# **JMIR Mental Health**

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# **Guest Editorial**

# Mobile Health for All: Public-Private Partnerships Can Create a New Mental Health Landscape

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# Abstract

Research has already demonstrated that different mHealth approaches are feasible, acceptable, and clinically promising for people with mental health problems. With a robust evidence base just over the horizon, now is the time for policy makers, researchers, and the private sector to partner in preparation for the near future. The Lifeline Assistance Program is a useful model to draw from. Created in 1985 by the U.S. Federal Communications Commission (FCC), Lifeline is a nationwide program designed to help eligible low-income individuals obtain home phone and landline services so they can pursue employment, reach help in case of emergency, and access social services and healthcare. In 2005, recognizing the broad shift towards mobile technology and mobile-cellular infrastructure, the FCC expanded the program to include mobile phones and data plans. The FCC provides a base level of federal support, but individual states are responsible for regional implementation, including engagement of commercial mobile phone carriers. Given the high rates of disability and poverty among people with severe mental illness, many are eligible to benefit from Lifeline and research has shown that a large proportion does in fact use this program to obtain a mobile phone and data plan. In the singular area of mobile phone use, the gap between people with severe mental illness and the general population in the U.S. is vanishing. Strategic multi-partner programs will be able to grant access to mHealth for mental health programs to those who will not be able to afford them-arguably, the people who need them the most. Mobile technology manufacturing costs are dropping. Soon all mobile phones in the marketplace, including the more inexpensive devices that are made available through subsidy programs, will have "smart" capabilities (ie, internet connectivity and the capacity to host apps). Programs like Lifeline could be expanded to include mHealth resources that capitalize on "smart" functions, such as secure/encrypted clinical texting programs and mental health monitoring and illness-management apps. Mobile phone hardware and software development companies could be engaged to add mHealth programs as a standard component in the suite of tools that come installed on their mobile phones; thus, in addition to navigation apps, media players, and games, the new Android or iPhone could come with guided relaxation videos, medication reminder systems, and evidence-based self-monitoring and self-management tools. Telecommunication companies could be encouraged to offer mHealth options with their data plans. Operating system updates pushed out by the mobile carrier companies could come with optional mHealth applications for those who elect to download them. In the same manner in which the Lifeline Assistance Program has helped increase access to fundamental opportunities to so many low-income individuals, innovative multi-partner programs have the potential to put mHealth for mental health resources in the hands of millions in the years ahead.

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# KEYWORDS

mHealth; policy; reimbursement; access

We are closer than ever to having viable mobile health (mHealth) options for people with psychiatric illnesses and must ensure that the most vulnerable members of society will be able to benefit from the opportunities these clinical technologies can provide. Worldwide, the majority of the adult population has

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access to mobile devices [1]. Even people with severe mental illnesses, who have historically been the last to gain access to technological innovations, now own and use mobile phones [2]. Like the general population, people with psychiatric conditions are interested in leveraging their personal mobile devices to

enhance their health, as demonstrated in numerous publications in this and other journals [3-5]. Clinical researchers across continents have responded to the public need by developing innovative mHealth approaches that use a range of mobile device functions such as texting, apps, and sensors for clinical assessment and treatment. The US National Institute of Mental Health, the largest funder of mental health research in the world, has already supported hundreds of technology-based studies, and mHealth for mental health projects continue to be funded annually. Private sector technology companies such as Google, Apple, and IBM as well as pharmaceutical companies are moving into the mHealth arena with an eye toward mental health. Research has already demonstrated that different mHealth programs are feasible, acceptable, and clinically promising for people with mental health problems [6-9]. A robust evidence base supporting the utility of different mHealth approaches is just over the horizon. Now is the time for policy makers, researchers, and the private sector to partner in preparation for the near future.

