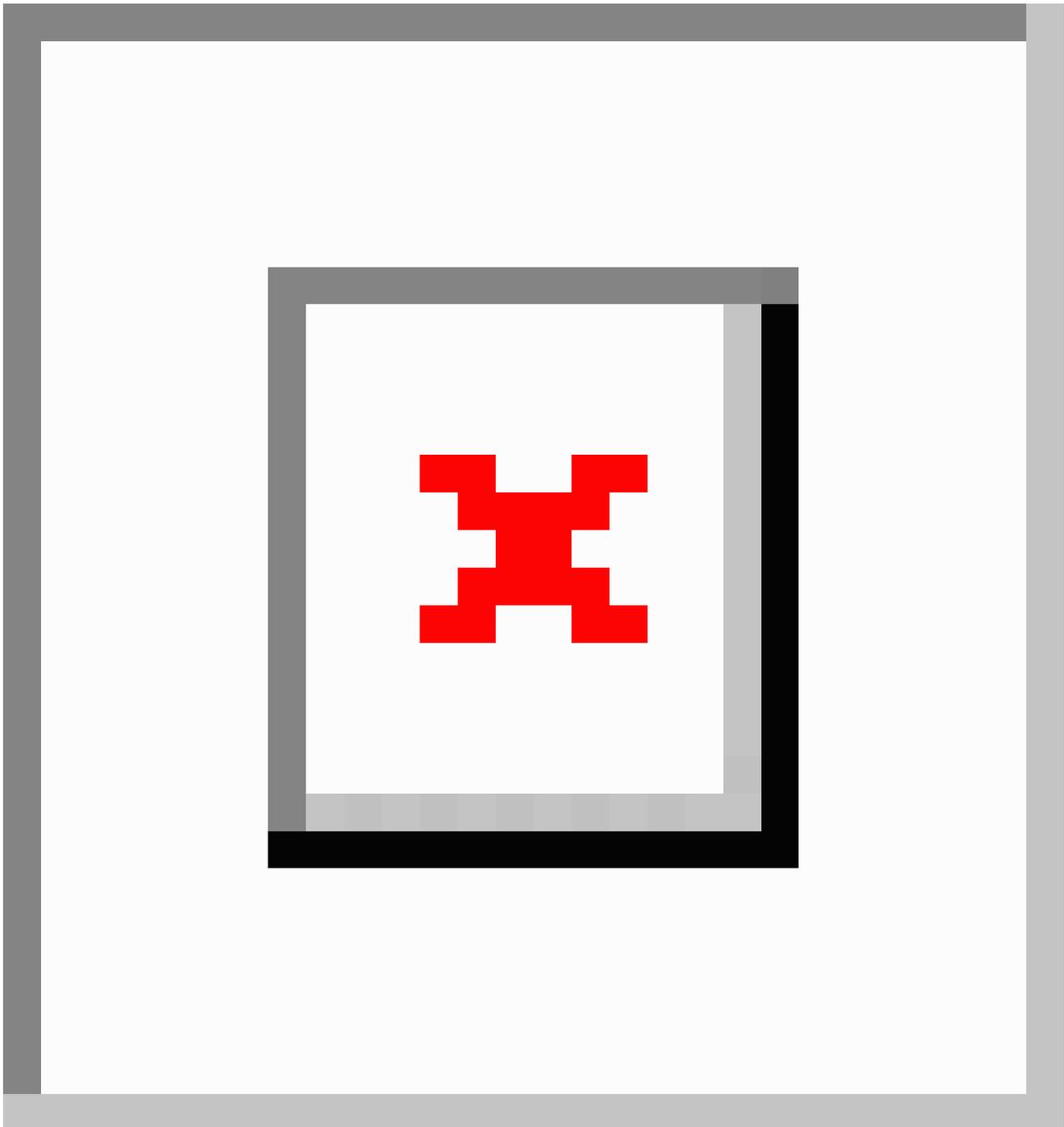
Participants were recruited through the MIND Institute's Subject Tracking System, flyers located at the local clinic, Alta California Regional Center, and advertisements placed in websites and local newspapers (Figure 1). In total, 91 volunteers were assessed for eligibility via a brief series of questions with the parent of the potential participant over the phone. The inclusion criteria included children aged 8-17 years with a diagnosis of ASD, below average intellectual functioning (IQ≤85), and normal to corrected normal vision and hearing. Participants were excluded if there were plans to change current behavioral or pharmacological treatment during the course of the study, if a caregiver reported disruptive behaviors that would interfere with WMT, or if the participant was unable to use a computer or tablet. A total of 37 of the 91 volunteers met the eligibility criteria and underwent an in-person assessment visit. Participants were further excluded at the in-person assessment if observable self-injurious behaviors were present or if their

IQ scores were greater than 85. Most of the volunteers (n=54) were excluded because their IQ was greater than 85. A total of 26 study participants (mean age 11.1 [SD 2.4] years) remained after exclusions. This sample included 21 males and 5 females, which reflects the ratio found in the ASD population [1]. The average IQ for the sample was 65 (range: 47-85; SD 14; Table 1).

Intellectual functioning was determined by current or previous testing, if it was available within the past 3 years with the Wechsler Intelligence Scale for Children, Fourth Edition, or

Stanford-Binet Intelligence Scales, Fifth Edition (SB-5). The verbal and nonverbal routing subtests of the SB-5 were administered to estimate the abbreviated IQ for participants without recent testing. The diagnosis of ASD was confirmed by documentation of previous assessments (The Autism Diagnostic Observation Schedule or the Autism Diagnostic Interview-Revised). If no prior diagnosis had been made, ASD diagnosis was confirmed through the Social Communication Questionnaire Lifetime (SCQ), for which the total SCQ score was greater than 15.

**Figure 1.** Flow of participant recruitment, participation, and outcomes assessed in feasibility study. WMT: working memory training; ASD: autistic spectrum disorder.



**Table 1.** Characteristics of participants (N=26).

Variable	Summary
Age in years, mean (SD)	11.1 (2.4)
<b>Gender, n (%)</b>	
Female	5 (19)
Male	21 (81)
<b>Race<sup>a</sup>, n (%)</b>	
Black	3 (12)
White	14 (56)
Asian	5 (20)
Other	3 (12)
Intelligence quotient (IQ), mean (SD)	65 (14)
<b>Training device, n (%)</b>	
Tablet	18 (69)
Personal computer (PC)	8 (31)
<b>Cogmed version, n (%)</b>	
JM <sup>b</sup>	15 (58)
RM <sup>c</sup>	11 (42)
<b>Current therapies, n (%)</b>	
Occupational therapy	15 (58)
Physical therapy	4 (15)
Speech therapy	21 (81)
Applied behavioral analysis	11 (42)
<b>Psychotropic medications, n (%)</b>	
ADHD <sup>d</sup> stimulant	1 (4)
ADHD nonstimulant	4 (15)
Antidepressant	3 (12)
Antipsychotic	6 (23)
Mood stabilizer	3 (12)
Other medications	2 (8)
No medications	15 (58)
<b>Comorbidities, n (%)</b>	
ADHD	6 (23)
Mood disorders	2 (8)
Anxiety disorders	3 (12)
Seizure disorders	3 (12)
Other mental disorders	2 (8)
Other physical disorders	2 (8)
<b>Completion and adherence, n (%)</b>	
Completed training <sup>e</sup>	25 (96)
Adherent to protocol <sup>f</sup>	19 (73)
Nonadherent <sup>f</sup>	5 (19)

Variable	Summary
Did not complete training <sup>c</sup>	1 (4)
Combined attrition <sup>g</sup>	6 (23)

<sup>a</sup>n=1 did not provide an answer.

<sup>b</sup>JM: Cogmed for preschool-aged children.

<sup>c</sup>RM: Cogmed for school-aged children.

<sup>d</sup>ADHD: attention deficit hyperactivity disorder.

<sup>e</sup>Required completing 25 sessions as reported by the Cogmed website.

<sup>f</sup>Required completion of 25 sessions within 6 weeks of start date.

<sup>g</sup>Not completing training or not adhering to protocol.

## Procedure

All procedures of the study were reviewed and approved by the University of California, Davis Institutional Review Board. After screening for criteria with the parents over the phone, parents provided written informed consent and participants over the age of 11 years provided assent. Tests assessing baseline WM, cognitive abilities, attentional functioning, and autism symptoms were administered at the participants' homes. After participants completed Cogmed training, researchers administered the same test battery to assess training effects. Data on training effects on objects measures of performance and rating scales will be presented in a separate publication. Parents completed posttraining surveys to evaluate feasibility of WMT. Participants were reimbursed US \$20 for their time in the initial assessment and US \$50 for the follow-up assessment.

## Intervention

All participants were instructed to complete 5 Web-based Cogmed Working Memory Training [47] sessions per week for 5 weeks, for a total of 25 training sessions. There were 2 difficulty levels for participants. Cogmed RM was developed for school-aged TD children, whereas Cogmed JM was for preschool TD children. Those who comprehended 9 of the 11 Cogmed RM games, as determined by researchers during the in-person assessment, were assigned to Cogmed RM (n=15), with the remainders assigned to Cogmed JM (n=11). The Cogmed JM groups required training for 15 min per session and the Cogmed RM group required training for 30 min per session. Participants were trained either on the Cogmed tablet app (n=18; use of finger for item responses), with tablets provided as necessary, or on the Cogmed website (n=8; use of PC with a mouse for item responses). See Table 1 for additional information.

Each training session was conducted at home in a location with limited distractions and parental supervision. As per the Cogmed's protocol, parents were trained as training aides by Cogmed coaches to ensure participants' motivation and focus. Researchers who underwent Cogmed Research Coach Training contacted parents by phone or email at least once a week to address concerns related to training. These coaches had online access to participants' frequency of use and performance on Cogmed tasks to track progress and provide feedback as necessary. Coaches also answered questions regarding software issues and took general feedback about use of the program.

Both Cogmed versions involved visuospatial WM span tasks, and, additionally, the RM version included verbal WM span tasks. Daily Cogmed JM training involved completing 3 of the 7 JM games, whereas the RM training involved the completion of 8 of the 10 RM games, with games rotated in each session to maintain novelty and interest. Both versions were adaptive; the difficulty gradually increased after correct trials and decreased after incorrect trials. Both versions emitted auditory and visual feedback after each trial to indicate success or failure at the task. After the completion of each training session, Cogmed JM users received a virtual fish for their digital aquarium, and Cogmed RM users played a racing game as a reward. For added motivation, parents gave a sticker after each session for a reward chart, and parents and participants decided on daily, weekly, and full training completion rewards.

## Measures

### Completion, Adherence, and Combined Attrition

The completion rate was defined as the percentage of participants who completed 25 sessions of Cogmed WMT. Although it is recommended by Cogmed that training should be completed in 5 weeks, training duration was extended to 6 weeks; it was presumed that participants would require more time to complete the training due to learning and behavioral challenges associated with ASD and ID. Participants were considered "adherent" if they finished 25 sessions within 6 weeks. Participants who took longer than 6 weeks to complete the training were considered "nonadherent" with the training protocol. The combined attrition rate was defined as the percentage of participants who did not complete 25 sessions and who were nonadherent with the training protocol.

### Posttraining Survey

At the end of training, parents completed a questionnaire with 16 Likert-scale and 3 open-ended questions. The questionnaire, adapted from a previous ADHD intervention study [48], aimed to measure subjective opinions regarding the feasibility of the program. Likert-scale questions comprised a 5-point scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) and inquired into participant motivation, parent satisfaction, and perceived utility. We summarized the responses by calculating both mean and SD and the percentage of parents who answered agree/strongly agree (satisfied/strongly satisfied), were neutral, or answered disagree/strongly disagree (dissatisfied/strongly dissatisfied) for each question.

Open-ended questions were asked about the pros and cons of the program and possible improvements.

### Statistical Analysis

Data were collected and managed using REDCap electronic data capture tools hosted at University of California, Davis [49]. Feasibility of Cogmed training was assessed both quantitatively and qualitatively. Quantitatively, descriptive statistics were calculated for the completion rate and Likert-scale questions. Qualitatively, deidentified data from open-ended questions were used for content analysis. Initially, phrases taken from the open-ended responses were tagged with low-level codes. These codes were compared and found to fit into 3 broad categories based on previous qualitative literature in computer-based training [50]: technological features, personal experiences, and strategy of use.

## Results

### Attrition

A total of 25 of the 26 participants (96%) completed all 25 sessions of Cogmed WMT. Of these 26 participants, 20 (77%) completed the WMT within 6 weeks and were considered adherent to protocol, 5 (19%) took more than 6 weeks and were considered nonadherent, and 1 participant (4%) completed only 16 sessions due to unsolved technical problems. The combined attrition rate (counting those who did not complete 25 sessions and did not complete the training within 6 weeks) was 23%. The combined attrition rates were similar across Cogmed JM and RM users. Of the 15 JM participants, 3 were considered nonadherent and 1 did not complete the training (combined attrition rate=27%). All 11 RM participants completed the training, but 3 were considered nonadherent (combined attrition rate=27%).

### Posttraining Ratings

Likert-scale questions queried parents about the 3 domains of satisfaction, perceived utility, and motivation (Table 2). The percentage of parents who agreed or strongly agreed with questions regarding program satisfaction was at least 88% for each item. Responses to questions about the perceived utility of the training were less consistent. There was mixed evidence about improvements in daily life (child's attention/behavior, peer relations, study skills, homework, self-esteem/attitude, and relationship with the parent), but most parents reported that they observed improvement on performance on the program itself (76% agree) and felt the WMT approach was appropriate for their child (84% agree). Regarding motivation, parents generally thought that their children found Cogmed to be enjoyable, with 72% of respondents agree to this item. However, many parents found it hard to maintain their children's motivation to train on a daily basis. The item asking whether it was easy to keep the child motivated, received a high number of "disagree" responses

(28%); similarly, only 32% of parents said that the child's motivation improved by end of training.

The pattern of parent responses was similar for Cogmed JM and RM versions, with a few exceptions. Parents of children assigned the JM version perceived more improvement in motivation and less improvement in homework (Multimedia Appendix 1). It is important to note, however, that only 19 of the 25 parents responded on the item asking about child's homework improvement, as some children were not assigned homework during the summer months of data collection. We also examined (data not shown) the responses of the 5 participants with comorbid ADHD who completed the training, and they were consistent with the pattern observed for those without comorbid ADHD.

### Posttraining Feedback

Content in open-ended responses was analyzed and classified into 3 main areas: (1) technological features, (2) personal experiences, and (3) usage strategies.

### Technological Features

Many of the parents had comments about game design, system functionality, and rewards. Comments about game features included discussion about the graphics and sound. One parent said her child enjoyed the "giggling sounds"; multiple participants liked the voice-over. Moreover, parents liked the reward games that children accessed when all daily tasks were finished. However, participants also reacted negatively to some stimuli, such as the cow sounds or spider graphics. Another area that parents noted as need improvement was game variability. Several parents indicated that motivation could be improved either by varying the games or by giving the child a choice about which game to play each day. Moreover, another common theme among technology-related comments was that there were "glitches" or "bugs" in the Cogmed WMT website.

### Personal Experiences

Several parents indicated that the WMT affected daily functioning in their children. Several described perceived increased abilities in their children associated with using WMT, such as increased focus, memory, and reaction time. However, some parents saw strong negative emotional reactions in their children. Tantrums, low motivation, and frustration were all reported, though pride at completing difficult tasks was also mentioned.

### Usage Strategies

Cogmed has several strategies to help improve adherence and outcomes, as described in the Methods section; these strategies generated many comments. For example, imposing breaks could be difficult or turn into a power struggle. Several comments mentioned appreciation of the coaches. Responses to the daily training length varied, with some parents wishing for shorter sessions and others wanting longer.

**Table 2.** Summary of parent posttraining ratings for 25 participants who completed all 25 sessions of Cogmed working memory training.

Item <sup>a,b</sup>	Mean (SD)	Frequency (%) <sup>c</sup>		
		Agree <sup>d</sup>	Neutral <sup>e</sup>	Disagree
<b>Satisfaction</b>				
Staff show interest and concern	4.52 (0.59)	24 (96)	1 (4)	0 (0)
Staff are skilled	4.56 (0.58)	24 (96)	1 (4)	0 (0)
Treatment is of high quality	4.24 (0.93)	22 (88)	2 (8)	1 (4)
I would recommend this to others	4.20 (0.58)	23 (92)	2 (8)	0 (0)
<b>Perceived utility</b>				
Child's attention/behavior improved	3.56 (0.65)	14 (56)	10 (40)	1 (4)
Child's peer relations improved	3.32 (0.63)	8 (32)	16 (64)	1 (4)
Child's study skills improved <sup>f</sup>	3.35 (0.57)	7 (30)	16 (70)	0 (0)
Child's homework improved <sup>g</sup>	3.47 (0.61)	8 (42)	11 (58)	0 (0)
Child's self-esteem/attitude improved	3.32 (0.63)	8 (32)	16 (64)	1 (4)
Relationship with child improved	3.44 (0.58)	10 (40)	15 (60)	0 (0)
Child made progress in training	3.88 (0.60)	19 (76)	6 (24)	0 (0)
WMT <sup>h</sup> approach is appropriate	3.96 (0.68)	21 (84)	3 (12)	1 (4)
<b>Motivation</b>				
Child enjoyed the training	3.76 (0.78)	18 (72)	5 (20)	2 (8)
Easy to keep child motivated	3.44 (1.08)	14 (56)	4 (16)	7 (28)
Training is as enjoyable as commercial games	2.64 (0.95)	4 (16)	6 (24)	15 (60)
Child's motivation improved by end of training	2.88 (1.01)	8 (32)	6 (24)	11 (44)

<sup>a</sup>Ratings scale: 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree.

<sup>b</sup>Item descriptions paraphrase actual questions.

<sup>c</sup>Percentages may not add to 100% due to rounding.

<sup>d</sup>Percent agree indicates percentage of sample responding with 4 or 5.

<sup>e</sup>Percent disagree indicates percentage of sample responding with 1 or 2.

<sup>f</sup>n=2 answered not applicable.

<sup>g</sup>n=6 answered not applicable.

<sup>h</sup>WMT: working memory training.

## Discussion

The purpose of this pilot study was to examine, for the first time, the feasibility of using a cognitive training program in children with ASD with low to moderate intellectual functioning. Although the vast majority of participants (96%) were able to complete the 25 Cogmed sessions, many of them (24%) needed more than 6 weeks, which is an extension of the 5-week period recommended by Cogmed. This suggests that although completion may be feasible for children with ASD, Cogmed's suggested training schedule may be too aggressive for this population.

Using a strict time requirement of completion within 6 weeks resulted in an attrition rate similar to the attrition rates found in previous research on children with ASD and no intellectual impairment (26%) [3] and children with ADHD (23%) [36]. In these previous studies, it is unclear whether participants were given the option of finishing training beyond 6 weeks; thus, the

overall completion rate in this study (96%) is not directly comparable. However, WMT studies that incorporated a flexible time requirement with other clinical populations reported similar completion rates. For example, Conklin et al [51] found that 88% of childhood cancer survivors completed training in 5-9 weeks. Also of note, Mawjee et al [52] found that children with ADHD had a higher Cogmed completion rate (78%) and showed more motivation when given shorter training lengths (15 min/session) than did those who were assigned standard-length training (45 min/session; 44% completion). In this study, participants assigned the JM version (15 min/session) had similar completion rates as those assigned the RM version (30 min/session), but similar to the findings of Mawjee et al [52], parents of children assigned the JM version perceived more improvement in their child's motivation than those assigned the RM version.

The sample in this study had significant levels of cognitive delay (mean IQ=65), and thus may have required more time to

complete the program due to the presence of learning difficulties. In support of this idea, Bennett et al [41] showed that a sample of children with Down syndrome who had a mean IQ less than 70 took 10-16 weeks to complete Cogmed WMT. Therefore, an appropriate training schedule should be further investigated for successful WMT implementation in populations with developmental delays.

Qualitative measurement of feasibility, as measured by parental survey, revealed overall satisfaction with the WMT. More than 85% of parents agreed with each satisfaction-related item, which is similar to findings from other studies that evaluated the feasibility of WMT in other populations [51,53]. On the basis of the open-ended responses in this study, it appears that in-home training, flexibility to set a preferred training time, and weekly coaching calls contributed to higher parent satisfaction. Although most parents reported that their children enjoyed the training, only half felt it was easy to keep their children motivated. This may be due to training difficulty, length of training (eg, RM vs JM), or technical problems.

Parents consistently reported agreement with items regarding perceived improvement in child attention and behavior and progress in training, but they reported mainly neutral responses to questions regarding improvement in academic or interpersonal relationship skills. This finding is consistent with the results in the study by Chacko et al [36], which showed Cogmed resulted in improvement in WM but did not transfer to improvement in daily life skills.

This study cannot make any conclusions regarding the effectiveness of WMT in children with ASD and ID. The goal of this study was to determine whether this population can engage in cognitive training in a home setting to permit future evaluation of the effectiveness of training. A future manuscript will present findings on the effectiveness of this training.

On the basis of the findings from the parent surveys, the authors suggest the following solutions for the successful implementation of computerized cognitive training programs for children with ASD. First, the training program should be deployable in such a way as to be nonaversive to children who have sensitivities to visual and auditory stimuli. Due to sensory processing issues, which are often found in children with ASD, some parents reported that their children found certain graphics (eg, spiders) and sounds (eg, “Boo” after an incorrect response) distressing. These stimuli were unavoidable; games could not be skipped and participants were not able to turn off sounds due to program’s use of auditory instructions. WMT programs should give users the option to edit graphics and sound settings or to skip games that induce distress.

Second, technical problems should receive high priority. Due to the characteristics associated with ASD, such as inflexibility and difficulty with routine change [7], technical problems may interfere more with adherence and motivation among individuals with ASD than among other populations. Indeed, open-ended responses showed that these problems often triggered frustration. The only participant who did not complete the training program experienced a software crash, which erased the record of his work, causing him to quit permanently. Individuals with ASD

may require a training program that is more fault-tolerant and less liable to crash.

Third, the use of behavior management techniques may facilitate adherence with computer training in this population. Certain behavioral problems such as temper tantrums and self-injurious behavior can hinder training. Although the coaches provided guidance on reinforcement techniques, additional behavioral strategies such as stimulus control, extinction, or relaxation training may further decrease the likelihood of disruptive behaviors and increase adherence to protocol.

Fourth, the training should be more intrinsically motivating to maintain the interest of children with ASD and ID. Because this study utilized the adaptive version of Cogmed, in which the difficulty level gradually increased after correct consecutive trials, participants were working at peak level at all times. To keep the interest, it is crucial that the training is also highly motivating. The posttraining surveys indicate that keeping participants motivated to use Cogmed WMT was difficult, and that Cogmed was not as enjoyable as commercially available games. We suggest that both of these issues can be improved with better game design; program developers should create more motivating gameplay or use interesting characters, stories, and goals to maintain participants focus.

### Limitations

Although this study offers novel information on a population that has been understudied in the cognitive training research, the findings must be interpreted in light of limitations. Because there was no control group, self-report biases may have inflated some feasibility responses. Future studies should consider a systematized qualitative design, such as a focus group, to provide more comprehensive information. Moreover, the sample size was relatively small; thus, increasing the number of participants in future research may further enhance the generalizability of the present findings. Future research should also consider including more severe cases of ASD, as some individuals were excluded due to self-injurious behavior or high levels of noncompliance.

The funding for this project was specifically given by the agency to fund feasibility projects to assess if potential interventions would be successful and worth exploring in larger, controlled design for individuals with autism. This paper met those requirements in addition to a sister manuscript, which is under preparation, assessing the effects of the cognitive training on objective measures of performance and rating scales.

### Conclusions

Assessing stakeholder perspectives in intervention research is critical throughout the design and implementation process. The development of computerized cognitive training procedures for children with ASD is likely to increase due to their accessibility. This feasibility study is the first to systematically evaluate the feasibility and parent evaluation of cognitive training among children with ASD and ID. Findings suggest greater feasibility if a flexible training schedule is used in future efficacy studies. In addition, although most parents reported satisfaction with the program assessed in this project, many parents reported software glitches and poor tolerance of graphics and sounds by

their children. This may be an issue more unique to children with ASD. Thus, parent satisfaction may be improved if users are given greater control over the graphics, sounds, and interactions with specific stimuli. Developers of gaming software for training in ASD would be wise to employ focus

groups to gather feedback on how the game stimuli are perceived. Future research will need to assess the efficacy, effectiveness, and generalizability of computerized cognitive interventions for children with ASD.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Summary of parent posttraining ratings by Cogmed version.

[\[PDF File \(Adobe PDF File\), 264KB - mental\\_v5i2e40\\_app1.pdf\]](#)

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## Abbreviations

- ADHD:** attention deficit hyperactivity disorder
- ASD:** autistic spectrum disorder
- ID:** intellectual disability
- JM:** Cogmed for preschool-aged children
- RM:** Cogmed for school-aged children
- SB-5:** Stanford-Binet Intelligence Scales, Fifth Edition
- SCQ:** Social Communication Questionnaire
- TD:** typical developing
- WM:** working memory
- WMT:** working memory training

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Original Paper

# Development and Feasibility Testing of Internet-Delivered Acceptance and Commitment Therapy for Severe Health Anxiety: Pilot Study

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## Abstract

**Background:** Severe health anxiety (hypochondriasis), or illness anxiety disorder according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition, is characterized by preoccupation with fear of suffering from a serious illness in spite of medical reassurance. It is a debilitating, prevalent disorder associated with increased health care utilization. Still, there is a lack of easily accessible specialized treatment for severe health anxiety.

**Objective:** The aims of this paper were to (1) describe the development and setup of a new internet-delivered acceptance and commitment therapy (iACT) program for patients with severe health anxiety using self-referral and a video-based assessment; and (2) examine the feasibility and potential clinical efficacy of iACT for severe health anxiety.

**Methods:** Self-referred patients (N=15) with severe health anxiety were diagnostically assessed by a video-based interview. They received 7 sessions of clinician-supported iACT comprising self-help texts, video clips, audio files, and worksheets over 12 weeks. Self-report questionnaires were obtained at baseline, post-treatment, and at 3-month follow-up. The primary outcome was Whiteley-7 Index (WI-7) measuring health anxiety severity. Depressive symptoms, health-related quality of life (HRQoL), life satisfaction, and psychological flexibility were also assessed. A within-group design was employed. Means, standard deviations, and effect sizes using the standardized response mean (SRM) were estimated. Post-treatment interviews were conducted to evaluate the patient experience of the usability and acceptability of the treatment setup and program.

**Results:** The self-referral and video-based assessments were well received. Most patients (12/15, 80%) completed the treatment, and only 1 (1/15, 7%) dropped out. Post-treatment (14/15, 93%) and 3-month follow-up (12/15, 80%) data were available for almost all patients. Paired t tests showed significant improvements on all outcome measures both at post-treatment and 3-month follow-up, except on one physical component subscale of HRQoL. Health anxiety symptoms decreased with 33.9 points at 3-month follow-up (95% CI 13.6-54.3,  $t_{11} = 3.66$ ,  $P = .004$ ) with a large within-group effect size of 1.06 as measured by the SRM.

**Conclusions:** Treatment adherence and potential efficacy suggest that iACT may be a feasible treatment for health anxiety. The uncontrolled design and small sample size of the study limited the robustness of the findings. Therefore, the findings should be replicated in a randomized controlled trial. Potentially, iACT may increase availability and accessibility of specialized treatment for health anxiety.

**Trial Registration:** Danish Data Protection Agency, Central Denmark Region: 1-16-02-427-14; <https://www.rm.dk/sundhed/faginfor/forskning/datatilsynet/> (Archived by Webcite at <http://www.webcitation.org/6yDA7WovM>)

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## KEYWORDS

health anxiety; illness anxiety disorder; hypochondriasis; internet intervention; feasibility; acceptance and commitment therapy; behavior therapy

## Introduction

Severe health anxiety is characterized by the preoccupation with fear of having a serious illness, which interferes with daily functions and persists despite medical reassurance [1]. In the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), the disorder was labeled hypochondriasis, but in the new Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) [2], severe health anxiety is now classified as illness anxiety disorder or somatic symptom disorder, if persistent and distressing physical symptoms are present. Severe health anxiety is highly prevalent in medical settings (0.3% to 8.5%) [1,3-5], and has an estimated lifetime prevalence of 5.7% in the general population [6].

Despite the high prevalence and the existence of effective psychological treatments [7], the disorder is still rarely diagnosed in the health care setting [8]. Health care professionals often lack the necessary knowledge about health anxiety, and when the disorder is recognized, there is often a lack of proper treatment options. Furthermore, a subgroup of patients tends to be care-avoidant, and this group is therefore at an even higher risk of diagnostic delay. As severe health anxiety is associated with extensive use of health care services [9,10] and occupational disability [11], and rarely remits if untreated [10], the limited accessibility to proper assessment and treatment is a major challenge to the health care system. Thus, evidence-based, easily accessible treatment options are warranted for this debilitating disorder.

Patient self-referral in combination with internet-delivered psychological treatment is a new approach that may facilitate treatment accessibility and broaden availability. As used here, internet-delivered treatment is a highly structured treatment that the patient accesses through a secure online platform. The patient is granted gradual access to content such as video clips, texts, audio files, and work sheets, and the treatment is guided and supported by a clinician through an embedded asynchronous message system. The basic principle is that internet-delivered treatment should target the same core treatment processes as face-to-face treatment, with only the mode of delivery changing [12]. Internet-delivered treatment compares favorably with face-to-face treatment as it is unrestrained by geographical distance and interferes less with work and family obligations. Thus, it may inflict less strain on the patients' daily activities. Furthermore, studies suggest that internet-delivered treatment is less stigmatizing and therefore less of a barrier for seeking treatment than face-to-face treatment [13]. In addition, compared to treatment in an outpatient clinic, internet-delivered treatment may involve fewer societal costs due to absence from work and travel expenses.

Internet-delivered treatment for common mental disorders has been investigated in well over 100 randomized trials, and a recent meta-analysis showed that internet-delivered cognitive-behavioral therapy (iCBT) for depressive and anxiety disorders can be just as effective as face-to-face-treatment [14]. In 3 randomized controlled trials (RCTs), Hedman-Lagerlöf and colleagues showed that iCBT can be highly effective for severe health anxiety [15-17]. Studies have also shown that the treatment effect is long-term and cost-effective [18].

Poor adherence to internet-delivered treatment is a widespread and well-documented concern [19,20], which may limit its potential effectiveness [21]. A recent meta-analysis found that the mean adherence to protocol was higher in internet-delivered acceptance and commitment therapy (iACT) compared to iCBT [22]. Acceptance and commitment therapy (ACT) is a new, promising treatment within the third wave of cognitive-behavioral therapies, which has shown a positive effect across a range of mental health conditions, including health anxiety [23-26]. ACT aims to increase "psychological flexibility" which is considered a core process across different disorders [27]. Patients with severe health anxiety report low psychological flexibility, which often narrows the behavioral responses to health anxiety [28]. Patients spend a lot of time and energy trying to control or avoid thoughts, feelings, and sensations associated with illness, limiting the focus on value-based activities and creation of a meaningful life. ACT deliberately does not focus on symptom reduction, since this focus can maintain the very same symptoms by continuing to control or avoid them. Instead ACT aims to improve 2 skills: acceptance of inner experiences and commitment to values-based behaviors. A recent trial on iACT for social anxiety and panic disorder suggested that iACT may be feasible for treating anxiety disorders [29]. However, to our knowledge, iACT for severe health anxiety has not previously been developed or tested.

The aims of this study were to (1) describe the development of a new treatment concept for patients with severe health anxiety encompassing patient self-referral, video-based diagnostic assessment, and treatment with iACT over 12 weeks; and (2) evaluate the feasibility and overall outcome of this new treatment concept. The feasibility evaluation included patients' feedback provided both at the video-based assessment and post-treatment interview, self-reported questionnaires, and the patients' attrition and adherence to the treatment. The evaluation did not apply a priori defined criteria of success, since this study was a proof of concept prior to conducting a larger, RCT.

## Methods

### Phase I: Development

Both the technical platform and the contents of the treatment were developed de novo (Multimedia Appendix 1). The treatment content was developed according to an evidence-based manual [30]. Decisions not informed by previous research were made in collaboration with an expert group consisting of 2 psychologists and 1 psychiatrist from the Research Clinic for Functional Disorders and Psychosomatics at Aarhus University Hospital in Denmark. This group was supplemented with 2 external psychologists with expertise in developing and conducting research on internet-delivered programs. Two focus group interviews with former patients were conducted to establish relevant themes to address in new treatment content (eg, patient videos). The technical platform was developed in collaboration with a Web-developer. New procedures—patient self-referral and video-based assessment—were applied.

### Self-Referral and Video-Based Assessment

Self-referral was developed and tested as a new treatment entry through the clinic's webpage, where patients could log into a portal using their unique Danish personal identification number. The self-referral procedure consisted of the following steps: (1) patients gave written consent for the clinician to access information on their health status through the electronic patient record prior to assessment, (2) patients were asked to describe their problem in an open text field "Please describe your health anxiety in your own words and how you feel at the moment," and (3) patients completed baseline screening questionnaires measuring health anxiety symptoms among others. Video-based assessment was implemented to support nationwide recruitment. A shortened version of the semi-structured psychiatric interview, Schedules for Clinical Assessment in Neuropsychiatry (SCAN) [31], was adapted for this purpose in order to focus and shorten the assessment. The final version was screened for severe health anxiety and the corresponding diagnoses of hypochondriasis, illness anxiety disorder, and somatic symptom disorder. Furthermore, depression, anxiety disorders including obsessive-compulsive disorder and other somatoform disorders according to the International Classification of Diseases (ICD-10) were assessed.

### Technical Platform

Accessibility, interactivity, contact, and technical solution are some of the focal points that define the functionality and appearance of internet-delivered treatment programs. The decisions regarding these focal points as they relate to the present study are described below.

#### Accessibility

Accessibility can range from full, open access to health care integrated programs with clinician-administered inclusion. Since this platform was developed and operated in a hospital setting, access was administered by health professionals to secure that the hospital's legal responsibility was ensured. Treatment progress was monitored and access to treatment modules was granted consecutively by the clinician.

#### Interactivity

Interactivity can range from fixed content with no interaction to more responsive content such as online exercises or games that are adapted based on the patient's interaction. The platform's content was designed to be relatively fixed (text, audio files, video clips, illustrations), but included interactive work sheets which were completed by the individual patient using embedded text fields. All sheets were automatically collected and stored in a folder on the front page and shared with the patient's personal clinician.

#### Contact

Contact can range from pure self-help to varying degrees and formats of contact (eg, written/telephone/video support to blended care where online tools are blended with face-to-face contact). The current platform enabled written, asynchronous clinician guidance (no real-time chat). This format was chosen to minimize interference with the patient's daily activities. Guidance was provided throughout the 12 weeks of treatment. Every patient had a designated personal clinician and messages were answered within 48 hours on weekdays. The content of the written guidance was not predetermined or restricted, and no limit was established concerning contact frequency and length.

#### Technical Solution

Technical solution can range from tools designed for mobile apps to extensive Web-based programs. The current platform was developed as a Web-based app built upon Drupal, a flexible open source content management system (CMS) and development framework. This solution was chosen because the treatment material is comprehensive and specialized functionality had to be added to the platform. The following solutions were developed: (1) a 2-factor authentication login which interfaces with the Danish public login system (NemID); (2) an embedded, securely encrypted message system for written communication; (3) an automatic text message (short message system, SMS) notification system (eg, notifies patients about new content such as messages, modules, questionnaires); and (4) a clinician-monitored control panel with automatic notifications with information about patient activity (eg, new messages, work sheets, activity, or missed questionnaires). In addition, the responsive design allows access to the treatment program through mobile devices and tablets.

#### Treatment Content: Intervention

The treatment content was based on an empirically tested group-based ACT program for patients with severe health anxiety [24,30], and clinical experience with the manual and focus group interviews with former patients receiving group treatment. Literature on internet-delivered treatments was also reviewed. All treatment content aims to target and affect core structures of health anxiety such as experiential avoidance of unpleasant illness-related thoughts, feelings, and bodily sensations that inhibit values-based actions. The treatment program trains acceptance of these unpleasant inner states, clarifies values, and simultaneously promotes values-based exposure. The overall intention is to improve the patient's psychological flexibility (ie, ensure they are able to experience

a more flexible and value-based behavioral repertoire when health anxiety is present). This includes the distinction between what can and cannot be changed. Since ACT is a behavior therapy, the treatment works through both the processes of accepting what cannot be controlled (thoughts, feelings, sensations), and change what can be controlled (behaviors). The progression of treatment processes is illustrated in [Table 1](#).

The number of modules in the original face-to-face manual was shortened from 10 to 7 ([Textbox 1](#)). Since this program was primarily based on self-help, the language was revised and simplified so that all content elements were self-explanatory. The front page features 10 widgets (messages, work sheets, acute help, and modules 1 to 7) ([Multimedia Appendices 2 and 3](#)). Each module has between 10 to 15 pages of content which is primarily text-based. The modules also contain audio files with guided exercises, such as mindfulness training, and patient videos with 5 former patients sharing their experience of health anxiety and treatment processes. The videos were produced to enhance treatment comprehension, recognition, and patient motivation. All videos and audio exercises are relatively short (between 4 to 20 minutes), and each module introduces at least 1 new video and audio exercise. Furthermore, illustrations were hand drawn, graphic design was added to structure different types of treatment elements, and written work sheets were embedded. All modules follow the same structure; the first page is an introduction to the following theme and a repetition of the previous one, next follows the main treatment content, and lastly a summary of the current module, clarifying questions and an introduction to weekly homework exercises. The homework consists of 2 alternating exercises each week: an audio exercise primarily based on mindfulness and a behavioral exercise based on values-based exposure ([Multimedia Appendices 4-6](#)).

## Phase II: Design of Feasibility Testing

### Study Design and Setting

This feasibility study took place from April 2015 to October 2015 at the Research Clinic for Functional Disorders and Psychosomatics at Aarhus University Hospital in Denmark. It was an open trial with no control group. Self-report questionnaires were obtained at baseline prior to diagnostic assessment, at post-treatment, and at 3-month follow-up. Patients

not completing any modules were excluded from the final analyses as the primary aim of the study was to evaluate the feasibility of the new treatment set-up and program. Treatment completion was defined a priori as 3 or more modules completed since the first 2 modules primarily consisted of psycho-education and did not explicitly include behavior change strategies. Semi-structured interviews with patients after end of treatment were conducted by the clinician assigned to the individual patient to explore the usability and acceptability of the procedure with self-referral, video-based assessment, as well as the treatment program. All participants provided written informed consent, and the study was approved by the Danish Data Protection Agency, Central Denmark Region (ID no. 1-16-02-427-14).

### Participant Recruitment and Eligibility

A total of 15 patients were recruited, 10% of the projected sample size for the RCT. This was considered sufficient for the feasibility evaluation of the treatment concept including self-referral, assessment, and treatment. Patients were recruited through the clinic's webpage, which announced information about the study, and presented a patient video about health anxiety. Patient self-referrals were screened for eligibility by a psychologist (first author) and then allocated to a video-based clinical assessment. The assessments were conducted by psychologists or psychiatrists trained in the use of the shortened version of SCAN [31]. Health information was assessed and the electronic patient record was examined before the interview. A psychiatrist provided supervision in regard to somatic questions. Eligible participants had to (1) report symptoms corresponding to fulfillment of the empirically-based diagnostic criteria for severe health anxiety in accordance with Fink et al [1]; (2) have a Whiteley Index-7 (WI-7) score above 21.4 (scale range 0 to 100), which is established as a clinically relevant cut-off score [10,24]; (3) be at least 18 years old; (4) be able to read and understand Danish; and (5) have a primary diagnosis of health anxiety if co-morbid disorders were present. Patients were excluded from the study if they (1) were at risk for suicide; (2) had current or previous episodes of psychosis; (3) had current abuse of alcohol, drugs, or medication; (4) were pregnant; and (5) did not give informed consent to the study.

**Table 1.** Treatment processes.

Module	Functional analysis	Mindfulness	Willingness and commitment	Values	Defusion	Acceptance
1	✓			✓		
2	✓	✓		✓		
3		✓	✓			✓
4		✓	✓	✓		
5		✓	✓	✓	✓	✓
6		✓		✓	✓	✓
7	✓					✓

**Textbox 1.** Overview of the treatment.

Treatment targets for each module

**Module 1: The first important step**

- What are health anxiety and acceptance and commitment therapy?
- Overview and introduction to the treatment
- Motivation and values for participation

**Module 2: Your experiences managing health anxiety**

- Model of health anxiety and introduction to values
- Control, avoidance and creative hopelessness
- Mindfulness and rumination about illness

**Module 3: Challenging and accepting anxiety**

- Evolutionary function of bodily symptoms of anxiety
- The workability of control and avoidance behavior
- Challenging (exposure) and accepting anxiety

**Module 4: You get to know your values when taking steps**

- Values sorting
- Values compass
- Values-based exposure-hierarchy

**Module 5: What is stopping me?**

- Inner barriers (thoughts, feelings, bodily sensations)
- Defusion and acceptance
- Mindfulness and self-as-context

**Module 6: Self-compassion and boundaries**

- How stress affects bodily symptoms
- Balancing maladaptive “all-or-nothing” behavior
- Personal boundaries, open up and self-care

**Module 7: Relapse prevention**

- Repetition of treatment principles
- Consolidating personal insights from the treatment
- Normalization of relapse and relapse prevention

**Measures**

The mean sum score of the scales presented below were transformed into a 0 to 100 score point scale according to equation 1:

$$(1) \text{ Scale} = [(score - minimum) \div (maximum - minimum)] \times 100$$

This was chosen to facilitate the comparison of changes between measures in this and previous studies [24,32].

**Primary Outcome**

The WI-7 [33] is a 7-item measure of health anxiety symptoms including items such as “Do you often worry about the possibility that you have a serious illness?” Each item is scored

on a 5-point Likert scale ranging from 0 to 4 (range 0 to 28), with higher scores indicating more severe health anxiety. WI-7 is broadly employed and has shown acceptable psychometric properties in primary care [10], and good sensitivity and specificity in screening for DSM-IV hypochondriasis [34].

**Secondary Outcomes**

The Symptom Checklist-92 (SCL-92) [35] subscale for depression (SCL-92 Dep) is a 13-item measure of depression (range 13 to 65). The subscale for anxiety (SCL-92 Anx) is a 10-item measure of anxiety (range 10 to 50). Each item is scored on a 5-point Likert scale ranging from 1 to 5, with higher scores indicating more severe illness.

The Short-Form Health Survey (SF-12) [36,37] with 12 items measures 2 dimensions of health-related quality of life (HRQoL): the physical component summary (PCS) and the mental component summary (MCS). Both scales range from 0 to 100, with higher scores indicating better physical and mental HRQoL.

Life satisfaction [38] is a 1-item measure scored on a 10-point Likert scale ranging from 0 to 10, where 0 and 10 encompass the “the worst possible life” and “the best possible life,” respectively.

The Acceptance and Action Questionnaire-II (AAQ-II) [39,40] is a 7-item measure of psychological flexibility. Each item is scored on a 7-point Likert scale ranging from 1 to 7 (range 10 to 70), with higher scores indicating better functioning.

### Statistical Analysis

Data were summarized using means and standard deviations. The mean differences from baseline to post-treatment and from baseline to 3-month follow-up were analyzed using paired *t* tests. The assumptions behind the paired *t* test were assessed by graphical inspection of a quantile-quantile (Q-Q) plot of the differences and a Bland-Altman plot. An estimate of within group effect sizes was calculated using the standardized response mean (SRM) according to equation 2, by the formula, where  $X_1$  and  $X_2$  are the means of the measurements at time points 1 and 2, respectively.  $SD_{DIFF}$  is the standard deviation of the variable containing the difference between the 2 measurements.

$$(2) \text{ SRM} = (X_1 - X_2) \div SD_{DIFF}$$

Adherence was measured as the mean number of modules completed, and exchanged messages in the program were summarized using means and standard deviations. All analyses were performed using Stata version 13 for Windows. The post-treatment interviews were conducted using semi-structured questions. The answers were not analyzed quantitatively.

## Results

### Patient Characteristics and Adherence

A total of 18 patients were self-referred of which 3 (3/18, 17%) withdrew prior to assessment (Figure 1). Of the patients, 15 (15/18, 83%), including 12 females (12/18, 67%) were assessed for eligibility, all of whom met the inclusion criteria and were included in the study. Socio-demographic and clinical details are shown in Table 2. Of the patients, 80% (12/15) completed treatment (ie, performed a minimum of 3 modules). The majority of the completers were considered active during all 12 weeks of treatment, independently of the number of modules finalized. One patient (1/15, 7%) dropped out prior to module 1 due to technical obstacles. Thus, post-treatment data on 14 (14/15, 93%) patients and 3-month follow-up data on 12 (12/15, 80%) patients were included in the final statistical analyses (Figure 1).

Of the patients, 12 (12/15, 80%) agreed to participate in the semi-structured interviews at post-treatment. Due to

cancellations, only 10 interviews were conducted. The patient who dropped out and 1 of the non-completers participated in the interview ensuring a varied evaluation.

### Feasibility of Patient Recruitment and Assessment

Online patient recruitment through the clinic’s webpage attracted the patient population of interest. All self-referred patients were judged to have health anxiety as their primary problem based on the first screening and they were invited for assessment. Patients reported that it was easy to find the trial and go through the steps of self-referral.

At the end of the video-based interview, patients commented on their user experience. Overall, patients found it convenient, and the majority expressed feeling more secure at home than having to go to the hospital. A few patients felt anxious prior to the assessment due to the new video-format, and technical issues did interrupt a few interviews. In spite of this, most patients expressed that the video-format did not interfere negatively with their sense of contact with the clinician during the assessment. All clinicians had no prior experience with the video-format, and they reported positively about the amount of clinical information the assessment allowed for.

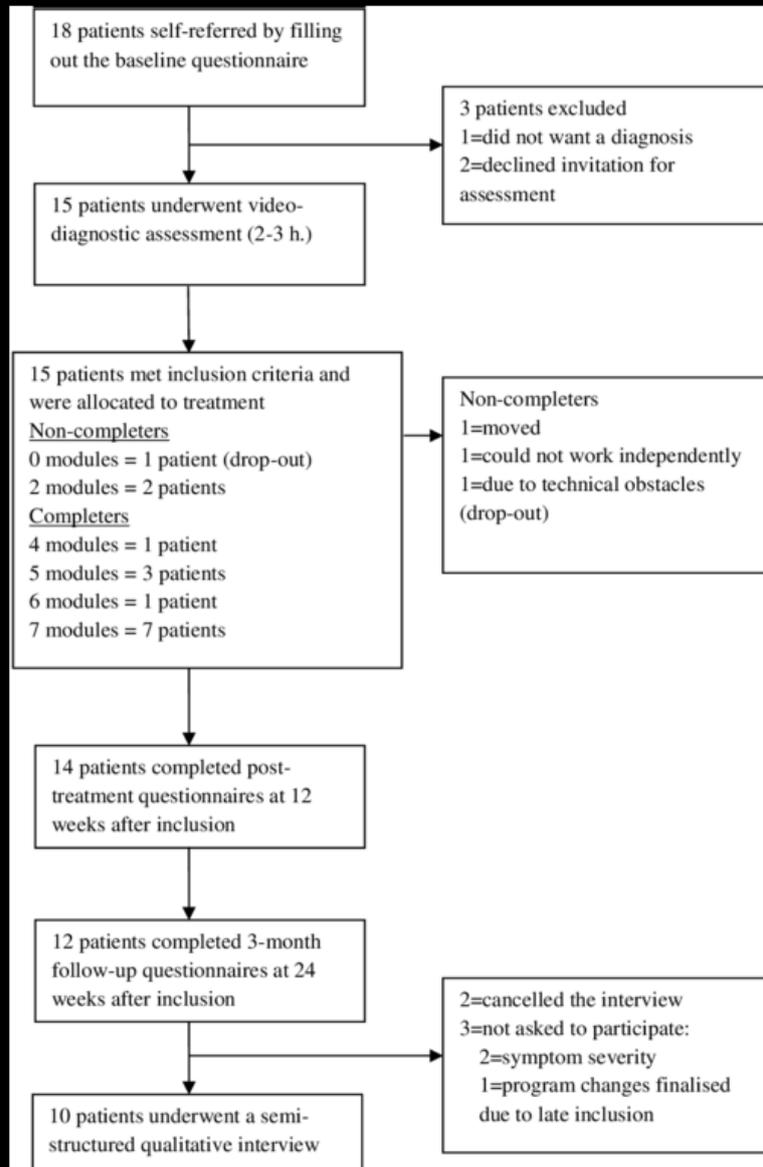
### Feasibility of the Treatment Platform and Content

The post-treatment patient interviews revealed overall satisfaction with relevance and progression of treatment themes and a positive response to the use of patient videos. There was no consistent pattern in content feedback (eg, some patients emphasized the importance of mindfulness exercises, and some patients did not use them at all). Patients sent an average of 12.9 (SD 7.76) messages (range 4-29) to their clinician, and clinicians sent an average of 18.5 (SD 3.46) messages (range 12-25) to their patient. Some patients expressed that this form of communication allowed for more honesty compared with earlier experiences with face-to-face therapy, whereas for others it was a hindrance. Therefore, some patients wrote many extensive messages where others consulted the clinician only to a limited extent. The clinicians reported that it was possible to have a good clinical sense of the patient. However, for those patients who did not use the clinician, the therapeutic reinforcement was missing to a larger extent. Furthermore, the patients were generally surprised by the amount of time they needed to complete a module.

### Changes in Outcome Measures

Mean, standard deviation, and percent changes at baseline, post-treatment, and 3-month follow-up are shown in the Table 3. Mean difference, CI, *P* values, and effect sizes are shown in Table 4. Patients reported statistically significant reductions in health anxiety symptoms from baseline to post-treatment with a difference in WI-7 score of 37.2 points (95% CI 24.1-50.4,  $t_{13} = 6.11$ ,  $P < .001$ ), and at 3-month follow-up with a difference of 33.9 points (95% CI 13.6-54.3,  $t_{11} = 3.66$ ,  $P = .004$ ) with large within-group effect sizes (SRM 1.06-1.63).

Figure 1. Study flowchart.



**Table 2.** Baseline characteristics of study sample (N=15).

Variable	Value
Age (years), mean (range)	38.8 (20.8-56.6)
<b>Sex, n (%)</b>	
Female	12 (80)
Male	3 (20)
<b>Education, n (%)</b>	
Basic school (9-15 years)	9 (60)
Further/higher education (<4 years)	6 (40)
<b>Work status, n (%)</b>	
Full-time employed	7 (47)
Part-time employed	3 (20)
Unemployed	0 (0)
Disability pension or flexible work	4 (27)
Other (eg, maternity leave)	1 (7)
<b>Absence from work, n (%)</b>	
No absence	10 (67)
Full-time absence	3 (20)
Part-time absence	2 (13)
<b>Living status, n (%)</b>	
Alone	2 (13)
With someone	13 (87)
Duration of health anxiety (years), mean (range)	15.2 (0.7-30)
Onset of health anxiety (years), mean (range)	23.6 (9-40)
<b>Psychiatric co-morbidity, n (%)</b>	
Other anxiety disorders	4 (27)
Depression	0 (0)
Other somatoform disorders <sup>a</sup>	2 (13)

<sup>a</sup>Somatization disorder or undifferentiated somatoform disorder.

**Table 3.** Mean, standard deviation and percent change at baseline, post-treatment, and 3-month follow-up. WI-7: Whiteley-7 Index. SCL-92 Dep: symptom checklist-92 depression. SCL-92 Anx: symptom checklist-92 anxiety. PCS: physical component summary. SF-12: short-form health survey. MCS: mental component summary. AAQ: acceptance and action questionnaire.

Outcome measure <sup>a</sup>	Baseline (T1; N=15)		Post-treatment (T2; N=14)		3-month follow-up (T3; N=12)	
	Mean (SD)		Mean (SD)	% <sup>b</sup>	Mean (SD)	% <sup>c</sup>
<b>Primary outcome</b>						
Health anxiety (WI-7)	80.9 (18.5)		43.6 (13.0)	-46	45.5 (29.6)	-44
<b>Secondary outcomes</b>						
Depression (SCL-92 Dep)	40.4 (13.2)		21.2 (13.3)	-48	16.2 (13.6)	-60
Anxiety (SCL-92 Anx)	43.8 (14.3)		27.5 (16.4)	-37	18.8 (12.6)	-57
PCS (SF-12)	44.7 (15.8)		46.2 (11.8)	3	48.5 (13.8)	9
MCS (SF-12)	28.7 (9.5)		43.6 (10.0)	52	44.3 (12.1)	54
Life satisfaction	45.7 (12.2)		59.3 (18.2)	30	71.7 (14.0)	57
<b>Process measure</b>						
Psychological flexibility (AAQ-II)	37.9 (15.8)		61.4 (20.0)	62	69.6 (16.3)	84

<sup>a</sup>High score is many symptoms, except for life satisfaction, SF-12, and psychological flexibility. Scale 0 to 100.