The Lifeline Assistance Program is a useful model to draw from [10]. Created in 1985 by the US Federal Communications Commission (FCC), Lifeline is a nationwide program designed to help eligible low-income individuals obtain home phone and landline services so they can pursue employment, reach help in case of emergency, and access social services and health care. In 2005, recognizing the broad shift toward mobile technology and mobile-cellular infrastructure, the FCC expanded the program to include mobile phones and data plans. The FCC provides a base level of federal support, but individual states are responsible for regional implementation, including engagement of commercial mobile phone carriers. Given the high rates of disability and poverty among people with severe mental illness, many are eligible to benefit from Lifeline and research has shown that a large proportion does in fact use this program to obtain a mobile phone and data plan [2]. In the singular area of mobile phone use, the gap between people with severe mental illness and the general population in the United States is vanishing.

Strategic multi-partner programs will be able to grant access to mHealth for mental health programs to those who will not be able to afford them—arguably, the people who need them the most. Mobile technology manufacturing costs are dropping. Soon all mobile phones in the marketplace, including the more

#### Ben-Zeev

inexpensive devices that are made available through subsidy programs, will have "smart" capabilities (ie, Internet connectivity and the capacity to host apps). Programs like Lifeline could be expanded to include mHealth resources that capitalize on "smart" functions, such as secure/encrypted clinical texting programs and mental health monitoring and illness-management apps. Mobile phone hardware and software development companies could be engaged to add mHealth programs as a standard component in the suite of tools that come installed on their mobile phones; thus, in addition to navigation apps, media players, and games, the new Android or iPhone could come with guided relaxation videos, medication reminder evidence-based self-monitoring systems, and and self-management tools. Telecommunication companies could be encouraged to offer mHealth options with their data plans. Operating system updates pushed out by the mobile carrier companies could come with optional mHealth apps for those who elect to download them. In the same manner in which the Lifeline Assistance Program has helped increase access to fundamental opportunities to so many low-income individuals, innovative multi-partner programs have the potential to put mHealth for mental health resources in the hands of millions in the years ahead.

## Dror Ben-Zeev, PhD

**Figure 1.** Dror Ben-Zeev, PhD, is a faculty member in the Department of Psychiatry at Dartmouth College and licensed Clinical Psychologist who specializes in development and evaluation of technology-based approaches in the study, assessment, and treatment of mental illness. Dr. Ben-Zeev serves as the Director of the Mobile Health (mHealth) for Mental Health Program, a multidisciplinary effort to harness mobile technology (e.g., texting, smartphone applications, multi-modal sensors) to improve the outcomes and support the recovery of people with psychiatric conditions.



# **Conflicts of Interest**

The author has an intervention content licensing agreement with Pear Therapeutics.

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# Abbreviations

FCC: US Federal Communications Commission mHealth: mobile health

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**Original Paper** 

# Implementation of a Substance Use Recovery Support Mobile Phone App in Community Settings: Qualitative Study of Clinician and Staff Perspectives of Facilitators and Barriers

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# Abstract

**Background:** Research supports the effectiveness of technology-based treatment approaches for substance use disorders. These approaches have the potential to broaden the reach of evidence-based care. Yet, there is limited understanding of factors associated with implementation of technology-based care approaches in different service settings.

**Objectives:** In this study, we explored provider and staff perceptions of facilitators and barriers to implementation of a mobile phone substance use recovery support app with clients in 4 service settings.

**Methods:** Interviews were conducted with leadership and provider stakeholders (N=12) from 4 agencies in the first year of an implementation trial of the mobile phone app. We used the Consolidated Framework for Implementation Research as the conceptual foundation for identifying facilitators and barriers to implementation.

**Results:** Implementation process facilitators included careful planning of all aspects of implementation before launch, engaging a dedicated team to implement and foster motivation, working collaboratively with the app development team to address technical barriers and adapt the app to meet client and agency needs, and consistently reviewing app usage data to inform progress. Implementation support strategies included training all staff to promote organization awareness about the recovery support app and emphasize its priority as a clinical care tool, encouraging clients to try the technology before committing to use, scaling rollout to clients, setting clear expectations with clients about use of the app, and using peer coaches and consistent client-centered messaging to promote engagement. Perceived compatibility of the mobile phone app with agency and client needs and readiness to implement emerged as salient agency-level implementation facilitators. Facilitating characteristics of the recovery support app itself included evidence of its impact for recovery support, perceived relative advantage of the app over usual care, the ability to adapt the app to improve client use, and its ease of use. The mobile phone itself was a strong motivation for clients to opt in to use the app in settings that provided phones. App access was limited in settings that did not provide phones owing to lack of mobile phone ownership or incompatibility of the app with clients' mobile phones. Individual differences in technology literacy and provider beliefs about substance use care either facilitated or challenged implementation. Awareness of patient needs and resources facilitated implementation, whereas external policies and regulations regarding technology use introduced barriers to implementation.