<sup>b</sup>Percent change from baseline to post-treatment, measured by  $((T1-T2)/T1) \times 100$ .

<sup>c</sup>Percent change from baseline to 3-month follow-up, measured by  $((T1-T3)/T1) \times 100$ .

**Table 4.** Change in outcome measures and effect sizes. MD: mean difference. SRM: standardized response mean. WI-7: Whiteley-7 Index. SCL-92 Dep: symptom checklist-92 depression. SCL-92 Anx: symptom checklist-92 anxiety. PCS: physical component summary. SF-12: short-form health survey. MCS: mental component summary. AAQ: acceptance and action questionnaire.

Outcome measure	Baseline to post-treatment (N=14)				Baseline to 3-month follow-up (N=12)			
	MD	95% CI	P value	SRM	MD	95% CI	P value	SRM
<b>Primary outcome</b>								
Health anxiety (WI-7)	37.2	24.1 to 50.4	<.001	1.63	33.9	13.6 to 54.3	.004	1.06
<b>Secondary outcomes</b>								
Depression (SCL-92 Dep)	19.2	11.2 to 27.3	<.001	1.38	21.5	10.5 to 32.4	.001	1.24
Anxiety (SCL-92 Anx)	16.3	3.3 to 29.2	.02	0.73	25.6	14.9 to 36.4	<.001	1.51
PCS (SF-12)	-3.3	-11.9 to 5.3	.42	0.23	-5.1	-13.3 to 3.0	.19	0.42
MCS (SF-12)	-15.0	-21.0 to -9.0	<.001	1.50	-15.3	-21.7 to -8.9	<.001	1.61
Life satisfaction	-13.6	-23.9 to -3.3	.01	0.76	-27.5	-37.3 to -17.7	<.001	1.78
<b>Process measure</b>								
Psychological flexibility (AAQ-II)	-23.5	-35.3 to -11.7	<.001	1.15	-31.2	-42.1 to -20.2	<.001	1.80

There were no significant changes in scores from post-treatment to 3-month follow-up which suggests stability of clinical outcome. Furthermore, patients reported significant reductions in symptoms of anxiety and depression, and significant increases in life satisfaction and psychological flexibility (Table 4). Effect sizes were moderate to large on all secondary outcomes (SRM 0.73-1.80), with the exception of the SF-12 PCS measuring physical functioning. Apart from life satisfaction, which further increased significantly from post-treatment to 3-month follow-up (SRM 0.96), there were no significant changes in scores from post-treatment to 3-month follow-up.

### Subsequent Revisions of the Treatment Program and Set-Up

The patient interviews gave rise to revision and further extension of some treatment themes and exercises. Furthermore, we learned that patients need to not only be motivated for internet-delivered treatment, but also to be able to work independently, prioritize their time with regard to treatment engagement, and have a minimum of technical know-how. To further improve adherence prior to the RCT, a patient recruitment video was developed to provide a clear picture of the treatment format, emphasizing the time and effort needed to participate in this type of treatment. This was also further addressed in the assessment interview. Patients who were ambivalent had up to 2 weeks to decide whether to enter the

randomization for the following trial. Based on the experience with the drop-out of 1 patient due to technical obstacles, we included a question about computer skills in the baseline questionnaire. We also enquired more about this in the assessment interview. Finally, due to discussions raised about changes in medication during the pilot study, an extra inclusion criterion was added for the RCT to ensure that patients had been stable on anxiety medication for at least 2 months prior to inclusion.

## Discussion

### Principal Findings

The main finding of this pilot feasibility study was that iACT encompassing online self-referral, video-based assessment, and internet-delivered treatment was a feasible treatment concept for patients suffering from severe health anxiety. We found overall positive outcomes with large improvements in health anxiety symptoms and medium to large improvements in anxiety, depression, HRQoL, and life satisfaction, which improved further during the 3-month follow-up period. The observed reductions in health anxiety symptoms were similar to those reported in a previous, uncontrolled, face-to-face pilot study, and a subsequent RCT on group-delivered ACT for patients with health anxiety [24,32]. Since health anxiety is considered a chronic disorder if untreated [10], spontaneous remission is unlikely to have contributed significantly to this effect. It is often debated whether symptom measures should be used as a primary outcome in ACT trials, since the treatment does not focus on symptom reduction but instead aims to increase behavioral flexibility and valued living. In our study, we also measured psychological flexibility, which did show the largest improvement (SRM 1.80). This supports the model of change suggesting that increased psychological flexibility is associated with general psychological well-being and might even precede symptom reduction [28,41]. Thus, symptom reduction is a welcomed treatment outcome but should not be mistaken as a therapeutic goal in treatment. In the present study, only 1 (1/15, 7%) patient dropped out, and 12 patients (12/15, 80%) completed 12 weeks of treatment. This was comparable to iCBT for health anxiety which has shown a similar completion rate of 85% [15]. Since the majority of patients completed the treatment, iACT seems to be an acceptable and feasible treatment for severe health anxiety.

### Strengths and Limitations

The thorough standardized clinical assessment and well-defined diagnostic inclusion criteria were strengths of this pilot study. Moreover, both completers and non-completers participated in the post-treatment interview and most data were available for patients at follow-up. Lastly, the study employed validated clinical outcome measures. Even though this study did not employ a randomized design, most outcomes pointed in the same direction: symptoms improved following iACT. The most important limitation of this study was the uncontrolled study design and small sample size. The design was chosen based on the aims of this study, and the sample size did not limit the feasibility evaluation, which was the primary aim. The preliminary observed clinical changes should be replicated in

a larger RCT to establish clinical relevance. Another limitation was that the video-based assessment was not evaluated systematically. We did discuss the technical and clinical implications at supervision, and asked the patients about their experience at the interview, but we did not collect our experiences in a structured manner. Lastly, the post-treatment patient interviews were not analyzed systematically and since they were conducted by the dedicated clinician, there was a risk of bias due to socially desirable answers.

### Patient Recruitment and Generalizability

Patient self-referral is rarely applied in a publicly funded health care system based on gatekeeping, where patients are referred primarily through the general practitioner. We found that the majority of those who self-referred fulfilled criteria for severe health anxiety, which may indicate that self-referral is a sensible recruitment procedure in patients with severe health anxiety. One explanation may be that patients with health anxiety often seek medical information via the internet, and may have come across the clinic's webpage while searching for explanations for their symptoms. The patient video on the webpage was likely to have further increased recruitment sensitivity as many patients reported that they recognized their own health anxiety from the patient's stories. Former studies support that patient self-referral is a feasible recruitment method for internet-delivered psychological treatment [42,43]. However, patient characteristics may differ compared to patients referred from the general practitioner to outpatient treatment. Prior to this study, we anticipated that the treatment setup would appeal to males and younger patients with less severe symptoms of health anxiety. Studies tend to find no age or gender difference in the distribution of health anxiety [10], yet males and younger patients seem to be less frequently referred to treatment [24]. However, in the present study, we recruited 80% (12/15) female patients, with an average age of 38.8 years. Moreover, patients had health anxiety for approximately 15 years and were quite impaired at referral, with an average WI-7 score of 81 (range 0 to 100). Online administration of questionnaires has shown to be a valid method for measuring symptoms of health anxiety, which suggests that the surprising level of symptom severity cannot be explained by this [44]. This might imply that a different patient subgroup was reached, even though the group did not differ in the expected direction. In the DSM-5, patients suffering from health anxiety are categorized as either care-seeking or care-avoiding [2]. It may be that self-referral appeals to more avoidant patients with health anxiety, thus making treatment accessible for a different subgroup. However, these speculations need to be investigated in a larger patient sample.

### Treatment Processes and Clinical Implications

The overall aim of iACT for health anxiety is to target and improve a patient's psychological flexibility, which previously has shown to be a central process of change [28,45]. This was done through several treatment processes as previously illustrated (Textbox 1). Specifically, we had a distinct focus on acceptance of inner experiences and values in order to broaden the behavioral repertoire from control and avoidance to values-based behaviors. This involved gradually changing

behaviors from unworkable short-term strategies to long-term goals in line with the chosen values. The distinct focus on personal values in ACT compared to CBT may explain why iACT tends to have better adherence to protocol compared to iCBT [22]. Future studies should include process measures to further understand the role of values and investigate the mediational effect on symptoms.

Clinician guidance was added to this treatment program because studies generally find that unguided internet-delivered treatment has higher attrition [20,46]. The asynchronous message system enabled a more flexible and patient-tailored contact in terms of individual needs of guidance. This was also reflected in the wide range of messages exchanged between each patient and their allocated clinician. The aim of the written guidance was to motivate patients, to validate patient efforts, to clarify misunderstandings, and to personalize treatment content. This study did not measure the quality of therapeutic alliance, but a former review on internet-delivered treatment across patient populations found client-rated alliances close to those found in face-to-face studies [47]. However, the review also reported

that clinicians rated the alliance lower than in face-to-face treatment. This is in line with the feedback from clinicians in the present study regarding patients who did not use their dedicated clinician. This may suggest that clinicians are affected more by the internet-delivered treatment modality than patients.

### Conclusion

Severe health anxiety is a disabling and costly disorder with a lack of accessible, specialized treatment options. Here, we showed that online self-referral, video-based assessment, and iACT may be a feasible treatment set-up for patients suffering from severe health anxiety. The promising outcome results also suggest potential efficacy for this iACT program which is currently being tested in a larger RCT. If proven effective, iACT may increase availability and accessibility of specialized treatment for health anxiety. Future studies need to evaluate the sensitivity of patient self-referral, and to compare characteristics in patients self-referred or referred through a health care professional, to determine whether different patient populations are reached.

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### Conflicts of Interest

EHL and BL are shareholders of DahliaQomit Inc, a company specializing in online psychiatric symptom assessment.

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### Multimedia Appendix 1

Video demonstration of the program.

[[MP4 File \(MP4 Video\), 10MB - mental\\_v5i2e28\\_app1.mp4](#) ]

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### Multimedia Appendix 2

iACT program.

[[PNG File, 934KB - mental\\_v5i2e28\\_app2.png](#) ]

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### Multimedia Appendix 3

Graphic design elements aiming to structure the treatment content throughout the program.

[[PNG File, 46KB - mental\\_v5i2e28\\_app3.png](#) ]

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### Multimedia Appendix 4

Illustration of long term consequences of health anxiety.

[[PNG File, 7MB - mental\\_v5i2e28\\_app4.png](#) ]

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### Multimedia Appendix 5

Illustration of control and avoidance as a mean to escape unpleasant thoughts, feelings and bodily sensations; here illustrated as 3 monsters.

[[PNG File, 4MB - mental\\_v5i2e28\\_app5.png](#)]

## Multimedia Appendix 6

Illustration of the principle of graded exposure.

[[PNG File, 283KB - mental\\_v5i2e28\\_app6.png](#)]

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## Abbreviations

**ACT:** acceptance and commitment therapy  
**DSM-IV:** Diagnostic and Statistical Manual of Mental Disorders, 4th edition  
**DSM-V:** Diagnostic and Statistical Manual of Mental Disorders, 5th edition  
**HRQoL:** health-related quality of life  
**iACT:** internet-delivered acceptance and commitment therapy  
**iCBT:** internet-delivered cognitive-behavioral therapy  
**MCS:** mental component summary  
**PCS:** physical component summary  
**RCT:** randomized controlled trial  
**SCAN:** Schedules for Clinical Assessment in Neuropsychiatry  
**SCL:** symptom checklist  
**SF-12:** short-form health survey  
**SRM:** standardized response mean  
**WI-7:** Whiteley-7 Index

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Original Paper

# Feasibility and Acceptability of a Web-Based Treatment with Telephone Support for Postpartum Women With Anxiety: Randomized Controlled Trial

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## Abstract

**Background:** Postpartum anxiety can have adverse effects on the mother and child if left untreated. Time constraints and stigma are common barriers to postpartum treatment. Web-based treatments offer potential flexibility and anonymity. *What Am I Worried About* (WaWa) is a self-guided treatment based on cognitive-behavioral and mindfulness principles for women experiencing postpartum anxiety. WaWa was developed in Australia and consists of 9 modules with optional weekly telephone support. WaWa was adapted to a Web-based version for use in England (Internet-based What Am I Worried About, iWaWa).

**Objective:** This study aimed to investigate the feasibility (engagement and usability) and acceptability (usefulness, satisfaction, and helpfulness) of iWaWa among English postpartum women with anxiety.

**Methods:** Postpartum (<12 months) women with mild-to-severe anxiety were recruited anonymously via social media during an 8-week period. Participants were randomized to the iWaWa treatment (8 weeks) or wait-list control group. Treatment and study feasibility and acceptability were assessed after the treatment, and anxiety symptoms were assessed at baseline, 8 weeks postrandomization, and 12 weeks postrandomization (treatment group only) using Web-based questionnaires. Semistructured telephone interviews were carried out after the treatment period for a more in-depth exploration of treatment acceptability and feasibility.

**Results:** A total of 89 eligible women were recruited through social media and randomized into the treatment (n=46) or wait-list control group (n=43). Women were predominantly Caucasian, well-educated, married, on maternity leave, first-time mothers and reported moderate levels of anxiety. Dropout rates were high, especially in the treatment group (treatment: 82%, 38/46; wait-list control: 51%, 22/43). A total of 26 women started iWaWa with only 2 women completing all 9 modules. Quantitative and qualitative data suggest iWaWa was experienced as generally useful and helpful. Participants enjoyed iWaWa's accessibility, anonymity, and weekly reminders, as well as the introduction to the principles of cognitive-behavioral therapy (CBT) and mindfulness. However, iWaWa was also experienced as not user-friendly enough, too long, and not smartphone-friendly. Parts of the content were experienced as not always relevant and appropriate. Participants felt that iWaWa could be improved by having it in a smartphone app format and by making the content more concise and inclusive of different parenting styles.

**Conclusions:** Despite interest in iWaWa, the results suggest that both the study and iWaWa were not feasible in the current format. However, this first trial provides useful evidence about treatment format and content preferences that can inform iWaWa's future development, as well as research and development of Web-based postpartum anxiety treatments, in general, to optimize adherence.

**Trial Registration:** ClinicalTrials.gov NCT02434406; <https://clinicaltrials.gov/ct2/show/NCT02434406> (Archived by WebCite at <http://www.webcitation.org/6xTq7Bwmd>)

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## KEYWORDS

anxiety; mental health; postpartum period; treatment; Internet; randomized controlled trial

## Introduction

### Postpartum Anxiety

Anxiety disorders such as generalized anxiety disorder, obsessive-compulsive disorder, panic disorder, and phobias in the first year after birth (postpartum) are common with prevalence rates ranging between 9.9% and 20% [1-3]. Anxieties in the postpartum period are often life-stage specific, for example, worries about baby's care and health and fear of criticism and inadequacy as a mother [4]. Postpartum anxiety disorders can either be a recurrence of a previous disorder or develop as a first episode. Symptom intensity and associated degree of impairment of these anxiety disorders can vary over the course of the postpartum period [5]. Despite available effective treatments [6-10], postpartum mental health problems often go undetected or untreated [11,12]. Low screening and diagnosis rates play a role, but some women with emotional difficulties postpartum are often more reluctant to disclose and seek help [13-15]. Possible reasons for this include being too busy to get around to seeking help and feeling too embarrassed or having no-one they felt comfortable talking to [14], as well as child care concerns [16].

The importance of having efficient and timely treatments is highlighted by the adverse effects of untreated mental health problems on the physical and psychological health of the mother, child, and family [17,18], as well as potential costs to society [11]. For example, it has been shown that maternal anxiety can affect infant bonding and feeding [19,20] and may negatively affect the child's cognitive and social development [17]. Considering the importance of treatment and unique postpartum barriers to accessing treatment, providing convenient and anonymous treatment seems essential.

### Web-Based Self-Help Treatments

One approach of offering anonymous and convenient treatment is Web-based self-help treatments, which run on computers, tablets, or smartphones and allow individuals to work through written therapy material without or with minimal therapist or mental health professionals' assistance. Many of today's parents search for information and support on the Web [21]. In addition, postpartum women who feel isolated or restricted by their baby's schedule experience Web-based resources as useful [22]. In a thematic analysis of motivators and barriers to a Web-based postpartum treatment, it was found that the offered flexibility and anonymity fitted women's postpartum circumstances [23]. This suggests that Web-based treatments may be an appropriate alternative or supplement to conventional face-to-face therapy for postpartum women.

Systematic reviews and one meta-analysis focusing on the perinatal period suggest that Web-based treatments can help

improve postpartum depressive symptoms [24-26], but so far none are specifically developed for postpartum anxiety [24]. A Web-based survey demonstrated that women with postpartum anxiety are interested in Web-based treatments [27], and a qualitative study of postpartum health care professionals (health visitors) in the United Kingdom reported a need for more treatment options for postpartum anxiety and that Web-based treatments could be useful to address this issue [28].

### The What Am I Worried About Treatment

On the basis of the identified interest and need, a self-help treatment for women experiencing moderate or severe symptoms of postpartum generalized anxiety disorder called *What Am I Worried About* (WaWa) developed in Australia [4] was transformed into a Web-based version called Internet-based WaWa (iWaWa). This study aimed to evaluate the feasibility and acceptability of iWaWa for women with postpartum anxiety problems in England. On the basis of the stage model of behavioral therapy research [29,30], the primary study objectives were to determine study feasibility by examining recruitment and attrition, examine iWaWa's feasibility in terms of engagement and usability, and examine user's acceptability of iWaWa in terms of usefulness, helpfulness, and satisfaction. The secondary objective was to examine potential changes in anxiety over the course of the treatment and compare with a wait-list control group.

## Methods

The study received ethical approval from the National Research Ethics Service, London—Dulwich Research Ethics Committee (ref: 15/LO/1827).

### Sample and Recruitment

#### Sample Size Calculation

Studies evaluating the feasibility of Web-based treatments for postpartum depression have recruited between 53 to 103 participants in total [31,32]. A power calculation indicated that 27 participants in each group would be required to achieve 95% power at a one-sided 5% significance level. In studies evaluating postpartum depression, Web-based treatments had attrition rates between 11.3% and 62.3%, with an average attrition of 34.2% [31,33,34]. About 18 more participants needed to be recruited to allow for 34.2% attrition. It was therefore aimed for a minimum of 36 participants per group (treatment vs wait-list control) (total=72).

#### Recruitment

Participants (n=89) were recruited over 8 weeks (March to May 2017) through Facebook, Twitter, and appropriate UK third-party parenthood websites, as well as through posters and

flyers in two clinical settings in England (hospital and health visiting clinic). The development of the promotional material was informed by mothers participating in patient and public involvement meetings. Monetary compensation was only offered for taking part in the follow-up interviews.

### **Eligibility Criteria**

Eligible participants had to have given birth in the last 12 months, be aged over 18 years, be living in England, be able to read and write English, have internet access, and have scored  $\geq 5$  on the Generalized Anxiety Disorder Scale (GAD-7) [35]. Women were excluded if they were receiving formal psychological treatment at the start of the study, reported self-harm or suicidal ideation, or had a stillbirth or the baby was seriously ill.

### **The Web-Based Treatment (iWaWa)**

#### **Origin and Format**

iWaWa is based on the WaWa self-help booklet for postpartum generalized anxiety disorder [4]. A licensing agreement with Monash University allowed researchers at the City, University of London to develop a Web-based version of WaWa for use in England in collaboration with the WaWa development team in Australia.

WaWa is based on cognitive-behavioral and mindfulness principles and consists of 3 sections: (1) Is this for me? (2) Practice, and (3) Understanding. In the first section, concepts such as generalized anxiety disorder, common worries during the perinatal period, and the cognitive-behavioral therapy (CBT) and mindfulness models are explained, and the program is outlined. The section on "Practice" consists of 7 worksheet modules that target life stage-specific anxieties and worries using guided activities. The last section provides background information about the biopsychosocial model of anxiety and a lay language description of CBT and mindfulness theories and practice. For more detailed information about the WaWa program, please refer to [4].

#### **iWaWa Format**

iWaWa, the Web-based WaWa version, was developed on and hosted by the Qualtrics Platform and a City University of London blog. For the Web-based format, the three main sections were divided into 9 modules (one "Is this for me?" module; seven "Practice" modules; and one "Understanding" module). A link to each module could be found on a password-protected blog page of the iWaWa study website. See [Multimedia Appendix 1](#) for two images of iWaWa. Sessions were made up of multimedia presentations (text, images, and audio) and Web-based interactive material (eg, textboxes, self-assessment with sliders, hotspot graphics).

Participants were advised to start with the first module, but were free to access the remaining modules in any order and as many times as they wished. iWaWa users were also offered optional weekly email and or text-message reminders and weekly 30-min telephone support with each practice module. The iWaWa coach (MA) was a health psychology doctoral student with a master's

in clinical psychology. An adapted version of the WaWa Health Professional's Guide was developed, which included checklists to record fidelity of program implementation and participant understanding and progress. No changes were made to iWaWa after the trial started.

### **Study Design and Procedure**

#### **Design**

**Figure 1** illustrates the study design and procedures including data collection time-points and measures. A 2 (groups) by 3 (time-points) randomized controlled trial was carried out. Using a blocked randomization design (generated on the Web), the participants were randomly allocated to an iWaWa treatment group or a wait-list control group. Data were collected at baseline, throughout the treatment, 8 weeks postrandomization, and 12 weeks postrandomization utilizing both quantitative (Web-based questionnaires) and qualitative methods (optional iWaWa module comments and semistructured interviews).

#### **Procedure**

The study website contained a link to the Web-based questionnaire consisting of the electronic informed consent procedure, the eligibility questions, and the baseline assessment. Women who were not eligible were provided with links to websites of organizations dealing with postpartum or general mental health problems and advised to contact their general practitioner or health visitor if concerned about their mental health.

Participants were quasi-anonymous. Treatment allocation was revealed to eligible participants via email, and participants created a personal identifier for the iWaWa modules and Web-based assessments. The personal identifier was also used to detect participants signing up multiple times. Treatment group participants were immediately emailed the link and password to the iWaWa program with telephone support, and wait-list control group participants were offered access to iWaWa without telephone support at 8 weeks postrandomization. Treatment group participants received one reminder email to start treatment, and all participants received one reminder email for the 8-week and 12-week follow-up assessments. Participants and the researcher (MA) responsible for the study management and analysis were not blinded.

#### **Measures**

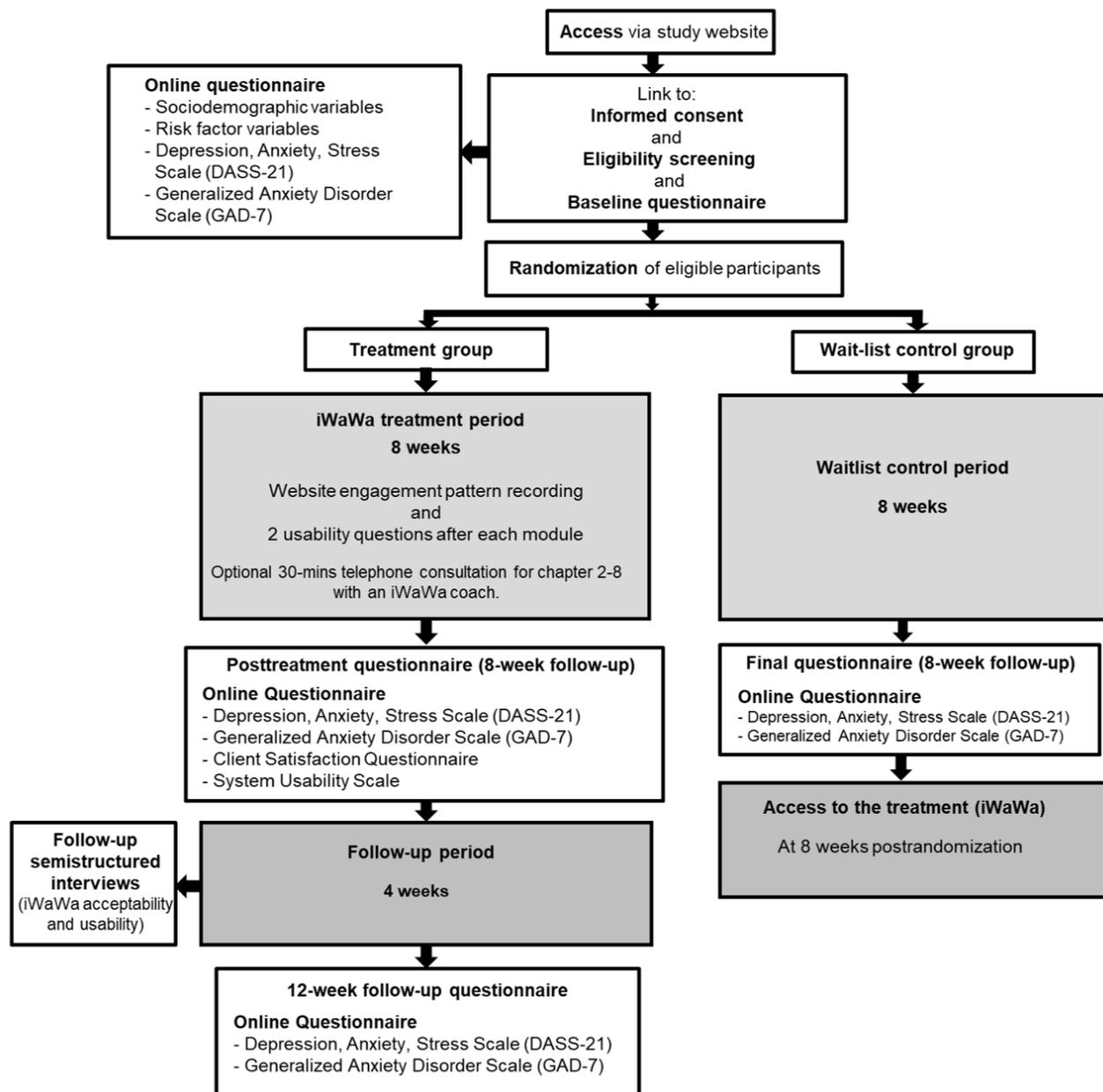
##### **Study Feasibility**

For study feasibility, the following parameters were recorded: (1) recruitment rate and recruitment source, (2) eligibility and consent rates, (3) dropout attrition rates, and (4) completeness of data collection and assessment response rates.

##### **Treatment Feasibility**

##### **Engagement**

Module views (module opened) and completion (all pages of the module were viewed), engagement with interactive components, and the number and duration of iWaWa support calls were recorded. Nonusage attrition rates were calculated.

**Figure 1.** Study design and procedure flowchart. iWaWa: Internet-based What Am I Worried About.

### Usability

Upon completion of each module, participants were asked to rate the module's clarity ("This module was clear and understandable.") on a 7-point Likert scale (1=strongly disagree to 7=strongly agree). At the 8-week postrandomization assessment, the System Usability Scale (SUS) [36] was used to determine treatment usability. The SUS is a 10-item instrument rated on 5-point Likert scale (0=strongly disagree to 4=strongly agree). The SUS has been found to be a highly robust and versatile tool [36] and has previously been used in a study evaluating the feasibility of Web-based treatment for postpartum depression [31]. The SUS was adapted by replacing "the system product" with "iWaWa." Scores were added together and multiplied by 2.5 to convert the original scores to 0-100. A score above a 68 is considered above average and below 68 is below average. Participants were also asked to rate how iWaWa fit

into their daily routine and potential future usage on a 7-point Likert scale (1=strongly disagree to 7=strongly agree). Participants were further asked to state any technical issues.

### Treatment Acceptability

#### Usefulness

At the end of each module, participants were asked to rate the module's usefulness ("I found this module useful") on a 7-point Likert scale (1=strongly disagree to 7=strongly agree). At the 8-week postrandomization assessment, participants were presented with the statement "I found iWaWa useful" rated on a 5-point Likert scale (1=strongly disagree to 5=strongly agree).

#### Satisfaction

The Client Satisfaction Questionnaire (CSQ-8) [27,28] was used to assess treatment satisfaction. The CSQ-8 consists of 8 items rated on 5-point Likert scale. The CSQ-8 demonstrated

excellent psychometric properties [37]. The CSQ-8 was adapted for this study by substituting “service” with “help” and “program” with “iWaWa.” The overall sum ranged from 8 to 32 with higher score indicating higher satisfaction.

### Helpfulness

The 8-week postrandomization assessment also included 6 items developed for this study and designed to measure perceived helpfulness with anxieties and worries (eg, “Using iWaWa made it easier to cope with my worries”) on 5-point Likert scale (1=strongly disagree to 5=strongly agree).

### Mental Health

Anxiety was measured using the GAD-7 [35]. The GAD-7 is a 7-item anxiety measure, and items are rated on 4-point Likert-scale ranging from 0 (not at all) to 3 (nearly every day). It demonstrated validity and reliability in clinical practice and research [35]. It has been suggested that the GAD-7 is a viable postpartum anxiety screening tool [38].

The Depression, Anxiety, and Stress Scale (DASS-21) [39] consists of 21 items rated on a 4-point Likert-scale ranging from 0 to 3. Higher scores indicate more severe symptoms. The DASS-21 has good internal consistency and concurrent validity [40,41].

### Participant Characteristics

In line with the Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and onLine TeleHealth (CONSORT-EHEALTH) checklist, demographics relevant to the digital divide as well as maternity characteristics were collected as part of the baseline questionnaire: age, ethnicity, education, employment, annual household income, relationship status, availability of computer, laptop, tablet, smartphone, number of previous children, and the number of weeks since giving birth.

### Qualitative Treatment Feasibility and Acceptability Evaluation

#### Comments

Participants could write an optional comment about their experience at the end of each iWaWa module and in the follow-up assessments.

#### Follow-Up Interviews and Survey

All treatment group participants (including dropouts) were invited to take part in an optional semistructured phone interview or Web-based survey to collect in-depth information about their treatment experience. Participants gave verbal consent before the start of the interview. Interviews were audio-recorded and conducted by the first author (MA) using a semistructured interview schedule with open-ended questions (see [Multimedia Appendix 2](#)). The same questions were used for the Web-based survey for which consent had to be provided electronically. Participants received a £10 Amazon voucher as a compensation for their time.

## Data Analysis

### Quantitative Data

Statistical analyses were performed with SPSS using a  $P < .05$  significance level. Descriptive statistics including means, standard deviations, percentages, and proportions were used to describe the characteristics of the overall sample and the two groups, as well as the iWaWa program feasibility and acceptability and study feasibility. Independent  $t$  tests and chi-square tests were used to explore whether participant characteristics differed between the groups or between participants who did and did not complete the follow-up assessments.

For the mental health measures, group differences and differences over time were analyzed using independent and dependent sample  $t$  tests. Due to the large amount of missing data for the follow-up assessments, an intention-to-treat analysis was deemed inappropriate [42], and only the data of those completing the assessments were compared. Two-tailed bivariate correlations were conducted to explore whether there is a relationship between anxiety scores and the variables “weeks postpartum” and “number of children.”

### Qualitative Data

The interview recordings were transcribed verbatim with all identifying information removed. Subsequently, the interview transcripts and the comments on the individual chapters were analyzed using inductive thematic analysis [43]. The software Quirkos was used to ensure systematic coding. The analysis identified general themes emerging from the comments and interviews.

## Results

### Participant Characteristics

**Table 1** presents detailed information about participant characteristics of all randomized participants, those lost to follow-up, and those completing the 8-week follow-up assessment.

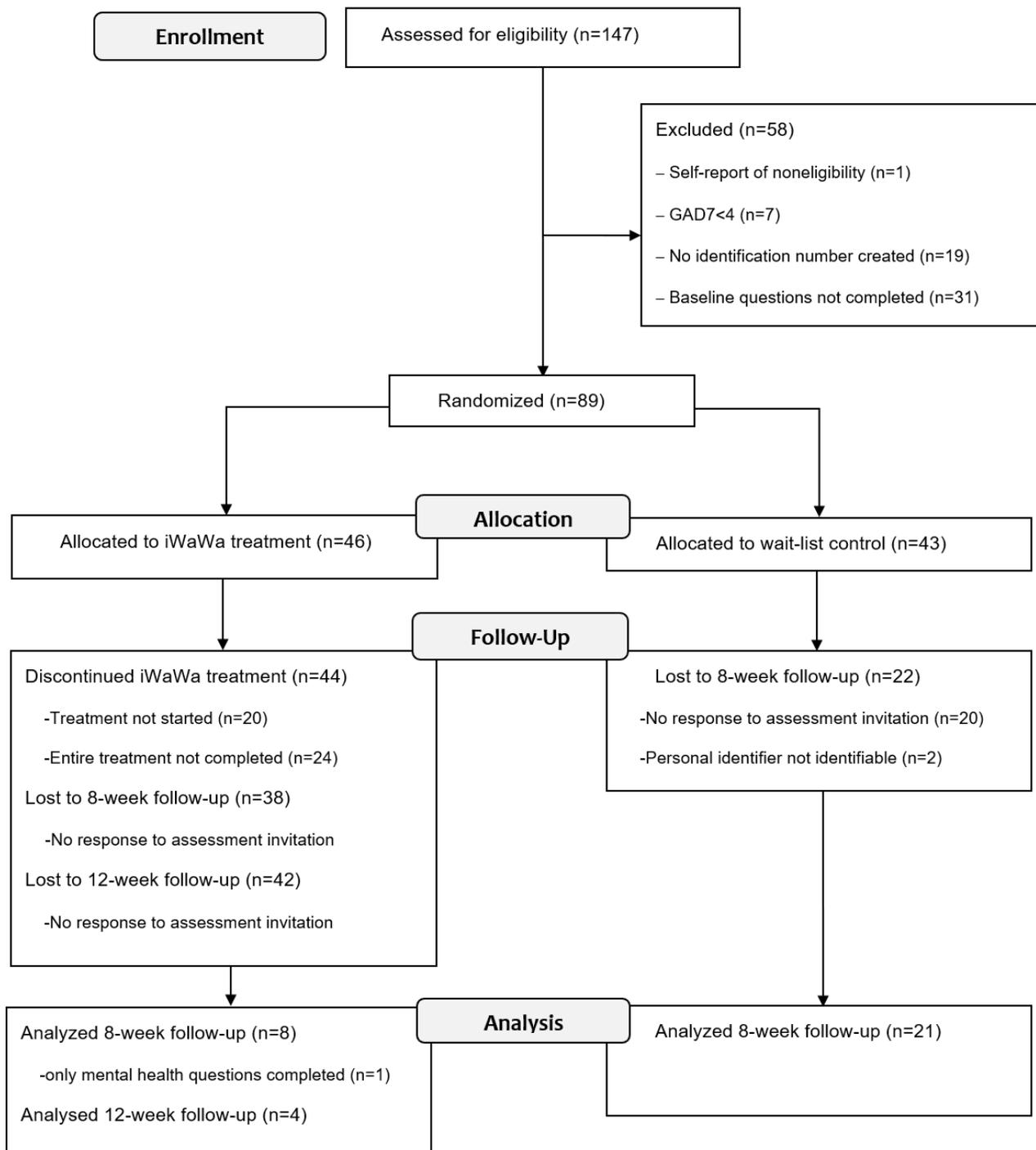
Participants were predominantly “Caucasian” (84/89, 94%), married (62/89, 69%), living with their partner/husband (79/89, 89%), and aged between 22 and 43 years (mean 32.02 years [SD 4.15 years]). Over half of the women had a bachelor’s degrees or higher and were on maternity leave. Slightly less than half of the women (38/89, 43%) had an income below £50,000 and about half (44/89, 49%) an income equal to or above £50,000. Women were between 1 and 52 weeks postpartum (mean 28.58 [SD 13.76]) and 72% (64/89) were first-time mothers (range 1-5 children [mean 1.36 (SD 0.68)]). The majority of participants reported having access to two or more technological devices (84/89, 94%). The two most commonly accessible devices were smartphone (88/89, 99%) and laptop (74/89, 83%).

**Table 1.** Participant characteristics of all randomized participants, those who were lost to follow-up, and those who completed the 8-week follow-up assessment.

Characteristic	All randomized participants			8-week follow-up assessment dropouts		8-week follow-up assessment completers	
	Total (n=89)	T <sup>a</sup> (n=46)	WLC <sup>b</sup> (n=43)	T (n=38)	WLC (n=22)	T (n=8)	WLC (n=21)
Age, mean (SD)	32.02 (4.15)	32.41 (3.55)	31.60 (4.71)	32.16 (3.80)	31.82 (5.30)	33.63 (1.69)	31.38 (4.13)
Number of children, mean (SD)	1.36 (0.68)	1.39 (0.77)	1.32 (0.57)	1.37 (0.79)	1.32 (0.58)	1.50 (0.76)	1.22 (0.58)
<b>Ethnicity, n (%)</b>							
Caucasian	84 (94)	43 (93)	41 (95)	35 (92)	20 (91)	8 (100)	21 (100)
Asian	4 (4)	2 (4)	2 (45)	2 (5)	2 (9)	0 (0)	0 (0)
Mixed or multiple ethnicity	1 (1)	1 (2)	0 (0)	1 (3)	0 (0)	0 (0)	0 (0)
<b>Highest level of education, n (%)</b>							
GCSE <sup>c</sup>	4 (4)	2 (4)	2 (5)	2 (5)	1 (4)	0 (0)	1 (5)
A-level	18 (20)	7 (15)	11 (26)	7 (18)	7 (32)	0 (0)	4 (19)
Bachelor's degree	38 (43)	20 (44)	18 (42)	18 (47)	9 (41)	2 (25)	9 (43)
Master's degree	20 (23)	12 (26)	8 (19)	9 (24)	4 (18)	3 (37)	4 (19)
Doctorate	4 (4)	3 (6)	1 (2)	1 (3)	0 (0)	2 (25)	1 (5)
Other	5 (5)	2 (4)	3 (7)	1 (3)	1 (5)	1 (13)	2 (10)
<b>Current occupation, n (%)</b>							
Student	2 (2)	0 (0)	2 (5)	0 (0)	1 (4)	0 (0)	1 (5)
Employed (full-time, part-time, or self)	25 (28)	18 (39)	7 (16)	16 (42)	4 (18)	2 (25)	3 (14)
Housekeeper or unemployed	10 (11)	3 (6)	7 (16)	2 (5)	5 (23)	1 (12)	2 (10)
Maternity leave	48 (54)	23 (50)	25 (58)	18 (47)	11 (50)	5 (63)	14 (67)
Other	4 (4)	2 (4)	2 (5)	2 (5)	1 (4)	0 (0)	1 (5)
<b>Household income, n (%)</b>							
<£10,000-£19,999	7 (8)	2 (4)	5 (12)	2 (11)	3 (14)	0 (0)	2 (10)
£20,000-£39,999	17 (19)	10 (22)	7 (16)	8 (21)	4 (18)	2 (25)	3 (14)
£40,000-£59,999	24 (27)	14 (30)	10 (23)	12 (32)	4 (18)	2 (25)	6 (28)
£60,000-£79,999	15 (17)	9 (20)	6 (14)	7 (18)	3 (14)	2 (25)	3 (14)
≥£80,000	19 (21)	9 (20)	10 (23)	7 (18)	4 (18)	2 (25)	6 (29)
Prefer not to say	7 (8)	2 (4)	5 (12)	2 (10)	4 (18)	0 (0)	1 (5)
<b>Relationship status, n (%)</b>							
Single or separated	6 (7)	2 (4)	4 (9)	2 (5)	2 (9)	0 (0)	2 (9)
Married or in a relationship	82 (92)	44 (96)	38 (88)	36 (95)	19 (86)	8 (100)	19 (90)
Prefer not to say	1 (1)	0 (0)	1 (2)	0 (0)	1 (4)	0 (0)	0 (0)
Weeks postpartum, mean (SD)	28.58 (14)	29.70 (14)	27.40 (14)	30.97 (14)	26.50 (15.)	23.63 (14)	28.33 (12)

<sup>a</sup>T: treatment group.<sup>b</sup>WLC: wait-list control group.<sup>d</sup>GCSE: general certificate of secondary education.

**Figure 2.** Flowchart of participants flow through all trial stages. iWaWa: Internet-based What Am I Worried About; GAD7: Generalized Anxiety Disorder Scale.



There were no significant differences between the treatment and wait-list control groups in demographic characteristics, except for relationship status ( $P=.03$ ). No differences were found between participants of the treatment and wait-list group who completed the 8-week follow-up assessment, and no differences were found between participants of the treatment and wait-list group who did not complete the 8-week follow-up assessment. There were also no differences between treatment group participants who started the iWaWa treatment and those who did not.

## Study Feasibility

### Recruitment

Figure 2 presents the CONSORT diagram showing participant flow and attrition through the trial. During the recruitment, 147 women accessed the initial assessment and consented to take part. A total of 58 (39%) were excluded (see Figure 2 for exclusion reasons). The remaining 89 (60%) were randomized into the treatment ( $n=46$ ) or wait-list control groups ( $n=43$ ).

Of the 89 randomized women, 86 (97%) had heard about the study from Facebook and 3 (3%) from friends.

### ***Dropout Attrition***

A total 21 out of 43 wait-list control participants (48.84%) completed the 8-week follow-up assessment. Eight of 46 (17%) treatment group participants responded to the 8-week follow-up assessment (one participant completed only the GAD-7 and DASS-21). There was a significant difference in attrition rates between the groups ( $P=.002$ ). Four of 46 (9%) women in the treatment group completed the final (12-week follow-up) assessment. One of the four had not completed the 8-week follow-up assessment.

### **Treatment Feasibility**

#### ***Engagement***

##### **iWaWa Modules**

Of the 46 treatment group participants, 26 participants (56%) viewed at least one module and on average 1.65 modules (SD 2.51; including repeat views). Two participants viewed all modules (4.34%). [Figure 3](#) illustrates the number of module views and completion by the treatment group. Of the 76 modules viewed, 61 (80.26%) were completed. Module 1 was most viewed with a marked reduction thereafter. Engagement with the 14 interactive components within the program ranged from 50% to 100% (mean 69 [SD 0.17]).

##### **Email, Text, and Phone Support**

Of the 25 women in the treatment group accessing module 1, 24 (96%) signed up for weekly reminders (email:  $n=16$ , text:  $n=6$ , email and text:  $n=2$ ). One woman requested a support call but did not respond when asked about a call date and time.

### ***Usability***

The average SUS usability score was 40.00 (SD 15.76;  $n=9$ ), indicating a usability below average. Module 2 was experienced as least clear and understandable (mean 4.25 [SD 1.75]), and module 1 as most clear and understandable (mean 6.20 [SD 0.62]). Out of 8 respondents, 5 (62%) did not agree with the statement that they could use iWaWa seamlessly as part of their daily routine. With the statement regarding regular usage after the study ended, 2 participants disagreed (25%). Regarding technical issues, iWaWa had a 2-day downtime due to a broken link.

### **Treatment Acceptability**

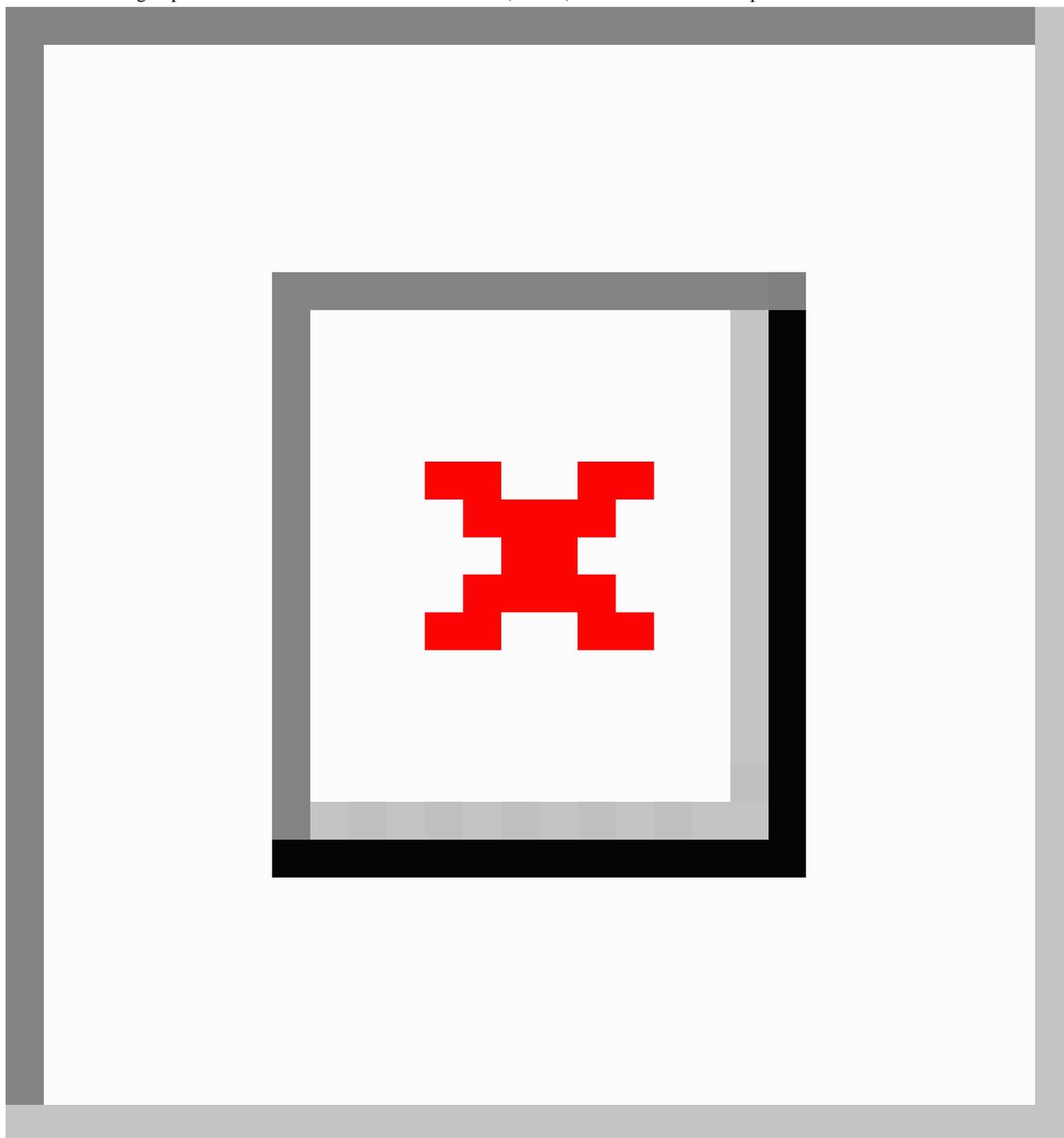
#### ***Usefulness and Satisfaction***

Module 8 was experienced as least useful (mean 3.50 [SD 2.12]) and module 7 as most useful (mean 6.00 [SD 0.82]). Of the 8-week postrandomization assessment respondents, 71% (5/7) rated iWaWa as useful, 14% (1/7) rated iWaWa as neither useful nor not useful, and 14% (1/7) as not useful. The average treatment satisfaction CSQ-8 score was 20.22 (SD 5.61) on a range of 8-31.

#### ***Helpfulness***

Of the 7 respondents, 71% (5/7) agreed that iWaWa helped them better understand anxiety, 57% (4/7) agreed that it helped them develop skills to manage anxiety, 57% (4/7) agreed that it helped them manage their unhelpful thoughts, 42.86% (3/7) agreed that it helped reducing distressing bodily sensations, 28% (2/7) agreed that it improved their well-being, and 43% (3/7) agreed that it made it easier to cope with their worries.

**Figure 3.** Treatment group Internet-based What Am I Worried About (iWaWa) module views and completion.



### **Qualitative Treatment Feasibility and Acceptability Outcomes**

Qualitative data comprised 31 comments from iWaWa modules and follow-up questionnaires and five interviews (13-18 min). Data saturation was assumed when no new themes emerged from the interviews and comments. Of the interviewees, one completed the first module and the remaining four between 4 to 9 modules.

#### **Themes**

Thematic analysis generated 3 key themes (presentation and format, content, and helpfulness) and 10 subthemes. [Figure 4](#)

presents a diagram of the themes and associated subthemes. [Textbox 1](#) contains quotes for each theme and subtheme.

Overall, participants described iWaWa as generally useful and straightforward but not user-friendly. Participants reported feeling that it was good to know that something like iWaWa is being developed and that it should be further developed to make it accessible to more women in the same situation.

**Theme 1: iWaWa Presentation and Format**

**Strengths Subthemes**

**Accessibility**

Participants enjoyed that iWaWa could be accessed from home at a time that suited them, which was reported important with a newborn baby and multiple children.

**Anonymity**

Women appreciated iWaWa’s anonymity. One participant stated that she would have not reached out for help any other way.

**Support Option**

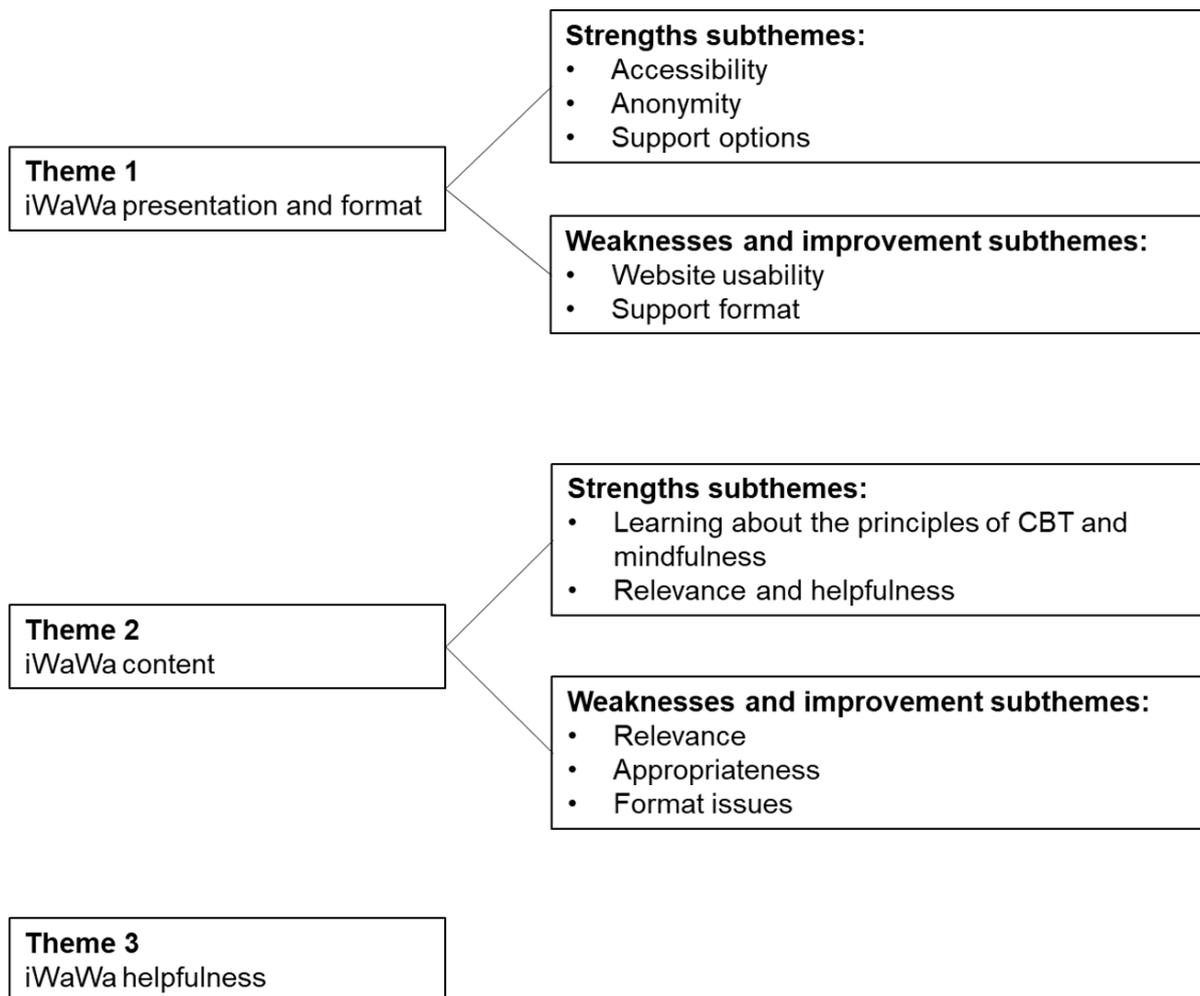
The weekly email and text messaging reminder option was described as a strength of iWaWa and the support phone calls as a valuable option.

**Weaknesses and Improvement Subthemes**

**Website Usability**

It was reported that iWaWa did not display well on their smartphones and that iWaWa was not very user-friendly and modern. Frustration was caused by having to find the iWaWa link for logging in. All stated they would prefer iWaWa as an easy to use smartphone app.

**Figure 4.** Diagram of qualitative themes and subthemes. CBT: cognitive-behavioral therapy; iWaWa: Internet-based What Am I Worried About.



**Textbox 1.** Quotes for all themes and subthemes of the thematic analysis.

Theme 1
<ul style="list-style-type: none"> <li>• Strengths subthemes: Accessibility           <ul style="list-style-type: none"> <li>• Interview 1: <i>I like the fact that I could do it in my own time at home...cause I have three children so it wasn't like I would have to try to have to make appointments and get child care so I could do it when they were in bed or you know whenever it sort of seemed to fit in with my lifestyle I suppose.</i></li> <li>• Interview 3: <i>I found it quite easy especially while I was breastfeeding on my phone or my tablet, so that was good.</i></li> </ul> </li> <li>• Strengths subthemes: Anonymity           <ul style="list-style-type: none"> <li>• Interview 5: <i>I generally feel pretty confident and happy and would not label myself as somebody with anxiety or any of those issues so I don't think I would have accessed help in another way because I didn't really want to be labeled as you know as an anxious or depressed or whatever.</i></li> </ul> </li> <li>• Strengths subthemes: Support options           <ul style="list-style-type: none"> <li>• Interview 3: <i>The reminders were good cause I would have forgotten about it otherwise, you know to do it. It was nice to have the link on the email rather than having to find the original one.</i></li> <li>• Interview 2: <i>I suppose for some people some of the modules might sort of trigger feelings or bring up things that were a bit difficult for them so I think having that option of support [call] is definitely useful.</i></li> </ul> </li> <li>• Weaknesses and improvement subthemes: Website usability           <ul style="list-style-type: none"> <li>• Module 1, Comment 3: <i>The pages weren't phone friendly- lots of scrolling left to right.</i></li> <li>• Module 1, Comment 4: <i>Doesn't work that well on an iPhone. Few mums have time to sit at the computer.</i></li> <li>• Interview 5: <i>I think the sort of user experience and interface and how you accessed it felt very old-fashioned compared to you know apps that feel a lot more kind of modern and easy to access on mobile and therefore fitting with your life a lot more easily.</i></li> <li>• Interview 4: <i>You have to keep clicking next and go to the next page...because if you're internet connect is not great and you click next then it takes a while for the next page to come up and you know it gets frustrating.</i></li> <li>• Interview 2: <i>I don't use apps very often but yeah if that could solve the presentation issue it I might have continued a bit longer.</i></li> </ul> </li> <li>• Weaknesses and improvement sub-themes: Support format           <ul style="list-style-type: none"> <li>• Interview 2: <i>I find it really hard to have any kind of phone conversation most of the time because you are always sort of having to jump up and hold the baby and deal with crying and even a 5-minute phone call could be quite challenging...I kind of just didn't have the energy and the time to engage in that.</i></li> <li>• Interview 5: <i>I didn't feel like I needed the other support...and I suppose it wasn't clear to me who the coach was and what their qualification or skills were and if it was help you with technical issues or to help you with or offer you more support with the with your worries.</i></li> </ul> </li> </ul>
Theme 2
<ul style="list-style-type: none"> <li>• Strengths subthemes: Learning about the principles of CBT and mindfulness           <ul style="list-style-type: none"> <li>• Interview 5: <i>I think that the whole of the first section explaining the principles themselves just absolutely completely changed the way I thought about certain things and helped me to go and put other things place in my life that helped me managed the anxiety so I went and signed up for a mindfulness app...and the fact that reframing unhelpful thoughts I find all of the principles really really useful and have applied it in lots of ways so that was the biggest thing for me with actually seeing ways that I could manage these sort of out of control worries without you know I don't know spending hours on the Internet.</i></li> </ul> </li> <li>• Strengths subthemes: Topic relevance and helpfulness           <ul style="list-style-type: none"> <li>• Interview 2: <i>I think cause you forget very quickly so it was pretty much just as relevant if it would have been the first time and you know each baby is different.</i></li> <li>• Interview 4: <i>It makes you realize that there are obviously other women who are experiencing these similar things and the fact that it's being written down by a professional some of those things and anxieties that I have they haven't listened to me and they have already written that and it makes you realize that there are other people with the same worries and even that can help make you feel better.</i></li> </ul> </li> <li>• Weaknesses and improvement subthemes: Relevance           <ul style="list-style-type: none"> <li>• Interview 5: <i>I didn't think about when your baby cries and how it makes you feel which I never had a concern or a problem with that so that just to me was too specific to make it feel like it was worth my time going through it.</i></li> </ul> </li> </ul>

- Module 3, Comment 2: *We didn't have any problems with breastfeeding. Also my daughter is now 5 months so a bit too late for us.*
  - Weaknesses and improvement subthemes: Appropriateness
    - Module 2, Comment 1: *The helpful actions were a bit ridiculous. Putting a baby down won't stop them crying. How can I have a cup of tea if they're still crying. The useful actions need to be rephrased about calming yourself down or give tips on how to calm a baby.*
    - Interview 1: *It came across sometimes as if it was approving of a certain type of parenting if that makes sense... So like with my first I ended up with a baby that would wake up every time that I would put her down and she would only sleep if I carried her around in the sling or she was in bed with me and it felt sometimes and that gave me a lot of anxiety because everyone around me was sort of saying you're gonna make a rod for your own back and I think if I had come across this program at that point I think the way some of it was written would have given me more anxiety... I sort of felt as if that would might be pushing some mums to make a decision that didn't feel right to them because they felt like that's what they should be doing sort of thing.*
    - Module 9, Comment1: *This course has been a great resource but I really feel it needs to be more inclusive of ALL parenting approaches in order not to increase the anxiety of those who have either chosen or fallen into a different path because that's what works for them. Statement such as "I can explore different settling methods to see what works best for my baby" would be far better.*
  - Weaknesses and improvement subthemes: Format issues
    - Interview 4: *In the evening once my baby was asleep and by the time I've eaten and done chores you're really tired and I found it just sometimes quite difficult cause there were yeah so many words.*
    - Interview 2: *I found it really hard to generate my own response, just when you are really tired and you haven't got much time, you got a crying baby...I suppose you could have a drop-down menu where you could choose from a list and then you could have space where could write in if they want.*
- Theme 3
- iWaWa helpfulness
    - Interview 1: *I still use them [mindfulness exercises] now if am feeling anxious then I try and concentrate on the moment and remember my breathing and all that so yeah I did definitely find it useful for me.*
    - Interview 2: *I think maybe to a fraction...I think it's got a lot of potential if it was designed in a really user-friendly quick easy way it could be a lot more useful you know the principle of it is good just a little bit of hard work.*

### **Support Format**

Regarding the support calls, women mentioned the importance of further highlighting the support call option and its purpose and credibility and more frequent reminders. One participant would have preferred a more anonymous option (eg, email or text chat).

### **Theme 2: iWaWa Content**

#### **Strengths Subthemes**

#### **Learning About the Principles of Cognitive-Behavioral Therapy and Mindfulness**

Women stated to have especially enjoyed the first module and felt the module provided them with “tools” that some were still using, for example, by downloading mindfulness apps.

#### **Relevance and Helpfulness**

Women stated that most included topics (anxieties) were generally relevant. Women described it as helpful to learn that other women experience same or similar anxieties.

#### **Weaknesses and Improvement Subthemes**

#### **Relevance**

Many participants stated that not all topics were as relevant and that some were too specific, which made them skip modules.

Women with multiple children felt that iWaWa could benefit from making the content more applicable to their situation.

#### **Appropriateness**

Several women reported to have experienced the content, especially the unhelpful and helpful actions and examples, as “ridiculous” and “a bit off-putting” and promoting a certain parenting style. It was suggested that the program content should be reflecting a range of parenting styles.

#### **Format Issues**

Participants felt that some of the content was repetitive and very “wordy” and could be improved by having more concise and shorter modules. It was mentioned that it was “labor-intensive” to generate their own examples for the exercises and that the exercise examples were described as “hard to relate to.” It was suggested to offer the option of using “pre-provided” statements for the exercises.

### **Theme 3: iWaWa Helpfulness**

Of the 5 interviewed women, 2 felt that iWaWa helped with their anxieties, 2 felt that it helped a bit, and 1 said that it probably would have helped if she had done more of the program. All felt that iWaWa could be more helpful with their anxieties if the presentation and content was improved.

**Table 2.** Mental health levels and scores at baseline, 8-week follow-up, and 12-week follow-up.

Measure	Baseline, mean (SD)			8-week follow-up, mean (SD)			12-week follow-up, mean (SD)
	Total (n=89)	T <sup>a</sup> (n=46)	WLC <sup>b</sup> (n=43)	Total (n=29)	T (n=8)	WLC (n=21)	T (n=4)
GAD-7 <sup>c</sup>	12.26 (4.21)	12.46 (3.96)	12.05 (1.98)	7.83 (4.52)	6.63 (5.29)	8.29 (4.24)	8.75 (4.03)
<b>DASS-21<sup>d</sup></b>							
Depression	8.16 (4.47)	8.28 (3.91)	8.02 (5.05)	4.34 (3.83)	2.75 (3.33)	4.95 (3.91)	4.75 (3.30)
Anxiety	6.52 (3.81)	6.22 (3.41)	6.84 (4.21)	3.90 (4.06)	3.38 (1.85)	4.10 (4.66)	3.00 (2.16)
Stress	11.82 (3.80)	11.63 (3.59)	12.02 (4.04)	8.38 (3.71)	7.13 (3.14)	8.86 (3.86)	10.75 (3.40)

<sup>a</sup>T: treatment group.

<sup>b</sup>WLC: wait-list control group.

<sup>c</sup>GAD-7: Generalized Anxiety Disorder Scale.

<sup>d</sup>DASS-21: Depression, Anxiety, and Stress Scale.

## Mental Health Outcomes

Table 2 contains the mental health outcomes for the treatment and wait-list control groups at baseline, the 8-week follow-up, and 12-week follow-up. A total of 28% (25/89) women scored in the mild anxiety range, 42% (37/89) in the moderate anxiety range, and 33% (27/89) in the severe anxiety range on the GAD-7 at the baseline assessment. There were no significant differences between the treatment and wait-list control groups on all mental health measures at baseline. At the 8-week assessment, no significant group differences were found for anxiety (GAD-7 and DASS-21 anxiety). For both groups, anxiety scores significantly reduced from baseline to the 8-week follow-up. There was no significant difference between the 8-week and 12-week follow-up in anxiety scores for the treatment group. Multimedia Appendix 3 illustrates the GAD-7 and DASS-21 anxiety scores for the 3 participants who started the iWaWa program and completed both follow-up assessments. There was no significant correlation between any of the anxiety scores and time since birth and number of children.

## Discussion

### Principal Findings

This study aimed to assess the trial's feasibility, iWaWa's treatment feasibility and acceptability, and explore changes in postpartum anxiety in association with iWaWa. Regarding the study's feasibility, the minimum sample size required was exceeded within the relatively short recruitment period (8 weeks). Facebook proved most successful for recruitment. However, there was a high dropout attrition from the study and also a high treatment nonusage attrition. Among women who accessed iWaWa, the treatment was experienced as generally useful and helpful but not user-friendly enough in terms of treatment format and content. Participants felt that iWaWa could be improved by having it as a smartphone app and by making the content more concise and inclusive of different parenting styles. Anxiety levels decreased significantly for both groups from baseline to the 8-week follow-up assessment, but there were no differences between the treatment and wait-list control group. However, due to high drop-out and nonusage attrition, especially in the treatment group, the results for mental health

cannot be interpreted reliably and will therefore not be further discussed. The results regarding recruitment and attrition, usability, and acceptability will be discussed in more detail below, including a comparison with previous literature and potential program improvements.

### Recruitment and Attrition

Within a relatively short recruitment period, the iWaWa trial successfully recruited more than the minimum calculated sample size through Facebook. The response rate is comparable to similar studies. A study recruiting women with postpartum anxiety for a Web-based online survey through Facebook had a similar response rate (220 respondents over 4 months) [44]. Two studies recruiting women in the United Kingdom with postpartum depression through website advertisement banners for a Web-based treatment had similar (249 respondents over 5 months [33]) and higher response rates (1403 respondents over two waves of 2-week recruitment periods [34]). The successful recruitment might indicate that there is an interest and potential need for a treatment such as iWaWa among postpartum Facebook users. Due to the inability to recruit participants in health care settings, it remains to be investigated whether recommendation or endorsement from health care professionals might have increased iWaWa's recruitment rates.

Dropout attrition in the iWaWa trial was high (49% to 91%). In comparison, in the open pilot study evaluating WaWa, dropout attrition ranged from 39% to 61%. However, it has been pointed out that many trials testing Web-based interventions often suffer from high attrition rates [45]. Due to the lack of other trials of Web-based postpartum anxiety treatments, attrition can only be compared with trials of postpartum depression. Regarding postpartum Web-based treatments, one study evaluating the feasibility for depression with minimal support (Netmums program) also reported a high attrition rate (76%) [34]. The study found that, like this trial, there was an initial high access with a small user subgroup continuing to access and use the program. The authors discussed the role of curiosity, and it has also been suggested that one session may satisfy the user's need [46]. The Netmums program's attrition reduced to approximately 20% at the posttreatment assessment when telephone support was added [33]. Similarly, the

Web-based MomMoodBooster program for postpartum depression with telephone guidance also reported comparably very low attrition rates [31,46]. When comparing iWaWa's attrition to postpartum depression trials, it has to be noted that a systematic review found higher Web-based intervention adherence rates for depression than anxiety [47].

There are a variety of factors that could have caused iWaWa's high attrition. Commonly identified reasons for dropout include the burden of the program, program information structure, content relevance, level of support, technical access issues, time constraints, lack of motivation, and improvement of the group [34,47,48]. The potential role of these factors regarding iWaWa's high attrition will be briefly discussed.

This study suggests that some women indeed experienced the access, length, and exercises of iWaWa as a burden. With the infant's demanding schedule, it is possible that iWaWa participants felt a lack of motivation or experienced time constraints. For Web-based postpartum depression treatments, adherence was high when scheduled support was offered [31,33,46]. Scheduled support was part of the original WaWa treatment and valued as strength of the treatment [4]. On the basis of a survey which found that telephone support was not the preferred mean of support among women with postpartum anxiety [44], it was decided for iWaWa's telephone support to be optional. Scheduled support might improve adherence of women wanting this type of support, but it might also put off women who do not feel the need or find it unsuitable. Offering to opt in for scheduled support at the treatment start might be an alternative for future iWaWa versions. Regarding content relevance, a qualitative study suggested that being able to identify with an online intervention program helps with adherence in Web-based psychological interventions [48]. As some of iWaWa's topics were not experienced as relevant, it could therefore be that some participants logged into iWaWa but dropped out because they experienced the topics as irrelevant. Concerning symptom improvement, a recent systematic review and meta-analysis found that the prevalence of postpartum anxiety decreases from 1-4 weeks to 5-12 weeks [1], and it could therefore be that the participant's symptoms improved and they no longer felt the need for iWaWa. In addition, almost half of the participants scored in the severe to extremely severe range of stress. It might be that participants were in need for stress management techniques, which could be incorporated in future iWaWa versions. The iWaWa program used an organic information structure design that allowed users to freely explore the modules. The use of a tunnel design, in which users navigate through content in a sequential order, has been identified as less likely to overwhelm users with options [49] and may increase use [50].

### **iWaWa's Usability and Acceptability**

Participants enjoyed iWaWa's accessibility, anonymity, and weekly reminders, as well as the introduction to the principles of CBT and mindfulness. This is in line with previous qualitative research regarding Web-based treatments for postpartum depression [23,32,51], as well as postpartum UK health care professionals (health visitors) [52].

iWaWa was rated and experienced as generally useful and helpful but not user-friendly enough. The iWaWa content was experienced as too long. A preference for brief modules was also identified by Web-based surveys among a sample of adults [53] and among women with postpartum anxiety [44]. Participants also felt that iWaWa's content was not inclusive of different parenting styles. WaWa's content was found to be acceptable in a small sample (n=7, in the posttreatment evaluation interview) pilot study in Australia [4]. It might therefore be important to investigate in more depth the needs of a larger and more diverse sample of women with postpartum anxiety so that iWaWa's content and format can be adapted to better meet their needs.

Women in this study also felt that not all topics were relevant. The need for Web-based treatments to be relevant to their own needs and circumstances was also discovered among women with postpartum depression [23,32]. Future iWaWa versions might benefit from presenting users with content most relevant to them (eg, anxiety topic needs and relevance assessment before the treatment starts).

Interactive components with space for responses were previously found to be valued among women with postpartum depression [23]. Even though most iWaWa users engaged with the exercises, many experienced them as difficult. The ease of usage of the interactive components seems important among iWaWa users, and therefore exercises of future iWaWa versions should be tested by potential users before implementation (eg, think-out aloud technique).

Regarding the format, iWaWa participants experienced the log-in process as difficult. The log-in process was also identified as difficult by women testing a Web-based postpartum depression treatment [32]. Participants also expressed that iWaWa was not smartphone-friendly, which was also reported by women testing a Web-based treatment for postpartum depression [32]. The preference for a smartphone-compatible treatment was also found in a survey among women with postpartum anxiety [44]. iWaWa was smartphone compatible, but iWaWa as a smartphone app might improve the ease of access and presentation on smartphones.

### **Limitations**

The generalizability of the results of this study is compromised due to the use of convenience sampling and a homogenous sample. Findings may therefore not be representative of women from different cultural or ethnic backgrounds, lower socioeconomic status, and more severe anxiety. In addition, most women were recruited through Facebook, so findings are limited to this self-selected pool of women. However, the homogeneous nature of this sample can also be a strength, as results can be generalized for this specific group. Furthermore, no incentives were offered during the enrollment, allowing for a sample with a genuine and intrinsic need. The generalizability may also be affected by the fact that the anxiety status was established by a screening instrument and not by a diagnostic tool. However, the GAD-7 is a frequently used anxiety screening tool and has been suggested as suitable for postpartum anxiety [38]. In addition, diagnostic interviews are less anonymous and iWaWa's

anonymity was highlighted as an important strength by the participants.

High dropout and nonusage attrition may have also biased the results. Therefore, findings regarding iWaWa's usability, acceptability, and mental health changes are limited to the experiences and views of a small sample. None of the women who did not start iWaWa took part in the follow-up interviews; so, no knowledge could be gained regarding what caused the early dropout.

The interviewer of this study was MA, who is a doctoral student investigating Web-based treatments for postpartum anxiety with personal experience related to this subject. These experiences may affect the collection, analysis, and interpretation of the data. Therefore, several actions were taken to minimize the likelihood of this risk. Participants were aware that the interviewer was the main study lead, but reassured of the importance of any feedback (positive and negative) for improving iWaWa. The qualitative analysis also included comments from the iWaWa modules and the follow-up assessment in which women might have felt more comfortable providing negative feedback. MA kept a reflective journal to consider how the treatment and interviewee responses affected

her own views on iWaWa throughout data collection, analysis, and reporting. An effort was made to consider this when analyzing the data. Interviewees were offered monetary compensation for their time, which might have confounded their responses.

## Conclusions

This study demonstrated that there is an interest in a postpartum anxiety Web-based treatment like iWaWa. However, the iWaWa study and program in the current format is not yet feasible and acceptable, and due to high dropout rates, the results on the impact of iWaWa on anxiety cannot be interpreted reliably. Nonetheless, the study revealed strengths and weaknesses of the iWaWa content and format, as well as highlighted potential areas of improvements. As a first study investigating the usability and acceptability of Web-based treatment specifically targeted at postpartum anxiety, these results provide useful information about Web-based treatment preferences that can help improve iWaWa and inform research and development to optimize usability, acceptability, and Web-based treatment adherence in this population. This study also contributes to filling the gap in evidence-based self-help for mild-to-moderate postpartum anxiety symptoms.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Two images of the iWaWa (Internet-based What Am I Worried About) program.

[[PDF File \(Adobe PDF File\), 507KB - mental\\_v5i2e19\\_app1.pdf](#) ]

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## Multimedia Appendix 2

Follow-up interview schedule.

[[PDF File \(Adobe PDF File\), 11KB - mental\\_v5i2e19\\_app2.pdf](#) ]

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## Multimedia Appendix 3

Illustration of the anxiety scores of study completers and iWaWa (Internet-based What Am I Worried About) starters for all assessments.

[[PDF File \(Adobe PDF File\), 186KB - mental\\_v5i2e19\\_app3.pdf](#) ]

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## Multimedia Appendix 4

CONSORT - EHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 518KB - mental\\_v5i2e19\\_app4.pdf](#) ]

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## Abbreviations

**CBT:** cognitive-behavioral therapy

**CONSORT-EHEALTH:** Consolidated Standards of Reporting Trials of Electronic and Mobile HHealth Applications and onLine TeleHealth

**CSQ-8:** Client Satisfaction Questionnaire

**GAD-7:** Generalized Anxiety Disorder Scale

**iWaWa:** Internet-based What Am I Worried About

**RCT:** randomized controlled trial

**SUS:** System Usability Scale

**WaWa:** What Am I Worried About

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Original Paper

# Team Resilience Training in the Workplace: E-Learning Adaptation, Measurement Model, and Two Pilot Studies

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## Abstract

**Background:** The majority of resilience interventions focus on the individual. Workplace resilience is a growing field of research. Given the ever-increasing interconnectedness in businesses, teamwork is a guarantee. There is also growing recognition that resilience functions at the team level.

**Objective:** The objective of our work was to address three shortcomings in the study of workplace resilience interventions: lack of interventions focusing on group-level or team resilience, the need for brief interventions, and the need for more theoretical precision in intervention studies.

**Methods:** The authors took an established evidence-based program (Team Resilience) and modified it based on these needs. A working model for brief intervention evaluation distinguishes outcomes that are proximal (perceptions that the program improved resilience) and distal (dispositional resilience). A total of 7 hypotheses tested the model and program efficacy.

**Results:** Two samples (n=118 and n=181) of engineering firms received the Web-based training and provided immediate reactions in a posttest-only design. The second sample also included a control condition (n=201). The findings support the model and program efficacy. For example, workplace resilience was greater in the intervention group than in the control group. Other findings suggest social dissemination effects, equal outcomes for employees at different stress levels, and greater benefit for females.

**Conclusions:** This preliminary research provides evidence for the capabilities of e-learning modules to effectively promote workplace resilience and a working model of team resilience.

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**KEYWORDS**

workplace; resilience; stress; quasi-experimental; experimental design; online learning; early intervention; questionnaire design; incentives; social support; psychological theory; gender

## Introduction

### Web-Based Resilience Training

Recent national studies indicate increases in worker stress [1,2] and its impact on disease [3] and health and productivity costs [4]. The increase in stress corresponds to growing interest in the topic of resilience within business, popular culture, and public health. Self-help books have titles such as *The Bounce Back Book* [5-7]. Trainings designed for enhancing military

resilience [8,9] include mobile apps [10]. Business training continues to grow [11-13] as do strategies promoting urban and institutional resilience [14]. Although resilience operates across individual, workplace, and social levels [15,16], most studies assess resilience as an individual trait [17,18].

This individual-level focus ignores research showing psychosocial factors impact stress and health [2,4]. Effective well-being solutions often target social and systemic factors [19-21], yet resilience interventions focus on individuals (see

meta-analysis [22]). Recent reviews of workplace resilience (WR) interventions—a meta-analysis of 37 studies [23] and a systematic review of 14 studies [24]—concluded that methodological weaknesses, lack of conceptual clarity, and measurement inconsistency limit efficacy of these interventions. Although training effects are small, resilience building via computer-based formats was seen to have potential. The studies described in this paper sought to promote a more proactive approach to resilience in the workplace [25]. WR can be defined as the overall ability of employees to “bounce back” from an obstacle or negative event in the workplace (eg, missing a deadline, workers out sick) and, together, use various resources to address that obstacle in a positive manner (eg, time and project management, wellness, and employee assistance services).

The study of WR interventions may be advanced in several ways. First, interventions could more fully address resilience at the group or team level. Indeed, recent studies support resilience as a team phenomenon [26-30]. Second, most interventions are classroom-based and lengthy, ranging from 2.5 days to 5 to 11 weeks [24]. Although Web-based learning (ie, e-learning) makes training less costly and easier to access, there is a need to adapt classroom programs—especially those that are evidence-based—into e-learning format. Scientific knowledge about effective e-learning offers guidelines for these adaptations [31,32]. Third, intervention models require more theoretical precision [22,24]. Definitions of resilience lack agreement, [33,34] likely because resilience is itself a multilevel construct [35,36] and comprises many resources (eg, social support, skill confidence, and stress management) [9,16]. Although these resources can be found both within persons (ie, an internal trait) [37] and among peers in the work environment [38], previous intervention models fail to distinguish these 2 basic levels.

### Team Resilience

To address these needs, we selected Team Resilience (TR), cited previously and also independently recognized as evidence-based by the national government [39], for adaptation to e-learning. TR is a valuable construct in the modern workplace; given our ever-increasing interconnectedness within businesses, teamwork is almost a guarantee. The original TR study was a randomized longitudinal clinical trial, based on theory [40,41]. Findings suggest promise for replication, including reductions in stress, substance use, and social-level problems among a high-risk sample of restaurant workers [40,42,43]. Personal resilience increased across training sessions [40]. TR also improved teamwork, helping workers to be more compassionate toward others [41]. Most workers who reported these positive gains had previously indicated having work-related alcohol problems. Similarly, in Vanhove et al’s review [23], resilience interventions that were designed to target high-risk samples may be more likely to show longer-term gains. Indeed, compared with control respondents, TR participants showed significant decreases in heavy drinking at 12 months [42].

TR promotes social dissemination, or peer-to-peer sharing, of resilience. Employees assessed at follow-up who were not

exposed to the original training or employed at the time of the intervention had reduced stress and exposure to counterproductive work behaviors (CWBs) [43]. CWBs included theft, bullying, physical fights, coworker rudeness, and arguing. Employees who did not attend training also reported benefits via coworkers, as a type of “spill-over” or “ripple” effect [44]. Specifically, 24% of respondents at 12 months who had heard about TR (but never themselves participated) reported personal benefit; 31% of respondents reported seeing their coworkers benefit. The clinical trial occurred during the 2008-2009 economic downturn, with restaurant closings nationwide, including several in the sample. The reductions in stress—especially during adversity—speak to the resilience function of TR.

### Team Resilience: A Promising Training Framework for Adaptation

Several factors suggest that TR is promising for e-learning: a detailed and modular training manual; evidence for effectiveness; potential for social dissemination; advances in our understanding of team or social resilience; and a strong theoretical basis. A core feature of TR was the inclusion of participant exercises on 5 resilience competencies [40,41]. This “Five C” framework was developed from studies, suggesting resilience exists *both* in the individual and among their social resources [45-52]. The following are the Five Cs:

- Centering (positive coping skills)
- Confidence (self-efficacy and positive thinking)
- Commitment (mental toughness, perseverance, and value-based behavior)
- Community (social support, connectedness, and unit cohesion)
- Compassion (empathy, perspective taking, and nurturing).

In their meta-analysis, Leppin et al [22] stated that the Five C framework is supported theoretically. Other studies validate the Five C’s competencies. For example, the commitment aspect led to more positive attitudes under conditions of adversity [53]. Moreover, a resilience training for Army personnel addressed compassion and community aspects through improved empathy and reduced loneliness [54].

To modify the previous classroom training for e-learning delivery, we reviewed original TR training manuals and studies on effective e-learning features. Such features include customization to the user or workplace, interactive elements, regular quizzing, personalized feedback, multimodule information, and psychoeducational resources [31,32,55]. The TR manuals were originally created by the first author, allowing for a more informed and encompassing transition to the Web-based presentation.

### A Guiding Model for Measurement

As noted, progress in the study of resilience has been limited because of lack of conceptual clarity. Recently, the use of “wise interventions” [56] suggests designing programs that are psychologically precise, brief, and aim to alter self-reinforcing processes that unfold over time. We borrow from this “wise intervention” approach to propose a limited model to study only

the short-term effects of the intervention. By focusing narrowly, we hope to discern how a brief electronic training might work.

**Figure 1.** Working model for brief intervention evaluation.

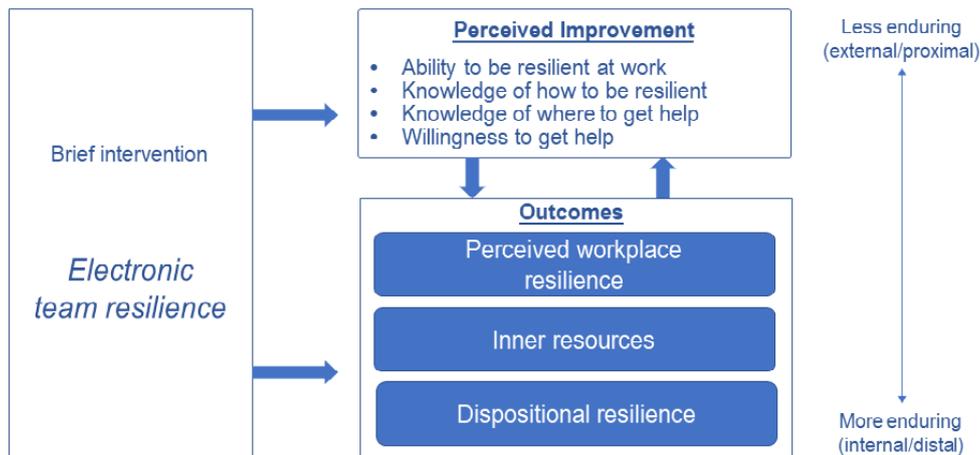


Figure 1 shows our working model, which only targets immediate psychological changes. As is typical in workplace training evaluations, participants are expected to report improvement in content areas targeted by the intervention, namely, their own resilience. We focus on 4 areas of *perceived improvement* (PI): ability to be resilient at work, knowledge of resilience, of where to get help, and willingness to get help. As Figure 1 notes (top), such PI implies a relatively immediate, proximal, and external response to training.

These perceived changes should correlate with proximal outcomes, yet ultimately affect distal outcomes also targeted by the intervention. We propose a “situational-to-dispositional” ordering of outcomes, from *perceived WR* (this is an employee’s ability to adapt to workplace stress and associated perceptions that their workplace and coworkers contribute to their resilience) to *recognition of inner resources* (IR) for resilience and to an enduring trait or *dispositional resilience* (DR). An employee’s recognition of her own WR should affect her behavior in a positive way, following Ajzen’s theory of planned behavior [57].

First, as a result of the training, participants should perceive that their workplace—including their coworkers—provides them with resources for resilience (ie, WR). For example, TR makes multiple references to their Employee Assistance Program (EAP) and other workplace health resources. Although newcomer employees learn about these resources during orientation, they may be overwhelmed with information. Reminders (in the context of resilience) are designed to heighten awareness of their workplace as a resource.

Second, the adapted TR guides users to focus on *internal resources* (eg, confidence, commitment) through self-reflection exercises, a common feature of other resilience programs (eg, [21,22,54]). Participants are expected to perceive that such resources help them deal with challenges. Relatively speaking, these IR are more internal and enduring than perceived changes in the work environment. However, they are less enduring than the more endogenous trait of resilience or DR. We do not expect a brief intervention, such as that described in this paper, to change DR in an immediate context. However, the proposed

model suggests that short-term changes (ie, improvement attributed to the training) may bolster longer-term increases in internal resilience. Hence, DR is a third factor in our model.

Furthermore, resilience may best be measured in the context of adversity (eg, *adaptive cycle*) [14]. Thus, resilience interventions may be more effective in populations with high stress [23]. Accordingly, a valid test of a resilience program should occur in the context of exposure to adversity. Ideally, such a test would first randomly assign 2 groups: an intervention group and a no-intervention control group. Both groups would then be exposed to a work-related challenge or adversity, with the intervention group then receiving the training. Hypothesized outcomes would be: (1) the intervention group would cope better with the challenge and (2) such coping would be best predicted by the most proximal variables in the model (eg, PI, followed by perceived WR). Before conducting such a randomized trial, the proposed model can yield insights through an initial feasibility assessment or quasi-experimental pilot test.

## Goals and Hypotheses

The primary goals of this pilot project were to assess (1) the feasibility of condensing a classroom training into e-learning and (2) employees’ reactions to the program using the working model described previously (see Figure 1).

A total of 7 hypotheses were derived from these goals:

H1: Employees receiving the pilot program would report improvements beyond those that might be expected by chance (reporting improvements beyond “none” or “little” on a 5-point scale; ie, greater than mean 2.5).

H2: Compared with a nonrandomized control group, employees receiving the pilot program would self-report greater levels of improvement in resilience.

As a study of self-reported resilience, we explore a new measure to distinguish ratings of WR, IR, and DR. H3 and H4 reflect these distinct outcomes:

H3: Compared with a control group, employees exposed to e-learning will self-report greater levels of resilience, especially for WR.

H4: Because the intervention focuses on workplace and TR, it is hypothesized that WR will most strongly correlate with PI. We also expect that (1) reported improvements would correlate positively with WR, while holding the other 2 forms of resilience constant; and (2) these relationships will only be present in the program group.

To support construct validity, we examined other distinctions between workplace and DR. Accordingly, variables should relate to those variables one would expect them to relate to (ie, convergent validity) and not relate to those expected to be different (ie, discriminant validity). For convergent validity, measures of resilience would be expected to show an inverse relationship with recent stress. For example, employees who have either DR or WR might be less inclined to experience recent stress; therefore, we examined how both of these correlate with stress:

H5: Recent stress will be inversely correlated with DR and WR.

This study purposely assessed only short-term reactions to training. As noted previously, research suggests resilience training may be more effective in a high-stress sample [23]. Thus, we did not expect short-term differences between workers recently experiencing high versus low stress. As a brief primary prevention approach, the program was not designed to have large enough “dose effects” to address significant stress. Accordingly:

H6: Self-reported PIs and resilience would not be different between employees with high and low stress.

One aspect of the original TR is its potential for social dissemination [43]. In this study, employees from different firms participated in 2 sample time frames (2015 and 2017). We tracked whether those employees in the 2017 sample came from firms that had previously used the program. Social dissemination suggests that employees from firms with previous use would gain more from the program. Specifically:

H7: Compared with employees from firms with no previous exposure to the resilience training (ie, no employees from the firms in 2017 completed the training in 2015), employees from firms that had exposure will show greater outcomes (greater PI, greater resilience).

This paper also explores other factors related to the sample. First, we examine whether the training is more effective for women. A recent meta-analysis suggested that women may benefit more from increases in resilience [18]. Second, the original TR was also developed for young, at-risk restaurant workers. We test the current adaptation in an adult workplace population that differs from the original sample. The same information presented in the original TR module is included in this project. However, we created a module that benefits from the advantages that e-learning content provides (more details below). Hence, this study aims to test the generalizability of

both content of the program in question and of the target population for this research.

## Methods

### Sample

Participants were recruited in 2015 and 2017 from firms within a national engineering association. Most firms were using a wellness benefit through the association for between 1 and 4 years. All 2015 participants were recruited to receive the program. In 2017, participants were also recruited to receive the program; a month later, only those who had not previously participated were then eligible to participate in a control sample. Table 1 summarizes demographics of the samples. Although some firms in the 2017 sample had previously participated in 2015, no data from those who had previously completed this training were used in analyses (ie, 17 participants were removed from the 2017 sample to prevent any data contamination).

#### Sample 1 (2015)

A total of 217 participants from 40 firms began the survey; 174 ultimately completed it. Firm size ranged from 6 to 142 participants. The average number of participants from each firm was 4.28 (SD 3.91). The sample was 56.9% (99/174) female, and the modal (40%) age group was 26 to 40 years. Most participants had at least a Bachelor's degree (78.7%; 117/174).

#### Sample 2 (2017)

A total of 121 experimental participants began the survey, and 118 ultimately completed it. The control group consisted of 186 individuals. More men (64.5%; 120/186) than women (35.5%; 66/186) participated in the control group ( $\chi^2_2=19.0, P<.01$ ). Overall, most participants had at least a Bachelor's degree (74.0%; 225/304). Moreover, 32 firms, ranging in size from 13 to 67 employees, participated in the intervention (mean per firm 3.69; SD 3.98). A total of 31 firms, ranging in size from 6 to 234 employees, comprised the control group (mean per firm 6.13; SD 7.33). The control sample was acquired after completion of the intervention. Specifically, the recruitment invitation asked employees to participate only if they had not previously done so.

### Procedures

Program participants were recruited by an email sent from the local “Wellness Champion” within their firm. A “Wellness Champion” is an employee within the business that takes it upon themselves, whether formally or informally, to help coworkers take advantage of the company's wellness resources. These champions also encourage participation in wellness programs, not unlike the one described in this paper. The association's wellness director first sent an email template to each champion, who then distributed the email to employees. The email invited confidential participation in a Web-based, e-learning resilience module and a postsurvey questionnaire.

On receipt of the invitation email, participants clicked a URL link and entered their name and email address (used only for tracking and incentive purposes) to begin the training program. Participants had access to the modules at all times, via desktop,

mobile, or tablet. More details about the program are discussed below.

**Table 1.** Demographic breakdown of participants in all samples.

Demographics	Sample 1 (2015; n=174)	Sample 2 (2017; n=304)	
	Program only	Program (n=118)	Control (n=186)
<b>Gender n (%)</b>			
Male	75 (43.1)	54 (45.8)	120 (64.5)
<b>Age in years, n (%)</b>			
18-25	18 (10.3)	13 (11.0)	29 (15.6)
26-40	70 (40.2)	58 (49.2)	75 (40.3)
41-50	35 (20.1)	22 (18.6)	38 (20.4)
≥51	51 (29.3)	25 (21.2)	44 (23.7)
<b>Education n (%)</b>			
Less than high school	1 (0.6)	7 (5.9)	3 (1.6)
High school	4 (2.3)	4 (3.4)	10 (5.4)
Some college	32 (18.4)	17 (14.4)	38 (20.4)
Completed college	98 (56.3)	56 (47.5)	93 (50.0)
Advanced degree	19 (22.4)	34 (28.8)	42 (22.5)

### **Incentives—Samples 1 and 2**

The same program was administered in 2015 and 2017. However, the 2 samples received different program completion incentives. Sample 1 received both individual- and firm-level incentives. Participants were informed at the beginning of the survey that they would be entered into a raffle to win a fitness armband. Sample 1 firms with the highest proportion of participants earned a US \$200 award to use their wellness program. Sample 2 participants received US \$5 for completing the program and an additional US \$5 for completing the survey. Sample 2 control group participants received a US \$5 Amazon.com gift card for filling out the survey after reading a short article on resilience tips.

### **Firm Participation Over Time**

For purposes of estimating social dissemination, we assessed how many 2017 participants came from 2015 firms. Of the 118 employees participating in the 2017 program, 36 participants came from 16 firms with no prior participation, 10 from 5 firms with one prior participant, and 54 from 11 firms with 2 or more participants. Of 201 employees participating in the 2017 control condition, corresponding numbers were 95 participants from 17 firms with no prior participation, 28 from 4 firms with one prior participant, and 56 from 10 firms with 2 or more participants. In 2017, 20 firms participated in the program condition, 19 firms participated in the control condition, and 12 firms participated in both conditions.

### **Web-Based Team Resilience**

The e-learning module sought to increase participants' ability to be resilient in the workplace, their knowledge of resiliency, their awareness of resources, and their willingness to access those resources when necessary. The program consisted of tips and strategies around building "5 Cs of Resilience" (ie,

Centering, Commitment, Community, Compassion, and Confidence).

We followed 6 design goals for developing the electronic module: (1) *brevity, ease of access, self-paced*—limit to 45 min, viewable in segments, with user ability to leave and return anytime; (2) *mimic team environment*—show scenarios of characters who are part of a team, with exercises guiding users to reflect on their own coworkers; (3) *tailored feedback*—require users to complete a self-assessment and receive feedback on personal resilience; (4) *customized EAP resources*—give access to behavioral health resources (EAP); (5) *guided facilitation*—provide a facilitator/narrator who shares personal stories around resilience; and (6) *team assessment of strengths*—require users to reflect on the Five Cs in their coworkers and also their perceptions of how coworkers view the user's own strengths.

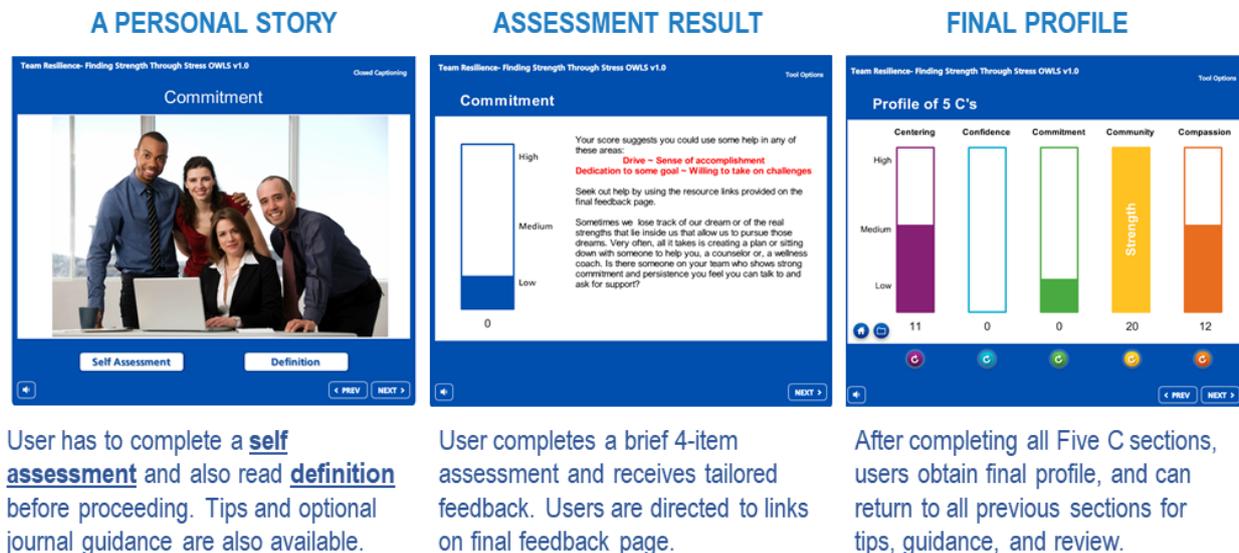
The module was created using Articulate Storyline (Articulate, New York, NY) and included video, audio, interactive exercises, and quizzes in 4 sections: (1) *Welcome* with videos introducing characters explaining the importance of a healthy team; (2) *Best Coworker Exercise* where users review the Five Cs as qualities that exist in coworkers; (3) *Resilience* where users (a) watch 2- to 3-min video vignettes of employees who used one of the Five Cs to overcome a health, stress, or performance challenge (often with the help of a coworker); (b) complete a self-assessment on the Five Cs; (c) review definitions, tips, and journal exercise reflecting on the Cs; and (4) a *Summary* where users (a) see a final profile of their previous self-assessments and (b) rate their team on the Five Cs. [Figure 2](#) shows the core sequence of each Five C component.

Participants in both samples were given 4 to 6 weeks to complete the program and accessibility from any computer or mobile device. The program contained 55 slides; the minimum number

of slides to be viewed to receive credit for the program was 38, but most participants viewed at least 45 slides. Immediately

after program completion, participants were automatically provided the survey link.

**Figure 2.** Core sequence of each Five C component and final profile.



User has to complete a self assessment and also read definition before proceeding. Tips and optional journal guidance are also available.

User completes a brief 4-item assessment and receives tailored feedback. Users are directed to links on final feedback page.

After completing all Five C sections, users obtain final profile, and can return to all previous sections for tips, guidance, and review.

### Control Condition

On completion of the 2017 program condition, wellness champions sent an email to employees asking for input from those who had never completed any wellness program. Participants filled out a survey after reading a one-page article featuring 8 tips on how to “build resilience” (eg, sleep, relaxation, ask for help). Participants were given 1 week to complete the survey. Any individual who had previously participated was removed from data analyses.

### Measures

A survey assessed participants in 4 areas: (1) demographic information; (2) PI or impact of the resilience module (eg, “My willingness to: be more resilient at work, use resilience resources, has...”); (3) measures in 3 areas of resilience: WR, IR, and DR; and (4) one satisfaction item (“Overall, how satisfied were you with the online module?”). Response options were on 5-point Likert scales for PI (1—“Stayed the same” to 5—“Improved greatly”) and for resilience (1—“Not true about me” to 5—“Very true about me”). WR was evaluated using 3 items derived from a review of recent writings on the topic [22,23,30] and developed specifically to assess TR training objectives. Items asked whether the workplace/coworkers contributed to one’s own resilience and to knowing workplace resources to help address hardship. In addition, 2 IR items were developed to further examine construct validity, ie, to distinguish between external resilience in the work setting and inner resilience. Items align with resilience concepts that informed the Five C model [45-52] and related to the self-assessment exercises (eg, “I have the inner resources to deal with life’s challenges”). DR was evaluated using 4 items adapted from the Connor-Davidson Resilience Scale [37] that had high loadings in their original study (eg, “I can deal with whatever difficulties come my way.”).

Reliabilities, assessed by combining data across all samples, were PI: alpha=.92; WR: alpha=.68; IR: alpha=.59; and DR: alpha=.86. The 2017 survey included an item asking about stress: “How much has stress hurt your ability to stay healthy and productive in the past month?” Response options ranged from “not at all” (1) to a “great amount” (5). This survey was given to participants on completion of the training program.

### Results

We compared responses for all items for samples 1 and 2 and found no significant differences (all  $P$  values > .05). Hence, samples 1 and 2 were combined into a single program group ( $n=299$ ).

### Perceived Improvement

H1 proposes the idea that the mean PI score would be greater than chance. A mean rating of 2.5 was used as a conservative baseline, as it represented the mid-point between improving “slightly” and “some.” For the program group, ratings on all 4 items reflected significant improvements (ability— $t_{298}=7.49$ ,  $P<.01$ ; knowledge of how to be more resilient— $t_{298}=12.82$ ,  $P<.01$ ; knowledge of where to get help— $t_{298}=10.83$ ,  $P<.01$ ; willingness to use the resources— $t_{298}=9.22$ ,  $P<.01$ ). For the control group, only one item differed from 2.5,  $t_{200}=2.26$ ,  $P=.03$ . This item—knowledge of how to be more resilient—was also highest rated, suggesting that both e-learning and the reading improved knowledge of resilience. In support of H2, ratings on all 4 items reflected higher ratings on improvements for program (overall mean 3.08; SD 0.88) than control (mean 2.54; SD 1.06),  $t_{498}=6.19$ ,  $P<.001$ .

### Resilience

H3 predicted that, across all 4 measures, resilience would be greater for program versus control participants. As expected,

the strongest effect was for WR; program (mean 3.85; SD 0.68) versus control (mean 3.11; SD 0.75),  $t_{498}=11.44$ ;  $P<.001$ .

H4 proposes that WR would correlate most strongly with PI. Again, training objectives sought to improve both TR *among* coworkers and access to resources *within* the work setting. As shown in Table 2 (left half), compared with IR and DR, WR had the only consistent relationship with PI. These relationships held across both program and control conditions and also when controlling for the 2 other aspects of resilience. There was an unexpected negative partial correlation between DR and PI ( $r_{\text{partial}}=-.19$ ), but other findings were consistent with H4.

H5 predicted that DR would have the strongest relationship with stress (measured in sample 2). Table 2 (right half) shows relationships between the resilience measures and recent stress. H5 is confirmed for the program group (correlation between DR and stress,  $r=-.56$ ). This relationship is maintained

( $r_{\text{partial}}=-.46$ ) after controlling for the other aspects of resilience. The relationship between both WR and IR and stress become insignificant after controlling for DR. In contrast to confirming H5 in the program group, there were no significant correlations between any resilience measures including DR and stress within the control group.

### Recent Stress (Before the Program)

There was no difference in stress levels between program (mean 2.58; SD 0.96) and control (mean 2.60; SD 1.04) participants. Because the brief resilience program focused on helping employees with stress, we explored whether those across 3 levels of stress (low, medium, and high) benefitted from the program (Table 3). Participants with low stress indicated that they felt stressed in the last month either “not at all” or “a little”; medium stress answered “some” or “much”; and high stress answered “a great amount.”

**Table 2.** Relationship of resilience measures to perceived improvement and stress.

Outcome	Perceived improvement				Stress <sup>a</sup>			
	Program		Control		Program		Control	
	<i>R</i>	Partial <i>r</i>	<i>r</i>	Partial <i>r</i>	<i>r</i>	Partial <i>r</i>	<i>r</i>	Partial <i>r</i>
Workplace resilience	.24 <sup>b</sup>	.24 <sup>b</sup>	.47 <sup>b</sup>	.44 <sup>b</sup>	-.36 <sup>b</sup>	-.13	-.08	-.05
Inner resources	.09	-.02	.27 <sup>b</sup>	.18 <sup>c</sup>	-.28 <sup>b</sup>	-.02	-.05	.01
Dispositional resilience	.06	-.06	.14	-.19 <sup>b</sup>	-.56 <sup>b</sup>	-.46 <sup>b</sup>	-.07	-.04

<sup>a</sup>Only measured in sample 2.

<sup>b</sup> $P<.01$ .

<sup>c</sup> $P<.05$ .

**Table 3.** Comparing program and control outcomes at different stress levels (sample 2). Adjusted means are shown, controlling for gender, age, and education.

Analysis	Stress level <sup>a</sup>						Analysis of variance		
	Program (n=118)			Control (n=186)			Main Effect		Interact
	Low	Med	High	Low	Med	High	Stress	Program	
Subsample, n	54	48	16	90	62	34	–	–	–
<b>Outcome</b>									
Perceived improvement	2.99	3.16	3.08	2.39	2.83	2.35	NS <sup>b</sup>	15.66 <sup>c</sup>	NS
Workplace resilience	3.91	3.76	3.35	3.19	3.08	2.98	5.17 <sup>c</sup>	42.37 <sup>d</sup>	NS
Inner resources	4.09	3.89	3.59	3.83	3.73	3.62	5.49 <sup>c</sup>	NS	NS
Dispositional resilience	4.31	4.20	3.31	4.08	3.97	3.88	18.33 <sup>c</sup>	NS	10.94 <sup>c</sup>
Satisfaction	3.41	3.60	3.44	3.12	3.19	3.00	NS	6.27 <sup>d</sup>	NS

<sup>a</sup>Low: not at all or a little; med: some; high: much or great amount.

<sup>b</sup>NS: nonsignificant.

<sup>c</sup> $P<.01$ .

<sup>d</sup> $P<.05$ .

**Table 4.** Gender differences in outcomes.

Item	Program, mean (SD)			Control, mean (SD)		
	Female (n=149)	Male (n=126)	<i>t</i> value ( <i>df</i> )	Female (n=66)	Male (n=120)	<i>t</i> value ( <i>df</i> )
Perceived improvement	3.10 (0.90)	3.08 (0.82)	0.19 (273)	2.66 (1.08)	2.46 (1)	0.63 (184)
Workplace resilience	3.96 (0.59)	3.81 (0.64)	2.02 <sup>a</sup> (273)	3.11 (0.72)	3.12 (0.66)	0.10 (184)
Inner resources	4.07 (0.60)	4.08 (0.58)	0.14 (273)	3.79 (0.61)	3.74 (0.70)	0.49 (184)
Dispositional resilience	4.19 (0.60)	4.27 (0.53)	1.16 (273)	3.88 (0.57)	4.07 (0.55)	2.23 <sup>a</sup> (184)
Satisfaction	3.67 (0.87)	3.44 (0.88)	2.17 <sup>a</sup> (273)	3.30 (1.04)	3.02 (0.97)	1.84 (184)

<sup>a</sup> $P < .05$ , both samples.

A two (condition) by three (stress level) analysis of variance (ANOVA) was conducted while controlling for demographics (gender, age, and education). There was a main program effect for PI, WR, and program satisfaction. Consistent with correlations in Table 2, all 3 types of resilience differed across stress levels. Program satisfaction was equal across stress groups. H6 proposed the program would be equally effective across stress levels. Hence, a test of the interaction term in the ANOVA should show no significance. Table 4 supports H6 with one exception for DR. Although the overall pattern shows decreasing DR as stress levels increases, significantly lower DR ratings occurred for high-stress employees in the program condition (mean 3.31). This may be because of the small sample size ( $n=16$ ) in this cell (see Table 3 for other findings).