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**Conclusions:** The conceptually grounded facilitators and barriers identified in this study can guide systematic targeting of strategies to improve implementation of mobile phone interventions in community treatment settings. Results also inform the design of technology-based therapeutic tools. This study highlights directions for research with regard to implementation of technology-based behavioral health care approaches.

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#### KEYWORDS

substance abuse; relapse prevention; mobile apps

# Introduction

Addiction and mental health treatment programs have been particularly slow to adopt evidence-based practices [1]. Incompatibility of time- and labor-intensive interventions with the realities of care systems presents operational barriers to transfer of evidence-based treatments into practice. Furthermore, a majority (90%) of individuals with substance use disorders do not receive treatment, suggesting that the current care system is either inaccessible or unacceptable to the 21 million Americans who present with substance use disorders annually [2]. For those who receive some form of treatment, the likelihood of relapse is high, particularly if recovery supports are not in place [3].

There is strong and growing evidence to support the effectiveness of technology-based treatment approaches for substance use disorders across the care continuum, including screening and assessment [4,5], treatment [6-15], and recovery support [16]. Such technology-based approaches can be delivered through computers, laptops, or tablets (eg, Web-based treatment for substance use disorders) or by way of mobile phones (eg, addiction recovery support app), either as stand-alone interventions or as augments to care. Studies have consistently demonstrated that technology-based approaches can work as well as, or better than, traditional therapeutic approaches delivered by trained clinicians [11,17,18].

Mobile phone technologies offer a promising platform for delivery of substance use treatment approaches. Use of mobile phone technologies continues to rapidly grow across age, race ethnicity and geography, and consumers increasingly rely on the Internet and mobile phone-based tools for health information [19]. Although disparities in access to mobile phones exist, access is increasing among even the most disadvantaged populations. Approximately 66% of adults in the United States now own a mobile phone, up from 58% in 2014 [20]. Ownership is highest among adults aged 50 years and under (particularly young adults) and lowest among those aged 65 years and older. Ownership is associated with relatively higher education and income levels for those older than 30 years. Mobile phone ownership is most financially tenuous for the subset of users who depend on their mobile devices the most (ie, low-income individuals who use mobile devices as their sole source of Internet access) [20]. Despite these disparities, mobile phone technologies offer the potential for many individuals to access support when they need it the most.

Technology-based substance use treatment approaches offer the potential for on-demand access to care across time and

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geographic location. These tools can also extend the reach of services to traditionally underserved and disfranchised populations who perceive stigma regarding service use, such as those with substance use conditions or mental illness. There is also growing support for the cost-effectiveness of technology-based substance use treatment approaches [21,22]. The Addiction Comprehensive Health Enhancement Support System (A-CHESS [16]) is a recovery support app for mobile phones. The app was developed to align with therapeutic constructs associated with substance use relapse prevention, including monitoring of use, relevant information about triggers and recovery, skill building and restructuring activities (ie, relaxation exercises, avoidance strategies), and support (eg, on-demand outreach to recovery support people, meeting locator, online peer discussion forum). In a randomized controlled study with clients who had completed residential treatment for alcohol dependence, those who used the mobile phone app demonstrated fewer risky drinking days and higher self-reported abstinence at 6 months relative to those who received standard care [16].

Despite strong empirical evidence to support the effectiveness of technology-based therapeutic approaches to substance use, the field is relatively nascent with regard to guidance on the process of implementing these approaches in community care settings. In this qualitative study, we explored provider and staff perceptions of implementation of the A-CHESS mobile recovery support app with clients in 4 addiction service settings. By identifying facilitators and barriers to implementation, we can begin to develop clearer guidelines to support adoption and implementation of technology-based tools in diverse settings.