### Assessing Dissemination Effects

Employees in the 2017 sample worked in firms that had different amounts of previous exposure to the resilience training. Both the 2015 and 2017 datasets allowed comparison of employees from “nonexposed” firms to those firms where employees may have learned something from previous participants. H7 posited that PI and WR would be strongest among employees from firms with two or more previous participants versus only one or no previous participants.

No differences in PI or WR were found across these 3 levels of previous exposure for either the program or control groups. However, stress was lowest among program participants coming from firms where two or more employees had previously had the training: none (mean 2.78; SD 0.96), one (mean 2.7; SD 1.06), or more than one (mean 2.39; SD 0.86),  $F_{2,81}=3.96$ ,  $P=.02$ . In addition, employees from firms with no previous exposure were the most satisfied; none (mean 3.89; SD 0.82), one (mean 3.3; SD 0.82), or more than one (mean 3.31; SD 0.93),  $F_{2,97}=4.93$ ,  $P<.01$ . Comparisons within control group found no differences in stress ( $F_{2,176}=1.32$ , *ns*) or satisfaction ( $F_{2,176}=1.97$ , *ns*).

### Gender Differences

Additional tests, shown in Table 4, explored differences between women and men. In the program group, females scored higher than males in both WR and satisfaction. However, in the control group, males scored higher than females in DR.

## Discussion

A total of 7 hypotheses were tested through an exploratory pilot study. Results generally support the conclusion that a brief Web-based resilience program can lead to proximal improvements in resilience as a social resource within work settings. This finding is supported by tests of H1, H2, and H3; the latter hypothesis included a control group comparison. Experimental versus control study comparisons showed positive outcomes for PI, WR, and satisfaction.

Stress has an impact on employee health and performance, and employees have a need for effective programs to address stress. Ideally, employers who purchase or promote such programs should know that their investments are wise ones, based on evidence [57]. Fortunately, there has been recent growth in the science of Web-based interventions to improve employee well-being and mental health (“digital mental health”) [58,59]. Previous reviews point to several characteristics that should make a WR program most useful: a basis in a theoretically precise model; relative brevity; ease of access; personalized feedback that engages users; some use of points or incentives for participation; and previous evidence for clinical effectiveness.

We add this to list the need for programs that enhance social well-being and educate workers about the impact of their own health on coworkers. This social focus can enhance potential dissemination or ripple effects [19], further adding to the efficacy of employer investment. This study incorporated all these characteristics into an e-learning design. We detailed the development and content of a new intervention based on an established evidence-based program. Our study tested the effectiveness of this new intervention, albeit without the inclusion of a fully randomized clinical trial and with limitations as discussed below.

In support of H4, PI (ratings of how much the training improved resilience at work) showed a correlation with WR. Several factors could account for these results. In particular, TR was designed to be distributed to employees *within* their workplace. It follows that the training would influence participants’ responses toward items that evaluate WR, but not as much with items that assess DR or IR.

In support of construct validity, only DR was significantly and inversely correlated with recent stress, after controlling for the

other resilience measures (Table 2, H5). H6 proposed that, because of the short-term focus of the training, the training was not expected to be differentially effective for those with low versus high stress. Additional tests support this hypothesis. However, those with low or moderate stress may benefit from a brief intervention (see Table 3).

Overall, findings also support a newly proposed working model for brief intervention evaluation that distinguishes proximal outcomes from longer-term dispositional resilience. Given the lack of clarity in previous resilience intervention studies, we hope that the findings from this study lead future researchers to clearly distinguish WR from dispositional measures.

Of special interest was a test of dissemination effects. We compared sample 2 (2017) employees from firms with no previous (2015) exposure to the resilience training with employees from firms that had previous exposure. H7 claimed that the previously exposed group would show more positive outcomes. Results did not show any differences among the variables in the working model for brief intervention evaluation (eg, PI, WR). However, those in the program group who came from firms with previous exposure reported less recent stress and lesser program satisfaction. It is difficult to say whether these employees benefited from their previous coworker's experience or whether those who were less stressed also self-selected into the program. However, the same finding was not apparent in the control sample, suggesting that TR may have made previous coworker's exposure more salient to current and new participants.

This study contained several important limitations. First, we used a nonrandomized quasi-experimental design, with a self-selected, convenience sample. Differences found between conditions may be due to preexisting characteristics in these groups or some other sampling artifact. This includes types of incentives used (between experimental and control groups), varying study time frames, and a sole focus on engineering firms. Although the findings of intervention-control comparisons are strengthened by the fact that there were 2 samples in the intervention condition, the control group was highly selected. Employees were recruited who specifically had not participated in any previous wellness program and who were asked to participate partly to share why they had not previously engaged in previous programs.

Other limitations may be considered in light of the pilot nature of the study. The measures that were used were themselves piloted, without full-scale development and factor analyses. Although the DR measure was adapted from Connor and Davidson [37], it was deliberately shortened. Additional items should be used to improve all scale reliabilities, especially more comprehensive and validated measures of recent stress or exposure to adversity.

Another limitation of this study was its focus on only immediate or proximal reactions. A more useful test would assess longer-term outcomes, especially taking ongoing stress into consideration. However, the workplace training literature suggests that utility types of reactions—as used here with PI—may correlate with more distal outcomes (eg, program satisfaction) [60,61]. The PI and the WR measures focused on knowledge, ability, and willingness to use WR, and results showed that the intervention improved the perceived utility of such resources. The improved perception of the workplace is noteworthy as the actual impact of training may depend on how much employees feel their organization cares about them [62].

Finally, the organizations sampled in this study varied in size, and none of them employed a substantial amount of people, compared with large organizations (ie, 500+ employees). It could be safely assumed that there is a positive linear relationship between the number of employees and the number of teams that are within the organization, which could result in stronger findings (eg, more dissemination throughout employees). This would be an interesting avenue to explore in further research, especially as research on small business wellness is limited [63].

Overall, this study is best viewed as an exploratory pilot. However, it makes several contributions. First this work also included both a new theoretical model and an e-learning extension or adaptation of an established classroom training. Furthermore, besides adapting the classroom training into an e-learning training, this work also tested the intervention on a different occupational sample (engineers) than the original study (restaurant workers). Findings suggest further and more rigorous tests of the model may be promising for the science of Web-based workplace TR training.

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## Conflicts of Interest

The Team Resilience program is owned by Organizational Wellness & Learning Systems in which one of the authors (JBB) has a financial interest.

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## Abbreviations

**ANOVA:** analysis of variance  
**CWB:** counterproductive work behavior  
**DR:** dispositional resilience  
**EAP:** Employee Assistance Program  
**IR:** inner resources  
**PI:** perceived improvement  
**TR:** team resilience  
**WR:** workplace resilience

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Original Paper

# Internet Use, Depression, and Anxiety in a Healthy Adolescent Population: Prospective Cohort Study

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## Abstract

**Background:** Psychiatric disorders, including conduct disturbances, substance abuse, and affective disorders, emerge in approximately 20% of adolescents. In parallel with the rise in internet use, the prevalence of depression among adolescents has increased. It remains unclear whether and how internet use impacts mental health in adolescents.

**Objective:** We assess the association between patterns of internet use and two mental health outcomes (depression and anxiety) in a healthy adolescent population.

**Methods:** A total of 126 adolescents between the ages of 12 and 15 years were recruited. Participants reported their typical computer and internet usage patterns. At baseline and one-year follow-up, they completed the Beck Depression Index for primary care (BDI-PC) and the Beck Anxiety Inventory for Primary Care (BAI-PC). Individual linear regressions were completed to determine the association between markers of internet use at baseline and mental health outcomes at one-year follow-up. All models controlled for age, gender, and ethnicity.

**Results:** There was an inverse correlation between minutes spent on a favorite website per visit and BAI-PC score. No association was found between internet use and BDI-PC score.

**Conclusions:** There is no relationship between internet use patterns and depression in adolescents, whereas internet use may mitigate anxiety in adolescents with higher levels of baseline anxiety.

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**KEYWORDS**

mental health; psychiatric disorders; internet use; social networking sites

## Introduction

**Background**

Psychiatric disorders, including conduct disturbances, substance abuse, and affective disorders, emerge in approximately 20% of adolescents [1]. Internet use is pervasive among teens, with 92% of American teens reporting daily internet use and 24% reporting nearly constant use [2]. The developmental tasks of adolescence include establishing autonomy, developing a self-image, and creating healthy social connections [1]. It

remains unclear how or whether internet use affects these developmental tasks. In parallel with the rise in internet use, prevalence of depression among adolescents has increased from 8.7% in 2005 to 11.3% in 2014 [3]. This observation of a parallel rise in internet use and depression has raised questions, spurred research, and fueled controversy.

Existing research on the association between internet use and mental health outcomes has focused on the effect of social networking site (SNS) use in the young adult and college population. As reviewed by Primack et al, there is a great deal

of controversy as to whether overall SNS use is associated with mental health outcomes in transitional age youth [4]. While some studies suggest that SNS users experience positive mental health effects such as increased perceived peer support, social capital, and overall life satisfaction [5,6], others show a correlation between increased SNS use and depression [7,8]. Less research has examined the effect of general internet use and internet use patterns on middle and high school-aged youth. Interestingly, one study found that both low-intensity and high-intensity self-reported internet use was associated with poorer mental health outcomes in adolescents [9]. Whether specific internet use patterns, such as time spent on interactive versus noninteractive sites and weekday versus weekend use, are associated with mental health outcomes remains unknown. Our prospective cohort study examines associations between self-reported patterns of internet use and depression and anxiety in a community-based sample of adolescents.

## Methods

### Study Participants

In 2009, English-speaking participants between the ages of 12 and 15 years were recruited from public schools, after-school programs, and community programs in a small New England

city (Table 1). Participants provided assent and parents provided written consent for study participation. Research ethics approval was granted by the Committee on Clinical Investigation at Boston Children's Hospital. Data were collected using the Measuring Youth Media Exposure procedure for recall estimation [10]. Media use and mental health status were measured annually with a computer-assisted self-interview in which participants reported typical amounts of time using computers and internet, favorite websites, how often and for how long they visited them each time. Favorite websites were assessed as interactive or not interactive, where any website that primarily functioned to connect people was coded as interactive. Examples of interactive sites included SNS (eg, Facebook), email sites (eg, Gmail), and online chat sites. The favorite website variable was subsequently treated as a dichotomous variable (interactive versus noninteractive) for statistical analysis.

### Data Collection

At baseline and one-year follow-up, participants completed the Beck Depression Inventory for Primary Care (BDI-PC) and the Beck Anxiety Inventory for Primary Care (BAI-PC), validated screening tools for detecting anxiety and mood disorders in adolescents [11].

**Table 1.** Participant characteristics (USA 2009).

Characteristics	Value
<b>Total participants, n</b>	
At start	126
At 1-year follow-up	103
Female gender, n (%)	59 (46.9)
Age, mean (range)	14.04 (12.56-15.94)
Nonwhite race, n (%)	57 (45.2)
<b>Internet use, mean (SD)</b>	
School day in min	53.37 (59.62)
Weekend in min	91.92 (128.25)
<b>Beck Depression Inventory for Primary Care, mean (SD)</b>	
Baseline	2 (6.2)
Follow-up	1.8 (2.5)
<b>Beck Anxiety Inventory for Primary Care, mean (SD)</b>	
Baseline	12 (2.9)
Follow-up	11.2 (6.1)
<b>Ownership, n (%)</b>	
Mobile internet device	61 (48.4)
Personal laptop	37 (29.4)
Personal cell phone	86 (68.3)
<b>Parental education (highest), %</b>	
Less than high school	17.4
Completed high school	30.6
At least some college	52

For each of these screening tools, participants ranked seven symptoms on a scale of 0 to 3, where 0 indicated the symptom was not present and 3 indicated a high severity of the symptom. Examples of questions about depression included sadness, pessimism, and loss of interest. Examples of questions assessing anxiety included worrying at bedtime, worrying about parents, and feelings of nervousness. Each of the scales is scored from 0 to 21, where scores of 0-3 indicate minimal, 4-6 mild, 7-9 moderate, and 10-21 severe symptom burden.

Data were analyzed using Statistical Package for the Social Sciences (SPSS) v.20 (IBM) software. Statistical significance was defined as  $P$  value  $<.05$ . Individual linear regressions were completed to determine the association between internet use at baseline and mental health outcomes at one-year follow-up. All

models controlled for age, gender, race, and baseline depression and anxiety.

## Results

A total of 126 adolescents were included at baseline. Of these, 23 participants were lost to follow-up and excluded from the analysis. Demographic as well as mean baseline and follow-up BDI-PC and BAI-PC are summarized in Table 1. A total of 48.4% of participants owned a mobile internet device, such as a cell phone with internet capabilities.

Linear regression beta coefficients between internet use and mental health outcomes are shown in Tables 2 and 3. There was an inverse correlation between minutes spent on a favorite website per visit and anxiety (BAI-PC score). No association was found between internet use and depression (BDI-PC score).

**Table 2.** Linear regression analysis using internet use to predict depression scores at 1-year follow-up.

Internet use variable <sup>a</sup>	Unstandardized coefficients		Standardized coefficient (beta)	$t$	$P$ value
	B	SE <sup>b</sup>			
Favorite site interactive?	.62	.71	.09	.88	.38
Visits/week on favorite site	.43	.29	.16	1.51	.14
Visits/week on interactive site	.21	.18	.12	1.20	.23
Minutes on favorite site/visit	-.29	.31	-.10	-.94	.35
Minutes on computer/school day	.00	.01	.01	.12	.91
Minutes on internet/school day	.00	.01	.06	.48	.63
Minutes email or chat/school day	.00	.01	-.06	-.51	.61
Minutes on computer/weekend day	.00	.00	.02	.19	.85
Minutes on internet/weekend day	.00	.00	.06	.49	.63
Minutes email or chat/weekend day	.00	.00	.05	.40	.69

<sup>a</sup>Covariates included age, gender, race, and baseline depression.

<sup>b</sup>SE: standard error.

**Table 3.** Linear regression analysis using internet use to predict anxiety scores at 1-year follow-up.

Internet use variable <sup>a</sup>	Unstandardized coefficients		Standardized coefficient (beta)	$t$	$P$ value
	B	SE <sup>b</sup>			
Favorite site interactive?	-.01	1.05	.00	-.01	.99
Visits/week on favorite site	.11	.43	.03	.27	.79
Visits/week on interactive site	-.20	.26	-.08	-.76	.45
Minutes on favorite site/visit	-1.06	.44	-.24	-2.39	.02
Minutes on computer/school day	-.01	.01	-.12	-.93	.35
Minutes on internet/school day	-.01	.01	-.09	-.74	.46
Minutes email or chat/school day	.00	.01	.02	.19	.85
Minutes on computer/weekend day	.00	.00	.01	.09	.93
Minutes on internet/weekend day	-.01	.00	-.20	-1.79	.08
Minutes email or chat/weekend day	.00	.00	-.09	-.77	.44

<sup>a</sup>Covariates included age, gender, race, and baseline depression.

<sup>b</sup>SE: standard error.

## Discussion

### Principal Findings

We found no relationship between internet use and depression in healthy adolescents. While time in minutes spent on each visit to a favorite website was negatively correlated with anxiety scores, no other measures of internet use were correlated with anxiety scores. Particularly, there was no relationship between preferred use of interactive websites and anxiety, suggesting that use of interactive websites is not associated with worse mental health outcomes. The correlation between increased time spent on a favorite website per visit and lower anxiety scores may indicate that adolescents are using their favorite website (either interactive or noninteractive) as a self-soothing tool to reduce anxiety. Overall, our results suggest a minimal effect of internet use on depression and anxiety.

The literature regarding the effect of internet use on mental health outcomes remains controversial [4]. Many of the studies that demonstrate a correlation between internet use and poor mental health outcomes have focused on problematic internet use, a pattern of internet use with features resembling addiction, such as impulsive or risky use resulting in social, occupational, or emotional impairment [12,13]. A prospective study of adolescents demonstrated that pathologic internet use at baseline was 1.5 times more highly associated with depression at the 9-month follow-up, compared with nonpathologic use [13]. The studies that have demonstrated no association between internet use and mental health outcomes have typically focused more on moderate, or nonpathologic use. One study of adolescent university students showed no relationship between SNS use and depression [14]. Additionally, Belanger et al demonstrated a U-shaped relationship between self-reported intensity (duration) of internet use and depression. Adolescents with high and low internet use had higher depressive scores, compared with moderate users [9]. The results of our study parallel this

work, as the participants of this study had a mean internet use of less than one hour on school days and approximately 1.5 hours on weekends, representing moderate internet use.

Importantly, the generalizability of our findings in the present is limited by the fact that the data were collected in 2009. Internet use has become much more pervasive over the last several years, particularly with the increased affordability and accessibility of handheld devices including smart-phones and tablets. The landscape and functions offered by SNS have also evolved, now with increased advertising, instant messaging, and media uploading capabilities. Our data may not capture how the increased role of the internet in forming and sustaining relationships affects mental health. Generalization of our results is also limited by the small sample size and reliance on self-reported internet use measures which may be limited in reliability. Further research that includes methodologies that allow for more contextualized measures of internet use, such as passive versus active use, social setting, and motivations for use, may provide additional information relevant to how patterns of internet use affect mental health in adolescents. Another limitation was that while our model controlled for age, gender, race, and baseline BDI-PC and BAI-PC scores, we were unable to control for other risk factors for depression and anxiety such as family history of mental illness, coping style, and trauma history. Finally, the population studied was a community-based population, and thus, these results may not be generalizable to a clinic-based population, such as those already receiving treatment for depression, anxiety, or other mental illnesses. Given these limitations and inconsistencies in previous studies, further research must be done.

### Conclusion

We were unable to detect an association between internet use and depression and anxiety in a community sample of adolescents.

### Authors' Contributions

All authors participated in study design and manuscript preparation. DSB and MR contributed to data collection. RPT contributed to data analysis.

### Conflicts of Interest

None declared.

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## Abbreviations

- BAI-PC:** Beck Anxiety Inventory for Primary Care  
**BDI-PC:** Beck Depression Inventory for Primary Care  
**SNS:** social networking site  
**SPSS:** Statistical Package for the Social Sciences

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Original Paper

# An Internet Resource for Self-Assessment of Mental Health and Health Behavior: Development and Implementation of the Self-Assessment Kiosk

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## Abstract

**Background:** Standardized measurement of physical and mental health is useful for identification of health problems. Personalized feedback of the results can influence health behavior, and treatment outcomes can be improved by monitoring feedback over time. However, few resources are available that are free for users, provide feedback from validated measurement instruments, and measure a wide range of health domains.

**Objective:** This study aimed to develop an internet self-assessment resource that fills the identified gap and collects data to generate and test hypotheses about health, to test its feasibility, and to describe the characteristics of its users.

**Methods:** The Self-Assessment Kiosk was built using validated health measurement instruments and implemented on a commercial internet survey platform. Data regarding usage and the characteristics of users were collected over 54 weeks. The rate of accrual of new users, popularity of measurement domains, frequency with which multiple domains were selected for measurement, and characteristics of users who chose particular questionnaires were assessed.

**Results:** Of the 1435 visits, 441 (30.73%) were visiting for the first time, completed at least 1 measure, indicated that their responses were truthful, and consented to research. Growth in the number of users over time was approximately linear. Users were skewed toward old age and higher income and education. Most (53.9%, 234/434) reported at least 1 medical condition. The median number of questionnaires completed was 5. Internal reliability of most measures was good (Cronbach alpha > .70), with lower reliability for some subscales of coping (self-distraction alpha = .35, venting alpha = .50, acceptance alpha = .51) and personality (agreeableness alpha = .46, openness alpha = .45). The popular questionnaires measured depression (61.0%, 269/441), anxiety (60.5%, 267/441), attachment insecurity (54.2%, 239/441), and coping (46.0%, 203/441). Demographic characteristics somewhat influenced choice of instruments, accounting for <9% of the variance in this choice. Mean depression and anxiety scores were intermediate between previously studied populations with and without mental illness. Modeling to estimate the sample size required to study relationships between variables suggested that the accrual of users required to study the relationship between 3 variables was 2 to 3 times greater than that required to study a single variable.

**Conclusions:** The value of the Self-Assessment Kiosk to users and the feasibility of providing this resource are supported by the steady accumulation of new users over time. The Self-Assessment Kiosk database can be interrogated to understand the relationships between health variables. Users who select particular instruments tend to have scores that are higher than those found in the general population, indicating that instruments are more likely to be selected when they are salient. Self-selection bias limits generalizability and needs to be taken into account when using the Self-Assessment Kiosk database for research. Ethical issues that were considered in developing and implementing the Self-Assessment Kiosk are discussed.

**KEYWORDS**

self-assessment; feedback; surveys and questionnaires; internet

## Introduction

### Background

Standardized measurement and feedback of aspects of health serves several purposes. Most basically, screening can identify health problems that would benefit from management or treatment. Screening is used for a wide range of health conditions, with variable effects on health outcomes [1-3]. Standardized measurement can also be used to motivate behavior change, for which purpose its effectiveness can be increased by adding personalized feedback about the meaning of scores, including comparison of personal results to population norms. For example, interventions to reduce unhealthy patterns of alcohol consumption in college students are more effective when combined with salient, personalized feedback to enhance motivation for change [4]. Standardized measurement can also serve to assess changes in health phenomena over time. In psychotherapy for mental health problems, for example, routine outcome monitoring with feedback to the therapist (and client) substantially increases the effect size of treatment, reduces dropout rates, and shortens the course of treatment [5]. As another example, cancer patients with metastatic solid tumors who routinely self-assessed common symptoms, with alerts to their oncologist when severe symptoms or worsening were recorded, had significantly increased survival compared with those who did not self-assess symptoms [6].

Many instruments that measure aspects of mental and physical health are available on the internet. These are commonly presented as single-domain measures. It is less common for multiple aspects of health to be measured in the same visit to a single website. Some available internet tools calculate scores automatically (eg, calculators of body mass index or Framingham cardiac risk score), whereas others require scoring by the user. Personalized feedback of scores contextualized with reference to population norms or validated cutoffs for categorical interpretation of scores is uncommon. Thus, commonly available internet tools do not readily serve all of the functions that make standardized health measures valuable.

### Objectives

Our goal was to develop an internet self-assessment resource that could be used without cost to the user, that would measure a wide range of aspects of mental and physical health with validated instruments, and that would provide both scores and evidence-based feedback about the meaning of those scores to users. We developed the Self-Assessment Kiosk, which provides a menu of health domains from which users can select whichever measures are of interest (Figure 1). After selecting from the menu, the user is then presented with the surveys that have been selected. After completing surveys, the user is provided with scores and feedback that puts the scores into context using established norms or validated cutoffs (Figure 2).

**Figure 1.** Screenshot of menu page of the Self-Assessment Kiosk.

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## The Self-Assessment Kiosk

Choose individual surveys

There are many surveys from which to choose. Check as many as you want. Please only check the surveys that you plan to complete on this visit because you have to finish everything you check to get a report.

<input type="checkbox"/> Current health status, about 10 minutes	<input type="checkbox"/> Childhood trauma and stressful events, about 3 minutes
<input type="checkbox"/> Physical symptoms, about 2 minutes	<input type="checkbox"/> Traumatic events over your lifetime, about 3 minutes
<input type="checkbox"/> Smoking, alcohol, drugs, about 5 minutes	<input type="checkbox"/> Pain severity and responses, about 5 minutes
<input type="checkbox"/> Overall level of function, about 4 minutes	<input type="checkbox"/> Relationship style, about 4 minutes
<input type="checkbox"/> Level of physical activity, about 1 minute	<input type="checkbox"/> Relationship with a health care provider, about 6 minutes (note: completing this survey may help you reflect on your relationship with a health care provider, but this survey does not provide feedback at this time)
<input type="checkbox"/> Goals for a healthier lifestyle, about 1 minute	<input type="checkbox"/> Health anxiety, about 3 minutes
<input type="checkbox"/> Depression, about 1 minute	<input type="checkbox"/> Sensitivity to the environment, about 2 minutes
<input type="checkbox"/> Anxiety, about 1 minute	<input type="checkbox"/> Coping strategies, about 4 minutes
<input type="checkbox"/> Attention and hyperactivity, about 5 minutes	<input type="checkbox"/> Personality, about 2 minutes
<input type="checkbox"/> Social support, about 1 minute	<input type="checkbox"/> Emotional Eating, about 3 minutes

**Figure 2.** Screenshot of sample results page from the Self-Assessment Kiosk.

## Your results

Scores are provided below for the scales that you completed with a little explanation of what they typically mean. Some scales do not produce results that can be interpreted.

**These results are not a medical opinion. They are based entirely on the information that you have provided and how that information has applied to other people. These results cannot substitute for actual assessment by a professional. If you have questions or concerns about your results, or are planning to make any changes, we strongly advise you to discuss them with a health professional.**

It is a very good idea to PRINT THIS PAGE BEFORE YOU CLOSE THE SURVEY. Your scores may be useful for future reference or to share with you doctor, counselor or therapist. Your scores cannot be retrieved after you close the survey.

This survey was done on **Wed Jan 03 2018.**

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**Harmful Drinking**  
Your alcohol risk score is 6. Scores above 8 indicates hazardous or harmful alcohol use.

- Lower scores may still be of concern in older persons, and people with serious illnesses.

Measured with the AUDIT survey, by T.F. Sabor and colleagues for the World Health Organization, 2001.

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**Depression**  
Your depression score is 11 on a scale from 0 to 27. This is considered MODERATE. This screening test is not a substitute for a professional assessment. If you have not talked about depression with a health professional we encourage you to have that conversation.

Measured with the PHQ-9 by Kroenke and Spitzer, 2001.

---

**Emotional Eating in Response to Tension or Anger**  
Your score is 3 on a scale from 0 to 44, which suggests that you have no desire to eat when you are feeling angry or frustrated, or if you have some desire it is not strong.

Measured with the Emotional Eating Scale by B. Arnou, J. Kenardy, and W.S. Agras, International Journal of Eating Disorders, 1995.

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**Emotional Eating in Response to Anxiety**  
Your score is 0 on a scale from 0 to 36, which suggests that you have no desire to eat when you are feeling anxious, or if you have some desire it is not strong.

Measured with the Emotional Eating Scale by B. Arnou, J. Kenardy, and W.S. Agras, International Journal of Eating Disorders, 1995.

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We encourage you to save this report for your records or print it to share with a health care professional, therapist or counsellor.

\*

The following necessary characteristics were determined before selecting a platform and instruments to include in the Self-Assessment Kiosk. First, the Self-Assessment Kiosk was intended to be free to users and free of advertising, and so, the costs of implementation and maintenance had to be low. Second, the survey platform used had to be able to score and store scores for many different questionnaires, to be able to score instruments with complex scoring instructions (beyond summing or averaging item scores), and to be able to select text for feedback to users corresponding to the user's score for each questionnaire. Third, the instruments chosen had to have several characteristics—good evidence for reliability and validity in peer-reviewed journals, published norms or validated cutoffs, to be brief, and to be free. Fourth, permission to use the instrument in the intended context had to be provided by the copyright holder. Adequate safeguards had to be in place to assure the privacy of the information provided.

In addition to serving as a health resource for users, the Self-Assessment Kiosk was also to provide a database for clinical research into the relationships between various aspects of physical and mental health. The authors of the Self-Assessment Kiosk were particularly interested in

relationships at the interface between aspects of mental illness, normal psychology, and physical health. As opposed to a hypothesis-driven database comprising measures of constructs specific to a hypothesis, a database that includes many aspects of physical and mental health can serve as a resource that can be interrogated for hypothesis generation or pilot testing of emerging hypotheses over time.

The purposes of this paper are to describe the development and implementation of the Self-Assessment Kiosk and to assess the nature and quality of the data that it collects. Our specific purposes were to test the feasibility of the Self-Assessment Kiosk as a self-assessment resource and as a research tool and to describe the characteristics of its users.

## Methods

### Study Design

The Self-Assessment Kiosk is an open survey. This study of users of the Self-Assessment Kiosk during its first 54 weeks is a cross-sectional study of a convenience sample. The sample consists of users of the Self-Assessment Kiosk who completed at least 1 questionnaire, indicated this was their first visit,

consented to research, and indicated that their responses were truthful.

### Development of the Self-Assessment Kiosk

The Self-Assessment Kiosk [7] measures over 20 domains of mental and physical health as well as demographic information and a profile of current medical status. Domains to measure and the instruments to measure them were suggested by the authors (RGM and JJH), with additional input from an advisory committee of the University of Toronto Department of Psychiatry Division of Consultation-Liaison Psychiatry. Permission to use surveys was obtained from the copyright holders. If permission was not granted, alternative instruments were substituted or instruments were excluded. Scoring instructions were obtained from peer-reviewed publications or from the instrument authors.

The Self-Assessment Kiosk was implemented on a commercial internet survey platform (Survey Gizmo, owned by Widgix LLC dba Survey Gizmo, the service provider), which provided the required scoring and skip-logic capabilities to enable adaptive questioning. The service provider implements technical privacy safeguards, which include Secure Sockets Layer linkage and Secure Hash Algorithm-256 with Rivest-Shamir-Adleman-2048 encryption. A service contract stipulates that the service users (authors) retain all rights to the information collected in the surveys, whereas the service provider retains the right to capture the information to use in aggregate (nonidentifying) forms for their own interests. Information is stored in the service provider's servers "for as long as is needed to provide services to our customers... [and] to comply with [the service provider's] legal obligations." Information is downloaded in a database, replaced by an updated cumulative database from time to time, which will be stored on the Sinai Health System server for the duration of the Self-Assessment Kiosk information collection plus 7 years (the latter being a requirement of the Sinai Health System Research Ethics Board, see below).

Legal liability toward users of the Self-Assessment Kiosk was addressed with disclaimers to prevent personalized feedback being interpreted as a medical or diagnostic opinion.

Most instruments selected for the Self-Assessment Kiosk are previously validated [8-28]. These are listed in Table 1 with a summary of instrument characteristics, scoring, and internal reliability (Cronbach alpha). Validated surveys are presented in the Self-Assessment Kiosk with the order of items specified by the instruments' authors (ie, item order is not randomized).

In addition to validated instruments, questions to assess demographic and descriptive characteristics of users were composed by the authors. To collect information on medical diagnoses (physical and psychiatric), adaptive questioning was used to first screen for any medical condition that requires prescription medication or visits to a health provider more often than routine checkups, and second for any diagnosis within a body system (eg, "High blood pressure, a heart condition, a

stroke or a condition of blood vessels."). Users who endorse a diagnosis within a body system are then provided a list of the most common diagnoses within that system plus an "other" (write-in) option. In this way, a large number of diagnostic conditions (84 plus "other") could be screened with a smaller number (17) of mandatory screening questions.

All users also complete measures of physical and emotional well-being at the time of the survey (visual analog scales from 0 to 100) and a seriousness check, which has been shown to increase the validity of Web-based self-reports [29]. The seriousness check used was the following: "Sometimes people 'check out' the Self-Assessment Kiosk without providing information that is true about them. That is fine, but we would like to know. Have you answered the questions in the surveys you completed today honestly, based on your current circumstances?"

A summary page provides scores and places these scores in context with brief text that is based on existing norms or validated cutoffs. Text for feedback to users based on instrument scores was written by the authors and presented to users via a combination of the survey platform's built-in user-feedback functions and scripts written in JavaScript and embedded in the survey. The Self-Assessment Kiosk was field tested by authors and volunteers until no bugs were detected in several consecutive usages before launch.

### The Self-Assessment Kiosk User Experience

Users of the Self-Assessment Kiosk are encouraged to use the resource as often as they wish. Therefore, at the start of any visit, users are asked if this is a first visit or a return visit. Users are also presented the option of providing a username, which allows information from different sessions to be linked by the authors. The user experience is identical whether they provide a username or not.

On the first visit (and at any subsequent visit if desired), users are provided information about the Self-Assessment Kiosk and presented with a research consent page. Users are informed that their experience is identical whether they agree that their information may be used for research purposes or not. The consent page informs users who the investigators are (RGM and JJH), the purpose of research ("to understand how aspects of psychological health and physical health are related to each other"), the length of the survey ("as little as 5 minutes or... over an hour, depending on how many surveys you decide to do"), and that aggregate results of this research, for those who consent, may be published in a medical or scientific journal or may be presented at a medical or scientific meeting. Users are informed about anonymity ("using the Self-Assessment Kiosk is anonymous... we do not ask for your name or your email address and we do not record information about your computer") and limitations on privacy protections ("however, the surveys do ask many personal questions, including questions about medical conditions, mental health conditions, age, gender, what country you live in, your ethnicity, and questions about traumatic or stressful life experiences).

**Table 1.** Domains measured and characteristics of instruments used in the Self-Assessment Kiosk.

Domain	Instrument	Summary of characteristics
Impact of illness	Illness Intrusiveness Rating Scale [8]	13 items rated 1 to 7; scale score is item sum; alpha=.94
Anxiety	GAD <sup>a</sup> -7 [9]	7 items rated on 4-point scale from 0 to 3; scale score is item sum; alpha=.91
Depression	PHQ <sup>b</sup> -9 [10]	9 items rated on 4-point scale from 0 to 3; scale score is item sum; alpha=.90
Physical symptoms	PHQ <sup>b</sup> -15 [11]	15 items rated on 3-point scale from 0 to 2; scale score is item sum; alpha=.81
Smoking	CAMH <sup>c</sup> monitor survey [12]	4 items probing current and past smoking, duration and amount; no summary score; internal reliability not applicable
Alcohol use problems	Alcohol use disorder identification test [13]	8 items rated on a 5-point scale from 0 to 4, 2 items rated on a 3-point scale as 0, 2, and 4; scale score is item sum (items 4 to 8 are skipped and scored 0 if sum of items 1 to 3=0); alpha=.85
Disability	Brief WHO <sup>d</sup> Disability Assessment Scale, WHODAS 2.0 [14]	12 items measuring function in different domains, each rated from 1 to 5; scale score is item mean; alpha=.93; plus 3 items probing number of disabled days in past month
Physical activity	Stanford brief activity survey [15]	2 items probing typical on-the-job activity and leisure activity, each with 5 possible response categories representing increasing intensity of activity. Scoring by categorization into 5 categories of overall activity, based on a 5x5 scoring grid; internal reliability not applicable
ADHD <sup>e</sup>	ADHD self-report scale [16]	18 items answered on a 5-point response scale which is then dichotomized (0 or 1) for each item. Outcome is dichotomous: low probability of ADHD (score of 0-3 on first 6 items) or high probability of ADHD (score of 4-6 on first 6 items); alpha (6-item)=.68, alpha (18-item)=.86
Social support	ENRICH <sup>f</sup> social support inventory [17]	6 items scored from 1 to 6; scale score is item sum; alpha=.92
Childhood adversity	Adverse Childhood Experience (ACE) Survey [18]	17 items answered yes or no to score 10 categories of types of adversity (0 or 1); summed to yield ACE score (0-10). Internal reliability not applicable
Lifetime trauma	Brief trauma questionnaire [19]	9 items used to survey the occurrence of types of traumatic exposure (yes or no); endorsed items were followed with 2 severity questions (yes or no); this yielded dichotomous assessment of exposure to traumatic experiences which led to serious injury or were perceived to threaten life or serious injury (yes or no); internal reliability was not applicable
Appraisal of pain	McGill pain questionnaire [20]	20 types of pain descriptor adjectives, 1 temporal pattern item, 6 types of pain severity adjectives, with adjectives ordered for scoring within categories, and categories varying from 3 to 6 possible responses (or 0 if left blank). Score is item sum (0-78); alpha=.78
Catastrophizing	Pain catastrophizing scale [21]	13 items scored 0 to 4; score is item sum; alpha=.95
Attachment insecurity	Experience in close Relationships-M16 [22]	16 items scored from 1 to 7, 8 items for attachment anxiety, 8 items for attachment avoidance (3 items are reverse scored); scores are item means; attachment anxiety alpha=.86, attachment avoidance alpha=.86
Treatment alliance	Human connection scale [23]	16 items scored 1 to 4; score is item sum; alpha=.92
Health anxiety	Health anxiety inventory [24]	18 items, scored on a 4-point scale from 0 to 3; score is item sum; alpha=.91
Sensitivity to Environment	Highly sensitive person scale [25]	11 items scored from 1 to 7; score is item mean; alpha=.94
Coping	Brief COPE [26]	28 items scored 1 to 4; 14 methods of coping scored as the mean of 2 items; alpha values: self-distraction=.35, active coping=.76, denial=.68, substance use=.96, emotional support=.84, instrumental support=.83, behavioral disengagement=.66, venting=.51, positive reframing=.83, planning=.81, humor=.81, acceptance=.50, religion=.83, and self-blame=.82
Personality	Ten-item personality inventory [28]	10 items scored on a 7-point scale from 1 to 7; mean of 2 items (1 reverse scored) for each of 5 personality domains; alpha values: extraversion=.71, agreeableness=.46, conscientiousness=.69, neuroticism=.72, and openness=.45

Domain	Instrument	Summary of characteristics
Emotional eating	Emotional eating scale [28]	25 items scored on a 5-point scale (0-4); 11 items are summed for eating in response to anger (0-44) and 9 items are summed for eating in response to anxiety (0-36); alpha values: anger=.90 and anxiety=.85

<sup>a</sup>GAD: generalized anxiety disorder.

<sup>b</sup>PHQ: Patient Health Questionnaire.

<sup>c</sup>CAMH: Centre for Addiction and Mental Health.

<sup>d</sup>WHO: World Health Organization.

<sup>e</sup>ADHD: attention deficit and hyperactivity disorder.

<sup>f</sup>ENRICH: Enhancing Recovery in Coronary Heart Disease.

The information that you provide will be stored within the survey system databases and downloaded to be stored on servers at Mount Sinai Hospital in Toronto, Canada... Information that travels on the internet and is stored on a computer is sometimes viewed by third parties by accident, because of government policies or a court subpoena, as a result of criminal hacking or for other reasons. Therefore, using the Self-Assessment Kiosk carries some risk of your personal, anonymous information being read by someone other than the researchers.”). Note that although there are technical safeguards against a privacy breach, the consent process emphasizes sources of risk and the primary safeguard of maximizing the anonymity of data.

Users are warned about risks of using the Self-Assessment Kiosk, which exist whether or not they consent to research. These are privacy risks (as above), and the risk that responding to surveys about mental health and trauma may cause distress or trigger bad memories. They are also informed of safeguards against this distress (“You will only see these surveys if you ask to. You are allowed to skip questions if you don’t want to answer them. Surveys that ask about traumatic experiences are preceded by a trigger warning that allows you skip them if you want to.”).

Users are also informed about the limitations on the validity of feedback (“Feedback puts your results in context, based on what similar results have meant for other people in research studies. The feedback is not about you personally, because completing surveys is not the same as a medical or psychological assessment. As a result, the feedback may or may not be accurate for you. Reading feedback about your answers to psychological or medical questions may raise concerns or questions for you that the providers of the Self-Assessment Kiosk are unable to answer or respond to. We encourage you to discuss these concerns and questions with a health professional.”). The process of providing information and obtaining consent has been approved by the Mount Sinai Hospital Research Ethics Board (REB #16-0186).

After choosing to consent to research or not, users choose individual domains to assess from a menu and are also offered bundles of preselected combinations of survey instruments, including the option of a comprehensive assessment (all instruments). The approximate time required for each instrument is provided in the selection menu (see [Figure 1](#)). To maximize anonymity and minimize distress, almost every item within the Self-Assessment Kiosk can be skipped if desired. Demographic and other descriptive characteristics of users are collected for

users who are visiting the Self-Assessment Kiosk for the first time and not for users who indicate they have visited previously.

As users can choose a large number of questionnaires, steps were taken to reduce fatigue. The presentation of survey items varies to maintain user interest, including check boxes, short write-in answers, radio buttons, and sliders. For users who select a large number of surveys, brief “fun fact” quizzes with immediate feedback about responses are interspersed between some surveys to provide variety and interrupt fatigue. The number of items per screen is generally less than 10 and varies from 1 to 15. Users can navigate with back buttons to revise answers if they wish.

After completing the selected surveys, users are provided with personalized feedback based on published norms and cutoffs on a summary page that can be saved as a file or printed for future reference. Feedback for scores that indicate a possible need for professional assessment or treatment includes the suggestion to discuss the results with a physician.

### Distribution of the Self-Assessment Kiosk

The target population of the Self-Assessment Kiosk is broad, consisting of any interested adult with access to the resource. It was marketed to potential users in various ways ([Multimedia Appendix 1](#)). Two email distribution notices were sent to primary care providers, psychotherapists and psychiatrists known to the authors, first in Sept 2016 and then in January 2017. Periodic notices were posted on a Twitter account that had approximately 1000 followers during the period of this study (@boiby). In each case, readers of the notice were encouraged to distribute it widely. Health-related Web resources were contacted to request that a link to the Self-Assessment Kiosk be included on websites. As a result of this snowballing method of distribution of the link to the survey, it is not known what websites or other internet sources provide access to the Self-Assessment Kiosk.

### Statistical Analysis

Descriptive data were tabulated to characterize users and their usage of the Self-Assessment Kiosk over its first 54 weeks after launch. In addition to the demographic characteristics of users, we calculated the rate of accrual of new users and the median number of questionnaires that are usually completed.

The popularity of each measurement domain was determined by calculating the rate at which each questionnaire was completed. To demonstrate the reduction in available sample size when the relationship between multiple questionnaires is

studied, we calculated the rate of completion of a combination of 3 questionnaires, then repeated this for a different combination of 3 questionnaires.

The influence of personal characteristics on the choice of which questionnaires to complete was tested with logistic regression entering the binary variable (completed or not completed) as dependent variable and age, gender, medical diagnosis (any or none), education, and income category as independent variables. Questionnaires that were completed by at least 20% of the user cohort were included in this analysis. Data were analyzed in IBM SPSS Statistics for Windows Version 24.0 (IBM Corporation, Armonk, New York).

## Results

### Description of the Cohort

In the first 54 weeks after its launch, the Self-Assessment Kiosk received 1435 visits. Of these, 762 visits included completion of at least 1 questionnaire, 601 for the first time and 161 as return users. The number of visits grew each week, by a median of 14 users per week (interquartile range 3-34). Of 601 first-time users who completed questionnaires, 73.4% (443/601) provided consent for the use of their information for research purposes. Of these, in answer to the question about the seriousness of their responses, 2 users indicated that their answers were not entirely truthful. This report concerns the remaining 441 people. Growth in the number of users over time was approximately linear after the first few weeks, as illustrated in [Figure 3](#).

Descriptive characteristics of the cohort are presented in [Table 2](#). The modal user was a highly educated, married, white woman with an income greater than \$75,000 annually. Most users were from Canada or the United States. Of users who provided

information about medical diagnoses, more than half (53.9%, 234/434) reported at least 1 medical condition. The median number of questionnaires completed on the first visit was 5 (interquartile range 2-10).

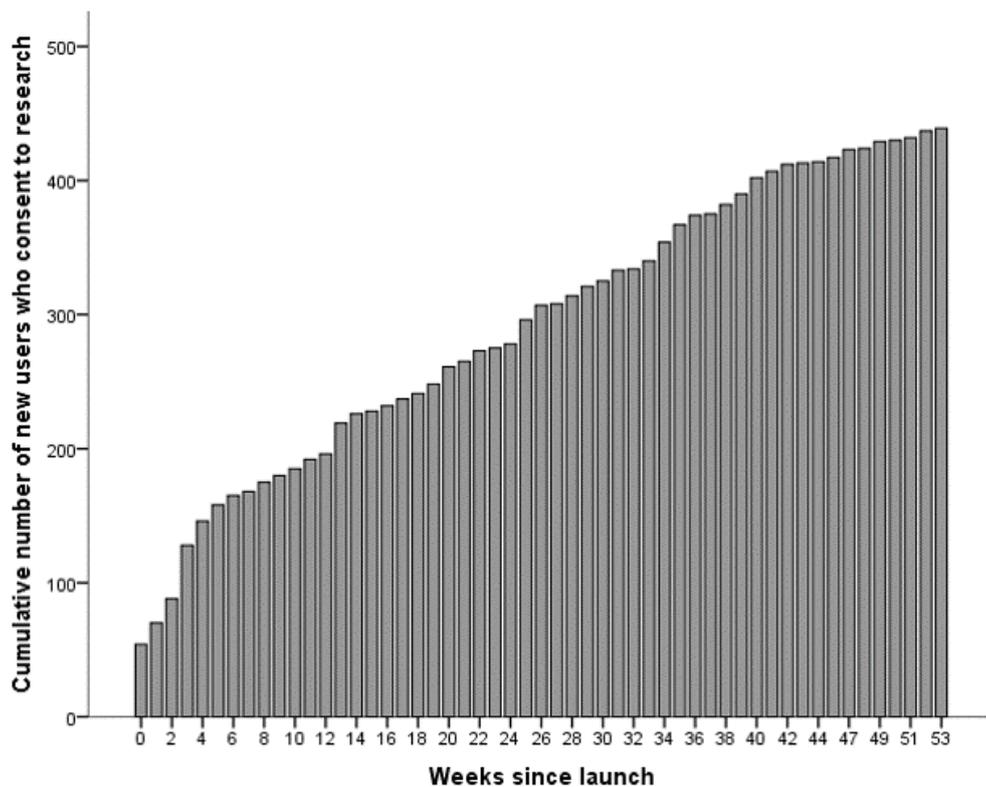
### Relationship of User Characteristics to Questionnaire Selection

As indicated in [Table 3](#), the most commonly chosen questionnaires measured depression (61.0%, 269/441), anxiety (60.5%, 267/441), attachment insecurity (54.2%, 239/441), and coping (46.0%, 203/441). Users' demographic characteristics were associated with the choice to complete or not complete most measures, although these characteristics explained a small portion of the variance in this choice ( $R^2 < .09$ ; [Table 3](#)). The most consistent trend was a lower tendency to complete measures in users with higher income.

The mean Patient Health Questionnaire-9 (PHQ-9) score of 269 Kiosk users who completed the measure of depression (mean 8.4, SD 6.3) was intermediate between previously studied populations [[10](#)] with major depressive disorder (mean 17.1, SD 6.1), other depressive disorder (mean 10.4, SD 5.4), or no depressive disorder (mean 3.3, SD 3.8). The distribution of PHQ-9 score of Kiosk users compared with these previous cohorts is shown in [Table 4](#).

The mean score of 267 Kiosk users who completed a measure of anxiety (GAD-7) was 7.2 (SD 5.1), which was intermediate between patients with generalized anxiety disorder (mean 14.4, SD 4.7) or no generalized anxiety disorder (mean 4.9, SD 4.8) in a previously reported study [[9](#)]. In this study, the distribution of GAD-7 scores was minimal (0-4): 37.8% (101/267), mild (5-9): 39.7% (82/267), moderate (10-14): 22.5% (60/267), and severe (15-21): 9.0% (24/267).

Figure 3. Accumulation of new users of Self-Assessment Kiosk who consent to research.



**Table 2.** Characteristics of 441 users of Self-Assessment Kiosk.

Characteristic	n (%) <sup>a</sup>
<b>Gender (N=437)</b>	
Female	336 (76.2)
Male	89 (20.2)
Other	12 (2.7)
<b>Age in years (N=433)</b>	
Under 30	86 (19.5)
30-50	198 (44.9)
51-65	110 (24.9)
Over 65	39 (8.8)
<b>Education (N=433)</b>	
High school or less	22 (5.0)
Some college, no degree or diploma	39 (8.8)
College diploma or bachelor's degree	132 (29.9)
Graduate or professional degree	240 (54.4)
<b>Income (N=383)</b>	
<\$35,000	68 (15.4)
\$35-75,000	89 (20.2)
\$75-150,000	120 (27.2)
>\$150,000	106 (24.0)
<b>Relationship status (N=427)</b>	
Single	127 (28.9)
Married or common-law	236 (53.5)
Separated or divorced	56 (12.7)
Widowed	8 (1.8)
<b>Country of birth (N=427)</b>	
Canada	367 (83.2)
United States	44 (10.0)
Other	16 (3.7)
<b>Race or ethnicity (N=426)</b>	
Asian	40 (9.1)
Black or African origin	11 (2.5)
White or European origin	336 (76.5)
Hispanic or Latino	6 (1.4)
Aboriginal or Native origin	2 (0.5)
Other	31 (7.1)

<sup>a</sup>Percentage of entire sample (N=441) adds up to less than 100% because of missing data.

**Table 3.** Relationship of user characteristics with choice to complete questionnaires or not.

Dependent variable (questionnaire completed)	n (%)	Odds ratios					Model	
		Gender	Medical diagnosis	Age	Education	Income	R <sup>2</sup>	P value
Depression <sup>a</sup>	269 (61.0)	1.5	0.9	0.9	0.9	0.6 <sup>b</sup>	.08	<.001
Anxiety <sup>c</sup>	267 (60.5)	1.7 <sup>d</sup>	1.0	0.8	0.8	0.8 <sup>d</sup>	.06	<.001
Attachment insecurity <sup>e</sup>	239 (54.2)	1.2	0.7	0.8	1.0	0.7 <sup>f</sup>	.04	.006
Coping <sup>g</sup>	203 (46.0)	1.5	0.8	0.9	1.0	0.7 <sup>f</sup>	.05	.003
Physical activity	177 (40.1)	1.0	0.9	1.1	0.8	0.9	.01	.55
Social support <sup>h</sup>	172 (39.0)	1.3	1.1	1.0	1.0	0.7 <sup>b</sup>	.05	.001
Physical symptoms <sup>i</sup>	165 (37.4)	1.0	0.9	1.0	0.7 <sup>d</sup>	0.8 <sup>d</sup>	.04	.01
Sensitivity to environment <sup>j</sup>	162 (36.9)	1.8 <sup>d</sup>	0.7	0.8	0.8	0.8	.05	.004
Stage of change	162 (36.7)	1.4	1.1	1.1	0.9	0.8	.02	.19
Health anxiety	156 (35.4)	1.4	0.8	0.9	0.8	0.9	.02	.15
Lifetime trauma <sup>k</sup>	148 (33.6)	1.3	1.2	0.9	1.1	0.6 <sup>b</sup>	.07	<.001
Childhood adversity <sup>l</sup>	144 (32.7)	1.2	1.1	0.8	1.0	0.6 <sup>b</sup>	.06	<.001
Alcohol use disorder	144 (32.7)	0.9	1.2	0.9	0.8	0.8	.03	.04
Attention deficit <sup>m</sup>	144 (32.7)	1.3	1.1	0.8	0.8	0.6 <sup>b</sup>	.08	<.001
Overall function <sup>n</sup>	131 (29.7)	1.0	1.1	0.7 <sup>d</sup>	0.7 <sup>d</sup>	0.8	.05	.002

<sup>a</sup>Completion of depression measure associated with lower income.

<sup>b</sup>P<.001.

<sup>c</sup>Completion of anxiety measure associated with female gender and lower income.

<sup>d</sup>P<.05.

<sup>e</sup>Completion of attachment measure associated with lower income.

<sup>f</sup>P<.01.

<sup>g</sup>Completion of coping measure associated with lower income.

<sup>h</sup>Completion of social support measure associated with lower income.

<sup>i</sup>Completion of physical symptom measure associated with lower education and lower income.

<sup>j</sup>Completion of sensitivity to environment measure associated with female gender.

<sup>k</sup>Completion of lifetime trauma measure associated with lower income.

<sup>l</sup>Completion of childhood adversity measure associated with lower income.

<sup>m</sup>Completion of attention deficit measure associated with lower income.

<sup>n</sup>Completion of overall function measure associated with lower education and younger age.

**Table 4.** Distribution of depression scores (PHQ-9) in Self-Assessment Kiosk users compared with other cohorts.

Severity	Self-Assessment Kiosk (N=269), n (%)	Comparison cohorts (from Kroenke [10]), n (%)		
		Major depression (N=41)	Other depressive disorder (N=65)	No depressive disorder (N=474)
Minimal (0-4)	89 (33.1)	1 (2)	8 (12)	348 (73.4)
Mild (5-9)	86 (19.6)	4 (10)	23 (35)	93 (19.6)
Moderate (10-14)	42 (15.6)	8 (20)	17 (26)	23 (4.9)
Moderately severe (15-19)	34 (12.6)	14 (34)	14 (22)	8 (1.7)
Severe (20-27)	18 (4.1)	14 (34)	3 (5)	2 (0.4)

## Proportion of Users Who Complete Multiple Questionnaires

Future studies of relationships between variables in the Kiosk will require studying responses from users who have completed questionnaires that measure each of the constructs involved in the relationship. In general, the more questionnaires that are involved in a relationship, the fewer the number of users who have provided complete information. To explore how large these user subsets might be, and thus how many users must accrue to study multivariable relationships, we calculated the available sample for 2 examples: (1) a study of a hypothesis regarding a relationship between depression, childhood adversity, and health anxiety and (2) a study of a hypothesis regarding a relationship between physical symptoms, harmful alcohol consumption, and attention deficit symptoms.

For the first example, of the 439 users, 61.3% (269/439) completed a measure of depression; of those, 27.8% (122/439) also completed a measure of childhood adversity; and of those, 22.1% (97/439) also completed a measure of health anxiety. For the second example, of the 439 users, 37.6% (165/439) completed a measure of physical symptoms; of those, 25.1% (110/439) also completed a measure of harmful drinking; and of those, 21.9% (96/439) also completed a measure of attention deficit. Thus, in these examples, a moderately complex hypothesis (3 variables) requires up to 2- to 3-fold greater participant accrual for a given sample size requirement than a single-variable study.

## Discussion

### Feasibility

The Self-Assessment Kiosk is a free resource available to the general public. Modest efforts at marketing resulted in a steady accumulation of new users over its first year of availability, such that the rate of new users was close to linear (Figure 1). The consistency of the accumulation of new users suggests that it is feasible to expect continued use of the resource over time.

Users of the Self-Assessment Kiosk tended to complete multiple questionnaires (median 5). Completion of multiple questionnaires allows the Self-Assessment Kiosk database to be interrogated to understand the relationships between variables, for purposes such as hypothesis generation. As users choose whatever combination of surveys that they prefer, assessing relationships between multiple instruments reduces the available sample size of users who have completed all relevant measures. However, 2 examples of 3-variable relationships that we tested indicate that this is a surmountable challenge, in that a 3-variable hypothesis requires just 2 to 3 times the size of Self-Assessment Kiosk users as a 1-variable hypothesis. The availability of sufficient users to test more complex hypotheses essentially depends on the rate of accumulation of new users, which in turn depends on time and marketing effectiveness.

### Characteristics of Users

Analysis of the range of scores of users of the PHQ-9 and GAD-7 indicates that users who select particular instruments tend to have scores that indicate the presence of some symptoms,

although these are less severe, on average, than those found in a clinical cohort. This indicates that users tend to choose instruments that are salient to them. With respect to using the Self-Assessment Kiosk database as a research resource, this introduces selection biases and needs to be taken into account when interpreting results.

### Reliability and Generalizability

The internal reliability of the measures used in the Self-Assessment Kiosk indicates that most instruments have retained the reliability that has been established in pen-and-paper versions when used in this new context. Lower internal reliability of 3 subscales of the coping instrument and 2 subscales of the personality instrument suggest the need for cautious interpretation of the results of these measures and ongoing reassessment of whether alternative measures of these constructs would be more robust for an open internet survey.

There are limits on the generalizability of results of analyses of data from the Self-Assessment Kiosk. Compared with the general population, users of the Kiosk were biased toward female gender, high income and education, and ages between 30 and 50 years. These demographic biases also make the Self-Assessment Kiosk a more appropriate research tool for hypothesis generation than for hypothesis testing. It is noteworthy that greater demographic representativeness may be possible with marketing that targets distribution to a wider population. Additionally, when the number of users is sufficiently large, users can be purposively sampled and stratified to create more representative cohorts.

### Ethical Issues

Ethical issues regarding the potential for harm were carefully considered before releasing the Self-Assessment Kiosk, including review by the Research Ethics Board of our institution. Related concerns about perceived legal liability were also considered and discussed with legal counsel. Issues considered and the remedies that were applied included the following. First, we considered the potential for harm when sensitive psychological information is provided to people without knowledge of their access to health and mental health services. This concern is balanced against the potential value of putting information about mental and physical health (which, by definition, is already known to a person who completes a self-report measure) into the context of established norms and correlations, which may provide either reassurance or motivation to seek treatment. Second, we specifically considered the related risk that asking about experiences of trauma could be retraumatizing or “triggering” in some circumstances. This concern was dealt with through informed consent, by providing explicit trigger warnings with options to skip trauma questionnaires (even after choosing these questionnaires in the menu) and allowing users to skip individual questions. Third, we considered the professional ethical imperative not to provide diagnostic assessment for people in the absence of psychiatric or psychological assessment. Diagnosis is not possible in the absence of professional evaluation and is not the intent of the Kiosk. This limit is clearly stated in disclaimer messages provided before collecting any information from Kiosk users and repeated when feedback is provided. The author of 1

instrument declined permission to use that instrument based on the concern that measurement in the absence of a professional relationship was deemed to fall short of professional ethical requirements, indicating that there is a range of opinions about this choice. Fourth, we considered the potential for harm as a result of an information breach of a database containing personal health information. This concern was dealt with by designing the Kiosk to provide all of its functions to users who remain

anonymous and through informed consent with respect to the residual risk.

### Summary

The Self-Assessment Kiosk demonstrates the feasibility of a low-cost, automated internet resource to provide a personalized menu of valid psychological measures with feedback to users. The data that users provide can serve as a rich source of investigation for the purposes of generating hypotheses and pilot data.

### Acknowledgments

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### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Advertising of the Self-Assessment Kiosk.

[[PDF File \(Adobe PDF File\), 301KB - mental\\_v5i2e39\\_app1.pdf](#)]

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## Abbreviations

- ADHD:** attention deficit and hyperactivity disorder
- CAMH:** Centre for Addiction and Mental Health
- ENRICHD:** Enhancing Recovery in Coronary Heart Disease
- GAD:** generalized anxiety disorder
- PHQ:** Patient Health Questionnaire
- WHO:** World Health Organization

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Original Paper

# A Smart Screening Device for Patients with Mental Health Problems in Primary Health Care: Development and Pilot Study

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## Abstract

**Background:** Adequate recognition of mental health problems is a prerequisite for successful treatment. Although most people tend to consult their general practitioner (GP) when they first experience mental health problems, GPs are not very well equipped to screen for various forms of psychopathology to help them determine clients' need for treatment.

**Objective:** In this paper, the development and characteristics of *CATja*, a computerized adaptive test battery built to facilitate triage in primary care settings, are described, and first results of its implementation are reported.

**Methods:** *CATja* was developed in close collaboration with GPs and mental health assistants (MHAs). During implementation, MHAs were requested to appraise clients' rankings (N=91) on the domains to be tested and to indicate the treatment level they deemed most appropriate for clients before test administration. We compared the agreement between domain score appraisals and domain score computed by *CATja* and the agreement between initial (before test administration) treatment level advice and final treatment level advice.

**Results:** Agreements (Cohen kappas) between MHAs' appraisals of clients' scores and clients' scores computed by *CATja* were mostly between .40 and .50 (Cohen kappas=.10-.20), and the agreement between "initial" treatment levels and the final treatment level advised was .65 (Cohen kappa=.55).

**Conclusions:** Using *CATja*, caregivers can efficiently generate summaries of their clients' mental well-being on which decisions about treatment type and care level may be based. Further validation research is needed.

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**KEYWORDS**

screening; primary health care; psychopathology; triage

## Introduction

**Background**

Mental well-being is fundamental to the functioning of communities and nations. However, the World Health Organization states that "[...] many people with mental health

problems do not receive the treatment and care they need, despite the development of effective interventions" [1]. Matching the level of provided care to the client's need for care is a difficult task because many factors have to be balanced simultaneously. Clients want access to the best care, but working hours of practitioners and clinicians are limited, and the interest

of society is to keep care affordable. To reconcile these conflicting interests, various models of care have been proposed.

In the Netherlands, the structure of mental health care most closely resembles a stratified model, where “the initial treatment is selected based on the client’s treatment needs” [2]. The lowest level of mental health care is provided in general practices. Dutch general practitioners (GPs) are supported by mental health assistants (MHAs) who have a background in psychology, psychiatric care, or social work. MHAs are capable of treating light and or stable mental problems, and they can help to link clients to social care agencies for housing, employment, and or debt counseling. To get access to either generalist or specialist mental health care providers, clients need a referral from their GP. MHAs advise GPs on whether clients should be treated in general practices or whether they should be referred to either generalist or specialist mental health care providers. We use the term triage here to label the decision process just described.

### Aims of This Study

Psychological tests and questionnaires have long been used to provide valuable information to guide mental health care interventions. In this paper, a Web-based computerized adaptive test (CAT) battery (named *CATja*) is described that was specifically designed to screen clients in general practices for various forms of psychopathology, thereby facilitating triage. The construction of items banks [3-5] and the derivation of parameter estimates for these item banks have been described elsewhere [6-9]. In this study, we describe the development of *CATja* and report first results of a pilot study where MHAs implement the tool in daily practice.

## Methods

### Developmental Approach

Autonomy plays a crucial role in a person’s motivation, especially for those who are mainly intrinsically motivated [10]. Adopting *CATja* would require the MHAs to change their working routine in many ways, and because the best way to promote change is to provide those who are supposed to change with feelings of ownership of the new situation [11], we included MHAs in the developmental process. In addition, their expertise was highly valued. We organized regular meetings where we inventoried the opinions and ideas of MHAs and where we gave specific recommendations (such as testing adaptively to tap a broad range of constructs efficiently or how to safeguard clients’ privacy). Furthermore, these meetings enabled us to judge whether our plans would be supported. An important contribution by the MHAs was that we should not focus solely on deficiencies (eg, psychopathology), but should also pay attention to clients’ strengths (eg, positive psychological constructs). In addition, MHAs had a strong preference for blended care (ie, a combination of e-assessment and face-to-face interview). Besides the scores on various dimensions, each client is uniquely characterized by a specific combination of situational and environmental factors (eg, life events, motivation to change). Information on all these characteristics that make individuals unique was preferred to be obtained in face-to-face interviews. Furthermore, because a significant proportion of clients are treated by MHAs and the relationship between therapist and

client is crucial for successful treatment [12], time spent on getting this auxiliary information during personal sessions is still spent in a valuable way, because these conversations probably strengthen the relationship between client and MHA.

### Computerized Adaptive Testing

In CAT, items that are presented to respondents are tailored to responses given to previous items. With each consecutive item, an updated person score is derived, and the item that increases measurement precision maximally for this score is used next. This process usually continues until a predefined measurement precision is reached. In CATs, much less items are needed to derive reliable scores compared with assessments with traditional questionnaires. For an introduction to CAT, see the study by Meijer and Nering [13].

### Content of the Alpha Version of CATja

The domains of psychopathology available in the alpha version were chosen based on (1) high prevalence in the target population (anxiety and depression), (2) the explicit wish of the envisioned end users (distress), and (3) severity of functional impairment (positive and negative symptoms of psychosis). Five psychopathology domains are currently available: anxiety and depression using the Patient Reported Outcome Measures Information System (PROMIS) item pools [9], positive and negative symptoms of psychosis based on the Prodromal Symptom Questionnaire [6], and the distress scale of the Four-Dimensional Symptom Questionnaire [7]. In addition, MHAs can assess the domains companionship and emotional support, using PROMIS item pools [8]. Thus, contrary to many existing eHealth screening tools [14], *CATja* incorporates domains of positive psychology as well as more severe symptoms of psychopathology (eg, hallucinations), and only uses items that are appropriate for a given client because of its adaptive testing routine.

### Sample Characteristics

We recruited MHAs by contacting Primary Care Consultants Northern Netherlands (ELAN), an organization that advises GPs in the north of the Netherlands on eHealth advancements. Four MHAs participated in the pilot study, and they assessed 31 MHAs’ clients in total (23 females). Clients were informed that their responses would be stored anonymously for research purposes, and they provided informed consent for this by selecting the hyperlink provided in the email that was sent to them by their MHAs. On average, clients were aged 30 years and 6 months (SD 12.2). All clients had achieved a high school degree, 3 graduated in applied sciences, and 3 graduated from university. With respect to relationship status, 9 clients chose the response option “living apart together,” 11 were living together, and another 11 clients reported to be single. Moreover, 12 clients reported to be still following education, 6 were looking for work, 4 were working part-time, and 9 were working full-time.

### Statistical Analyses

To get a first impression on how implementing *CATja* would change the information available to MHAs and how their decisions concerning clients’ triage would be affected, we did the following. For each domain on which clients were to be

tested, we asked MHAs to estimate clients' quartile scores before administering *CATja*. These estimates were compared with the quartile scores computed by *CATja*. In addition, we requested MHAs to appraise expected treatment levels before testing their clients with *CATja* and to report final treatment levels advised after testing. We compared these initial and final treatment levels. The questionnaire used can be found in [Multimedia Appendix 1](#). For all domains and treatment level advised, we computed coefficients of agreement.

## Results

The alpha version of *CATja* consisted of 3 interfaces (see [15]). When the domains and constructs to be assessed have been chosen, an invitation is sent to the client by email, which contains a hyperlink that leads to *CATja*'s test administration interface. In this email, the client is informed that some information on their demographic background will be requested, and that their answers will be stored anonymously for research purposes. When responding, clients can change answers given to previous items, and revised scores are calculated. When finished, a report is automatically generated and sent to the MHA. In this report, several concepts that are essential for correct interpretation of the report are explained: the norm groups that served as reference for scores, the concept of quartiles ( $Q_i$ ), and the meaning of quartiles for psychopathology domains and positive psychological domains. For all psychopathology domains, low scores ( $Q_1$  and  $Q_2$ ) are indicative of healthy functioning, whereas for companionship and

emotional support, high scores ( $Q_3$  and  $Q_4$ ) indicate healthy functioning. The main part of the report consists of a table with quartile scores for the domains administered. All items presented are given together with the response options chosen by the client at the end of the report.

Not all clients were tested on all domains; the number of subjects on which agreement could be based varied from 2 for negative symptoms of psychosis to 16 for anxiety and depression. In [Table 1](#), the cross-tabulation of the quartile scores estimated by MHAs and the quartile scores computed by *CATja* is shown.

In 31 of 91 cases, clients' scores estimated by MHAs before test administration and clients' scores as computed by *CATja* were identical. The proportion of agreement equaled .35 (weighted kappa=.14). In case appraisals by MHAs and quartiles given by *CATja* were not congruent, MHAs' appraisals were typically higher than quartiles computed by *CATja*. This trend was present only for the domains of psychopathology, not for the domains companionship and emotional support. Furthermore, agreement seemed to depend on the homogeneity of domain content. That is, agreement for the distress domain (2/15=.13) was lower than for anxiety (7/16=.44), depression (8/16=.50), and emotional support (6/14=.43). In 7 of 11 cases (weighted kappa=.57), the initial judgment of treatment level to be advised to clients and the final advice (after test administration) of treatment level were in agreement. In case of disagreement, initial treatment levels were always higher than final treatment levels advised to clients.

**Table 1.** Agreement between clients' quartile scores appraised by mental health assistants before test administration and quartile scores computed by *CATja* (all domains and constructs).

Quartile estimated by MHA <sup>a</sup>	Quartile <i>CATja</i>			
	Q1	Q2	Q3	Q4
Q1	5	3	1	0
Q2	13	8	10	2
Q3	10	8	16	1
Q4	5	2	3	2

<sup>a</sup>MHA: mental health assistant.

## Discussion

The first results for the new screening device are promising, because the information obtained with it seems to add useful information to existing practice. Psychopathology domain scores as appraised by MHAs before test administration usually were higher than the domain scores reported by *CATja*. Furthermore, with respect to the treatment level advice, in case of no agreement, final treatment levels recommended to clients were always lower than the initial appraisals (before test administration). A tentative explanation for these findings would be that MHAs use the knowledge of the scores reported by *CATja* to lower the treatment levels they advise their clients. Under the assumption that the psychopathology domain scores computed by *CATja* are better estimates than the psychopathology domain scores appraised by MHAs,

implementing *CATja* to determine the treatment level to be advised to clients would lead to less referrals to more specialized mental health care. Note that this preliminary finding, which would imply cost reduction, is opposite to what has been reported for other triage tools [16]. This result should be further tested in a study that includes many more clients in a randomized controlled treatment design where half of the participating MHAs use *CATja* and the other half does not. For all cases in which clients are referred to either generalist or specialist health care services, caregivers could be requested to rate the appropriateness of the referrals. On average, referrals for which *CATja* was used should be judged as more appropriate than those in the control condition. Another criterion for the incremental value of *CATja* would be to request clients to judge the degree to which they think their condition did improve since they contacted their GP.

## Acknowledgments

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Client form: Clients' domain scores estimated by MHAs and MHAs' appraisals of expected treatment levels.

[[PDF File \(Adobe PDF File\), 39KB - mental\\_v5i2e41\\_app1.pdf](#)]

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## Abbreviations

**CAT:** computerized adaptive testing

**GPs:** general practitioners

**MHAs:** mental health assistants

**PROMIS:** Patient Reported Outcome Measures Information System

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Original Paper

# Preliminary Evaluation of a Web-Based Psychological Screening Tool in Adolescents Undergoing Minimally Invasive Pectus Surgery: Single-Center Observational Cohort Study

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## Abstract

**Background:** Preoperative anxiety and depression are predominant risk factors for increased postoperative pain. Thoracic wall deformities in adolescents often cause low self-esteem, which contributes to psychological concerns. Several studies have suggested a relationship between preoperative mental health support and enhanced recovery after surgery.

**Objective:** This study investigated the validity of screening questionnaires concerning psychological trait and state characteristics via a patient-specific online platform.

**Methods:** Patients scheduled for elective pectus surgery between June 2017 and August 2017 were invited to participate in clinical interviews and online self-report questionnaires. All patients were recruited in the Anesthesiology Department, Antwerp University Hospital, Belgium. This single-center observational cohort study was performed in accordance with the ethical standards of the International Council for Harmonisation–Good Clinical Practice guidelines and the Declaration of Helsinki after obtaining study approval by the Institutional Review Board and Ethics Committee of the Antwerp University Hospital, Belgium (study identifier: 17/08/082). An online preoperative psychological inventory was performed using the Rosenberg Self-Esteem Scale, Hospital Anxiety and Depression Scale, and State-Trait Anxiety Inventory. Postoperatively, pain intensity and interference were assessed using the Multidisciplinary Pain Inventory, Coping With Pain Questionnaire, and numeric pain rating scale assessment. Patient satisfaction of the Web-based platform was evaluated.

**Results:** A total of 21 adolescent patients used our Web-based psychological perioperative screening platform. Patients rated the mobile phone app, usability, and accessibility of the digital platform as good or excellent in 85% (17/20), 89% (17/19), and 95% (20/21) of the cases, respectively. A total of 89% (17/19) of the patients rated the effort of generating answers to the online questionnaires as low. The results from the completed questionnaires indicated a strong negative correlation between self-esteem and the anxiety trait ( $R=-0.72$ ,  $P<.001$ ) and overall anxiety characteristics ( $R=-0.49$ ,  $P=.04$ ). There was a positive correlation between depressive and anxiety characteristics and the anxiety trait ( $R=0.52$ ,  $P=.03$  and  $R=0.6$ ,  $P=.02$ , respectively) measured by the online self-report questionnaires. Moreover, preoperative anxiety was positively correlated with postoperative pain interference ( $R=0.58$ ,  $P=.02$ ). Finally, there was a negative correlation between self-esteem and pain interference ( $R=-0.62$ ,  $P=.01$ ). Conclusions: Perioperative screening of psychological symptoms and trait characteristics with specific treatment, if necessary, could further improve postoperative pain and overall health status. Research on eHealth technology, even for psychological patient care, is rapidly increasing.

**Trial Registration:** ClinicalTrials.gov NCT03100669; <https://clinicaltrials.gov/ct2/show/NCT03100669> (Archived by WebCite at <http://www.webcitation.org/6zPvHDhU5>)

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**KEYWORDS**

mental health; telemedicine; pectus carinatum; funnel chest

## Introduction

Pectus excavatum and carinatum occur in 1 of 400 to 1000 children, with a 4:1 male-to-female predominance [1]. Many patients experience aesthetic challenges and even a compromised self-esteem during the vulnerable phase of puberty. Surgery is more often planned for aesthetic reasons than a necessary correction due to compression of underlying organs. Although minimally invasive repair of pectus (MIRP) has become common practice because of surgical stress response reduction, less blood loss, and a smaller incision, it still remains associated with severe postoperative pain. Moreover, the intensity of postoperative pain following MIRP has been shown to be the overriding factor in a patient's perception of the quality of the postoperative period. The fact that many adolescents experience moderate to severe pain for the first time and develop a new dependence on their parents further contributes to their decreased well-being after the surgical procedure. Many investigators have shown that preoperative psychosocial factors such as anxiety further increase postsurgical pain [2-4].

Recently, several authors assessed quality of life and self-esteem following surgical pectus repair [5-7]. Not surprisingly, adolescents with a chest wall deformity have lower self-esteem and higher anxiety or even depressive characteristics than healthy controls. Moreover, children and parents experience surgery as a stressful period and often feel underprepared for the operation, postoperative pain, and recovery. Many of them reported an interest in perioperative psychosocial screening. Previous research by Rabbits et al [8] showed that health care providers agree that families would benefit from enhanced coping skills. Therefore, investigators have proposed a flexible screening tool to examine anxiety and dysfunctional coping strategies in children undergoing major surgery [8].

Little research has been conducted on the influence of preoperative psychological questionnaires on postoperative pain via eHealth services. With such services, patients and their

relatives can complete questionnaires when and where they want, making participation less demanding. Even more, caregivers can introduce mental health screening before surgery as part of the surgical care.

The primary aim of the study was to develop and implement a Web-based patient platform for preoperative psychological yellow flag screening and early identification of risk factors for subacute or persistent postoperative pain. In addition, the applied screening battery was evaluated for usefulness in adolescents undergoing elective pectus surgery and feasibility for online questionnaire completion.

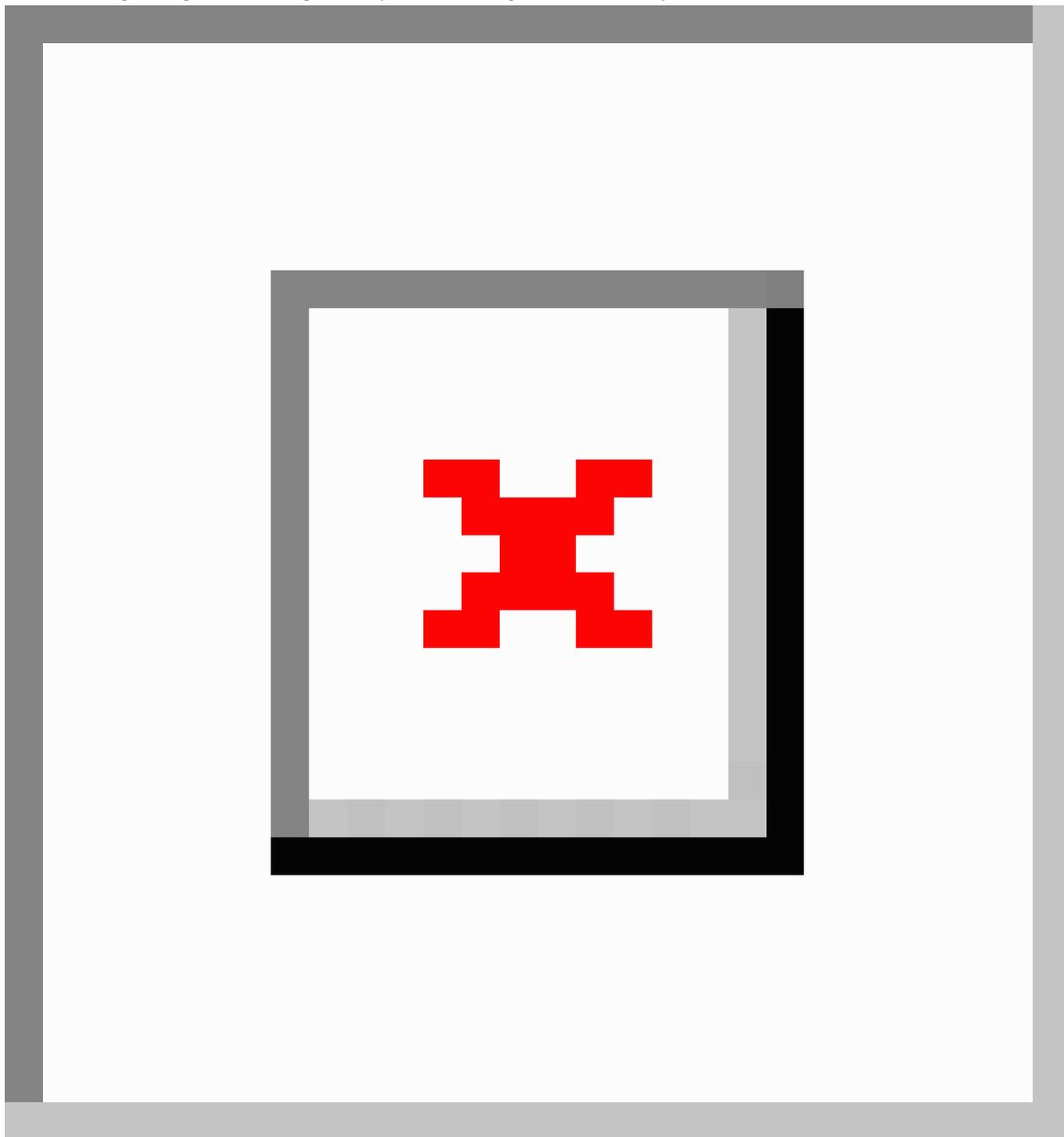
Psychological variables and their relationship with postoperative outcome parameters such as persistent, subacute pain were assessed. Finally, self-esteem was evaluated, being an important indirect factor contributing to persistent pain via the development of anxiety, depression, or maladaptive coping strategies.

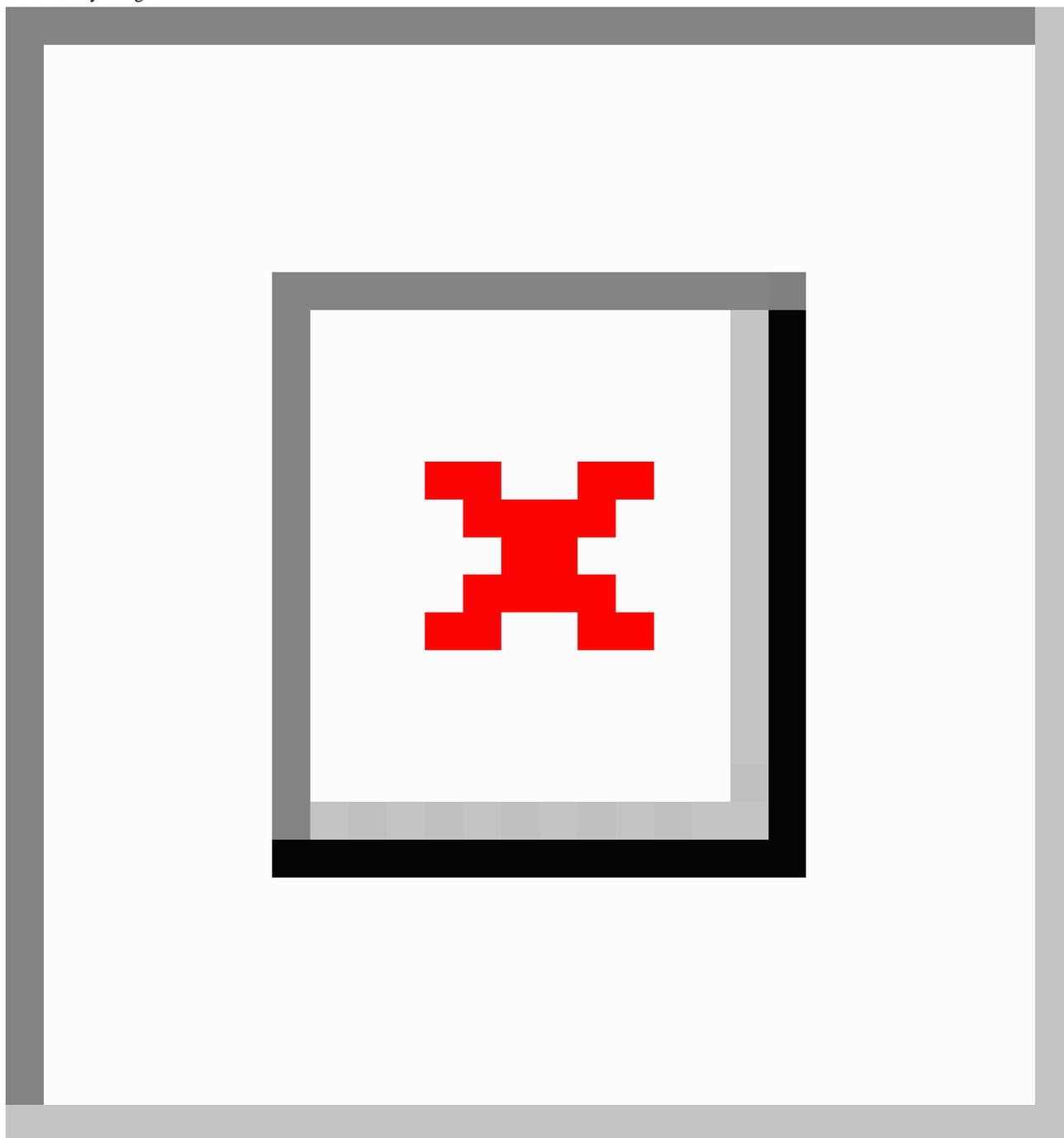
## Methods

### Recruitment

A total of 22 patients were scheduled for elective pectus surgery during summer holidays (June to August 2017) and were invited for clinical interviews and to complete online self-report questionnaires. All patients were recruited in the Anesthesiology Department, Antwerp University Hospital, Belgium (Figure 1). This single-center observational cohort study was performed in accordance with the ethical standards of International Council for Harmonisation–Good Clinical Practice and the Declaration of Helsinki after obtaining study approval by the Institutional Review Board and Ethics Committee of the Antwerp University Hospital, Belgium (study identifier: 17/08/082). Patients with a history of psychiatric disease, chronic opioid use (more than 3 months), or revision surgery were excluded. No single patient reported clinically relevant preoperative pain symptoms.

**Figure 1.** Flow diagram of patient screening and study inclusion during the summer holidays of 2017.



**Figure 2.** Study design.

Analyses of variance revealed no significant differences between pectus excavatum and pectus carinatum patients with respect to age or body mass index. The Haller index for defining the severity of the deformity in pectus excavatum patients based on computed tomography (CT) varied from 3.00 to 7.00 (mean 3.59 [SD 1.47]; median 3.00 [95% CI 2.24-4.95]) in the 50% of pectus excavatum patients who had CT performed. The mean age of the subjects was 14.82 (SD 1.30) years, and the majority of the participants (20/21, 95%) were men; 90% (19/21) were not the only child in the family, and 52% (11/21) had a high education level (general secondary education–high school). [Figure 2](#) shows a flowchart of the study.

### Web-Based Platform

To provide patients with an individualized approach, we developed an electronic medical record coupled with a set of questionnaires. The Antwerp Personalized Pain Initiative app (Appi@home, see [Figures 3](#) and [4](#)) supports an innovative approach by offering an online platform. Patients are provided with a unique code that allows them to fill out the preselected questionnaires. In addition, the patient becomes an active participant in the global preventive and further therapeutic approach, if necessary.

## Preoperative Psychological Assessments

### *State-Trait Anxiety Inventory*

The State-Trait Anxiety Inventory (STAI) Form Y is an instrument used to assess state and trait anxiety. State anxiety is defined as fear, nervousness, and discomfort temporarily induced by situations perceived as dangerous or threatening in which the autonomic nervous system is activated. State anxiety can vary in intensity and change over time. Trait anxiety involves rather stable individual differences in the predisposition to experiencing fear, stress, and discomfort. People with high trait anxiety characteristics will experience certain situations as more threatening or dangerous than people with low trait anxiety. In this study, the Dutch version (STAI-version-DY-2) was used. This 20-item scale is designed to assess pervasive feelings of trait anxiety. Items are rated by respondents on a 4-point Likert-type scale. Higher scores indicate higher levels of anxiety, and norm tables are available for different groups. The STAI-version-DY-2 has demonstrated acceptable internal consistency ( $\alpha > .85$ ) and 1-month test/retest reliability ( $r > .70$ ) in adolescents, healthy adults, and military samples [9]. Van Der Ploeg et al [10] developed a Dutch translation [11].

### *Hospital Anxiety and Depression Scale*

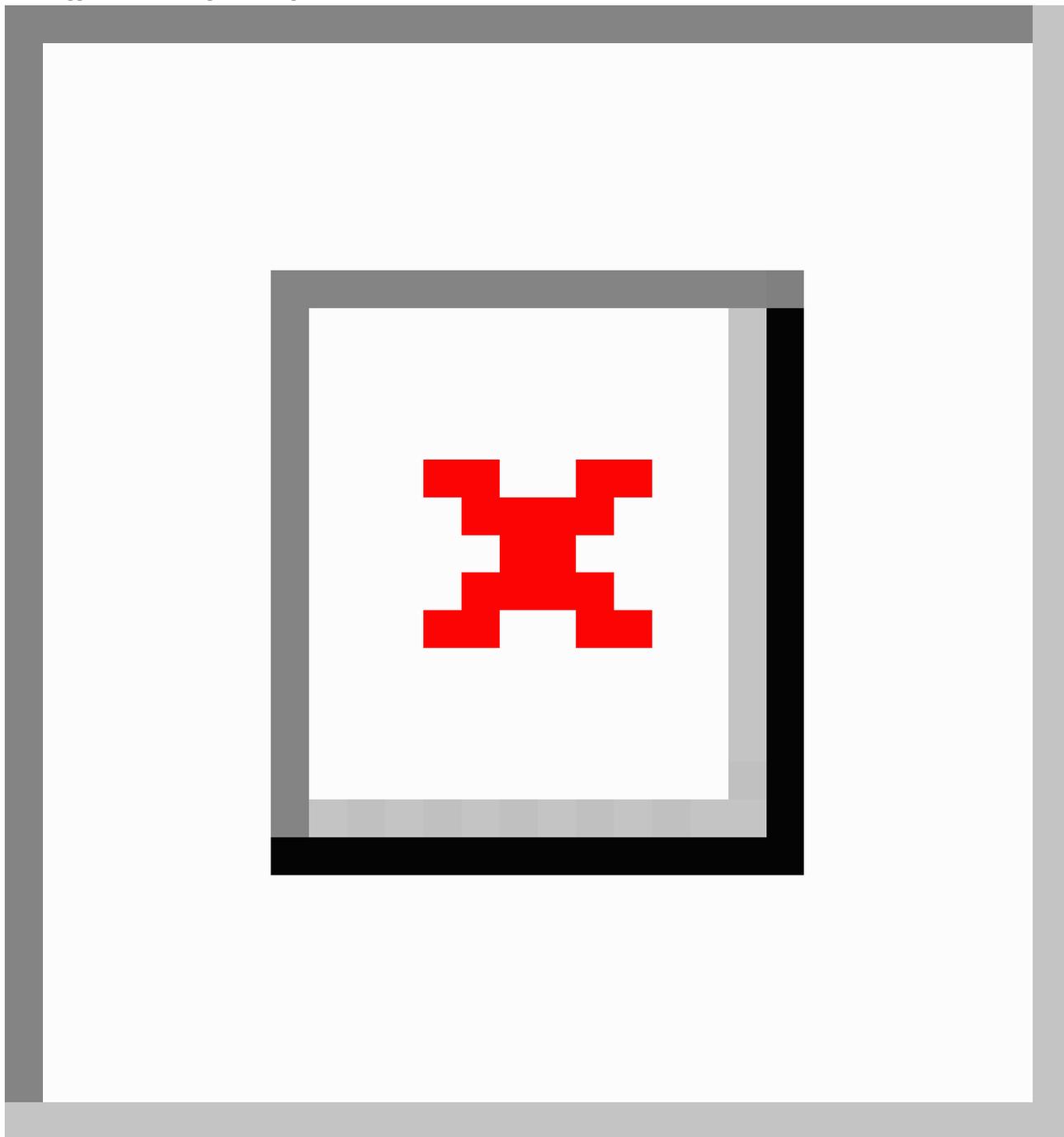
The Hospital Anxiety and Depression Scale (HADS) has been developed to detect states of depression and anxiety in a hospital setting. It assesses core components of anxiety and depression without involving physical complaints. The questionnaire has 2 subscales, anxiety and fear, and each subscale consists of 7

items. Higher scores indicate more emotional complaints. Cutoff scores are available for quantification. For each subscale, a score of 8 or greater is associated with possible anxiety or depression. A score of 11 or greater is associated with probable anxiety or depression. The questionnaire was developed as a screening tool and can exclude but not assess emotional disorders [12,13]. The basic psychometric properties of the HADS as a self-rating instrument should be considered quite good in terms of factor structure, intercorrelation, homogeneity, and internal consistency [14]. Spinhoven et al [15] validated a Dutch version that was used in this study.

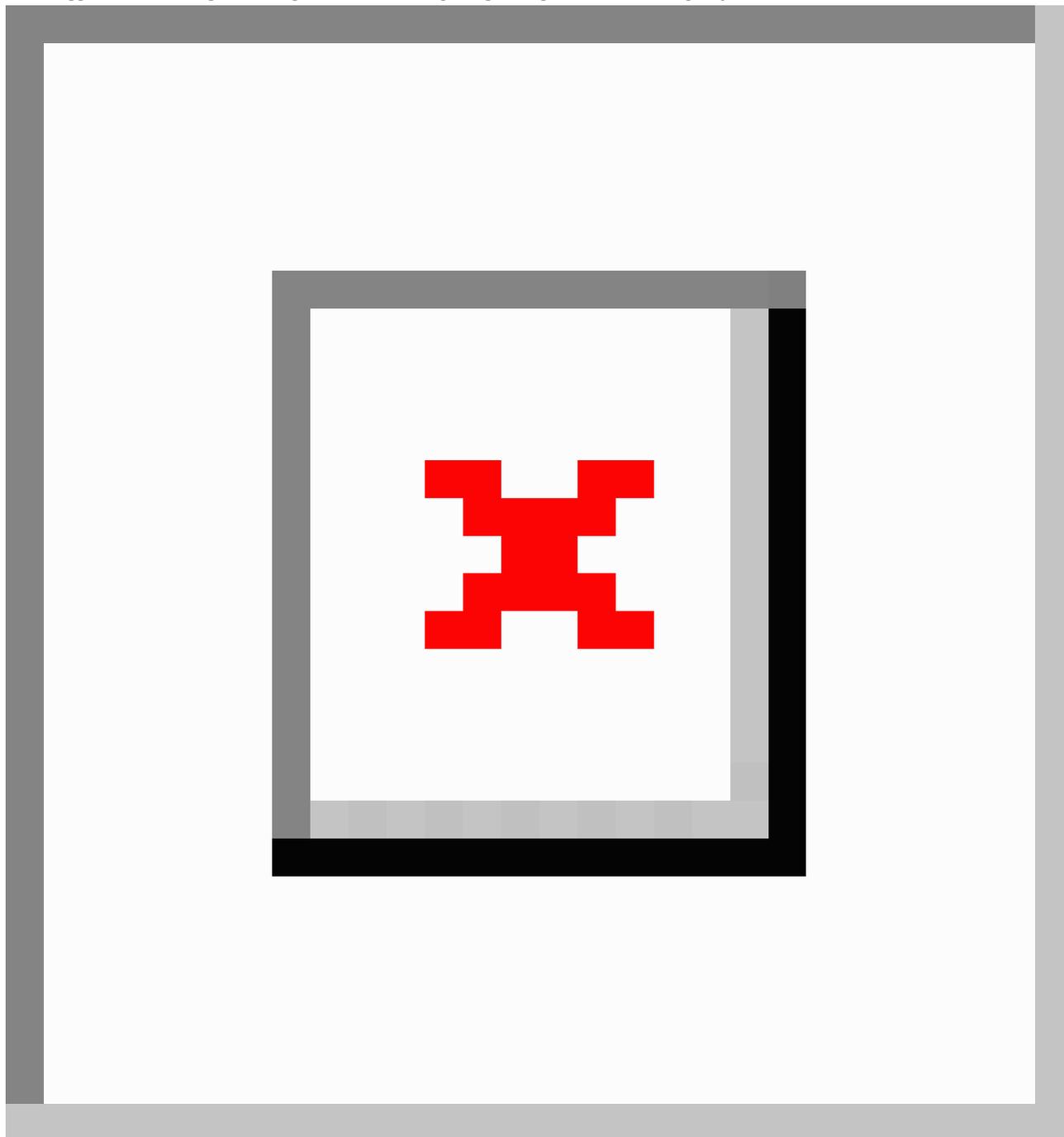
### *Rosenberg Self-Esteem Scale*

The Rosenberg Self-Esteem Scale (RSES) is a self-report measure for self-esteem containing 10 items that was constructed for the investigation of a person's feelings about themselves in terms of self-confidence and intrinsic value. Self-esteem is an important measure for screening problems of social adaptation and predicting mental health problems. Items are rated by respondents on a 4-point Likert-type scale [16]. We used 2 scoring procedures for optimal interpretation of our results. The total score ranges from 0 to 30 according to the first procedure and from 10 to 40 according to the second procedure. The higher the total scores, the higher the level of self-esteem. Franck et al [17] developed the Dutch translation and evaluated the psychometric properties. The results showed high internal consistency and high congruent validity. Their findings support the usefulness of the Dutch RSES as a measure of self-esteem [17].

Figure 3. Appi@home online platform—patient view.



**Figure 4.** Appi@home online platform—provider view listing completed questionnaires (Vragenlijsten).



## Postoperative Psychological Assessments

### *Multidimensional Pain Inventory*

Kerns et al [18] applied cognitive behavioral concepts on chronic pain and developed the (West Haven–Yale) Multidimensional Pain Inventory (MPI). This questionnaire assesses different pain-relevant aspects. The subjective characteristic of pain and the consequences on different aspects of the patient's life are the main objectives of the questionnaire [18]. Lousberg et al [19] developed a Dutch version of the questionnaire (MPI-DVL). The MPI-DVL consists of 61 items, ordered in 3 parts. The first part, used by the authors to assess the psychosocial aspects of pain, consists of 5 subscales: pain severity, interference, life control, affective distress, and social support. Items are rated

by respondents on a 7-point Likert-type scale. The authors evaluated the psychometric properties of the Dutch version, and their results showed good reliability and validity [19]. In this study, the first 2 subscales (pain severity and interference) are used for data analyses.

### *Coping With Pain Questionnaire*

The Coping Strategy Questionnaire (CSQ) is an instrument developed to assess the coping strategies people use when experiencing pain. Research has shown that people develop their own coping style resulting from past experiences with pain and a general coping style for difficult situations. This instrument contains 44 items designed to evaluate 8 strategies for coping with pain (reinterpreting pain sensations, using coping

self-statements, ignoring sensations, diverting attention, praying/hoping, catastrophizing, increasing behavioral activities, and exhibiting pain behaviors). The perceived effectiveness of the coping efforts was assessed with 2 items: control over pain and the ability to decrease pain [20]. Spinhoven et al [21] developed the Dutch version of the CSQ, the Coping With Pain Questionnaire (CPQ), which is slightly different. The CPQ contains 44 items in 8 subscales (diverting attention, reinterpreting pain sensations, using coping self-statements, ignoring pain sensations, praying/hoping, catastrophizing, increasing behavioral activities, and perceiving control over pain). The respondent answers questions on a visual analog scale (VAS) for the CPQ instead of a 7-point Likert-type scale (for the CSQ). The respondents indicate how often they use a specific coping behavior by putting a line on a 10-cm-long line with end points defined as “I never do that” and “I always do that.” The psychometric properties of the instrument are good [21]. CPQ active and passive coping indices were calculated according to the method described by Soares and Grossi [22] and Nicholas et al [23]. The scores of 5 subscales (diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, and increasing behavioral activities), which reflect active coping, were calculated to determine an active coping index. Two scales (catastrophizing, praying/hoping) that refer to passive coping were used to create a passive coping index. The subscale that assessed perceived control over pain was the self-efficacy index [22,23].

### Numerical Rating Scale

The numerical rating scale (NRS) is an 11-point scale used for pain assessment. Self-report by a patient is considered the gold standard for pain intensity measurement. Caregivers familiar with communicating with patients in pain asked the patient how much pain they had suffered from in the previous 24-hour period. All patients were educated in pain rating, where 0

represents “no pain” and 10 represents “the worst pain possible,” using whole numbers. The mean score after the first 5 postoperative days was calculated [24]. Patients continued the pain intensity registration through the platform until completion of the postoperative questionnaires, 7 days after hospital discharge.

### Daily Activity and Patient Mobility

Patients were assessed according to their mobility and daily activity by the attending physiotherapist. Every patient was given a daily score based on the exercise executed as part of the rehabilitation process after surgery during hospitalization. Scores ranged from 1 (exercise in the supine position), 2 (sitting), 3 (standing), to 4 (walking).

### Statistical Analysis

A paired sample *t* test was used to assess differences in RSES bifactor questionnaire scoring after data normality assessment with the Shapiro-Wilk test. Associations between questionnaire scores were determined with a Spearman correlation coefficient. Statistical analyses were performed with SPSS Statistics software (IBM Corp). Statistical significance was considered when  $P < .05$ .

## Results

### Patient Demographics and Questionnaire Responses

The demographic patient characteristics are presented in Table 1. Eighteen adolescents completed the preoperative questionnaires, and 16 fully completed the postoperative questionnaires (Table 2). Furthermore, from the raw CPQ data, coping subscales were calculated to score the pectus patients on 3 coping categories (active coping strategy, passive coping strategy, and self-efficacy).

**Table 1.** Sociodemographic characteristics (N=21).

Characteristic	Result
Type of deformity, n, PE <sup>a</sup> : PC <sup>b</sup>	15:6
Gender, n, male: female	20:1
Age, years, mean (SD)	14.81 (1.33)
Height, cm, mean (SD)	173.67 (8.88)
BMI <sup>c</sup> , kg/m <sup>2</sup> , mean (SD)	18.44 (2.03)

<sup>a</sup>PE: pectus excavatum.

<sup>b</sup>PC: pectus carinatum.

<sup>c</sup>BMI: body mass index.

**Table 2.** Anxiety and depression characteristics, self-esteem rating, multidimensional pain questionnaire results, and coping with pain evaluation via eHealth technology.

Questionnaire	Score, mean (SD)
HADS <sup>a</sup> fear	6.11 (3.27)
HADS depression	3.50 (2.81)
STAI <sup>b</sup>	37.94 (6.88)
RSES <sup>c</sup>	21.56 (3.55)
<b>MPI<sup>d</sup></b>	
Pain severity	1.88 (0.78)
Pain interference	3.20 (0.69)
<b>CPQ<sup>e</sup> (raw data)</b>	
Diverting attention	3.88 (2.05)
Reinterpreting pain sensation	23.29 (12.30)
Catastrophizing	9.59 (8.42)
Ignoring pain sensation	25.18 (12.69)
Praying/hoping	23.47 (14.64)
Coping self-statements	38.94 (12.12)
Increasing behavioral activities	21.71 (9.84)
Perceiving pain control	11.59 (4.65)
<b>CPQ subscale</b>	
Active coping score (raw data)	23.52 (7.41)
Passive coping score (raw data)	16.53 (9.22)
Self-efficacy score (raw data)	11.59 (4.65)

<sup>a</sup>HADS: Hospital Anxiety and Depression Scale.

<sup>b</sup>STAI: State-Trait Anxiety Inventory.

<sup>c</sup>RSES: Rosenberg Self-Esteem Scale.

<sup>d</sup>MPI: Multidimensional Pain Inventory.

<sup>e</sup>CPQ: Coping With Pain Questionnaire.

## Detailed Questionnaire Data

### *Hospital Anxiety and Depression Scale*

The HADS fear subscale indicated the presence of an anxiety disorder. The overall mean score was 6.11 (SD 3.27). The mean score ranged from 0 to 7, which indicated the absence of anxiety states prior to surgery. Thirteen patients scored between the range of 0 to 7 (no anxiety), 3 patients scored between the range of 8 to 10 (possible anxiety), and 2 patients scored in the range of 11 or higher (probable anxiety).

The HADS depression subscale indicated the presence of a depressive disorder. The overall mean score was 3.50 (SD 2.81). This mean score ranged from 0 to 7, which indicated the absence of depressive states prior to surgery. Sixteen patients scored between the range of 0 to 7 (no depression), and 2 patients scored between the range of 8 to 10 (possible depression).

### *State-Trait Anxiety Inventory*

The DY-2 version of the STAI measured trait anxiety. The overall mean score of the study sample was 37.94 (SD 6.88).

Compared with available data on controls (normal group of male military recruits approximately 18 years old), the overall mean score was in decile 6 indicating a mean level of anxiety.

### *Rosenberg Self-Esteem Scale*

The RSES is a measure of global self-esteem. The mean score of the overall patient sample was 21.56 (SD 3.55) and was above the theoretical midpoint of 15. No single patient scored beneath this cutoff. The results can be compared with the data from the study by Schmitt and Allik [25], in which self-esteem levels were compared across 53 nations. The mean scores of this study sample were above the Belgian mean level of 19.66 (SD 5.28). The results of this study sample were higher than the average level of global self-esteem.

### *Multidimensional Pain Inventory*

The MPI measured different pain-relevant aspects. The mean score of the study sample was compared with available normative data (mean and standard deviation) of the International Association for the Study of Pain Primary Site: Thoracic Region [18]. The overall mean pain severity score was

1.88 (SD 0.78), which was lower than the mean score of the normative sample (5.01 [SD 0.82]). The overall mean pain interference score was 3.20 (SD 0.69), which was lower than the mean score of the normative sample (5.01 [SD 0.80]).

### Coping With Pain Questionnaire

The CPQ assessed different pain coping strategies. The mean raw subscale scores were compared with those of a normal group of patients with chronic low back pain or neck pain. The decile scores are written in parentheses below. The overall mean diverting attention score was 23.29 (SD 12.30; decile 5). The overall mean reinterpreting pain sensation score was 8.47 (SD 6.99; decile 2). The overall mean catastrophizing score was 9.59 (SD 8.42; decile 2). The overall mean ignoring pain sensation score was 25.18 (SD 12.69; decile 4). The overall mean praying/hoping score was 23.47 (SD 14.64; decile 6). The overall mean coping self-statements score was 38.94 (SD 12.12; decile 6). The overall mean increasing behavioral activities score was 21.71 (SD 9.84; decile 3). The overall mean perceiving pain control score was 11.59 (SD 4.65; decile 7). Note that these scores represent the pain coping ability of the study sample. The mean postoperative pain (day 1 to day 5) was low (mean NRS 1.89, mean MPI pain severity 1.88), reflecting the need to develop strategies to cope with pain.

### Postoperative Pain

As shown in Table 3, all included patients received a postoperative evaluation score involving pain assessment (NRS) during hospital admission and a reassessment before postoperative questionnaire completion.

### eHealth Technology

The primary variable was a patient's global assessment of the feasibility for the mobile phone app, internet platform, and accessibility of the questionnaires (using a 4-point categorical scale where 1=poor, 2=fair, 3=good, and 4=excellent). Twenty patients rated the eHealth implementation at the final interview after questionnaire completion.

Secondary end points included the time burden for questionnaire completion (using a 5-point categorical scale, where 1=low burden, 2=rather low, 3=average, 4=rather high, and 5=high) and response burden after a single reminder of the importance of questionnaire completion.

Patients rated the mobile phone app, individual online platform usability, and accessibility as good or excellent in 85% (17/20),

89% (17/19), and 95% (20/21) of responses, respectively. No individual scored the usability or accessibility as poor. Regarding the time burden assessment, 67% (12/18) indicated a (rather) low effort for questionnaire completion, and 22% (4/18) mentioned an average effort was required. Overall, 76% (16/21) of the patients were able to complete the online questionnaires within the imposed deadline.

### Correlations

#### Preoperative Psychological Screening Tool

Assessing the usefulness of the online implemented questionnaires, correlations have been calculated. The results (see Table 4) showed a strong negative correlation between self-esteem (RSES) and anxiety characteristics (HADS anxiety) and between self-esteem and anxiety trait scores (STAI). Furthermore, there was a positive correlation between STAI and anxiety characteristics and depression symptoms (HADS anxiety and depression).

#### Pain Measurement, Inpatient Versus Outpatient Evaluation

The study findings showed a low positive correlation between the mean pain scores for the first 5 days after surgery and the pain severity scores measured with the postoperative questionnaire after hospital discharge ( $R=0.35$ ,  $P=.18$ ), although the differences were not significant. No correlation was found between daily activity scores and pain severity and pain interference.

#### Preoperative Psychological Screening Tools and Postoperative Outcome Measures (Pain and Coping Characteristics)

Finally, the results demonstrated a negative but nonsignificant correlation between self-esteem and pain interference ( $R=-0.62$ ,  $P=.14$ ; Table 5). There was a positive correlation between present anxiety characteristics and passive coping behavior ( $R=0.55$ ,  $P=.03$ ; Table 6) and anxiety trait and pain interference ( $R=0.58$ ,  $P=.02$ ). A clearly positive correlation was noted between postoperative pain score after hospital discharge and pain severity assessed by the MPI ( $R=0.62$ ,  $P=.02$ ).

No significant correlation was found between preoperative psychological screening questionnaires and mean postoperative pain scores or between coping and pain (passive coping index vs pain,  $R=0.26$ ,  $P=.32$ ; catastrophizing vs pain,  $R=0.04$ ,  $P=.87$ ).

**Table 3.** Pain rating scores up to 5 days after surgery and highest mean pain score before postoperative questionnaire completion (first week after hospital discharge).

Numerical rating scale for pain assessment	Score, mean (SD)
Postoperative day 1	1.36 (1.43)
Postoperative day 2	2.10 (2.00)
Postoperative day 3	1.91 (1.38)
Postoperative day 4	2.71 (1.79)
Postoperative day 5	2.09 (1.15)
First 5 postoperative days	1.89 (0.82)
Highest mean score before questionnaire completion	3.13 (1.83)

**Table 4.** Correlation between the preoperative psychological dimensions.

Variables	Self-esteem		Depressive characteristics		Anxiety characteristics		Anxiety trait	
	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>
Self-esteem		1.00	.56	-0.15	.04	-0.49	<.001	-0.72
Depressive characteristics				1	.21	0.31	.03	0.52
Anxiety characteristics						1.00	.02	0.55
Anxiety trait								1.00

**Table 5.** Correlation between preoperative psychological screening and postoperative pain.

Variables	Postoperative pain scores (inpatient)		Postoperative pain scores (after discharge)		Pain severity		Pain interference	
	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>
Depressive characteristics	.96	0.01	.87	-0.44	.70	0.11	.09	0.46
Anxiety characteristics	.30	0.26	.22	-0.32	.47	-0.20	.09	0.46
Anxiety trait	.38	0.22	.64	-0.13	.78	-0.08	.02	0.58
Self-esteem	.34	-0.24	.51	0.18	.75	0.09	.01	-0.62

**Table 6.** Correlation between preoperative psychological screening and coping strategies.

Variables	Passive coping		Catastrophizing		Self-control	
	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>	<i>P</i> value	<i>R</i>
Depressive characteristics	.12	0.41	.31	0.27	.49	-0.19
Anxiety characteristics	.03	0.55	.55	0.16	.99	-0.01
Anxiety trait	.89	0.04	.41	0.22	.32	-0.28
Self-esteem	.95	-0.02	.88	0.04	.21	0.34

## Discussion

### Principal Findings

The appearance of a chest wall deformity can decrease a patient's psychological well-being such that self-perception is a major contributor to therapeutic decision making [5]. See comment in PubMed Commons below Furthermore, surgical care may cause severe stress or even psychological trauma [8]. Many investigators have shown that preoperative psychosocial factors such as anxiety increase postsurgical pain [2-4]. Moreover, patients undergoing thoracic surgery are prone to the development of chronic pain after surgery, which is often neuropathic and therefore more difficult to treat. Although psychological care is finally gaining attention and importance, many health care workers find it difficult to implement these challenging pain reduction strategies [26].

The primary aim was to introduce and evaluate the usefulness of eHealth technology for psychological screening purposes in an integrated surgical care model. Furthermore, 5 questionnaires were evaluated in assessing psychological variables (yellow flags such as depression, anxiety, and coping) involved in the transition from acute to persistent (subacute) pain in adolescent pectus patients. Finally, self-esteem was measured as an indirect parameter for pain persistence, as it is shown to be related with the incidence of yellow flags.

### eHealth Technology

eHealth is a relatively new practice in health care that includes electronic processes and communication. Although concerns are rising about user privacy and confidentiality, its importance is growing significantly [27,28]. We conducted this study to investigate its usefulness as part of a holistic surgical care process in adolescent pectus patients.

This study confirmed the easy accessibility of internet-based psychological screening questionnaires. Most patients quoted a low effort for questionnaire completion, reflecting patient compliance. Since we introduced an internet platform, patients can complete their tasks when and where they want, highlighting the importance of patient independency and responsibility.

In general, the implementation of Web-based questionnaires containing a preoperative psychological assessment can improve surgical outcomes for patients and their families if the optimal screening questionnaire depending on the surgical population is chosen.

### Psychological Variables and Type of Screening Questionnaire

It is well known that psychological characteristics play an important role in the development of persistent postsurgical pain; previous studies [29] have shown that trait anxiety increased pain after surgery [30-32]. In our data, preoperative

depressive and anxiety states did not correlate with pain severity or pain intensity. This result is, however, somewhat inconsistent with the existing literature that shows that these states play a major role in chronification of pain [2-4,32]. One possible explanation is that psychological factors play a role in the development of chronic pain (defined as the persistence of pain for more than 3 months). The questionnaires used in this study protocol were, however, completed in the first week after discharge. Unfortunately, there was no long-term evaluation or a reassessment by retaking the applied screening battery. Consequently, further research is necessary to derive conclusions about chronic pain development and the extrapolation of the results to other patient populations.

Our results showed that anxious patients tended to engage more often in passive coping, which leads to maladaptive behaviors and cognitions about pain. This finding is in accordance with the literature on the chronification of pain. A study by Kaczynski et al [31] evaluated pain coping as a mediator of associations between anxiety and functional disability in adolescents with chronic pain. The authors indicated that relationships between anxiety systems and pain-related outcomes are complex. Their results showed that the association between anxiety and disability was mediated by passive coping [31].

There was no correlation between anxiety, depressive states, catastrophizing, and the experience of self-control. The overall mean catastrophizing score was low. This result is inconsistent with the literature on coping behaviors [33,34]. However, some authors have remarked on the concept of catastrophizing in children and adolescents [35-38]. One general remark should be made on the results of coping behavior and pain intensity and interference. The mean NRS score in the early postoperative phase was 1.89 (SD 0.82). The mean MPI pain severity score and interference after discharge were 1.88 (SD 0.78) and 3.20 (SD 0.69), respectively. These scores were low and could be attributable to the multidisciplinary follow-up before and after surgery. A pain sensation that is acceptable may indicate that the patient was able to cope with it. Conversely, because of the use of more adaptive coping styles, the pain was generally under control. Nevertheless, pain scores increased the first week after hospital discharge.

We found several significant correlations: anxious predisposition and interference of pain, self-esteem and interference of pain, anxiety states and passive coping, self-esteem and anxiety measures, and depressive states and anxious predisposition. It is most likely that the relationships between anxiety, pain coping, and disability are bidirectional and contribute to a vicious circle of increasing pain-related disability as outlined in the fear avoidance model of pain by Vlaeyen and Linton [39] (Figure 5).

It is important to note that all study patients followed a specific postsurgical pathway that focused on pain (recovery). All patients had a preoperative consultation in the multidisciplinary pain center in which education about the eHealth system was provided. In addition to this practical information, the medical staff also provided information on acute, subacute, and chronic

pain and self-management methods. During hospitalization, a multidisciplinary team of anesthesiologists, surgeons, physiotherapists, and nurses followed the postoperative rehabilitation protocol. Each provider could anticipate the concerns of the patients very quickly. This process of reassurance, encouraging questions, and cognitive reappraisal is important to reduce distress and anxiety, consistent with the findings of Sjoling et al [40]. This personal and specialized approach could be used therapeutically to address the experience of distress associated with hospitalization.

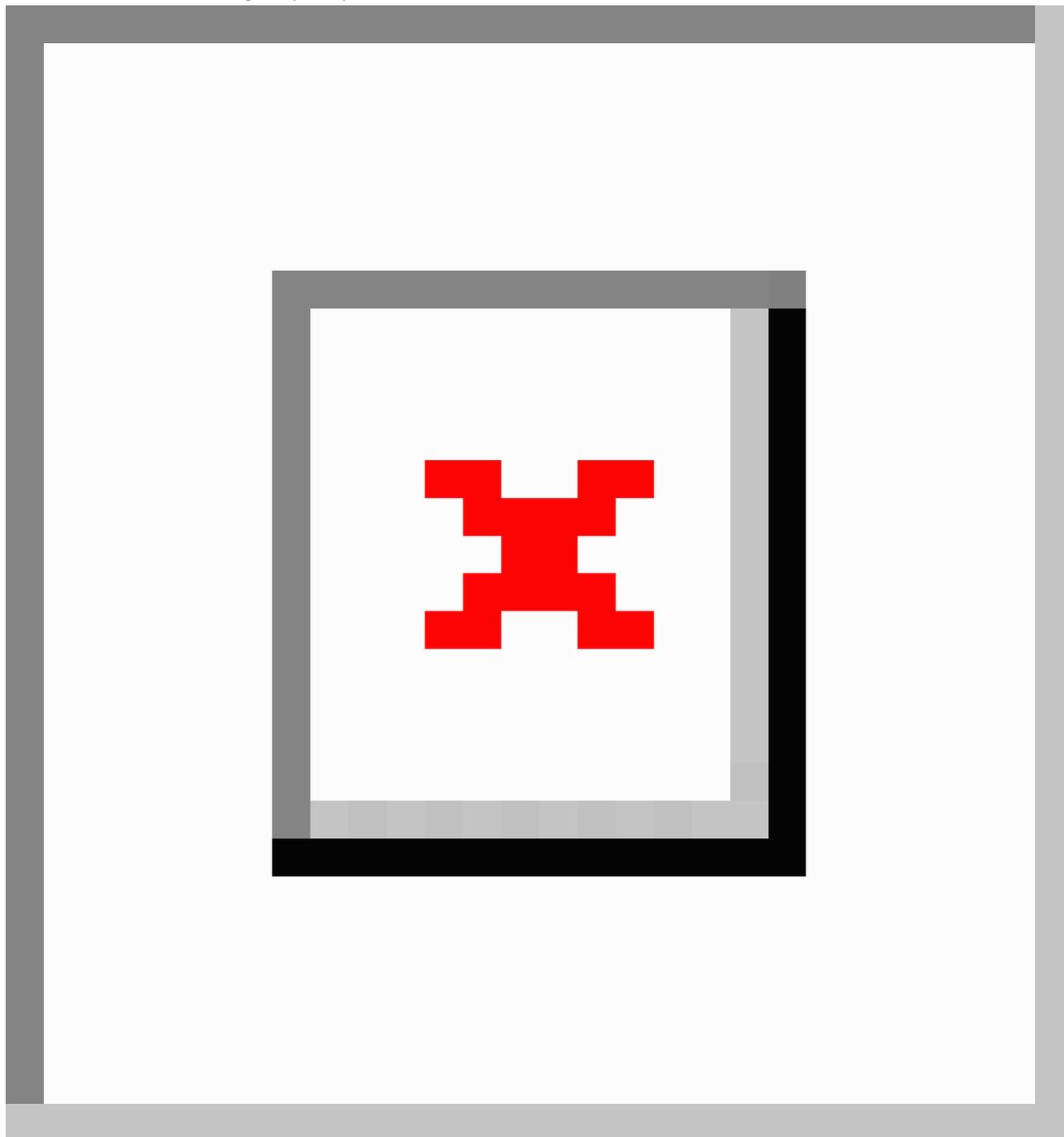
### Self-Esteem in Pectus Patients

Our results showed that preoperative anxiety is related to lower self-esteem, which is in accordance with the literature [22,41,42]. The mean self-esteem scores of this study sample were higher than the average Belgian levels of global self-esteem. This result is inconsistent with the expectation that pectus patients experience low self-esteem. Despite these findings, self-esteem played a role in the interference of postsurgical pain.

Self-esteem is an interesting measure in this population. There is a high comorbidity between depression and anxiety disorders. Low self-esteem is a transdiagnostic factor, for example, in both disorders. Improving self-esteem is an important treatment goal for therapy in depressive or anxious patients. Sowislo and Orth [41] evaluated the vulnerability and scar models of low self-esteem and depression, as well as low self-esteem and anxiety. The vulnerability model states that low self-esteem contributes to depression and anxiety, whereas the scar model states that low self-esteem is a consequence of depression and anxiety. The authors meta-analyzed the available longitudinal data. For depression, the findings supported the vulnerability model. For anxiety, the effects were relatively balanced; they found evidence for both theories. The authors speculated on why depression and anxiety were differentially linked to low self-esteem. They described, for example, that self-focused attention as a mediator is differentially related to depression and anxiety [41]. Additionally, many researchers further documented the concept of self-focus and suggested correlations between self-esteem and depressive and anxiety states [43-46].

We can question the use of the RSES in the measurement of self-esteem in children with pectus pathology. The RSES is a frequently used, short, and well-studied measure. In our study sample, all scores were relatively high. The study by Knudsen et al [47] reported the same ceiling effect in the use of the RSES as a measure of self-esteem. The purpose of their study was to assess the effects of surgical corrections of the pectus carinatum on health-related quality of life and self-esteem. Only one of 36 participants had low self-esteem (<15 points) according to the RSES before surgical correction, and self-esteem was within the normal range (>15 points) in all patients at the 6-month follow-up. This ceiling effect could be explained by the use of generic questions, resulting in high scores for self-esteem before surgery [47]. However, the RSES still remains a good measure of self-esteem [48], although some alternative multidimensional measures could be more sensitive.

**Figure 5.** Fear avoidance model of pain by Vlaeyen and Linton [39].



Some authors [49,50] question the factor structure of the RSES. Current debate focuses on whether the RSES has a uni- or bidimensional structure (positive and negative self-esteem). Franck et al [17] evaluated the difference between the 1- and 2-factor models of the Dutch RSES questionnaire, and the questionnaire appears to represent a 1-dimensional construct of self-esteem, contaminated by the method effect primarily associated with the specific nature of the items. The predisposition to answer negatively worded items differently is associated with cognitive ability, age, cultural group membership, lower academic motivation, etc. The positive and reverse negative scores were 11.39 (SD 1.82) and 10.17 (SD 2.53), respectively ( $P=.06$ ), indicating that patients answered

consistently, independent of the positive or negative formulation of the items.

### **Limitations**

The limitations of our exploratory study need to be acknowledged. First, all questionnaires used were self-report instruments. Therefore, response bias may play a role, as results can vary due to small introspective abilities or socially desirable answering [51,52]. Second, we emphasize a potential time bias between hospital pain assessment and psychological evaluation via the MPI and CPQ. However, one may suggest an aberrant self-report from patients with a high postoperative pain score. A more precise evaluation of pain and coping technique could improve outcome variables. Furthermore, the reassessment of

the preoperative questionnaires in the postoperative period could be of particular value. Nevertheless, minimal patient effort should be pursued. Third, the design of this proof-of-concept study may not use the questionnaire of choice in the assessment of self-esteem in adolescent pectus patients, as there was no significant difference in scores compared with those of healthy Belgians. To distinguish adolescent pectus patients with respect to self-esteem characteristics, a more sensitive and specific questionnaire is necessary.

## Conclusion

If caregivers involved in a surgical care process use innovative eHealth techniques as a simple, accessible psychological screening tool, along with adequate treatment if necessary, postoperative outcome parameters may further improve. As a fast, straightforward, and accessible instrument, an online platform can not only increase patient participation in rehabilitation but also alert the provider when yellow flags are present. To determine if this technique may be helpful in reducing postoperative pain, the length of hospital stay, and the development of chronic pain after surgery, more research is imperative.

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## Conflicts of Interest

None declared.

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## Abbreviations

**APPI:** Antwerp Personalized Pain Initiative  
**CPQ:** Coping With Pain Questionnaire  
**CSQ:** Coping Strategy Questionnaire  
**CT:** computed tomography  
**HADS:** Hospital Anxiety and Depression Scale  
**MIRP:** minimally invasive repair of pectus  
**MPI:** Multidisciplinary Pain Inventory  
**NRS:** numeric rating scale  
**RSES:** Rosenberg Self-Esteem Scale  
**STAI:** State-Trait Anxiety Inventory  
**VAS:** visual analog scale

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Original Paper

# Harnessing Social Media to Explore Youth Social Withdrawal in Three Major Cities in China: Cross-Sectional Web Survey

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## Abstract

**Background:** Socially withdrawn youth belong to an emerging subgroup of youth who are not in employment, education, or training and who have limited social interaction intention and opportunities. The use of the internet and social media is expected to be an alternative and feasible way to reach this group of young people because of their reclusive nature.

**Objective:** The aim of this study was to explore the possibility of using various social media platforms to investigate the existence of the phenomenon of youth social withdrawal in 3 major cities in China.

**Methods:** A cross-sectional open Web survey was conducted from October 2015 to May 2016 to identify and reach socially withdrawn youth in 3 metropolitan cities in China: Beijing, Shanghai, and Shenzhen. To advertise the survey, 3 social media platforms were used: Weibo, WeChat, and Wandianba, a social networking gaming website.

**Results:** In total, 137 participants completed the survey, among whom 13 (9.5%) were identified as belonging to the withdrawal group, 7 (5.1%) to the asocial group, and 9 (6.6%) to the *hikikomori* group (both withdrawn and asocial for more than 3 months). The cost of recruitment via Weibo was US \$7.27 per participant.

**Conclusions:** Several social media platforms in China are viable and inexpensive tools to reach socially withdrawn youth, and internet platforms that specialize in a certain culture or type of entertainment appeared to be more effective in reaching socially withdrawn youth.

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**KEYWORDS**

adolescent; social withdrawal; hikikomori; youth social issues; Web survey; China

## Introduction

*Hikikomori*, a form of pathological social withdrawal behavior that was first identified in Japan, describes youth and young adults who largely become recluses (mainly in their parents' homes) and do not engage in education, employment, or training for months or years [1]. Their *hidden* or *non-engaged* behavior [2-6] makes studying *hikikomori* an extremely challenging research topic.

The most common research recruitment methods to identify young people in social withdrawal include referrals from mental health professionals [7-9], parents [10], and household surveys [11]. However, because of the small sample sizes of referrals and the low cost-efficiency of household surveys, researchers have suggested that alternative recruitment methods are needed to expand our understanding of this emerging worldwide youth phenomenon [1,3,4,7,12].

Wong and colleagues [13], for instance, were one of the very few investigators to adopt an alternative study methodology to engage potentially withdrawn young people. They used a telephone survey to study potentially withdrawn individuals in Hong Kong. In their study, a sample of 80,000 mobile numbers was randomly generated and contacted. They finally contacted 2854 eligible individuals, 1010 of whom completed the telephone survey. Of these, 70 individuals reported spending most of the day and nearly every day at home and persistently avoiding social situations (such as going to school or working) and social relationships (such as friendships and contact with family members). The main limitations of their study included lack of a population-based representative sample and a small sample of individuals who could be considered socially withdrawn. However, at that time, telephone survey was the least costly and most feasible method to study this youth phenomenon in Hong Kong. With the overall cost of HK \$110,000 (around US \$14,066.5), the cost per participant is HK \$108.91 (US \$13.93), which is derived by dividing the total number of completed surveys by the sum of total personnel (excluding the research team members') cost and administrative costs.

Despite the rising concerns of scholars in mainland China about the existence of youth in social withdrawal [14,15], there are, as far as we know, no empirical studies that have been conducted on this emerging youth issue. Only a few case studies of potential socially withdrawn youths have been reported by youth social workers [15]. It is observed that less-developed social welfare services, coupled with low awareness of this youth issue among the public and even social service professionals, are some of the underlying barriers to launching a large-scale investigation of this population. Therefore, there is a need to explore innovative research approaches to reach a wider youth population. The use of the internet for data collection, which has been proved efficient in the West, could become a new recruitment strategy in China.

According to a recent report of the prevalence of the internet in China, by the end of December 2015, the total number of internet users in China had reached 688 million, 75.1% of whom were aged between 10 and 39 years [16]. Beijing, Shanghai,

and Guangdong province were the top 3 areas with internet use rates above 70%. Sina Weibo and WeChat are now 2 of the most popular social media sites in China. Akin to a hybrid of Twitter and Facebook, Weibo combines the functions of a microblog and a social networking site and had accumulated 282 million monthly active users (MAUs) and 126 million daily active users as of June 2016 [17]. According to the annual report by the Chinese Academy of Social Science, as of 2014, the population aged between 10 and 39 years accounted for 78.7% of microblog users, and 82.2% were users of Sina Weibo [18]. The Chinese instant messaging program WeChat had attracted 806 million MAUs as of June 2016 [19]. With its group chat function and public accounts for individuals and organizations, WeChat has become a top platform of communication in China's Web-based communities. Many social networking websites that have more specific focuses and target groups (eg, douban website for its focus on reviews of cultural products and activities, renren website for students to reconnect with old school friends, and Wandianba for people who are interested in video games and board games) also attract large numbers of users [20].

Given the ubiquity of the internet and social media among young people in China and the previous successful experience of Chinese scholars who recruited more than 1000 Weibo users to complete their survey on mental health issues (eg, [21]), we were interested in experimenting with various Web-based means to facilitate the administration of a research survey among young people in China. The main aim was to identify recruitment methods that are feasible and appropriate for use in a future study of pathological social withdrawal among young people in China to expand our understanding on this emerging but methodologically challenging issue in many countries.

## Methods

### Study Population

The recruitment area for the survey covered 3 major metropolitan cities in mainland China: Beijing, Shanghai, and Shenzhen (a major city in Guangdong Province). According to the 2010 census data, the population aged between 10 and 39 years in the 3 cities is 28,417,551, accounting for 53.6% of their overall population. A cross-sectional open Web survey was conducted from October 2015 to May 2016 to identify and reach our target population, ie, youth in social withdrawal.

### Recruitment

The survey was created and stored using a Chinese survey platform called Sojump, which is operated by Changsha Xingran Information Technology Company and is one of the biggest survey platforms in China. The survey host provided a unique link to the survey, and its system helped to block attempts by respondents with the same internet protocol (IP) address or the same electronic device to fill out the survey more than once. After completing the survey, respondents were able to review their answers and were reminded to finish unanswered mandatory items before submission.

Three recruitment methods were experimented sequentially. They included (1) Weibo, (2) WeChat group and microblog, and (3) an online game website.

### Method 1

Weibo was chosen as the main social media platform to administer the survey. The procedure was as follows:

1. An official Weibo account was created for the research team to post invitations and information related to the survey
2. Weibo's paid advertising service was adopted to send out survey invitations to Weibo users who met the following inclusion criteria:
  - IP addresses in Beijing, Shanghai, and Shenzhen
  - registered age on Weibo is between 13 and 39 years.

Material incentives were adopted to increase the survey response rates. Once the respondents finished the questionnaire, they were given a chance to enter a lottery for a CNY ¥500 (US \$77.44) cash coupon. Only the winner was asked to leave the mobile phone number and be further contacted. As each Weibo account is tied with 1 mobile phone number and the survey information will only be pushed to each eligible user once at a random time point, this has reduced the chance of repeated attempts by same participants by using different Weibo accounts or electronic devices.

### Method 2

Upon monitoring the effectiveness of Weibo in reaching the target population, to compensate for the low response rate, the research team also advertised the survey via WeChat with different approaches:

1. The survey information was sent to 2 WeChat groups: the group of the first author's college alumni (with 61 members), most of whom reside in Beijing and Shanghai and are working in domains related to education, and a group of strangers who joined a free distance course on psychotherapy arranged by a training center (with 98 members)
2. Personal microblog on WeChat: through a professor at a renowned university in Shanghai, 2 students majoring in public health posted the survey link on their microblogs on WeChat; they attracted 18 responses within a 2-week period.

### Method 3

With the permission of the administrator of 1 popular online game website, we were able to advertise the survey on Wandianba website [22] among its more than 8000 registered members. Members in these groups were allowed to forward the survey link to people they knew. The respondents recruited from these approaches could enter the "red envelope lucky draw" (a function developed by WeChat), and each respondent could win a random amount of "lucky money" up to CNY ¥10. A summary of the Web survey details according to the Checklist for Reporting Results of Internet E-Surveys guidelines [23] is provided in [Multimedia Appendix 1](#). The survey invitation and post for different platforms is shown in [Multimedia Appendices 2 and 3](#).

## Ethical Considerations

The respondents' consent to participate in the study was obtained online. They were required to read and approve an informed consent form before proceeding to the questionnaire. Assent from adolescent participants was collected with the same consent process described above. The information sheet of the study was designed at the reading level of a 13 year old.

To limit response bias, the nature of the study was introduced in a general sense as concerning youth and internet use. The questions in the survey pertain to this general introduction, and no deception is involved throughout the research. At the end of the questionnaire, a message containing contact information and numbers for crisis intervention hotlines of local nongovernmental organizations that offer mental health services in the 3 cities was provided to the respondents to encourage them to seek help if they felt distressed upon completing the questionnaire.

## Data Security and Confidentiality

Because sensitive information such as risk behavior was collected in the survey, measures were taken to ensure data security throughout the research. During the data collection process, only the principal investigator had access to the account on the website that hosted the survey. The survey host also followed the cyber security protocol to prevent data leakage. Once data collection was finished, all of the research data were coded and stored on password-protected drives. Ownership of and access to the data were restricted to the research team. The study obtained ethical approval from the Human Research Ethics Committee for Non-Clinical Faculties at the University of Hong Kong (Ref# EA1508009).

## Measurements

### Social Withdrawal Symptoms as Dependent Variables

This study used a modified version of the definition of *hikikomori* proposed by Teo [1,3]. In brief, the survey inquired about (1) physical isolation or withdrawal to a particular place, (2) lack of social connectedness and interaction, and (3) duration of social withdrawal. For this study, we used a 3-month rather than 6-month duration of symptoms because recent research has suggested similar characteristics of individuals with a shorter duration of symptoms. Participants were assigned to the withdrawal group (only meeting criteria 1 and 3: staying at home almost every day for more than 3 months), the asocial group (only meeting criteria 2 and 3: persistently avoiding social interaction for more than 3 months), or the *hikikomori* group (meeting all 3 criteria). Participants who did not meet any of the 3 criteria were assigned to the comparison group.

The independent variables comprised the demographics, individual, social, and parental domains of participants, which are the major dimensions discussed in youth social withdrawal research [4].

### Demographics

The respondents were invited to provide their profile information, including age, gender, highest education level, marriage status, and parental information.

### Internet Social Capital Scales

The scales were used to measure the quantity and quality of respondents' social networks both online and offline. They comprise 2 parallel 5-point Likert scales to test respondents' online and offline social capital. In each scale, 20 items measure the respondents' bonding and bridging social capital [24].

### Common Measurements for Social Media Advertising

Weibo uses metrics similar to dominant advertising services (eg, Facebook) to show the popularity of each post, including impressions, clicks, reach, and click-through rate: (1) an impression is defined as a single time an ad is shown to a user regardless of whether the user clicks on the ad, (2) a click is when a user clicks a link in an ad, (3) reach is the number of unique people who received impressions of an ad, and (4) click-through rate is calculated by the number of clicks of a received ad divided by the number of impressions.

### Statistical Analyses

Descriptive statistics for the continuous variables were illustrated by means and standard deviations, whereas categorical variables were shown by numbers and percentages. Fisher exact test and the Mann-Whitney-Wilcoxon test were used to compare the categorical and continuous variables, respectively, between the comparison group and the withdrawal group, the asocial group, and the *hikikomori* group.

## Results

### Overall Recruitment

The Web-based questionnaire was administered at 3 sites (ie, Weibo, WeChat, and Wandianba). According to the statistics generated by Weibo, the survey was exposed 596,772 times to targeted users and reached 206,139 users. Of these, 517 (click-through rate=0.087%) either clicked on the survey link or forwarded the post to others. However, only 85 completed

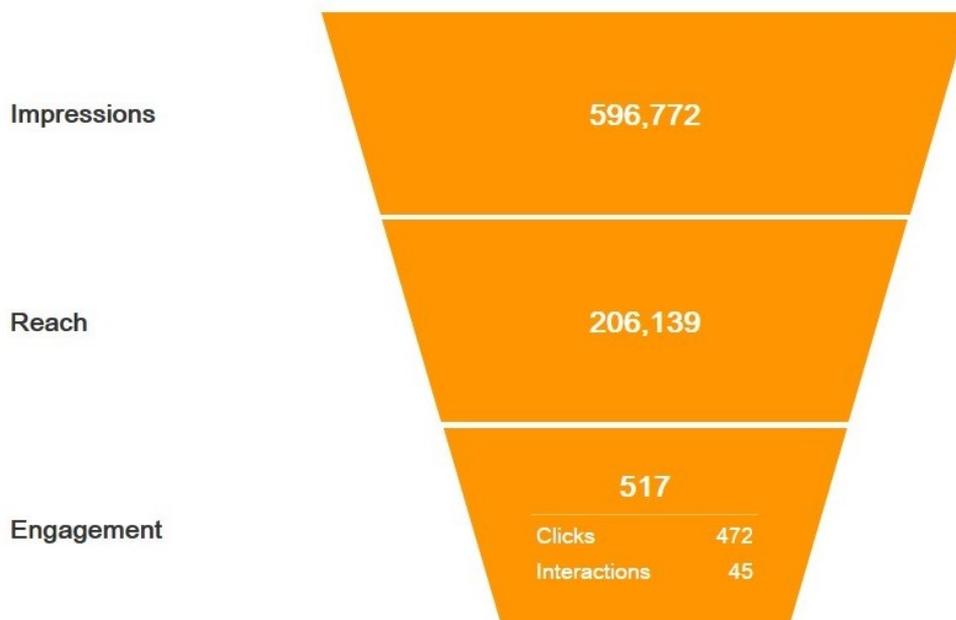
the survey via Weibo (Figure 1). The posts on WeChat groups yielded 43 responses, and Wandianba attracted 9 responses (Table 1). The survey host recorded a total of 192 visits with independent IPs to the survey, making the completion rate 71.4%. The survey ultimately collected a total of 137 responses within a period of 7 months.

### Costs of Social Media Advertising

Advertising on Sina Weibo is managed on the internet, and pricing is based on a bidding system. There are 2 ways to bid for the target group among advertisers with the same aim: to pay per 1000 impressions and to pay per click. During the 7-month advertising on Sina Weibo, we tried both methods of advertisement with different bidding prices based on factors such as the response rate and the number of advertisers opting for the same target group in different time periods. On the first day of advertisement, we chose to pay by impressions. A price of CNY ¥10.8 (around US \$1.67) per 1000 impressions was set; however, there were no responses. Thus, starting on October 20, 2015, the bidding method was changed to pay by click starting with prices ranging from CNY ¥10 per click to CNY ¥20 per click (the average price was CNY ¥12.5). It was found that the bidding price did not significantly influence the response rate. However, the number of visits to the recruitment page and the responses to the survey decreased remarkably during the seasonal marketing campaign of the e-commerce website (taobao, the largest e-commerce website in China).

Ultimately, the cost of the 7-month campaign on Sina Weibo was CNY ¥3300 (US \$511.07), and the overall service charges (including monthly fee, administration fee for the lucky draw, and distribution of cash rewards) from the survey host (Sojump) and cash rewards (CNY ¥1000 in total) were CNY ¥3128 (US \$484.44). Thus, the average cost to reach a participant who completed the survey through Sina Weibo was CNY ¥46.92 (US \$7.27).

**Figure 1.** Effectiveness funnel of Weibo.



**Table 1.** Survey administration procedure and distribution of responses.

Media	Administration period	Additional remarks	Number of responses
Weibo	Oct 19 to Oct 20, 2015	Charged by per 1000 impressions; because none of these impressions were transferred into responses, the advertising strategy was changed to the interaction rate from Oct 20 onwards	85
	Oct 20, 2015, to May 20, 2016	Charged by per click of the link	
WeChat groups	Feb 2 to Feb 22, 2016	During the period of Chinese New Year, the survey information was posted on several WeChat groups.	43
Wandianba website [22]	Apr 1 to Apr 30, 2016	The research team posted the survey information on several internet communication platforms that appeal to young people, including Mop, Hupu, Tianya, Baidu Tieba, and Wandianba. However, except for Wandianba, where the administrator approved the attempt to advertise the survey, other platforms immediately banned and deleted the messages posted	9

Except for the incentives in the form of cash coupons of random amounts, there was no additional cost for advertisement via WeChat group and Wandianba. As compared with the average cost per participant of a telephone survey targeting the same population, the cost is relatively lower and could be a viable method in future studies.

### Preliminary Findings on the Population of Hikikomori in Mainland China

In total, 137 participants completed the survey. Of the 137 responding participants, 85 were recruited through Weibo (over 7 months at a cost of around US \$500), 43 from WeChat (over 20 days at no cost), and 9 from Wandianba website (over 30 days at no cost). Among the 137 participants, 108 (78.8%) did not show evidence of social withdrawal symptoms and therefore were classified as the control, or comparison, group. The

remaining 29 (21.2%) participants had symptoms of social withdrawal and were classified as follows: the 13 (9.5%) who indicated that they stayed at home nearly every day for a period of more than 3 months were categorized as the withdrawal group; the 7 (5.1%) participants who reported that they avoided most social contact for a period of more than 3 months were categorized as the asocial group; and the 9 (6.6%) participants who met both the withdrawal and asocial criteria for more than 3 months were categorized as the *hikikomori* group. Both the withdrawal group and the *hikikomori* group were more likely than the comparison group to access the Web-based survey through Wandianba but were less likely to assess the survey through WeChat (Table 2). The *hikikomori* group was more likely than the comparison group to access the Web-based survey through a computer.

**Table 2.** Comparison of access to the survey categorical and continuous variables of the classified participants using Fisher exact test and Mann-Whitney-Wilcoxon test, respectively.

Online behaviors	Comparison group	Withdrawal group	<i>P</i> value	Asocial group	<i>P</i> value	<i>Hikikomori</i> group	<i>P</i> value
<b>Mode of survey administration</b>							
Phone, n (%)	83 (76.9)	10 (77)	>.99	4 (57)	.36	4 (44)	.047
Computer, n (%)	25 (23.1)	3 (23)		3 (43)		5 (56)	
<b>Platform to survey</b>							
Weibo, n (%)	64 (59.2)	10 (77)	.04	6 (86)	.42	5 (56)	.007
WeChat, n (%)	40 (37.0)	1 (8)		1 (14)		1 (11)	
Wandianba, n (%)	4 (3.7)	2 (15)		0 (0)		3 (33)	
Time spent on questionnaire (in seconds), mean (SD)	757.80 (768.52)	644.08 (165.58)	.91	870.00 (1031.51)	.29	835.33 (653.50)	.67
<b>Number of online friends</b>							
Weibo, mean (SD)	94.60 (212.40)	24.09 (55.07)	.02	7.60 (9.24)	.07	57.17 (119.46)	.37
WeChat, mean (SD)	163.40 (313.38)	57.36 (92.56)	.003	104.00 (42.78)	.97	27.33 (26.10)	.004
QQ <sup>a</sup> , mean (SD)	196.89 (173.86)	155.55 (182.07)	.17	136.00 (72.32)	.62	127.29 (210.30)	.04
Frequency of contacting online friends, mean (SD)	1.84 (1.19)	1.77 (0.83)	.76	1.14 (0.38)	.13	2.56 (1.42)	.09

<sup>a</sup>QQ: a widely used instant messaging software in China.

**Table 3.** Comparison of sociodemographics categorical variables of the classified participants using Fisher exact test.

Characteristics	Comparison group, n (%)	Withdrawal group, n (%)	<i>P</i> value	Asocial group, n (%)	<i>P</i> value	Hikikomori group, n (%)	<i>P</i> value
<b>Gender</b>							
Male	43 (39.8)	5 (38)	>.99	2 (29)	.70	6 (67)	.16
Female	65 (60.1)	8 (62)		5 (71)		3 (33)	
<b>Age in years</b>							
<18	13 (12.3)	6 (46)	.02	0 (0)	.47	1 (11)	>.99
18-24	56 (52.8)	5 (38)		5 (83)		5 (56)	
>24	37 (34.9)	2 (15)		1 (17)		3 (33)	
<b>Education level</b>							
Above secondary Form 3	91 (84.3)	8 (62)	.06	7 (100)	.59	8 (89)	>.99
Form 3 or below	17 (15.7)	5 (38)		0 (0)		1 (11)	
<b>Marital status</b>							
Single	82 (79.6)	8 (67)	.29	6 (100)	.59	6 (67)	.40
Married/cohabitating	21 (20.4)	4 (33)		0 (0)		3 (33)	
<b>Family structure</b>							
Both parents	95 (88.0)	10 (77)	.38	6 (86)	>.99	8 (89)	>.99
Others	13 (12.0)	3 (23)		1 (14)		1 (11)	
<b>Employment status</b>							
Student	40 (37.0)	8 (62)	.01	3 (43)	>.99	3 (33)	.10
Employed	64 (59.3)	3 (23)		4 (57)		4 (44)	
Unemployed	4 (3.7)	2 (15)		0 (0)		2 (22)	
<b>Visited psychiatric hospital or clinics</b>							
Yes	3 (2.8)	0 (0)	>.99	0 (0)	>.99	2 (22)	.047
No	105 (97.2)	13 (100)		7 (100)		7 (78)	

**Table 4.** Comparison of social capital continuous variables of the classified participants using the Mann-Whitney-Wilcoxon test.

Social capital	Comparison group, mean (SD)	Withdrawal group, mean (SD)	<i>P</i> value	Asocial group, mean (SD)	<i>P</i> value	Hikikomori group, mean (SD)	<i>P</i> value
Online bonding	25.05 (6.10)	24.69 (5.54)	.79	26.71 (6.90)	.70	28.56 (5.94)	.16
Online bridging	32.34 (7.81)	36.85 (8.31)	.07	35.43 (9.69)	.13	36.33 (8.49)	.18
Offline bonding	35.57 (5.81)	33.62 (6.41)	.12	37.43 (4.79)	.64	32.89 (5.62)	.20
Offline bridging	35.81 (7.08)	36.15 (8.44)	.97	38.00 (6.95)	.43	30.56 (8.93)	.07

The withdrawal group had fewer online friends on Weibo and WeChat than the comparison group, whereas the *hikikomori* group had fewer online friends on WeChat and QQ (a widely used instant messaging software in China) than the comparison group. The withdrawal group was younger and included more students (62%, 8/13) and unemployed individuals (15%, 2/13) than the comparison group (Table 3). The *hikikomori* group was more likely to have visited psychiatric hospital or clinics than other participants. The withdrawal group had more online bridging social capital than the comparison group, whereas the *hikikomori* group had less offline bridging social capital than the comparison group (Table 4). There was no significant

difference between the asocial group and the comparison group in terms of the studied variables.

## Discussion

### Principal Findings

As far as we know, this is the first quantitative study to evaluate *hikikomori* and social withdrawal behavior among young people in China. Given the high penetration of social media among young people in China, we explored the feasibility of using various social media platforms to recruit young people to participate in our Web survey.

The response from the 3 recruitment methods shows very interesting patterns. Although Weibo helped in recruiting the largest portion of participants, it took 7 months to reach that number, whereas it took only 20 days to recruit 43 participants through personal contacts using WeChat. Although it took a month to recruit 9 participants at Wandianba, 3 of those participants were *hikikomori*. In other words, online gaming sites merit further exploration as a venue to identify socially withdrawn youth in China.

Despite the small dataset, we identified 13 physically withdrawn youths, 7 asocial youths, and 9 *hikikomori*, making the percentages among the overall participants 9.5% (13/137), 5.1% (7/137), and 6.6% (9/137), respectively. This finding indicates that we reached a high percentage of individuals at risk of social withdrawal behavior and that we appeared to have targeted the correct group of people through our various social media recruitment methods. Although the data collected from convenient/snowball sampling could be biased, it seems that the use of WeChat and social networking sites that cater to particular user groups are especially effective in reaching over 6% of potential socially withdrawn youth in China, with reference to the prevalence rate in modern society of around 2% [4,13]. This exploratory study also consolidates our experiences with online questionnaire administration in China.

### Challenges Awaiting to be Addressed

First, because of the tight internet censorship of the Chinese Government, to avoid being shut down, internet content providers will self-censor their content [25]. For example, there were several words in our questionnaire (eg, names of illicit drugs) that were considered sensitive, and the research team was asked by the survey host (Sojump) to change the wording or the display of the words. On the basis of this incident, it is estimated that similar surveys distributed through official avenues such as schools and residential committees are very likely to be sanctioned.

Second, following the auction principle set up by Weibo, the research team acted as a bidder offering a price that represents the maximum willingness to pay for an advertisement. The team had to compete with other commercial advertisers to gain audiences. However, because social media platforms are pervasively used for commercial purposes, the cost of administering the survey has increased. In addition, there are several waves of commercial campaigns in China, such as the big sales on November 11 (known as “Single’s Day”), December 12 (known as “Double Twelve”), and Chinese New Year’s Eve, and responses stagnated during these marketing periods. Therefore, to make the advertisement cost-effective, it is important to find a strategy to buffer the impact of these commercial campaigns on response rate.

### Suggestions for Future Research

Our findings suggest 4 approaches to secure a higher response rate for Web-based surveys in China. First, the use of a prominent Sina microblog account to promote the survey was especially conducive to data collection. In our study, we created a new account to introduce the information of the Web survey, which limited exposure to the targeted population and raised

administration costs. In contrast, Guan et al [21] used a celebrity account to promote their survey and easily gathered more than 1000 responses within a shorter period. Therefore, we highly recommend that future research should use a microblog account with a greater fan base.

Second, the length of the survey should be within the participants’ attention spans. Although several measures were used to shorten the survey, such as using a short version of the scale and adopting skip logic to ensure that certain scales were only shown to respondents who met the criteria of the target population, the average time to complete the survey was 15 min. Although the duration is not unbearable to general participants, it is still a challenge to sustain participants’ attention; 192 participants with independent IP addresses entered the survey but only 137 of them completed it, resulting in a completion rate of 72.4%.

Third, the use of scales and the presentation of the survey should be intelligible to the targeted population. Comments from participants left on Wandianba regarding the survey recorded several complaints about the format of the questions. To individuals without much exposure to psychological measurement, many questions in the survey seemed redundant, such as the same set of questions asked regarding different variables such as online social capital and offline social capital. Researchers can also consider using application programming interfaces provided by social media to collect users’ publicly available digital records. For instance, users’ profiles and messages can be extracted to show their psychological [21,26] and behavioral features [27].

Fourth, the snowball sampling method we used on the Wandianba website has helped us to reach 9 potential severely withdrawn young people. This seems to be an effective recruitment method. In fact, this method is similar to a more advanced snowball sampling technique named as respondent-driven sampling. In respondent-driven sampling, a sample is collected using a chain-referral procedure, meaning that respondents are selected not from a sampling frame but from the social network of existing members of the sample. In addition, researchers keep track of who recruited whom and their numbers of social contacts, and then a mathematical model of the recruitment process weighs the sample to compensate for nonrandom recruitment patterns. This model is based on a synthesis and extension of 2 areas of mathematics, Markov chain theory and biased network theory, which were not part of the standard tool kit of mathematical sampling theory. The resulting statistical theory enables researchers to provide both unbiased population estimates and measures of the precision of those estimates [28]. This extends the realm within which statistically valid samples can be drawn, to include many groups of importance to public health, public policy, and arts and culture [29]. In the future, adopting the respondent-driven sampling method may be useful to recruit a bigger and more targeted sampling with a statistical weighting technique.

### Implication for Practice of Helping Professionals

The findings of the withdrawal group, the asocial group, and the *hikikomori* group suggested that they tend to converge on internet platforms that specialize in a certain culture or type of

entertainment. For example, in our case, the gaming website Wandianba seems to appeal to socially withdrawn youth regardless of their withdrawal status. This feature indicates the necessity for social workers and other service providers to develop sufficient knowledge about popular youth culture and websites in their attempts to work with socially withdrawn youths [30]. This not only opens up possible channels to reach out to socially withdrawn youths but also serves as an approach to engage these young people.

Although it is found that online or cyber social capital can positively contribute to individuals' well-being [31,32], no study has yet measured their social relationships and social networks online and how they affect young people's social withdrawal behavior. Our study reveals an intriguing phenomenon in that young people in the asocial group did not avoid all kinds of social interaction. Moreover, by connecting with people from different backgrounds online, the withdrawal group could establish significant online bridging social capital. However, the *hikikomori* group might be prone to cut themselves off from weak ties, such as those with former colleagues and classmates, and as a result, offline bridging social capital cannot be built. The findings indicate the need to adopt a strength-based approach in working with different types of socially withdrawn youths. By examining and capitalizing on how those who work with socially withdrawn youths develop and maintain online social relationships with these young people, we may finally help them to figure out ways into the real social world.

## Limitations

Although internet use has reached nearly 50% in China [33], it clearly does not include everyone in some target audiences. Socioeconomic factors such as internet and smartphone accessibility limit the types of individuals who are exposed to a survey [34]. This clearly limits the audience reach. In addition, as a general limitation of the Web survey, the nonresponse rate increases the bias of estimators [35]. It is likely that the socially withdrawn youths who responded to the survey were those who were still motivated to connect with the outside world. Young people who totally cut themselves out from the social world might not be reached through this study. Moreover, studies that examine sensitive topics may not be as feasible in countries such as China because of internet censorship and a government-controlled media environment. This situation calls for a joint effort from mental health professionals, social workers, and psychiatrists to codevelop research and practices to assist the young people to reconnect with our society [36].

## Conclusion

As the first attempt to understand the population and situation of *hikikomori* in mainland China, this study has explored 3 different Web-based platforms in China (ie, 2 prevalently used social media Weibo and WeChat and 1 online gaming website) to reach youth in social withdrawal. We found that these platforms are viable and serve as inexpensive tools to reach socially withdrawn youth. It was also found that given the behavioral pattern of socially withdrawn youth, they tend to disengage from common social interaction, internet platforms that specialize in a certain culture or type of entertainment were more likely to reach such population.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Checklist for Reporting Results of Internet E-Surveys summary.

[[PDF File \(Adobe PDF File\), 28KB - mental\\_v5i2e34\\_app1.pdf](#) ]

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## Multimedia Appendix 2

Survey invitation.

[[PDF File \(Adobe PDF File\), 124KB - mental\\_v5i2e34\\_app2.pdf](#) ]

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## Multimedia Appendix 3

Survey message pages on Weibo.

[PDF File (Adobe PDF File), 58KB - [mental\\_v5i2e34\\_app3.pdf](#) ]

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## Abbreviations

**IP:** Internet protocol

**MAUs:** monthly active users

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Review

# Efficacy of Acceptance and Commitment Therapy in Reducing Suicidal Ideation and Deliberate Self-Harm: Systematic Review

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## Abstract

**Background:** Since its emergence in the 1980s, acceptance and commitment therapy (ACT) has become a reputable evidence-based psychological therapy for certain disorders. Trials examining the efficacy of ACT are spread across a broad spectrum of presentations, such as chronic pain, anxiety, and depression. Nevertheless, ACT has very rarely been trialed as an intervention for suicidal ideation (SI) or deliberate self-harm (DSH).

**Objective:** The objective of this review is to assess the efficacy of ACT in reducing SI and DSH and to examine the suitability of reported SI, DSH, and other measures in determining the efficacy of ACT.

**Methods:** We systematically reviewed studies on ACT as intervention for SI and self-harm. Electronic databases, including MEDLINE, PubMed, EMBASE, PsycINFO, SCOPUS, Cochrane Central Register of Controlled Trials, and the Cochrane Database of Systematic Reviews, were searched. The reference lists of included studies and relevant systematic reviews were examined to identify additional publications. Search terms were identified with reference to the terminology used in previous review papers on ACT and suicide prevention. The study design was not restricted to randomized controlled trials. Screening was completed by 2 reviewers, and all duplicates were removed. Publications were excluded if they were not published in English, were multicomponent therapy or were not based on ACT, or lacked a validated measure or structured reporting of SI/DSH outcomes.

**Results:** After removing the duplicates, 554 articles were screened for relevance. Following the screening, 5 studies that used ACT as an intervention for suicidal or self-harming individuals were identified. The studies used diverse methodologies and included 2 case studies, 2 pre–post studies, and 1 mHealth randomized controlled trial.

**Conclusions:** The review found that ACT is effective in reducing SI in the 2 pre–post studies but not in other studies. However, given the small number and lack of methodological rigor of the studies included in this review, insufficient evidence exists for the recommendation of ACT as an intervention for SI or DSH.

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**KEYWORDS**

suicidal ideation; suicide; deliberate self-harm; depression; mental health; acceptance and commitment therapy; cognitive behavioral therapy; mHealth; psychology; ACT

## Introduction

Suicide is one of the leading causes of death worldwide, and the World Health Organization attributes over 800,000 deaths per year to suicide [1]. It has tragic and drastic effects, and, globally, for every person who dies by suicide, 20 more people attempt to take their life but do not die [1]. Many are bereaved in the aftermath of a suicide. Family members, friends, and those close to the deceased are at an increased risk of suicide themselves. Therefore, understanding and implementing methods for reducing suicide are critical, as is the prioritization and recognition of suicide as a solvable major public health problem.

For the purpose of this review, suicide is defined as the act of deliberately killing oneself, and deliberate self-harm (DSH) is defined as any nonfatal suicidal behavior, such as intentional self-injury, poisoning, or self-harm with or without a fatal intent. Suicide and DSH are preventable, and therapeutic approaches that specifically target suicidal ideation (SI) provide successful results [2-4]. Cognitive behavioral therapy (CBT) can reduce SI and treat depression and insomnia [5]. The use of CBT as an intervention for suicidality has been tested in a number of randomized controlled trials (RCTs), with some evidence for its efficacy [6-8]. CBT for suicide prevention and CBT for suicidal patients have also had positive effects on SI [2,3].

An evidence base for the “third wave” of CBTs, such as dialectical behavioral therapy (DBT), mindfulness-based CBT (MBCT), and acceptance and commitment therapy (ACT), has been established over the last 15 years [9]. DBT is highly effective in treating presentations of self-harm among those with borderline personality disorder and is frequently delivered as group therapy [10]. MBCT has become an acceptable alternative to CBT. In MBCT, the practice of mindfulness activities is considered a useful addition to standard CBT activities [11]. Given the strong evidence for the efficacy of third-wave therapies for other indications [9-12], it is worth examining whether ACT shows promise in the area of suicide prevention.

ACT attempts to increase psychological flexibility mainly by targeting experiential avoidance—the tendency to avoid unwanted thoughts or emotions [13]. The 6 core processes of ACT are as follows: (1) acceptance of uncomfortable private experiences (thoughts, feelings, or physical sensations); (2) cognitive defusion/distancing from one’s own uncomfortable thoughts; (3) being present (directing attention to present events and experiences rather than focusing on the past or future); (4) self-awareness in the present moment through the “observing self;” (5) identification of personal values; and (6) commitment to action in line with the identified values. Since the publication of *Acceptance and Commitment Therapy* in 1999 by the treatment’s cocreators—Steven Hayes, Kirk Strosahl, and Kelly Wilson [13]—the number of ACT-based RCTs has increased [12]. Unsurprisingly, ACT has been used to treat common mental health conditions, such as depression, anxiety, addiction, and stress, as well as physical conditions, such as chronic pain [12,14,15]. However, trials that examine the efficacy of ACT in targeting SI/DSH continue to lack.

There is good reason to hypothesize that ACT may be effective in reducing SI and DSH by improving psychological flexibility [16]. Some of the predominant psychological frameworks that attempt to explain suicide, particularly the entrapment/cry of pain model, include escape from pain as a key factor [17-19]. Escape, referred to as experiential avoidance, is one of the key target areas of ACT treatment. The application of mindfulness skills, acceptance of distress, and defusion from distressing thoughts may improve an individual’s ability to live with the discomfort of severe emotional pain. Finally, the identification of personal values and taking up of positive action aligned with these values may lead to an integrated individual, thereby improving wellbeing.

To date, reviews of ACT for SI or DSH have not been published. A 2014 meta-analysis of the efficacy of ACT examined 60 RCTs that focused on psychiatric disorders, somatic disorders, and stress at work [12]. Of these studies, none examined SI or DSH. A 2016 meta-analysis and metaregression of studies that examined the effectiveness of psychotherapy in reducing suicidal attempts and nonsuicidal self-injury rates included 32 RCTs, none of which included ACT as a treatment despite the brief mention of its promise [20]. Hacker et al [21] highlighted the efficacy of ACT in systematic reviews but were critical of the broad range of presentations reviewed and the lack of specificity on common mental health problems. We have attempted to overcome this limitation with our focus. Given that some authors have proposed that ACT treatment has the potential to be an effective intervention for suicidal individuals [22,23], the available evidence must be reviewed. For this review, we aimed to examine (1) whether ACT is an effective treatment for SI or DSH and (2) the suitability of reported SI, DSH, and other measures in determining the efficacy of ACT.

## Methods

This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines [24].

### Search Strategy and Selection Criteria

The following electronic databases were systematically searched: MEDLINE, PubMed, EMBASE, PsycINFO, SCOPUS, Cochrane Central Register of Controlled Trials, and the Cochrane Database of Systematic Reviews. A comprehensive set of search terms was identified with reference to terminology used in previous review papers for ACT [9,12] and suicide prevention [4,25]; these terms were combined with MeSH terms relevant to each of the databases. Search terms included “acceptance and commitment therapy” or “acceptance-based therapy” and either “suicide,” “ideation,” “assisted suicide\*,” “attempted suicide\*,” “self-injurious behavior,” “self-mutilation,” “self-harm,” “self-poison\*,” “self-inflicted wounds,” “drug overdose,” “overdose,” or “parasuicide\*.” In addition, the reference lists of all included studies and relevant reviews were examined to identify additional relevant publications.

Despite the emergence of ACT in the late 1990s, no date restrictions were placed on searches that were completed on

December 11, 2017. A study was eligible for inclusion if it satisfied the following criteria: (1) The study used ACT as an intervention. Multicomponent therapy types were excluded because of our interest in examining the efficacy of ACT when used as a standalone therapeutic intervention. Interventions could be delivered to individuals or groups or through technology. (2) The study assessed suicidal behavior by using a validated measure or structured reporting. Suicidal behavior was defined in its broadest terms and ranged from SI to the various forms of self-harm indicated in the search terms. (3) The study is an original peer-reviewed article published in English. Given the recency of third-wave interventions, study design was not restricted to RCTs. Instead, all research designs were included (eg RCTs, quasiexperimental, pre–post, single group, and case studies). Finally, the age of participants was unrestricted. [Appendix 1](#) provides search term details.

### Selection Process

After the removal of duplicates, 2 researchers (JT and JN) independently reviewed the relevance of all titles and abstracts that were returned by the search. Studies considered irrelevant by both the reviewers were excluded. The full texts of the remaining articles were then independently examined by the same 2 authors to confirm eligibility. Included articles and reasons for exclusion were compared to achieve consensus and, where necessary, disputes were settled by a third researcher (FS).

### Data Extraction

One author (JT) extracted the study characteristics and outcome variables, which were independently checked by JN. The following variables were extracted: author name, publication year, sample type, control group details, program format, participant age, program length, and follow-up interval. Outcome data on SI/DSH, depression, and psychological flexibility (acceptance and mindfulness) were also extracted.

### Risk of Bias

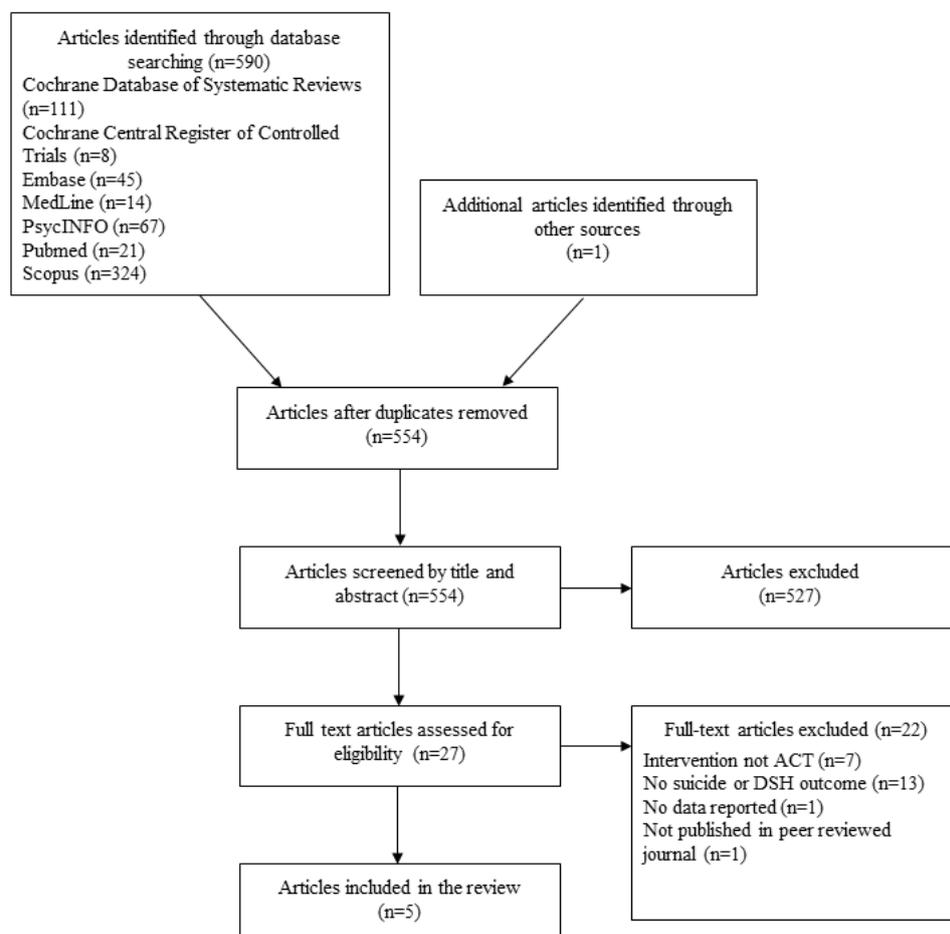
The study quality and risk of bias of the included RCTs were assessed using the Cochrane Collaboration “Risk of Bias” tool [26].

## Results

### Study Selection

The database search identified 590 articles and 1 article was found through a google scholar search. After removing duplicates (n=37), the titles and abstracts of the remaining 554 articles were screened for relevance, and 527 articles were excluded. The full texts of the 27 remaining articles were then examined, and 5 studies were finally included in the review ([Figure 1](#)).

**Figure 1.** Study selection flow diagram. ACT: acceptance and commitment therapy; DSH: deliberate self-harm.



## Study Characteristics

The characteristics of the included studies are presented in [Table 1](#), and the outcome variables are presented in [Table 2](#). All 5 studies focused on individual therapy rather than group therapy. This review included 1 mHealth RCT (N=61), 2 pre–post studies (N=981, N=35), and 2 case studies (N=2, N=3).

## Study Quality and Risk of Bias

The risk of bias was evaluated for the 1 RCT study included in this review, as shown below ([Table 3](#)). Overall, the study was judged to have a low risk of bias across all domains, except for the blinding of participants and personnel (high risk).

## Included Studies

### Study 1: Tighe et al (2017)

This study [27] aimed to evaluate the effectiveness of an ACT-based self-help mobile app (ibobbly) that targets SI, depression, psychological distress, and impulsivity among Aboriginal and Torres Strait Islander youth in remote Australia. A two-arm randomized controlled trial comprising 61 Aboriginal and Torres Strait Islander Australians aged 18-35 years was conducted in the Kimberley region of Western Australia. The

mean age of the participants was 26 years (SD 8.1). Among the participants, 64% were identified as female. Participants in group 1 immediately received the ibobbly app, which delivered acceptance-based therapy over 6 weeks. Participants in group 2 were waitlisted for 6 weeks and then received the app for the following 6 weeks. The primary outcome was the frequency and intensity of SI in the previous weeks as identified through the Depressive Symptom Inventory—Suicidality Subscale (DSI-SS) [28]. Secondary outcomes were the Patient Health Questionnaire 9 (PHQ-9) [29], the Kessler Psychological Distress Scale (K10) [30], and the Barratt Impulsivity Scale [31]. The key outcome variable for this review was the DSI-SS.

Although a significant improvement in suicidality was reported postintervention in the ibobbly arm ( $t=2.40$ ;  $df=58.1$ ;  $P=.02$ ), this difference was not significant compared with that reported in the waitlist arm ( $t=1.05$ ;  $df=57.8$ ;  $P=.30$ ). However, participants in the ibobbly group showed substantial and statistically significant reductions in PHQ-9 and K10 scores of 42% and 28%, respectively, compared with those in the waitlist group ( $P=.007$  and  $P=.02$ , respectively). No differences were observed in impulsivity. The SI, distress, and depression measures of the waitlisted participants improved after 6 weeks of using the app.

**Table 1.** Summary of included studies.

Authors	Sample	Study intervention	Control condition	Suicide/Self-harm specific outcome variables	Length of intervention	Follow-up intervals	SI <sup>a</sup> /DSH <sup>b</sup> results
Tighe et al (2017)	Aboriginal and Torres Strait Islander Australian youth ages 18-35 (N=61)	ACT <sup>c</sup> mHealth app (ibobbly)	Waitlist (6 weeks)	SI (DSI-SS <sup>d</sup> )	Self-help app over 6 weeks	None	30% reduction in SI but nonsignificant
Walser et al (2015)	Veterans (N=981)	ACT-D <sup>e</sup> (specifically designed for veterans)	None	SI (BDI-II <sup>f</sup> , 1 SI Item)	12-16 psychotherapy sessions	None	20.5% reduction in prevalence of SI among participants
Ducasse et al (2014)	Psychiatric patients (N=37)	ACT	None	SI (C-SSRS <sup>g</sup> ), Scale for Suicidal Ideation (SSI score) and suicidal ideation on a visual analog scale (self-report)	7 weekly 2 h sessions	1 week and 3 months	Significant reductions in all SI measures at 1-week and 3-month follow-up
Luoma & Valatte (2012)	Case studies (N=2)	ACT	None	Case study reports on suicidal ideation and self-harm.	38 psychotherapy sessions (n=1)	1 year (n=1) and unspecified (n=1)	Reductions in SI (N=2).
Rassaque et al (2012)	Case studies (N=3)	ACT	None	Interviews and hospital ward reports measuring suicidal ideation and self-harm expression	20 minute one-to-one sessions over 2 to 3 weeks	Unspecified	“a marked reduction in self-harm and suicidal ideation” (n=1), “changes in expression of self-harm or suicidal ideation” (n=2)

<sup>a</sup>SI: suicidal ideation.

<sup>b</sup>DSH: deliberate self-harm.

<sup>c</sup>ACT: acceptance and commitment therapy.

<sup>d</sup>DSI-SS: Depressive Symptom Inventory—Suicidality Subscale.

<sup>e</sup>ACT-D: acceptance and commitment therapy for depression.

<sup>f</sup>BDI-II: Beck Depressive Inventory.

<sup>g</sup>C-SSRS: Columbia-Suicide Severity Rating Scale.

**Table 2.** Outcome measures reported in the included studies. An "X" indicates the presence of the measure.

Measure	Tighe et al (2017)	Walser et al (2015)	Ducasse et al (2014)	Luoma and Valatte (2012)	Razzaque et al (2012)
Scale for Suicidal Ideation			X		
Suicidal Ideation (Self-Assessment Visual Analog scale)			X		
Columbia-Suicide Severity Rating Scale (suicidal ideation subscore=severity and intensity items)			X		
Suicidal Ideation	X				
Beck Depressive Inventory-II		X	X		
Patient Health Questionnaire	X				
Kessler 10	X				
Barrett Impulsivity Scale	X				
Acceptance and Action Questionnaire		X	X		
Five-Facet Mindfulness Questionnaire		X		X (n=1)	
Mini International Neuropsychiatric Interview (French version)			X		
Screening Interview for Axis II Disorder			X		
Inventory of Depressive Symptomatology			X		
Functioning Assessment Short Test			X		
Pharmacological treatment and number of visits for psychiatric emergencies (previous 3 months)			X		
Psychological pain on a visual analog scale			X		
State-Trait Anxiety Inventory			X		
Beck Hopelessness Scale			X		
World Health Organization Quality of Life measure			X		
Clinical Global Index					X

**Table 3.** Risk of bias for the randomized controlled study reported by Tighe et al (2017) [27].

Entry	Judgment	Support for judgment
Random sequence generation (selection bias)	Low risk	<ul style="list-style-type: none"> <li>Quote: "using block randomization stratified by gender (16 per block), using computer-generated randomization"</li> <li>Comment: Probably done.</li> </ul>
Allocation concealment (selection bias)	Low risk	<ul style="list-style-type: none"> <li>Quote: "Each block randomization was performed offline by a member of the research team at the Black Dog Institute and sent to the research officer in Broome."</li> <li>Comment: Probably done.</li> </ul>
Blinding of participants and personnel (performance bias)	High risk	<ul style="list-style-type: none"> <li>Quote: "research officer in Broome who was responsible for and not blind to the intervention allocation"</li> <li>Comment: Probably not done.</li> </ul>
Blinding of outcome assessment (detection bias; patient-reported outcomes)	Low risk	<ul style="list-style-type: none"> <li>No blinding of outcome assessment used. Outcome measures were self-reported and it is unlikely that the outcome measurement would be influenced by blinding.</li> </ul>
Incomplete outcome data addressed (attrition bias)	Low risk	<ul style="list-style-type: none"> <li>Follow-up: minimal missing data. 2/31 missing from intervention group; 0/30 missing from control group. Reasons unlikely to be related to outcome.</li> </ul>
Selective reporting (reporting bias)	Low risk	<ul style="list-style-type: none"> <li>Quote: "The study protocol has been published."</li> </ul>

### Study 2: Walser et al (2015)

Walser et al (2015) [32] conducted a pre-post evaluation to measure the effectiveness of ACT in treating depression and SI in a group of veterans (N=981). They utilized a modified version of ACT for depression (ACT-D) specifically designed for veterans. The mean age of the participants was 50.5 years (SD 12.5), and 75% of the participants were identified as male. The intervention, which encompassed the 6 core processes of ACT, was administered over 12-16 individual psychotherapy sessions. Depression and SI were measured using the Beck Depressive Inventory (BDI-II) [33]. Experiential acceptance and mindfulness (2 goals of ACT) were also measured to determine their effect on depression and SI. Experiential acceptance was measured with the Acceptance and Action Questionnaire [34], and mindfulness was measured with the Five-Facet Mindfulness Questionnaire (FFMQ) [35]. The key outcome variable for this review is the BDI-II (suicide item).

The percentage of participants with no SI increased from 44% at baseline to 65% at follow-up because SI scores significantly decreased. Depression significantly reduced, as indicated by BDI-II scores. Specifically, scores decreased by 32% and 40% in participants with and without SI at baseline, respectively. Increases in mindfulness scores were associated with a reduction in depression severity across time ( $P=.04$ ). Decreases in experiential avoidance scores were associated with a reduction in SI across time ( $P=.02$ ). However, mindfulness scores were not significantly related to SI scores over time.

### Study 3: Ducasse et al (2014)

In 2014, Ducasse et al [36] conducted a pilot study on adjunctive ACT with a cohort of French outpatients (N=35) who were diagnosed with suicidal behavior disorder on the basis of DSM-5 criteria (Section III) [37]. All had attempted suicide in the previous year. The study featured an ACT program as an add-on to treatment-as-usual. Among the participants, 57% were identified as male. The median age was 38.4 years (18-60, no mean age reported). The intervention was delivered through 7 individual weekly sessions. Each session lasted for 2 h, and written summaries were provided at the end of each session for practice at home. One suicide was reported in the first month of the study. The authors reported that this suicide had no clear link to the study. Measures were taken at 1 week prior to program, 1 week postprogram, and 3 months after program completion.

The Columbia-Suicide Severity Rating Scale (C-SSRS) [38], Scale for Suicidal Ideation (SSI) [39], and the Inventory of Depressive Symptomatology (IDS-C30) [40] were administered. Self-assessments included the following: (1) SI on a visual analog scale from 0 (none) to 10 (maximum); (2) depression severity using the Beck Depression Inventory-II [33]; (3) psychological pain on a visual analog scale from 0 (none) to 10 (maximum); (4) anxiety state using the State-Trait Anxiety Inventory [41]; (5) hopelessness using the Beck Hopelessness Scale [42]; (6) quality of life using the World Health Organization Quality of Life measure [43]; and (7) acceptance using the Acceptance and Action Questionnaire (AAQ) [34]. The key outcome variables for this review were the C-SSRS and the SSI.

All scores between 3 visits significantly decreased ( $P<.001$ ). The C-SSRS SI subscore and SSI score (7, 0-22 vs 0, 0-10;  $P<.001$ ) significantly decreased from preintervention to the 1-week postprogram follow-up (20, 0-30 vs 0, 0-20, respectively;  $P<.001$ ). The intensity of current and previous SI during the last 15 days significantly decreased between inclusion and 1-week postprogram follow-up (1, 0-10 vs 0, 0-3; 2, 0-9 vs 0, 0-5, respectively; both  $P<.001$ ). The SI (C-SSRS) subscore was correlated to the AAQ score ( $P=.04$ ,  $r=-0.37$ ) but not to BDI-II score. At 3-month follow-up, all SI scores remained significantly low. However, the actual scores were not reported. This study also reported a reduction in depression between baseline and 1-week follow-up (BDI-II [13, 2-28 vs 4.5, 0-24;  $P<.001$ ]) and IDS-C30 scores (28, 12-61 vs 8, 0-31;  $P<.001$ ).

### Study 4: Luoma and Villatte (2012)

Luoma and Villatte [44] reported on 2 case studies. One case included 1 patient with chronic SI, and the other included 1 patient with transient SI. The patients were treated "largely from an ACT perspective."

#### Case Study 1

Anne (22) underwent ACT therapy while on a waitlist for DBT for assistance with intense emotional dysregulation, deliberate self-injury, and suicide risk. Anne had a history of suicide attempts, had been struggling with persistent suicidal thoughts, and met the criteria for multiple Axis I and II disorders. Over the course of therapy, significant increases on the FFMQ [35] were reported in line with overall decreases in symptomatology and borderline features. The authors reported a reduction in SI and DSH but did not state the measures used. After 18 treatment sessions, Anne's level of psychological distress had fallen to subclinical levels on 2 symptom inventories (not specified in the paper). Treatment continued biweekly for 20 additional weeks before termination. At 1-year follow-up, Anne's mindfulness scores remained high, and she no longer met the current criteria for any psychological disorder.

#### Case Study 2

Considerably limited background information was provided for the second case study, which featured a 47-year-old male. Mark initiated therapy after attempting suicide shortly after losing his family in a motor vehicle accident. The authors reported that after 6 months of ACT, Mark no longer considered suicide as a viable option. However, the authors did not describe the psychological measures used in the case.

### Study 5: Razaque (2012)

Razaque's study [45] detailed the delivery of ACT to 3 patients in the psychiatric intensive care unit of Goodmayes Hospital in East London. All 3 had a lengthy history of regular bouts of violence toward themselves or others. The first had a primary diagnosis of schizoaffective disorder, with an average of 2-3 psychiatric admissions per year. The second and third participants were diagnosed with bipolar affective disorder. Their presentations included frequent bouts of violence toward themselves, family members, carers, and ward staff. The treatment consisted of 20 min one-to-one ACT sessions delivered daily over 2-3 weeks.

Violence and aggression toward others were measured in addition to self-harm expression and/or SI. Aggressive and abusive behaviors were recorded in regular nursing shift reports. No specific measure was used for the measurement of self-harm or SI. However, interviews and ward reviews were used to record changes in self-harm expression and SI. In addition to reductions in derogatory auditory hallucinations, self-harm and SI markedly reduced for the patient diagnosed with schizoaffective disorder. The aggressive and abusive behaviors of the 2 patients diagnosed with bipolar disorder reduced.

## Discussion

### Principal Findings

This review aimed to understand if ACT can successfully reduce SI or self-harm and to examine the suitability of the measures used in the included studies. The review found few empirical investigations on ACT that specifically target the reduction of SI/DSH, with only 1 RCT among the 5 studies. This is the first review we are aware of that has examined the impact of ACT on the reduction of SI/DSH.

All 5 studies examined SI by using various measures, and only the 2 case studies examined DSH. All studies reported a reduction in SI, and both case studies reported reductions in DSH over the course of the interventions. The degree of the reduction in SI varied: Tighe et al [27] reported a nonsignificant 30% reduction in SI scores, and Walser et al reported a significant 20.5% reduction in the prevalence of SI among participants at follow-up [32]. Ducasse et al [36] reported significant reductions in all SI measures at 1-week and 3-month follow ups [36]. However, the effective evaluation of ACT treatment was diminished given that the ACT component of the participants' therapy was provided as an add-on to treatment-as-usual. The authors of this trial concluded that ACT might help reduce the intensity and frequency of SI by increasing acceptance and valued action and by reducing risk factors, such as hopelessness and psychological pain [36]. The 2 case studies measured and reported a reduction in SI and DSH [44,45].

Although this review focuses on SI and DSH, the secondary measures of depression, acceptance, and mindfulness are crucial for evaluating the effectiveness of ACT. Among the 5 studies included in this review, 3 reported outcomes for depression. This review supports the existing body of evidence that highlights the effectiveness of ACT in this common presentation [12]. Tighe et al [27] found that depression scores in the intervention group significantly reduced by 42% relative to that in the waitlist group. Walser et al [32] reported a 32% and 40% reduction in the depression scores of the cohort of veterans with and without recorded SI at baseline, respectively. The pre-post study conducted by Ducasse et al [36] lacked a control group but showed significant reductions for all measures, including depression. The positive results of ACT on depression support recent research that highlights the potential of ACT as an intervention for common mental health conditions, such as depression and anxiety [12,46]. Furthermore, the reductions in depression and SI reported by the included studies support previous research demonstrating that reductions in depression

can lead to reductions in SI [47,48]. The use of the BDI-II by Walser et al [32] to measure depression and the presence of SI provided limited data on SI/DSH. The use of focused SI/DSH measures in future studies would likely enrich analyses. Notably, most measures were not common between studies. However, 2 of the 5 studies included the AAQ and the FFMQ, which are key measures of acceptance and mindfulness (key goals of ACT treatment). Including these measures in future studies on ACT would be useful because their analyses could show potential associations with SI/DSH. The use of established standardized measures of SI/DSH in RCTs and case studies would also improve the evidence base for ACT.

The 5 studies included 3 distinct cohorts of participants. The mHealth RCT by Tighe et al [27] targeted Aboriginal and Torres Strait Islander youth. Walser et al [32] targeted veterans of the United States Army, and Ducasse et al [36] targeted French outpatients with a recent suicide attempt. In the 2 included case studies, 3 of the 5 participants were suffering from severe distress in hospital settings. Across these diverse populations, ACT was positively associated with a reduction in SI. The methodological quality of the studies was low, with just 1 (Tighe et al) [27] including a control group. The 2 studies that reported positive results for SI through case studies (N=2 and N=3) had limited participants and lacked robust research frameworks from which to draw conclusions [44,45]. Both studies report impressive reductions in SI for all the 5 individuals studied; however, the studies had numerous limitations, including lack of specificity in the measurement of SI and self-harm reports (apart from hospital ward reports). Details regarding treatment-as-usual, such as medication administration to participants, were not provided. Notably, the only RCT included in this review delivered therapy through a self-help mobile app [27]. Whether this is indicative of an increasing adoption of mHealth is worth considering [49-51].

All 5 studies showed that ACT is associated with symptom changes. This result provides a rationale for the largescale systematic evaluation of the efficacy of ACT as an intervention for suicidal behavior. Tighe et al [27] reported significant reductions in depression and distress on standardized measures and a 30% reduction in SI scores. This reduction, however, was nonsignificant between groups. All 5 participants whose case studies were presented improved significantly with marked reductions in SI/DSH [44,45]. In addition to the significant results for SI, the 2 pre-post studies showed improvements on the AAQ, a measure of psychological flexibility [32,36]. Walser et al [32] showed that their improvements on the AAQ are associated with a reduction in SI scores across time. Similarly, Ducasse et al [36] found a significant correlation between SI and AAQ scores, such that increased acceptance is associated with reduced SI. Accepting reality and reducing avoidance are fundamental aims of ACT, and this therapeutic work is aligned with the theories of suicide that focus on an individual's sense of entrapment and/or desire to escape their current reality [17-19]. Further trials are needed to test how increases in experiential acceptance and mindfulness affect SI/DSH scores and whether targeting these factors might increase reductions in SI/DSH.

## Conclusion

The number of studies included in this review is too small to support the claim that ACT can effectively assist in the reduction of SI/DSH. Given the limited research that has been conducted

on this topic to date, the efficacy of ACT in reducing SI or DSH requires further testing, particularly through controlled trials. The early evidence presented in this review suggests that the potential mechanisms of action, such as changes in experiential avoidance and mindfulness, should receive focus.

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## Authors' Contributions

JT and JN reviewed all publications for relevance and FS settled disputes. All authors made substantial contributions to the review design, writing, and editing.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Database search terms.

[[PDF File \(Adobe PDF File\), 36KB - mental\\_v5i2e10732\\_app1.pdf](#)]

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## Abbreviations

**ACT:** acceptance and commitment therapy  
**ACT-D:** acceptance and commitment therapy for depression  
**BDI-II:** Beck Depressive Inventory  
**C-SSRS:** Columbia-Suicide Severity Rating Scale  
**CBT:** cognitive behavioral therapy  
**DBT:** dialectical behavioral therapy  
**DSH:** deliberate self-harm  
**DSI-SS:** Depressive Symptom Inventory—Suicidality Subscale  
**FFMQ:** Five-Facet Mindfulness Questionnaire  
**IDS-C30:** Inventory of Depressive Symptomatology  
**K10:** Kessler Psychological Distress Scale  
**MBCT:** Mindfulness-Based Cognitive Therapy  
**PHQ-9:** Patient Health Questionnaire 9  
**RCT:** randomized controlled trial  
**SBD:** Suicidal Behavior Disorder  
**SI:** suicidal ideation  
**SSI:** Scale for Suicidal Ideation

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Original Paper

# A Web-Based Transdiagnostic Intervention for Affective and Mood Disorders: Randomized Controlled Trial

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## Abstract

**Background:** Research increasingly supports a transdiagnostic conceptualization of emotional disorders (ie applying the same underlying treatment principles across mental disorders, without tailoring the protocol to specific diagnoses), and many international researchers are currently investigating this issue.

**Objective:** The aim of this study was to evaluate the efficacy and acceptability of a Web-based transdiagnostic program using a sample of Romanian adults diagnosed with anxiety and/or depression.

**Methods:** Volunteer participants registered for the study and completed a series of online self-report measures. Participants who fulfilled basic inclusion criteria on these measures were contacted for a telephone diagnostic interview using the Structural Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, 4th Edition Axis I Disorders (SCID-I). Enrolled participants were randomized to either the active treatment group (N=69) or the wait-list control group (N=36) using a 2:1 ratio. The transdiagnostic treatment was based on the Unified Protocol for Transdiagnostic Treatment of Emotional Disorders (UP; Barlow et al, 2011) that addresses common underlying mechanisms of anxiety and depression. Participants randomized to the active treatment condition received 10 weeks of Web-based treatment based on the UP. Throughout treatment, graduate students in clinical psychology provided guidance that consisted of asynchronous written communication on a secure Web platform. After the intervention, participants in both study conditions were invited to complete a set of self-report measures and a postintervention SCID-I interview conducted by a different team of graduate students blinded to participants' group and diagnostic status. Six months later, participants in the active treatment group were invited to complete an online follow-up assessment.

**Results:** During the intervention, active treatment participants completed on average 19 homework assignments (SD 12.10), and we collected data from 79.0% (83/105) at postintervention and 51% (35/69) at follow-up for self-report measures. Postintervention SCID-I interviews were collected from 77.1% (81/105) participants. Relative to the wait-list control group, the transdiagnostic intervention yielded overall medium to large effect sizes for the primary outcome measures (within-group Hedges  $g=0.52-1.34$  and between-group  $g=0.39-0.86$ ), and also for anxiety sensitivity ( $g=0.80$ ), symptom interference ( $g=0.48$ ), and quality of life ( $g=0.38$ ). Significant within-groups effects *only* were reported for the active treatment group on Panic Disorder Severity Scale-Self Report (PDSS-SR,  $g=0.58-0.65$ ) and Yale-Brown Obsessive Compulsive Scale (Y-BOCS,  $g=0.52-0.58$ ).

**Conclusions:** Insignificant between-group differences for the Y-BOCS and PDSS-SR could be explained by the small number of participants with the associated primary diagnostic (eg, only 3 participants with obsessive compulsive disorder) by the choice of outcome measure (PDSS-SR was not rated among the evidence-based measures) and by the fact that these disorders may be more difficult to treat. However, the overall results suggest that the transdiagnostic intervention tested in this study represents an effective treatment option that may prove easier to disseminate through the use of Web-based delivery systems.

**Trial Registration:** ClinicalTrials.gov CT02739607; <https://clinicaltrials.gov/ct2/show/study/NCT02739607> (Archived by WebCite at <http://www.webcitation.org/6yY1VeYIZ>)

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## KEYWORDS

transdiagnostic; anxiety disorders; depressive disorder; cognitive therapy

## Introduction

### Background

The evidence-based approach to psychotherapy consists of a continuous effort devoted to explore the most effective strategies to reduce psychopathology used by researchers around the world. As support for the effectiveness of manualized, disorder-specific cognitive behavioral therapies (CBTs) emerged, some researchers geared their efforts toward gaining a broader understanding of psychopathology. Arguments for the high comorbidity of affective and anxiety disorders were fueled by the fact that about half of the clients diagnosed with one disorder also have a second diagnostic [1]. Such disorders present overlapping symptoms and share risk and maintaining factors, which further suggests a set of common higher order factors (ie, positive and negative emotions) across various Axis I diagnostic categories [2,3]. Barlow and colleagues [4] also convincingly argued that affective and anxiety disorders may be related to a number of common underlying mechanisms, while only trivial differences seem to separate them. This broader conceptualization of psychopathology inspired researchers and clinicians to develop transdiagnostic programs with common intervention components that match the higher order factors within a parsimonious and elegant framework [5-7]. Recently, numerous researchers joined this paradigmatic shift [8], planning [9] and publishing an amounting number of studies on this topic [10], and in 2017, the *Journal of Anxiety Disorders* dedicated a special issue to current and ongoing transdiagnostic approaches for anxiety.

As the literature evolved, the transdiagnostic label was used to cover conceptually dissimilar constructs. In an effort to gain a common understanding of this term, Sauer-Zavala and colleagues [11] suggested three classes of treatment approaches that are currently labeled as transdiagnostic: (1) universally applied therapeutic principles, (2) empirically based modular strategies, and (3) the shared mechanism approach. The universal therapeutic principles represent a *top-down* approach where general intervention techniques are used across disorders. For example, in the cognitive therapy framework, patients are encouraged to identify cognitive distortions and reevaluate experiences in a more realistic fashion, whereas in the acceptance and commitment therapy framework, patients are encouraged to be more accepting, to cultivate cognitive defusion, mindfulness, and to pursue their life values. The modular strategy represents an approach where relevant intervention strategies are used to address each problem presented by an individual patient regardless of his diagnostic. Finally, the shared mechanism approach focuses on addressing common underlying mechanisms according to theoretical models of psychopathology. For example, transdiagnostic interventions

from this category (ie, Unified Protocol for Transdiagnostic Treatment of Emotional Disorders, UP) use a *bottom-up* approach by identifying the core vulnerabilities that contribute to the development and maintenance of multiple disorders and then design strategies to target them. However, research on the nature of shared mechanism or core underlying processes for affective and anxiety disorders is still emerging [12,13].

A number of individual studies have investigated the efficacy of transdiagnostic treatments, all with promising results [6,14]. In one of the largest randomized controlled trials (RCTs) of a transdiagnostic approach to date, Barlow and colleagues compared their UP with gold-standard, evidence-based protocols designed to treat the diagnostic-specific symptoms (ie, single-disorder protocols, SDPs) of generalized anxiety disorder (GAD), social anxiety disorder (SAD), obsessive compulsive disorder (OCD), and panic disorder/agoraphobia (PD/A). In this trial, the UP produced significant reductions in symptom severity across these disorders that were statistically equivalent to SDPs both at acute outcome and at 6-month follow-up [15]. In a series of 4 studies, Titov and colleagues [16-19] compared their transdiagnostic program with disorder-specific programs designed to address GAD, major depressive disorder (MDD), SAD, and PD/A, and those programs were delivered using either a clinician-guided or a self-guided format. Their results consistently showed equivalence between the two approaches (transdiagnostic vs disorder-specific) and the two treatment formats [16-19].

Recent reviews and meta-analytic studies also support the efficacy of transdiagnostic approaches. For example, after analyzing 11 studies where transdiagnostic interventions for various anxiety disorders were compared with wait-list control or treatment as usual, a moderate effect was revealed at posttreatment ( $d=0.68$ ), which was maintained at follow-up [20]. The full spectrum of transdiagnostic packages for anxiety and affective disorders using a wide range of delivery methods (individual, group, computerized, or Internet supported) were included in a recent evaluation of 50 studies [21]. Here, large pre- to posttransdiagnostic treatment effect sizes (ESs) were found for depression (Hedges  $g=0.91$ ) and anxiety ( $g=0.86$ ) and moderate effects for quality of life (QoL;  $g=0.69$ ). When the transdiagnostic treatments were compared with wait-list control or treatment as usual or attention training interventions, medium ES emerged for anxiety ( $g=0.65$ ) and QoL ( $g=0.46$ ), whereas large ES emerged for depression ( $g=0.80$ ). Transdiagnostic and diagnostic-specific intervention programs for anxiety disorders were compared, and both program types yielded large ES and overlapping CIs [22]. Finally, a synthesis of 17 studies demonstrated that computerized or Internet-delivered transdiagnostic interventions outperformed their respective control groups on anxiety, depression, and QoL [23]. So it

appears that the new generation of transdiagnostic programs are at least as effective as existing disorder-specific CBT protocols in reducing anxiety symptoms.

Advances in the evidence-based practice paradigm demand thorough investigations of intervention programs conducted in various cultures and contexts. Before being classified as highly effective, any new program should be validated by results obtained by at least two independent research teams [24]. Although previous research seems to favor transdiagnostic interventions for anxiety and depressive disorders, continued research is needed to further evaluate the efficacy of such programs around the world. To date, it is unclear how effective shared mechanism transdiagnostic programs are when used in various contexts and whether an abbreviated version delivered using a Web-based format represents a viable and effective treatment option. Moreover, combining the positive features of transdiagnostic programs with the advantages of Internet-delivered interventions (treatment fidelity, reduced costs, increased accessibility by disarming geographical barriers, and schedule conflicts) represents an important, innovative avenue for testing and disseminating evidence-based treatments.

### Study Aim

This study is part of the ongoing effort to explore the effectiveness of transdiagnostic programs as a way to strengthen the evidence-based approach to effective treatments [13,21,22]. Specifically, we evaluated the efficacy and acceptability of an established transdiagnostic treatment for anxiety and affective disorders [5] implemented in Romania using a Web-based guided delivery format. To our knowledge, this is the first evaluation of the UP using a Web-based format and at the same time the first time it was used on a Romanian sample. The UP was designed to address common underlying mechanism, and therefore, it pertains to the shared mechanism approach, being different from other transdiagnostic programs in terms of both design and components. Immediate and long-term (6 months) treatment effects were measured for a large sample of adults

with anxiety and/or affective disorders that were randomized to either an active treatment condition or a wait-list control group. Our hypothesis was that participants receiving the study treatment would display significantly lower levels of depression and/or anxiety symptoms at the end of the treatment compared with those in the wait-list control group and that these improvements would be maintained 6 months following treatment. We also hypothesized that participants' anxiety, sensitivity, and symptom interference would decrease, and their life quality would increase as a result of the treatment. Finally, we explored the impact of the intervention on participants' perfectionism level, hoping to see a significant decrease on this emotion-driven behavior.

## Methods

### Overview

The study was approved by the Ethical Commission of West University of Timisoara, Romania (4509/26.02.2016) and was registered on ClinicalTrials.gov as NCT02739607. Written informed consent was obtained from all participants by surface mail.

### Participants

A total of 105 participants with a clinical diagnostic of either an affective disorder, an anxiety disorder, or any combination of affective and anxiety disorders were selected for this study. The online recruitment process was designed to be broadly inclusive, with few exclusion criteria. Eligibility and ineligibility criteria for participants are shown in [Textboxes 1](#) and [2](#).

Individuals taking psychotropic medications at the time of enrollment were required to be stable on the same dose for at least 4 weeks before enrolling in the study. Furthermore, participants were asked neither to change their psychotropic medications nor to begin another psychosocial treatment program during the study.

#### Textbox 1. Eligibility criteria.

Individuals were eligible for the study if they

1. were fluent in Romanian
2. were at least 18 years of age
3. had at least one self-report score within the cut-off range specified for each screening measure (eg, Beck Depression Inventory-II between 15-51, SPIN between 21-50, Penn State Worry Questionnaire between 45-68, YBOCS between 8-31, Panic Disorder Severity Scale-Self Report between 6-15, and *Posttraumatic stress disorder Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* between 38-72)
4. received at least one current diagnostic of an affective (major depression or dysthymia) and/or an anxiety disorder on Structural Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, 4th. Edition Axis I Disorders
5. had no obstacle to participation (ie, had Internet access, did not have plans to travel for an extended time during the treatment, etc)

**Textbox 2.** Ineligibility criteria.

Participants were excluded from the study if they

1. reported significant suicidal ideation (a score of 2 or above on the Beck Depression Inventory-II suicide item) or parasuicidal behavior (as measured by the Screening Questionnaire of the Structural Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, 4th Edition)
2. had one or more incompatible psychological disorders (ie, personality disorder, bipolar disorder, or psychosis)
3. displayed extremely high clinical symptoms (ie, over the highest specified cut-off score) on the self-report clinical measures (see also inclusion criteria 3)
4. currently receiving a psychosocial treatment

All excluded participants were directed toward other resources such as face-to-face psychotherapy and/or psychiatric assessment and treatment.

Participants who intended to remain anonymous were encouraged to create a special email account for this study. The Web platform did not allow multiple ID's for the same email account. A confirmation message was sent to the email account provided by the participant as a logistical measure.

**Study Procedure**

The study was advertised in the local and national media following a press conference organized by the West University of Timisoara, Romania in April 2016. Interested participants could freely register or enroll for the study online [25]. After electronically signing the informed consent (ie, compulsory check box), participants were instructed to complete a series of online self-report measures as part of the screening process (see the Measures section). Participants who completed the online screening and scored in the range of the cut-off scores (mild to moderate clinical symptoms) were contacted and invited to take a phone interview using the Structural Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, 4th. Edition Axis I Disorders (SCID-I). The screening interviews (N=162) were conducted by graduate clinical psychology students, who were supervised by an experienced clinical psychologist. If participants met the diagnostic criteria for at least one affective and/or anxiety disorders, they were invited by email to take part in the study. At the end of the recruitment process, all registered participants received general feedback about their screening results. Excluded participants were informed about the reason for their status and guided to seek appropriate help in their community, whereas included participants were informed that they would be randomly assigned to either the immediate or the 10-week delayed treatment. Overall anxiety and depression symptom severity were collected online from all participants during the odd weeks of the program, while only the immediate treatment group received the transdiagnostic intervention. After the 10-week program, all included participants were invited to complete the postintervention online assessment and were contacted by phone to complete a diagnostic interview using the SCID-I. A different team of six graduate students blinded to participants' preintervention diagnostic and group conducted the postintervention interviews under supervision. The postintervention online assessment included the same self-report measures as the screening, plus the *Treatment Satisfaction Questionnaire* for the active treatment group. After the

postintervention assessment, the wait-list control group was invited to take part in the transdiagnostic treatment. Finally, a 6-month follow-up assessment was taken for the immediate-treatment group only, as the wait-list control group was lost to follow-up.

**The Transdiagnostic Treatment**

In this study, participants received a Web-based transdiagnostic intervention for anxiety and mood disorders. The Romania version of the program was based on Barlow and colleague's UP [5]. UP treatment modules were adapted for the online environment, but the treatment structure was conceptually similar. We retained only nine treatment sessions for our guided intervention, as our previous experience suggests this represents an adequate length for treating participants over the Internet [26]. In this study, a simplified treatment version was used with similar outcome results as the longer version [26]. The transdiagnostic program was designed as a stand-alone intervention, and the program content was unchanged during the trial. At the beginning of the treatment, participants were encouraged to complete one session per week and the associated homework assignments. The program first sought to increase participants' motivation for the transdiagnostic treatment and guided them to define a set of specific treatment goals (session 1). Then participants were encouraged to intentionally notice their intense emotional experiences and to monitor them on a daily basis (session 2). Participant's reaction to their intense emotions and a set of mindfulness exercises were addressed in the following week (session 3). The role of cognitive processes and the impact of cognitive distortions were presented next (session 4). The emotional avoidance and the concept of perfectionism as an instance of emotion-driven behavior (session 5) and the opposite action as a first attempt to practice exposure or behavioral activation (session 6) were presented next. Session 7 was entirely dedicated to confronting intense emotions via imaginary or in-vivo exposure, while session 8 continued the exposure process by guiding participants to confront their physical sensations. Finally, participants were asked to review the strategies learned throughout the entire program and to device a relapse prevention plan for the future (session 9). All participants were guided through the program in the same order (sessions 1-9), and access to the next session was granted if participants partially completed their homework assignments of the previous session.

Active treatment participants could access the nine sessions using their own device (computer, tablet, etc) at a time and place of their convenience. Eight graduate students in clinical

psychology assisted and guided participants throughout the treatment by monitoring their activities on the platform and by exchanging written communications through an internal email system. Shortly before the study, the graduate students undertook an 8-hour training where the transdiagnostic concepts and principles were presented and exemplified by four case studies. Supervised by an experienced psychotherapist, the graduate students provided personalized feedback for participants' homework assignments and answered their questions within a 24h interval. In terms of the frequency of message exchange, if participants did not initiate a written message with the graduate student assigned to them (which was seldom the case), they received a weekly feedback for their homework assignments. In case of inactivity, a participant received up to three written reminders on the platform, at a rate of one message per week. All participants were assisted free of charge for a 10-week interval: 9 weeks for each session and one extra week for their eventual delays. During this time, participants in the wait-list control group were only invited to complete the online self-report measures. After the 10-week treatment ended, no further guidance was provided, but participants continued to have access to the treatment for the next 6 months (until the follow-up assessment).

Our Web platform consists of two distinct but interconnected modules designed for online assessment and online psychotherapy. The Web platform was design as an infrastructure to facilitate written asynchronous communication. Access to the platform is controlled by ID and password, and all sensitive content is encrypted and stored on a secure server. The platform was previously tested during an open trial designed for healthy participants, and the only improvement consisted of the auto-save option for homework assignments. The Web platform was developed by a Romanian information technology team coordinated by the first author.

### Study Design, Randomization, and Power

To empirically investigate the efficacy of a Web-based transdiagnostic program, we used a (phase II) simple RCT design in which participants were assigned to either an immediate treatment or wait-list control group. Study design complied with the CONSORT EHEALTH checklist (see [Multimedia Appendix 1](#)). Randomization followed a 2:1 ratio, such that two-thirds of the participants were assigned to the immediate treatment group to maximize engagement and retain most participants for the postintervention assessment. The randomization was conducted with all included participants 1 day before starting the intervention program. One of the authors (AR), who was not involved in the selection process, generated the pseudorandom allocation sequence of participants' ID by using an available online tool (<https://www.randomizer.org>). Technically, included participants were allocated to either the active treatment group or the wait-list control group by the graduate students working on the Web platform.

To estimate study power for two independent groups (one-tailed comparison), we used G\*Power [27,28]. The RCT was powered to detect an ES of  $d=0.60$  at posttreatment (Cronbach  $\alpha=.05$ ) at a power of 89% (1-beta). Although the 2:1 allocation ratio

decrease study power, it was used to maximize participants' involvement in the active treatment group.

### Outcome Measures

As the transdiagnostic intervention addressed simultaneously more than one disorder, more than one primary outcome measure was included. In our opinion, limiting the primary outcome measures to only one dimension would not have accurately reflected the outcomes of this trial.

#### Primary Outcome Measures

*Beck Depression Inventory-II* (BDI-II) [29] is a widely used 21-item measure of current depression. Data on the scale's reliability and validity were reported in clinical samples [29,30], and the scale is considered an evidence-based outcome measure [31].

*Penn State Worry Questionnaire* (PSWQ) [32] is a 16-item measure of general anxiety or worry with excellent psychometric proprieties [33]. Compared with other anxiety disorders, PSWQ scores are higher for a GAD clinical sample [33,34], and the scale is considered an evidence-based outcome measure [35].

*Social Phobia Inventory* (SPIN) [36] is a 17-item measure design to assess participants' social anxiety. The scale has good to excellent psychometric proprieties [36,37] and was considered an evidence-based outcome measure [38].

*Yale-Brown Obsessive Compulsive Scale* (Y-BOCS) [39] assesses the presence or severity of obsessions (items 1-5) and compulsions (items 6-10). The Y-BOCS has demonstrated good convergent validity, is sensitive to treatment-related change [39], and is considered an evidence-based outcome measure [40].

*Panic Disorder Severity Scale-Self Report* (PDSS-SR) [41] is a 5-item scale designed to capture panic symptoms. The PDSS-SR displays good internal consistency and construct validity [41].

*Posttraumatic stress disorder (PTSD) Checklist for Diagnostic and Statistical Manual of Mental Disorders-5th Edition* (PCL-5) [42] is a 20-item measure designed to assess participant's level of posttraumatic stress. The scale demonstrated very good reliability and validity [42].

*Overall Anxiety Severity and Impairment Scale* (OASIS) [43] is a 5-item questionnaire developed to capture anxiety-related symptom severity and impairment across anxiety disorders. This measure has good to excellent psychometric proprieties [43,44].

*Overall Depression Severity and Impairment Scale* (ODSIS) [45] is also a 5-item instrument designed to measure severity and impairment of depressive symptoms. In a recent psychometric evaluation, the ODSIS demonstrated high internal consistency and good convergent and discriminant validity [45].

#### Secondary Outcome Measures

*Anxiety Sensitivity Index* (ASI) [46] is a 16-item questionnaire designed to assess fear of anxiety-related symptoms. The ASI displays a high internal consistency [46] and test-retest reliability

[47] and is considered an evidence-based outcome measure [48].

*Quality of Life Inventory* (QOLI) [49] consists of 16 items pertaining life satisfaction. Respondents rate each item on its importance and overall satisfaction. Validity of the QOLI was demonstrated by positive correlations with other related measures of well-being and negative correlations with measures of psychopathology [49].

*Work and Social Adjustment Scale* (WSAS) [50] is a 5-item measure that captures the symptoms interference in work, home management, leisure, and family relationships. The WSAS has been successfully used in previous studies [51].

*Almost Perfect Scale-Revised* (APS-R) [52] is a 23-item questionnaire with three subscales: high standards, order, and discrepancy. Each item is rated on a 7-point scale, and higher scores indicate higher levels of perfectionism. The APS-R demonstrated good to excellent psychometric proprieties [52,53].

## Statistical Methods

Analyses were performed in SPSS version 24.0 (IBM Corp). Group differences in baseline characteristics were analyzed using the independent samples *t* test and the chi-square test. The postintervention and follow-up data were analyzed based on the intention-to-treat framework by the means of linear mixed models. This approach uses all available observations (maximum likelihood estimation) and allows for correlation between longitudinal data. For all the outcomes, time (baseline vs post intervention) was set as the within-group factor, and trial condition (transdiagnostic vs wait-list control group) was used as the between-groups factor. For the two outcomes that were also measured during the odd weeks of the treatment (ie, OASIS and ODSIS), the time factor had seven levels (ie, baseline, week 1, week 3, week 5, week 7, week 9, and post intervention). We analyzed these two aforementioned variables both together with the entire set of outcomes (baseline vs post intervention comparison) to estimate the postintervention ES, and separately, to get a better grasp on the evolution of anxiety and depression symptoms during the treatment. Hence, we conducted separate analyses for each outcome with group, time, and group by time interaction as fixed effects and a random intercept for subject with an identity covariance structure. The group by time interactions express the mean change in outcomes from baseline to post treatment between the two trial groups. The fix effects of gender, previous psychotherapy experience in the past 4 years (dummy coded: yes or no), and treatment credibility were added to each model. Moreover, to investigate the long-term effects of the intervention on each outcome, and as the follow-up measures were collected only for the treatment group, we applied linear mixed models with time (baseline vs post treatment vs 6 months follow-up) as fixed factor and random intercept for subject. The fix effect of total number of homework assignments completed by participants (treatment adherence) was also added to each of these models. We made baseline to post treatment and baseline to follow-up comparisons to test the extent to which symptom amelioration was preserved in time.

We computed Hedges *g* effects size estimates for both between-groups and with-group comparisons. Between-groups comparisons were based on the mean differences from baseline to post treatment and the baseline SDs within each group. Within-group ESs were calculated for baseline to post treatment and for baseline to 6-month follow-up comparisons by correcting for the correlation between each pair of time points.

## Clinical Significance

To determine the clinical significance of this trial, we adopted the algorithm used by Ellard and colleagues [54] for both responder status and high end-state functioning. More precisely, at the post intervention, participants were considered *responders* if they evidenced a decrease of 30% or larger on at least two indicators from the following three measurement categories: (1) the specific diagnostic measure associated with their principal diagnostic (eg, BDI-II, PSWQ, SPIN, PDSS-SR, Y-BOCS, and PCL5), (2) the symptom interference measure (WSAS), or (3) the postintervention SCID-I interview (where they did not meet the diagnostic criteria for their principal disorder). The more stringent criteria for *high end-state functioning* involve the simultaneous fulfillment of two conditions: (1) not meeting diagnostic criteria for their principal diagnostic on the postintervention SCID-I interview and (2) displaying a subclinical score on either the WSAS or the disorder-specific measure associated with their principal disorder identified at baseline. Participants who changed psychotropic medication or started another treatment were excluded from these analyses.

## Results

### Participants' Recruitment, Dropout, and Attrition

Out of the 411 participants who expressed initial interest for the study, only 240 completed the online screening measures and were assessed for eligibility. Of those, 135 participants failed to meet initial study inclusion criteria. The 105 included participants were randomized into the treatment (N=69) and the control group (N=36). After the intervention, we conducted the SCID-I interview with 54 participants (78%, 54/69) from the active treatment group and with 29 participants (81%, 29/36) from the wait-list control group. A similar percentage of postintervention self-report measures were collected from both groups (see Figure 1). During the 10-week intervention program, 5 participants (7%, 5/69) from the treatment group and 3 (8%, 3/36) from the control group started or changed their psychotropic medication or started another psychosocial treatment.

Participants adherence during the program is illustrated in the attrition diagram (see Figure 2). Six-month follow-up assessment questionnaire were collected from 36 participants (52%, 36/69) in the active treatment group.

### Demographics and Baseline Clinical Status

Details regarding participants' demographic characteristics are presented in Table 1. Participant's overall mean age was 34.27 (SD 10.55, range 21-70), most of them having at least a college degree (44.2%, 46/105). The majority were females (80.9%, 85/105 overall). A lower proportion of males ended up in the

wait-list control group compared with the active treatment group ( $P=.049$ ). Therefore, we controlled for this variable in all subsequent analyses. Overall, 36.5% (38/105) received psychotherapy during the last 4 years. Even though not statistically significant ( $P=.07$ ), there was a lower proportion of participants who benefited from psychotherapy in the previous 4 years in the active treatment group than in the wait-list control group. Hence, we also controlled for this factor in the main analyses. In all other respects, the treatment and control groups were similar in terms of demographic characteristics, including their time spend online.

Principal and comorbid clinical diagnostics are also presented in [Table 1](#). Overall, disorders ranged between 1 and 5, with an average of 1.67 disorders per participant (SD 0.93).

### **Treatment Credibility**

Both the active treatment group (mean 39.42, SD 8.40) and the wait-list control group (mean 36.42, SD 8.07) perceived the intervention as credible (the minimum and maximum possible scores range from 0-50), with no significant differences between the two groups ( $t_{97}=1.72$ ,  $P=.09$ ).

### **Treatment Adherence**

Treatment adherence was estimated using participants' online behavior: (1) how often they accessed the online treatment (number of logins) and (2) how often they were actively engaged with the content of the treatment (number of completed homework assignments—possible range 0-41). During the 10-week treatment period, the average number of platform accesses was 46.76 (SD 29.86) per participant (logins ranged between 2-149). Overall, the active treatment group participants completed 1355 homework assignments (mean 19.63, SD 12.10), and on average, participants completed 2.18 weekly assignments. Throughout the treatment, participants sent written messages to graduate students (mean 8.03, SD 6.78, range 0-28) and received written messages from them (mean 25.91, SD 9.38, range 8-44). At the end of the treatment, participants estimated to have spent an average 4 hours/week in treatment-related activities (SD 3.53; median 2.5 hours/week). As expected, a negative correlation was observed between the number of completed homework assignments and the number of disorders diagnosed after the treatment ( $r=-.23$ ,  $P=.04$ ).

**Figure 1.** The flowchart depicting participants' recruitment and progress throughout the program. SCID-I: Structural Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, 4th Edition Axis I Disorders.

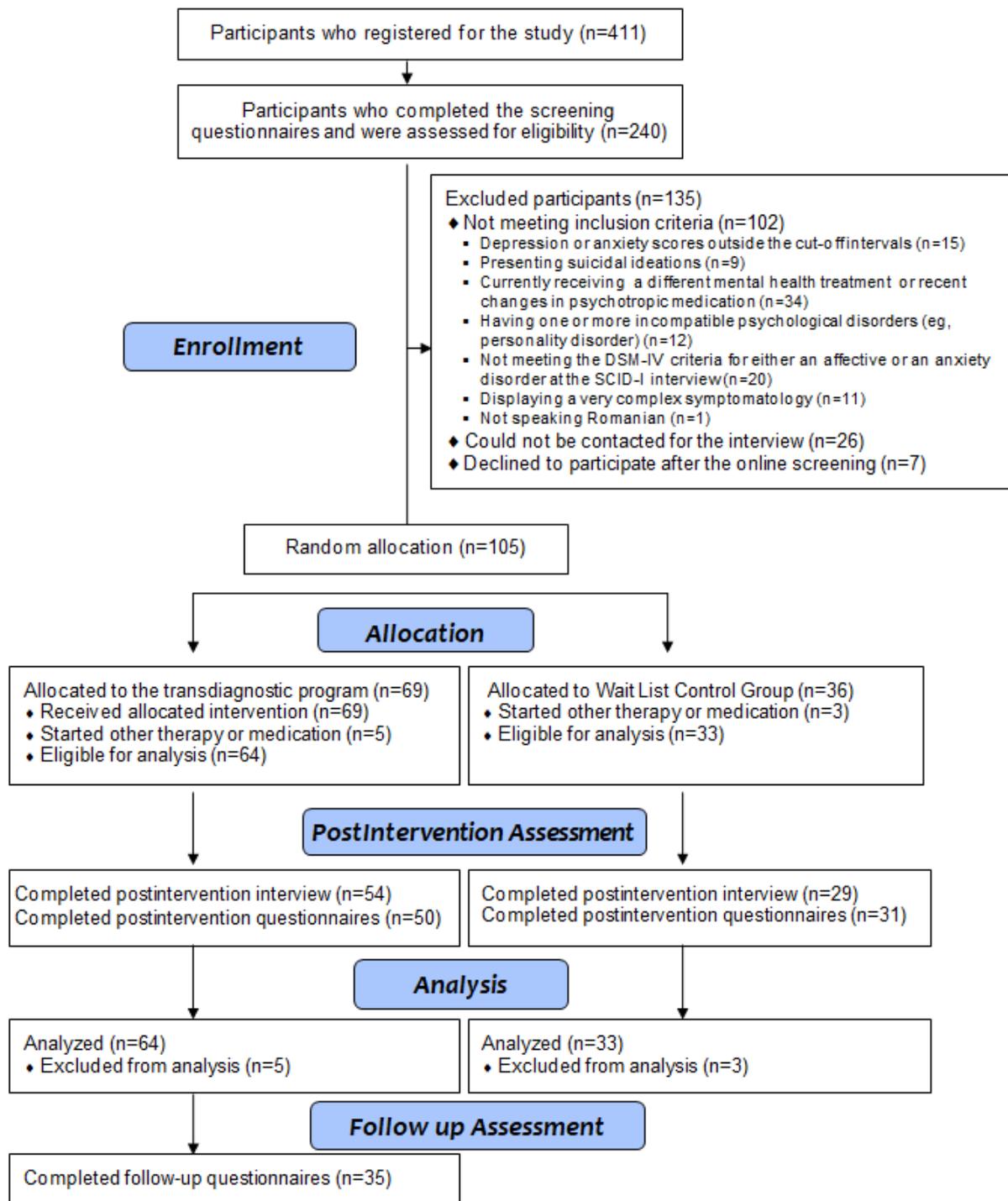
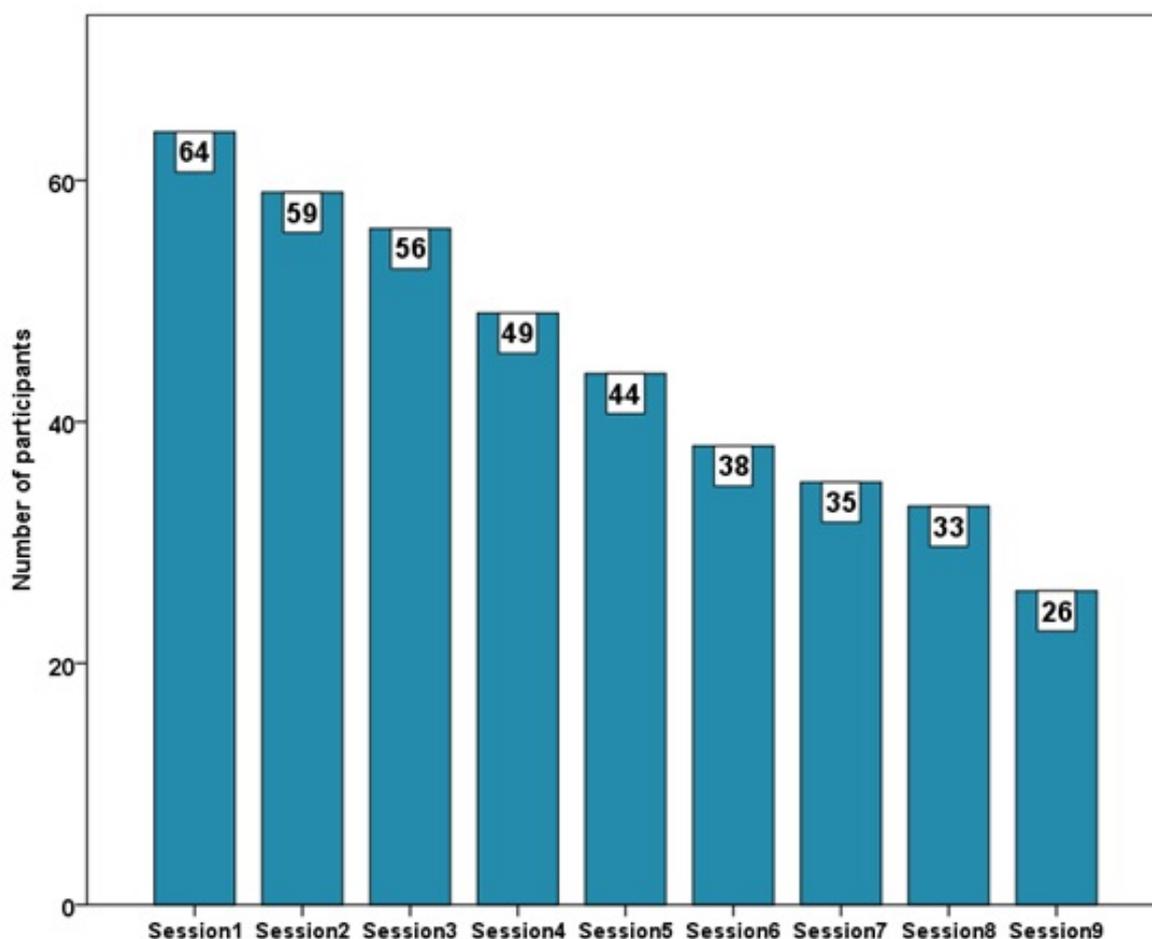


Figure 2. Attrition diagram.



### Effectiveness of the Intervention on Primary Outcomes

Table 2 includes the observed means and estimated marginal means for the primary outcomes measures. Linear mixed model results for the effectiveness of the intervention at post treatment and Hedges  $g$  ESs are displayed in Table 3. There were significant group by time interactions for BDI-II, PSWQ, and PCL-5 scores. SPIN scores were significantly reduced in the crude model, but the adjusted one drifted toward a trend ( $P=.05$ ). The group by time interactions were nonsignificant for Y-BOCS and PDSS-SR, whereas the overall anxiety and depression measures (ODSIS and OASIS) yielded significant interaction effects. Hence, the transdiagnostic intervention was successful in reducing participants' depression and anxiety, displaying between-group ESs that ranged from small (Hedges  $g$  was 0.39 for SPIN) to large (Hedges  $g$  was 0.86 for PCL-5).

The evolution of participants' overall anxiety (OASIS) and overall depression (ODSIS) during the intervention is displayed in Figures 3 and 4. For both figures, intent to treat data was used (estimated marginal means). As can be intuitively visualized on the two graphs, the linear mixed model results revealed significant group by time interactions for both overall anxiety

( $t_{399.94}=-4.09$ ,  $P<.001$ ) and overall depression ( $t_{399.22}=-3.07$ ,  $P=.002$ ). More precisely, during the nine measurement occasion, there was a significant reduction in overall anxiety (mean difference  $-0.51$ , 95% CI  $-0.76$  to  $-0.27$ ) and overall depression (mean difference  $-0.44$ , 95% CI  $-0.73$  to  $-0.16$ ) for the treatment group participants as compared with those on the wait list.

### Effectiveness of the Intervention on Secondary Outcomes

Table 4 includes the descriptive statistics for the secondary outcomes, and Table 5 displays the group by time interaction results of the linear mixed models and the Hedges  $g$  ES estimates. Participants that benefited from the transdiagnostic intervention reported significant improvements from baseline to post treatment as compared with those in the control group regarding symptom interference (WSAS), anxiety sensitivity (ASI), and a trend for QoL (QOLI,  $P=.54$ ), whereas the group by time interaction for perfectionism (APS-R) was nonsignificant. ESs were also medium to large ( $g=0.38$  for QOLI and 0.80 for ASI). Additional analyses were conducted for Back Anxiety Inventory, Emotion Regulation Questionnaire, and Emotional Stability (see Multimedia Appendix 2).

**Table 1.** Baseline characteristics of the participants in the two groups and entire sample.

Variable	Active treatment group (n=69)	Wait-list control group (n=36) <sup>a</sup>	All participants (n=105) <sup>a</sup>	Statistic ( <i>df</i> )	<i>P</i> value
<b>Age (years)</b>				<i>t</i> test=0.56 (102)	.57
Mean (SD)	34.68 (11.63)	33.46 (8.1)	34.27 (10.55)		
Range	21-70	21-60	21-70		
<b>Gender, n (%)</b>				Chi-square=3.8 (1)	.049
Male	17 (25)	3 (9)	20 (19.2)		
Female	52 (75)	32 (91)	84 (80.8)		
<b>Educational level, n (%)</b>				Chi-square=4.3 (5)	.49
Postdoctoral studies	1 (1)	0 (0)	1 (1.0)		
Doctoral degree	1 (1)	1 (3)	2 (1.9)		
Master degree	18 (26)	11 (31)	29 (27.9)		
Undergraduate degree	28 (41)	18 (51)	46 (44.2)		
High school degree	19 (28)	5 (14)	24 (23.1)		
Trade school degree	2 (3)	0 (0)	2 (1.9)		
<b>Marital status, n (%)</b>				Chi-square=2.7 (4)	.60
Never married	26 (38)	16 (46)	42 (40.4)		
In a relationship	15 (22)	6 (17)	21 (20.2)		
Married	18 (26)	11 (31)	29 (27.9)		
Divorced	8 (12)	2 (6)	10 (9.6)		
Widowed	2 (3)	0 (0)	2 (1.9)		
<b>Principal diagnostic, n (%)</b>				Chi-square=7.5 (7)	.37
GAD <sup>b</sup>	14 (20)	12 (33)	26 (24.8)		
SAD <sup>c</sup>	18 (26)	5 (14)	23 (21.9)		
MDD <sup>d</sup>	14 (20)	5 (14)	19 (18.1)		
PD/A <sup>e</sup>	11 (16)	7 (20)	18 (17.2)		
PTSD <sup>f</sup>	2 (3)	3 (8)	5 (4.7)		
Specific phobia (SP)	2 (3)	2 (6)	4 (3.8)		
OCD <sup>g</sup>	3 (4)	0 (0)	3 (2.8)		
Other	5 (7)	2 (6)	7 (6.7)		
<b>Comorbid diagnostic, n (%)</b>				Chi-square=7.4 (7)	.38
Any	35 (51)	19 (53)	54 (51.4)		
GAD	8 (12)	4 (11)	12 (11.4)		
SAD	13 (19)	2 (6)	15 (14.3)		
MDD	8 (12)	8 (22)	16 (15.2)		
PD/A	3 (4)	1 (3)	4 (3.8)		
PTSD	0 (0)	1 (3)	1 (1)		
SP	2 (3)	2 (6)	4 (3.8)		
OCD	0 (0)	0 (0)	0 (0)		
Other	1 (1)	1 (3)	2 (1.9)		
<b>Previous psychotherapy (in the last 4 years), n (%)</b>				Chi-square=3.2 (1)	.07
Yes	21 (30)	17 (49)	38 (36.5)		

Variable	Active treatment group (n=69)	Wait-list control group (n=36) <sup>a</sup>	All participants (n=105) <sup>a</sup>	Statistic ( <i>df</i> )	<i>P</i> value
No	48 (70)	18 (51)	66 (63.5)		
<b>Previous psychiatric diagnostic, n (%)</b>				Chi-square=0.0 (1)	.96
Yes	20 (29)	10 (30)	30 (28.8)		
No	49 (71)	25 (71)	74 (71.2)		
<b>Currently under medication, n (%)</b>				Chi-square=0.0 (1)	.98
Yes	6 (9)	3 (9)	9 (8.7)		
No	63 (91)	32 (91)	95 (91.3)		
<b>Time spent online (hours/day)</b>				<i>t</i> test=0.77 (102)	.44
Mean (SD)	4.95 (3.77)	5.43 (3.41)	5.11 (2.99)		
Range	1-13	1-15	1-15		

<sup>a</sup>One participant failed to complete the demographic questionnaire.

<sup>b</sup>GAD: generalized anxiety disorder.

<sup>c</sup>SAD: social anxiety disorder.

<sup>d</sup>MDD: major depressive disorder.

<sup>e</sup>PD/A: panic disorder/agoraphobia.

<sup>f</sup>Posttraumatic stress disorder.

<sup>g</sup>OCD: obsessive compulsive disorder.

### Primary Outcomes at Follow-Up

Within-group analyses for participants who received the transdiagnostic intervention revealed statistically significant improvements from baseline to post treatment for all the primary outcome measures (see Table 6). The reported ESs were also medium to large (*g* s: between 0.52 for Y-BOCS and 1.34 for OASIS). A similar pattern of results was found for the follow-up data. Treatment gains were generally maintained 6 months post intervention, with some measures displaying a further decrease at follow-up (ie, *g*=0.92 for SPIN).

### Secondary Outcomes at Follow-Up

Significant improvements from baseline to post treatment were reported for symptom interference (WSAS), QoL (QOLI), anxiety sensitivity (ASI), and discrepancy (APS-R; see Table 7). Most gains were maintained or improved 6 months following the intervention, except QOLI. Interestingly, after the program, participant's high standards seem to decrease substantially (*P*=.02; *g*=0.32), and the ES for discrepancy increased from a small (*g*=0.25) to a medium effect (*g*=0.63).

### Clinical Significance

At the end of the treatment, 56% (22/69) participants from the active treatment group were classified as responders, compared with 17% (6/36) from the wait-list control group ( $\chi^2_1=11.3$ , *P*=.001). Moreover, after the program, 27% (18/69) active treatment group participants were classified as being in a high end-state functioning compared with only 6% (2/36) from the wait-list control group ( $\chi^2_1=7.3$ , *P*=.007). Data were also analyzed separately for reduction in the specific self-report

measure associated with participants principal diagnostic (25%, 17/69 in the active treatment group vs 9%, 3/36 in the wait-list control group,  $\chi^2_1=4.1$ , *P*=.04), for reduction in principal diagnostic (44%, 30/69 in the active treatment group vs 6%, 2/36 in wait-list control group,  $\chi^2_1=15.3$ , *P*<.001), and for reductions in symptom interference (33%, 23/69 in the active treatment group vs 21%, 8/36 in wait-list control group,  $\chi^2_1=1.8$ , *P*=.17). Finally, based on linear mixed models, we compared the reduction in the number of mental disorders from baseline to post treatment between the active intervention group and the wait-list control group. The group by time interaction was statistically significant: beta=-.92, 95% CI -1.35 to -0.49;  $t_{90.78}=-4.25$ , *P*<.001; *g*=0.93, 95% CI 0.50-1.35). Compared with the wait-list control group, participants in the active treatment group yielded a drop of almost one mental disorder as a result of the transdiagnostic intervention.

### Treatment Satisfaction

After the intervention, most treated participants declared to be satisfied or very satisfied with the program, displaying a mean score of 4.25 (SD 0.87) on a 5-point scale. They also declared that the information offered within the program was highly qualitative (mean 4.55, SD 0.77), and they considered the therapeutic-related activities as demanding (mean 2.75, SD 0.76). More importantly, most participants declared that the treatment helped them to better cope with their current difficulties (mean 3.34, SD 0.75). Finally, using a 10-point scale, participants declared that the transdiagnostic program appeared logical (mean 8.57, SD 1.99) and that they are confident to recommend it to someone facing similar difficulties (mean 8.38, SD 2.18).

**Table 2.** Observed means and estimated marginal means of the primary outcome measures at baseline, post intervention, and follow-up assessment.

Primary outcome	Observed means (SD)		Estimated means (standard error of mean)	
	Treatment <sup>a</sup>	Control <sup>b</sup>	Treatment (n=69)	Control (n=36)
<b>MDD<sup>c</sup> (BDI-II<sup>d</sup>)</b>				
Baseline	24.01 (11.71)	24.44 (12.33)	22.22 (1.65)	22.98 (2.29)
Post intervention	10.81 (10.77)	19.52 (15.11)	8.93 (1.75)	19.63 (2.41)
Follow-up	9.95 (9.27)	N/A	10.64 (1.55)	N/A <sup>e</sup>
<b>GAD<sup>f</sup> (PSWQ<sup>g</sup>)</b>				
Baseline	62.10 (9.39)	63.39 (12.67)	61.46 (1.57)	62.97 (2.17)
Post intervention	53.53 (11.41)	60.68 (12.42)	52.14 (1.66)	61.42 (2.28)
Follow-up	50.54 (10.75)	N/A	40.58 (1.25)	N/A
<b>SAD<sup>h</sup> (SPIN<sup>i</sup>)</b>				
Baseline	35.15 (15.15)	36.08 (13.95)	36.32 (2.02)	39.71 (2.80)
Post-intervention	27.76 (13.74)	34.07 (14.12)	27.34 (2.16)	36.60 (2.96)
Follow-up	24.00 (12.56)	N/A	21.99 (1.75)	N/A
<b>OCD<sup>j</sup> (Y-BOCS<sup>k</sup>)</b>				
Baseline	11.91 (8.55)	12.42 (9.00)	12.13 (1.13)	13.12 (1.57)
Post intervention	7.87 (6.64)	9.55 (8.52)	7.71 (1.22)	11.17 (1.67)
Follow-up	6.43 (5.71)	N/A	7.04 (1.11)	N/A
<b>PD/A<sup>l</sup> (PDSS-SR<sup>m</sup>)</b>				
Baseline	5.74 (5.85)	7.28 (6.77)	5.76 (0.78)	8.49 (1.08)
Post intervention	2.31 (3.36)	5.58 (6.49)	2.63 (0.83)	6.79 (1.13)
Follow-up	2.37 (4.22)	N/A	2.57 (0.76)	N/A
<b>PTSD<sup>n</sup> (PCL-5<sup>o</sup>)</b>				
Baseline	43.87 (13.97)	41.75 (15.97)	41.96 (2.18)	40.23 (3.03)
Post intervention	25.74 (16.39)	33.28 (18.08)	22.41 (2.52)	33.47 (3.19)
Follow-up	23.65 (15.63)	N/A	24.38 (2.47)	N/A
<b>Anxiety (OASIS<sup>p</sup>)</b>				
Baseline	9.44 (3.88)	9.19 (4.21)	9.38 (0.56)	9.67 (0.78)
Post intervention	4.52 (3.39)	7.44 (4.92)	4.33 (0.62)	7.83 (0.82)
Follow-up	4.74 (3.94)	N/A	4.61 (0.61)	N/A
<b>Depression (ODSIS<sup>q</sup>)</b>				
Baseline	8.53 (5.13)	8.25 (4.31)	7.99 (0.67)	7.96 (0.93)
Post intervention	3.68 (3.78)	6.06 (5.62)	3.22 (0.74)	6.03 (0.98)
Follow-up	4.23 (4.07)	N/A	4.25 (0.70)	N/A

<sup>a</sup>Unfortunately not all participants completed all self-report measures at postintervention and follow-up assessments. Therefore, the number of participants who provided postintervention data was as follows: 53 for MDD, GAD, SAD, and OCD; 51 for PD/A; 46 for PTSD; 50 for Anxiety; and 50 for Depression. The number of participants who provided follow-up data were as follows: 38 for MDD; 37 for GAD; 36 for SAD; 34 for PTSD; and 35 for OCD, PD/A, anxiety, and depression.

<sup>b</sup>The number of participants who completed postintervention data was 31 for MDD, GAD, SAD, OCD, and PD/A and 32 for PTSD, anxiety, and depression.

<sup>c</sup>MDD: major depressive disorder.

<sup>d</sup>BDI-II: Beck Depression Inventory-II.

<sup>e</sup>N/A: not applicable.

<sup>f</sup>GAD: generalized anxiety disorder.

<sup>g</sup>PSWQ: Penn State Worry Questionnaire.

<sup>h</sup>SAD: social anxiety disorder.

<sup>i</sup>SPIN: Social Phobia Inventory.

<sup>j</sup>OCD: obsessive compulsive disorder.

<sup>k</sup>Y-BOCS: Yale-Brown Obsessive Compulsive Scale.

<sup>l</sup>PD/A: panic disorder/agoraphobia.

<sup>m</sup>PDSS-R: Panic Disorder Severity Scale-Self Report.

<sup>n</sup>PTSD: posttraumatic stress disorder.

<sup>o</sup>PCL-5: PTSD Checklist for DSM-5.

<sup>p</sup>OASIS: Overall Anxiety Severity and Impairment Scale.

<sup>q</sup>ODSIS: Overall Depression Severity and Impairment Scale.

**Table 3.** Estimated differences in mean change of primary outcomes between baseline and post intervention for the transdiagnostic intervention group versus the wait-list control group.

Primary outcome and model (crude <sup>a</sup> or adjusted <sup>b</sup> )	Estimate of mean change difference (95% CI)	<i>t</i> ( <i>df</i> )	<i>P</i> value	Between-group Hedges <i>g</i> (95% CI)
<b>MDD<sup>c</sup> (BDI-II<sup>d</sup>)</b>				
Crude	-9.41 (-13.85 to -4.98)	-4.22 (85.11)	<.001	
Adjusted	-9.94 (-14.51 to -5.37)	-4.33 (81.54)	<.001	0.83 (0.41-1.25)
<b>GAD<sup>e</sup> (PSWQ<sup>f</sup>)</b>				
Crude	-7.50 (-11.61 to -3.39)	-3.63 (87.98)	<.001	
Adjusted	-7.76 (-12.04 to -3.49)	-3.61 (82.85)	.001	0.73 (0.31-1.14)
<b>SAD<sup>g</sup> (SPIN<sup>h</sup>)</b>				
Crude	-6.47 (-12.23 to -0.69)	-2.23 (85.00)	.02	
Adjusted	-5.87 (-11.93 to 0.18)	-1.93 (80.30)	.05	0.39 (-0.01 to 0.80)
<b>OCD<sup>i</sup> (Y-BOCS<sup>j</sup>)</b>				
Crude	-2.23 (-5.58 to 1.13)	-1.32 (80.79)	.19	
Adjusted	-2.47 (-5.95 to 1.01)	-1.41 (76.25)	.16	0.28 (-0.12 to 0.69)
<b>PD/A<sup>k</sup> (PDSS-SR<sup>l</sup>)</b>				
Crude	-1.58 (-3.59 to 0.43)	-1.56 (79.29)	.12	
Adjusted	-1.44 (-3.54 to 0.66)	-1.37 (77.98)	.17	0.23 (-0.17 to 0.63)
<b>PTSD<sup>m</sup> (PCL-5<sup>n</sup>)</b>				
Crude	-12.58 (-19.73 to -5.44)	-3.50 (83.31)	.001	
Adjusted	-12.79 (-20.24 to -5.35)	-3.42 (79.40)	.001	0.86 (0.45-1.28)
<b>Anxiety (OASIS<sup>o</sup>)</b>				
Crude	-3.35 (-5.16 to -1.55)	-3.69 (86.02)	<.001	
Adjusted	-3.20 (-5.07 to -1.33)	-3.40 (82.17)	.001	0.80 (0.38-1.21)
<b>Depression (ODSIS<sup>p</sup>)</b>				
Crude	-2.69 (-4.67 to -0.73)	-2.73 (80.64)	.008	
Adjusted	-2.85 (-4.88 to -0.82)	-2.79 (77.63)	.006	0.58 (0.17-0.99)

<sup>a</sup>Crude model: raw association (without being adjusted for supplementary covariates).

<sup>b</sup>Adjusted model: adjusted for gender, previous psychotherapy experience in the past 4 years (dummy coded: yes or no), and treatment credibility.

<sup>c</sup>MDD: major depressive disorder.

<sup>d</sup>BDI-II: Beck Depression Inventory-II.

<sup>e</sup>GAD: generalized anxiety disorder.

<sup>f</sup>PSWQ: Penn State Worry Questionnaire. <sup>g</sup>SAD: social anxiety disorder.

<sup>h</sup>SPIN: Social Phobia Inventory.

<sup>i</sup>OCD: obsessive compulsive disorder.

<sup>j</sup>Y-BOCS: Yale-Brown Obsessive Compulsive Scale.

<sup>k</sup>PD/A: panic disorder/agoraphobia.

<sup>l</sup>PDSS-SR: Panic Disorder Severity Scale-Self Report.

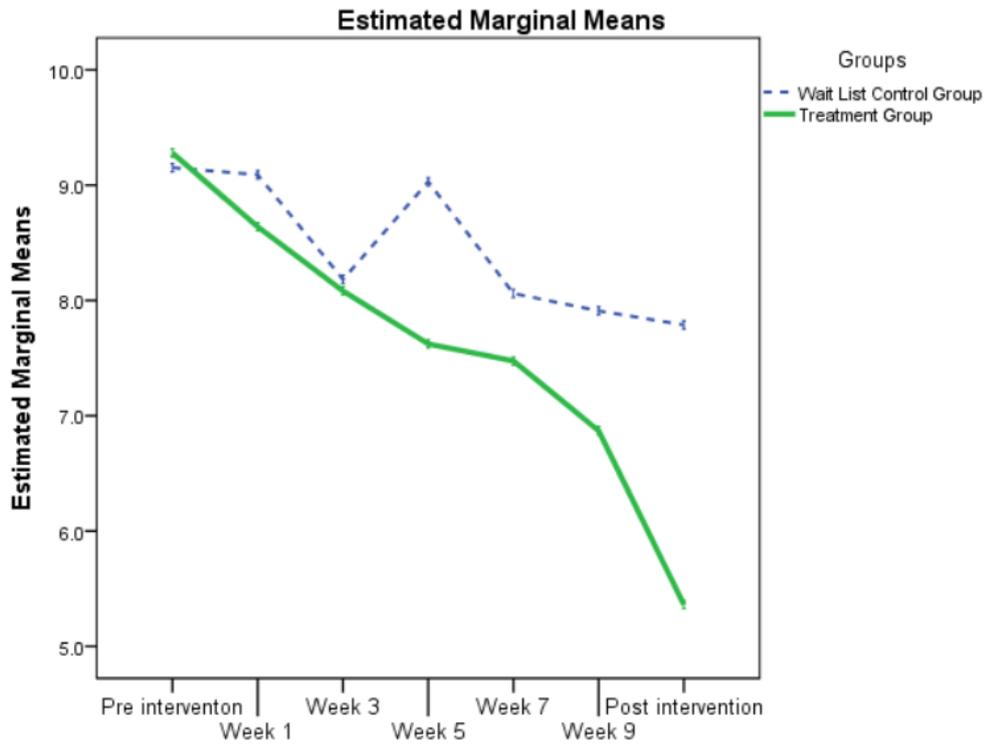
<sup>m</sup>PTSD: posttraumatic stress disorder.

<sup>n</sup>PCL-5: PTSD Checklist for DSM-5.

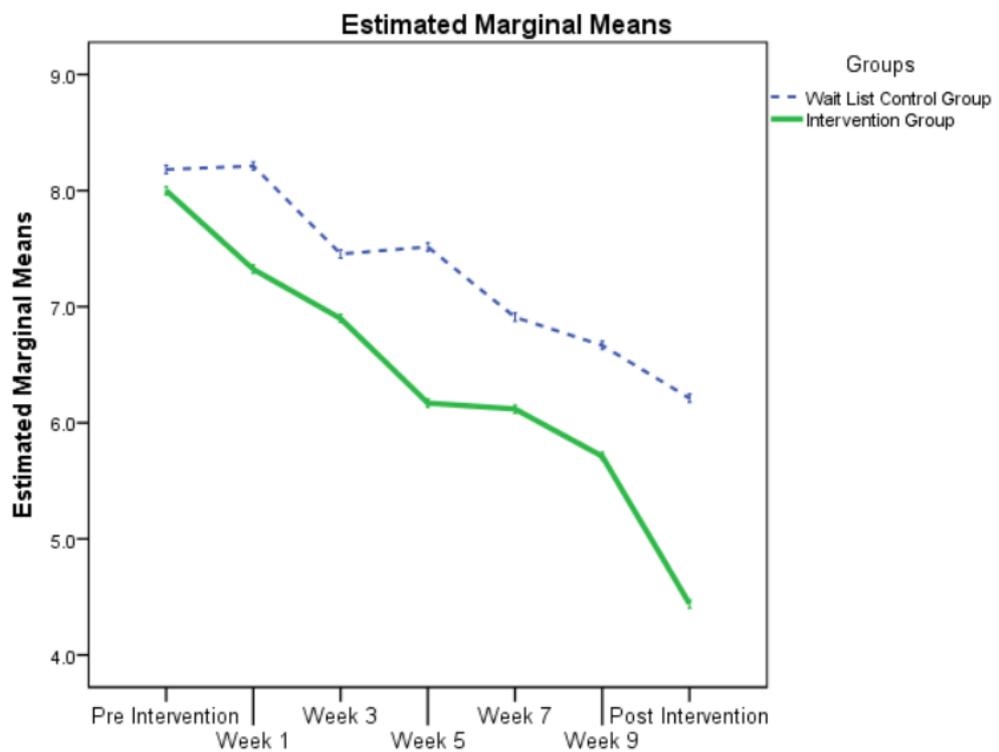
<sup>o</sup>OASIS: Overall Anxiety Severity and Impairment Scale.

<sup>p</sup>ODSIS: Overall Depression Severity and Impairment Scale.

**Figure 3.** The evolution of the two groups during the treatment on the Overall Anxiety Severity and Impairment Scale (OASIS).



**Figure 4.** The evolution of the two groups during the treatment on the Overall Depression Severity and Impairment Scale (ODSIS).



**Table 4.** Observed means and estimated marginal means of the secondary outcome measures at baseline, post intervention, and follow-up assessment.

Secondary outcome	Observed mean (SD)		Estimated mean (standard error of mean)	
	Treatment <sup>a</sup>	Control <sup>b</sup>	Treatment (n=69)	Control (n=36)
<b>Symptom interference (WSAS<sup>c</sup>)</b>				
Baseline	19.38 (9.00)	18.97 (9.55)	18.32 (1.25)	17.95 (1.73)
Post intervention	11.90 (8.83)	14.97 (9.30)	10.57 (1.39)	14.61 (1.82)
Follow-up	11.06 (8.59)	N/A <sup>d</sup>	11.44 (1.41)	N/A
<b>Quality of life (QOLI<sup>e</sup>)</b>				
Baseline	0.45 (1.82)	0.78 (1.82)	0.48 (.25)	0.92 (0.35)
Post intervention	1.35 (1.73)	1.03 (1.77)	1.24 (0.28)	0.99 (0.36)
Follow-up	1.03 (1.69)	N/A	1.01 (0.26)	N/A
<b>Anxiety sensitivity (ASI<sup>f</sup>)</b>				
Baseline	29.81 (11.18)	31.71 (12.43)	30.85 (1.62)	34.29 (2.25)
Post intervention	19.86 (12.15)	29.36 (12.81)	19.45 (1.80)	32.24 (2.38)
Follow-up	14.77 (8.42)	N/A	15.51 (1.59)	N/A
<b>Perfectionism (APS-R<sup>g</sup>)</b>				
<b>High standards</b>				
Baseline	38.62 (7.14)	40.47 (5.46)	38.17 (0.93)	40.11 (1.29)
Post intervention	38.74 (6.41)	39.28 (6.14)	37.92 (1.02)	39.22 (1.35)
Follow-up	36.31 (6.52)	N/A	36.56 (1.02)	N/A
<b>Order</b>				
Baseline	20.12 (5.69)	20.00 (4.93)	20.60 (0.78)	20.51 (1.09)
Post intervention	21.16 (4.91)	19.25 (5.94)	20.76 (0.82)	19.72 (1.11)
Follow-up	20.94 (4.93)	N/A	19.88 (0.77)	N/A
<b>Discrepancy</b>				
Baseline	58.80 (15.81)	57.22 (17.14)	58.53 (2.44)	59.44 (3.83)
Post intervention	55.02 (19.52)	51.66 (16.43)	53.56 (2.64)	53.32 (3.52)
Follow-up	49.86 (15.26)	N/A	48.57 (2.52)	N/A

<sup>a</sup>Unfortunately not all participants completed all self-report measures at postintervention and follow-up assessments. Therefore the number of participants who provided postintervention data was as follows: 50 for symptom interference; 46 for quality of life; 49 for anxiety sensitivity, and for perfectionism; and 35 participants provided follow-up data for all secondary outcomes.

<sup>b</sup>The number of participants who completed postintervention data was as follows: 32 for symptom interference and perfectionism; 30 for quality of life; and 31 for anxiety sensitivity.

<sup>c</sup>WSAS: Work and Social Adjustment Scale.

<sup>d</sup>N/A: not applicable.

<sup>e</sup>QOLI: Quality of Life Inventory.

<sup>f</sup>ASI: Anxiety Sensitivity Index.

<sup>g</sup>APS-R: Almost Perfect Scale-Revised.

**Table 5.** Estimated differences in mean change of secondary outcomes between baseline and post intervention for the transdiagnostic intervention group versus the wait-list control group.

Secondary outcome and model (crude <sup>a</sup> or adjusted <sup>b</sup> )	Estimate of mean change difference (95% CI)	<i>t</i> (degrees of freedom)	<i>P</i> value	Between-group Hedges <i>g</i> (95% CI)
<b>Symptom interference (WSAS<sup>c</sup>)</b>				
Crude	-4.13 (-8.14 to -0.13)	-2.05 (82.03)	.04	
Adjusted	-4.41 (-8.48 to -0.35)	-2.16 (81.16)	.03	0.48 (0.07-0.88)
<b>Quality of life (QOLI<sup>d</sup>)</b>				
Crude	0.73 (0.04-1.41)	2.11 (78.44)	.03	
Adjusted	0.69 (-0.01 to 1.40)	1.96 (74.35)	.05	0.38 (-0.03 to 0.78)
<b>Anxiety sensitivity (ASI<sup>e</sup>)</b>				
Crude	-9.09 (-13.91 to -4.27)	-3.76 (79.54)	<.001	
Adjusted	-9.35 (-14.26 to -4.44)	-3.79 (78.06)	<.001	0.80 (0.38-1.22)
<b>Perfectionism (APS-R)</b>				
<b>High standards</b>				
Crude	0.62 (-1.99 to 3.22)	0.47 (82.17)	.63	
Adjusted	0.64 (-2.06 to 3.34)	0.47 (79.31)	.64	-0.10 (-0.50 to 0.31)
<b>Order</b>				
Crude	0.96 (-0.49 to 2.40)	1.32 (77.38)	.19	
Adjusted	0.94 (-0.54 to 2.41)	1.26 (75.42)	.21	-0.17 (-0.58 to 0.23)
<b>Discrepancy</b>				
Crude	0.32 (-6.12 to 6.76)	0.09 (83.51)	.92	
Adjusted	1.15 (-5.48 to 7.79)	0.35 (80.21)	.73	-0.07 (-0.47 to 0.33)

<sup>a</sup>Crude model: raw association (without being adjusted for supplementary covariates).

<sup>b</sup>Adjusted model: adjusted for gender, previous psychotherapy experience in the past 4 years (dummy coded: yes or no), and treatment credibility.

<sup>c</sup>WSAS: Work and Social Adjustment Scale.

<sup>d</sup>QOLI: Quality of Life Inventory.

<sup>e</sup>ASI: Anxiety Sensitivity Index.

<sup>f</sup>APS-R: Almost Perfect Scale-Revised.

**Table 6.** Within-group estimated changes in primary outcomes for the active treatment group. All estimates are adjusted for treatment adherence (total number of homework assignments completed by participants).

Primary outcome	<i>F</i> ( <i>df</i> )	<i>P</i> value	Estimate (95% CI)	<i>P</i> value	Within-group Hedges <i>g</i> (95% CI)
<b>MDD<sup>a</sup> (BDI-II<sup>b</sup>)</b>					
Time	53.23 (2,88.82)	<.001			
Baseline vs post test			-13.09 (-15.89 to -10.29)	<.001	1.18 (0.85-1.51)
Baseline vs follow-up			-12.66 (-15.78 to -9.53)	<.001	1.17 (0.69-1.65)
<b>GAD<sup>c</sup> (PSWQ<sup>d</sup>)</b>					
Time	33.80 (2,95.69)	<.001			
Baseline vs post test			-8.96 (-11.64 to -6.28)	<.001	0.85 (0.54-1.15)
Baseline vs follow-up			-11.01 (-14.02 to -7.99)	<.001	1.06 (0.67-1.46)
<b>SAD<sup>e</sup> (SPIN<sup>f</sup>)</b>					
Time	23.13 (2,90.19)	<.001			
Baseline vs post test			-8.96 (-12.59 to -5.33)	<.001	0.61 (0.31-0.91)
Baseline vs follow-up			-13.24 (-17.38 to -9.09)	<.001	0.92 (0.54-1.31)
<b>OCD<sup>g</sup> (Y-BOCS<sup>h</sup>)</b>					
Time	10.79 (2,83.17)	<.001			
Baseline vs post test			-4.03 (-6.02 to -2.03)	<.001	0.52 (0.23-0.81)
Baseline vs follow-up			-4.39 (-6.69 to -2.09)	<.001	0.58 (0.19-0.95)
<b>PD/A<sup>i</sup> (PDSS-SR<sup>j</sup>)</b>					
Time	13.67 (2,72.75)	<.001			
Baseline vs post test			-3.24 (-4.59 to -1.88)	<.001	0.65 (0.31-0.99)
Baseline vs follow-up			-3.06 (-4.59 to -1.52)	<.001	0.58 (0.17-0.99)
<b>PTSD<sup>k</sup> (PCL-5<sup>l</sup>)</b>					
Time	33.53 (2,88.28)	<.001			
Baseline vs post test			-18.43 (-23.59 to -13.25)	<.001	1.22 (0.77-1.67)
Baseline vs follow-up			-18.93 (-24.59 to -13.27)	<.001	1.25 (0.65-1.84)
<b>Anxiety (OASIS<sup>m</sup>)</b>					
Time	39.05 (2,92.25)	<.001			
Baseline vs post test			-4.93 (-6.16 to -3.69)	<.001	1.34 (0.95-1.74)
Baseline vs follow-up			-4.72 (-6.10 to -3.35)	<.001	1.18 (0.61-1.75)
<b>Depression (ODSIS<sup>n</sup>)</b>					
Time	29.28 (2,81.84)	<.001			
Baseline vs post test			-4.67 (-5.98 to -3.37)	<.001	1.00 (0.65-1.35)
Baseline vs follow-up			-4.08 (-5.53 to -2.62)	<.001	0.85 (0.44-1.27)

<sup>a</sup>MDD: major depressive disorder.<sup>b</sup>BDI-II: Beck Depression Inventory-II.<sup>c</sup>GAD: generalized anxiety disorder.<sup>d</sup>PSWQ: Penn State Worry Questionnaire.<sup>e</sup>SAD: social anxiety disorder.<sup>f</sup>SPIN: Social Phobia Inventory.<sup>g</sup>OCD: obsessive compulsive disorder.<sup>h</sup>Y-BOCS: Yale-Brown Obsessive Compulsive Scale.<sup>i</sup>PD/A: panic disorder/agoraphobia.

<sup>j</sup>PDSS-R: Panic Disorder Severity Scale-Self Report.

<sup>k</sup>PTSD: posttraumatic stress disorder.

<sup>l</sup>PCL-5: PTSD Checklist for DSM-5.

<sup>m</sup>OASIS: Overall Anxiety Severity and Impairment Scale.

<sup>n</sup>ODSIS: Overall Depression Severity and Impairment Scale.

**Table 7.** Within-group estimated changes in secondary outcomes for the active treatment group. All estimates are adjusted for treatment adherence (total number of homework assignments completed by participants).

Secondary outcome	<i>F</i> ( <i>df</i> )	<i>P</i> value	Estimate (95% CI)	<i>P</i> value	Within-group Hedges <i>g</i> (95% CI)
<b>Symptom interference (WSAS<sup>a</sup>)</b>					
Time	19.98 (2,84.19)	<.001			
Baseline vs post test			-7.25 (-9.90 to -4.61)	<.001	0.79 (0.46-1.13)
Baseline vs follow-up			-7.75 (-10.69 to -4.79)	<.001	0.86 (0.43-1.29)
<b>Quality of life (QOLI<sup>b</sup>)</b>					
Time	5.50 (2,83.04)	.006			
Baseline vs post test			0.69 (0.28-1.12)	.001	0.39 (0.13-0.64)
Baseline vs follow-up			0.39 (-0.07 to 0.85)	.10	0.21 (-0.04 to 0.47)
<b>Anxiety sensitivity (ASI<sup>c</sup>)</b>					
Time	55.30 (2,81.78)	<.001			
Baseline vs post test			-11.17 (-13.88 to -8.45)	<.001	1.00 (0.69-1.32)
Baseline vs follow-up			-14.25 (-17.25 to -11.25)	<.001	1.38 (0.91-1.86)
<b>Perfectionism (APS-R<sup>d</sup>)</b>					
<b>High standards</b>					
Time	2.99 (2,85.85)	.05			
Baseline vs post test			-.37 (-2.07 to 1.34)	.66	0.05 (-0.21 to 0.31)
Baseline vs follow-up			-2.26 (-4.16 to -.36)	.02	0.32 (0.02-0.63)
<b>Order</b>					
Time	.69 (2, 81.40)	.50			
Baseline vs post test			0.09 (-0.90 to 1.09)	.85	-0.02 (-0.21 to 0.17)
Baseline vs follow-up			-0.54 (-1.65 to 0.57)	.33	-0.09 (-0.13 to 0.33)
<b>Discrepancy</b>					
Time	9.40 (2,86.06)	<.001			
Baseline vs post test			-4.62 (-8.75 to -.49)	.03	0.25 (0.02-0.48)
Baseline vs follow-up			-9.99 (-14.59 to -5.39)	<.001	0.63 (0.30-0.96)

<sup>a</sup>WSAS: Work and Social Adjustment Scale.

<sup>b</sup>QOLI: Quality of Life Inventory.

<sup>c</sup>ASI: Anxiety Sensitivity Index.

<sup>d</sup>APS-R: Almost Perfect Scale-Revised.

## Discussion

### Principal Findings

The broader transdiagnostic conceptualizations of emotional disorders have recently attracted researchers' attention as a promising and parsimonious approach to treatment [11-13,15,21,23,55]. This study was designed to examine the efficacy and acceptability of an Internet-delivered, clinician-assisted transdiagnostic program for depression and

anxiety disorders in Romania. The broadly inclusive intake criteria allowed us to select 105 participants with a principal diagnostic of MDD, GAD, SAD, PD/A, OCD, and PTSD, with more than half of them (51.4%, 54/105) having at least a second clinical diagnostic.

As predicted, the transdiagnostic program led to significantly greater reductions (relative to the wait-list control group) in symptom severity across both principal and comorbid disorders, as well as significant decreases in functional impairment that

were maintained over time. Furthermore, participants receiving the treatment evidenced greater rates of recovery on several symptom measures (except Y-BOCS and PDSS-SR), and were less likely to meet criteria for mental disorders following treatment. Moderate to large ES estimates were obtained for most diagnostic-specific measures (ie, BDI-II, PSWQ, SPIN, and PCL-5), as well as for the general measures of anxiety and depression (OASIS and ODSIS), suggesting that transdiagnostic treatments may be effective across a range of affective and anxiety disorders. Our effects were comparable (overlapping 95% CI) with those reported in other transdiagnostic trials [6,15].

The between-group insignificant differences and small ES for OCD and PD/A could be explained on the one hand by the small number of participants meeting diagnostic criteria for OCD (N=3) and on the other hand by the measurement choice for PD/A (ie, PDSS-SR was *not* classified as an evidence-based measure [48]). Moreover, Erickson and colleagues mentioned that OCD participants seem to be less motivated and more complex cases, distracting people with other anxiety disorders participating in a group transdiagnostic program [56]. Finally, after comparing several Web-based intervention programs [57], only a trend decrease for the PD/A diagnostic number was observed, whereas all other anxiety disorders (ie, GAD and SAD) yielded significant results. A larger study that allows differential efficacy comparison between primary diagnostics could further clarify this issue.

Relative to the wait-list control group, our transdiagnostic intervention also led to significantly greater improvements in symptom interference, anxiety sensitivity, emotional stability, QoL (at trend level), and one component of emotion regulation. Improvements in this area are not particularly surprising given the focus of the program on emotion and the development of emotion regulation skills, but is encouraging to see nevertheless. Anxiety sensitivity, conceptualized as the fear of bodily sensations, was first associated with panic disorder. However, recent research has demonstrated that it may be common across emotional disorders [58,59]. Results from this study replicate those from Boswell and colleagues providing additional support for the transdiagnostic relevance of anxiety sensitivity [58].

The other transdiagnostic process—perfectionism—displayed consistent within-group improvements 6 month after the intervention, when both high standards and discrepancy subscales significantly decreased. Although our transdiagnostic program explicitly addressed perfectionism as an instance of emotion-driven behavior, it seems that the effects of the intervention were mostly visible on the long term for perfectionism. In another intervention program conducted by our group, we found a significant decrease in perfectionism following a 45-day intervention [60]. Despite the fact that the aforementioned program was designed to comprehensively address perfectionism in nine sessions, only a small percentage of participants displayed a decrease of more than 50% from their initial perfectionism level (recovery rates between 0%-4.9%), whereas higher impact was observed for associated levels of depression and anxiety (recovery rates between 14.6%-31.7%) [60]. Such results are in line with previous literature supporting the trait-like stability of perfectionism [61].

## Treatment Satisfaction

The overall treatment satisfaction was high; participants acknowledging to have received qualitative information related to their disorders and to be better equipped to cope with their current difficulties. The treatment approach appeared logical to most participants, and they seemed willing to recommend the transdiagnostic program to other people with similar problems. This suggests that the program appears useful to participants and could eventually be implemented to similar samples of internet users outside of the present trial. One potentially positive feature that could be added in clinical practice is a short (bimonthly) telephone contact that could contribute to solving simple problems and facilitate participant involvement.

## Advantages of Web-Based Transdiagnostic Interventions

The transdiagnostic programs definitely represent a successful approach to treatment as they are better designed to address comorbidity. Transdiagnostic programs are broadly inclusive and can elegantly address multiple problems in a parsimonious manner [15]. It was previously reported that participants seemed interested to find out more about symptoms and coping strategies that are not directly related to their current difficulties, but represent core underlying mechanisms for multiple disorders [62,63]. Moreover, the Web-based format of our intervention allowed successful administration of the program with only a brief therapist training. In addition, it is generally accepted that Web-based programs are less time-intensive for practitioners, as some of the therapy tasks (ie, explaining the relationships between thoughts, feelings, and behaviors) are carried out by the computerized system, and human effort is directed toward more complex therapy tasks (ie, assisting each participant and offering personalized feedback) (see Andersson [64]). Moreover, by providing remote access to the program, participants from rural areas could easily access the program despite the scarcity of available clinicians in their neighborhood [65].

## Study Limitations

Finally, our results should be considered in light of several limitations. First, although this study included patients with a range of affective and anxiety disorders, it was not adequately powered to investigate the differential efficacy of the transdiagnostic program for each primary diagnostic category, particularly in the wait-list control group. Therefore, we could not meaningfully compare the effects of the program as a function of principal diagnostic, but this might be an important question for future studies. Second, we excluded participants with very complex symptoms (N=11), and the mean number of baseline diagnostics per participant were somehow smaller in our sample (1.67) compared with other trials (eg, 2.3 comorbid diagnostic [15]). This represents an inherent limitation associated with the treatment delivery format, as it was argued that Web-based programs may not be sufficient for the most severe cases [66]. Third, only half of the participants in the active treatment condition completed the follow-up questionnaires. Although such dropout rates are not uncommon in Web-based studies [67], the results should be interpreted with caution as this might favor treatment effects overestimations. Fourth, a relatively high attrition rates was observed in our trial,

as only 44/69 participants completed at least five sessions, and only 23/69 completed all nine sessions. This is somehow surprising considering that we included a motivational interviewing in session one and used a 2:1 ratio to offer a greater number of participants the possibility to start the treatment immediately after the initial assessment. It is possible that factors related to participants' characteristics (ie, expectation to have a Skype-like interaction with the therapists) could have played a role in the initial adherence, whereas other factors (ie, treatment workload) could have played a role in the subsequent involvement with the program. Moreover, a possible confound is that participants who finished all or most of the treatment sessions were (over)motivated to seek treatment before it started. However, to disentangle the factors that play a significant role in the adherence process, future study should consider a broader conceptualization of this process that involves therapy-related factors, patient-related factors, disorder-related factors, and socioeconomic and health-system factors [68]. In this context,

low adherence could represent a mismatch between one or more of the aforementioned factors (see also [69,70]).

### Study Summary

Summarizing, efficacious treatments for affective, anxiety, and related disorders exist [23,55,71-73], but implementing them in other contexts and cultures is still limited [74]. The transdiagnostic intervention tested in this study offers a treatment option that capitalizes on the shared mechanisms approach, with an increased dissemination potential through the use of a Web-based delivery system. This format minimizes direct clinician involvement, which greatly reduces one of the primary barriers to dissemination of empirically supported psychological treatments; namely, training community clinicians to utilize these treatments effectively and with fidelity. Overall, the results of this study also provide further support for the efficacy and acceptability of transdiagnostic evidence-based treatments targeting emotion (dys)regulation. Further research evaluating such programs, particularly in community settings, is needed.

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### Conflicts of Interest

The Romanian team developed the e-cbt.ro web-platform that is exclusively used for research purposes.

### Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 549KB - [mental\\_v5i2e36\\_app1.pdf](#) ]

### Multimedia Appendix 2

Supplementary analysis.

[PDF File (Adobe PDF File), 65KB - [mental\\_v5i2e36\\_app2.pdf](#) ]

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## Abbreviations

- APS-R:** Almost Perfect Scale-Revised
- ASI:** Anxiety Sensitivity Index
- BDI-II:** Beck Depression Inventory-II
- CBT:** cognitive behavioral therapy
- ES:** effect size
- GAD:** generalized anxiety disorder
- MDD:** major depressive disorder

**OCD:** obsessive compulsive disorder  
**OASIS:** Overall Anxiety Severity and Impairment Scale  
**ODSIS:** Overall Depression Severity and Impairment Scale  
**PCL-5:** PTSD Checklist for DSM-5  
**PD/A:** panic disorder/agoraphobia  
**PDSS-SR:** Panic Disorder Severity Scale-Self Report  
**PSWQ:** Penn State Worry Questionnaire  
**PTSD:** posttraumatic stress disorder  
**QoL:** quality of life  
**QOLI:** Quality of Life Inventory  
**RCT:** randomized controlled trial  
**SAD:** social anxiety disorder  
**SCID-I:** Structural Clinical Interview for DSM-IV  
**SDP:** single-disorder protocol  
**SPIN:** Social Phobia Inventory  
**UP:** unified protocol  
**WSAS:** Work and Social Adjustment Scale  
**Y-BOCS:** Yale-Brown Obsessive Compulsive Scale

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