We used the Consolidated Framework for Implementation Research (CFIR) [23,24] as an organizing framework for the study. The CFIR represents a unifying typology of implementation models and constructs associated with successful implementation of innovations in health service delivery systems [25-27]. The framework outlines key constructs in 5 domains, including characteristics of the intervention, characteristics of individuals using the intervention, qualities of the organization in which the intervention is implemented and of the broader community-social environment within which organizations operate, and the implementation process itself. The CFIR framework has been used in a number of health service areas, including weight management [28], health information [29], mental health care [30-33], and technology-based approaches to behavioral health care [34]. The framework provided a foundation from which to identify facilitators and barriers to implementation of the A-CHESS mobile phone app with clients in the community service settings.

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# Methods

The first author's institutional review board (IRB) approved the study. Participating service sites were members of the Comprehensive Health Enhancement Support System Health Education Consortium (CHEC), organized by the A-CHESS app development researchers at the University of Wisconsin, Madison (UW). The purpose of the CHEC was to study how A-CHESS would be used by service organizations in naturalistic implementations. As part of consortium membership, agencies made a donation (\$10,000) to support consortium activities and agreed to participate in studies generated from consortium member interests, as possible. The UW team provided member agencies with access to A-CHESS and ongoing technical assistance. Technical assistance included training materials for program setup and monthly telephone support.

Eight agencies participated in the first year of the consortium, representing substance use treatment, community behavioral health, and drug court settings located in the Northeast (2), Midwest (2), South (2), and West (2) of the United States. Each agency committed to make A-CHESS available to up to 100 clients over a 1-year period. Agencies determined how and with whom A-CHESS would be used at their organization as well as how to engage clinical and administrative staff in the implementation process.

## **Participating Agencies**

Dartmouth researchers presented the plan for this implementation process study to the 8 consortium agencies during a regular CHEC monthly teleconference and sent a separate follow-up email invitation to each consortium member. Of the 8 sites, 4 (50%) agreed to participate in this study. Four consortium agencies elected not to participate, primarily owing to lack of time and delays in implementation of A-CHESS. Agencies that participated in the study did not differ from those that did not participate on key demographic indicators, including type of setting, services provided, and client demographics.

All 4 participating organizations were within the first year of implementation of A-CHESS. Agency details include:

1. A northeastern addiction recovery center that specializes in services to veterans used A-CHESS in combination with medication-assisted treatment for veterans with a high rate of alcohol detox admissions. The agency provided mobile phones and data plans to clients, through funding from a federal grant, to foster standardization of client experience and internal technical support. The medical director, nurse case manager, and director of information technology were interviewed for this study.

2. A northeastern drug court program integrated A-CHESS into their substance abuse treatment program for offenders. Mobile phones and data plans were provided to clients through a federal grant. Interviews were conducted with the change leader, the caseworker, and the peer recovery coach hired to support implementation.

3. An addiction treatment center based outside a major northeastern city offered A-CHESS to "alumni" of its inpatient

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treatment program. Only clients with compatible mobile phones were offered the A-CHESS app. Interviews were conducted with the alumni services coordinator, the inpatient administrator, and the training director involved in implementation.

4. An outpatient behavioral health agency in the Midwest offered A-CHESS as a resource for posttreatment support for clients with mobile phones. Interviews were conducted with the agency program director, training director, and clinical supervisor overseeing implementation of A-CHESS at the agency.

## **Stakeholder Recruitment**

For each participating agency, 3 stakeholders were invited to participate in the study. Stakeholders represented leadership and clinical perspectives on the implementation of A-CHESS. Because the study focused on agency efforts to promote implementation of the mobile phone app, clients were not included as stakeholders. All stakeholders who were invited agreed to participate.

#### Interviews

An interview guide was created to elicit stakeholder perspectives on the implementation process of the A-CHESS mobile phone app. The guide included probes associated with the decision to become a consortium member, preimplementation planning and preparation strategies, implementation experiences, monitoring of progress and success, experiences of technical assistance and support, and plans for sustainability.

#### Sample

A total of 12 stakeholders were interviewed for the study (3 from each agency). Participants were 50% female, predominantly white (91%), and ranged in age from 25 to 53 (mean: 36.7) years. A postdoctoral researcher trained in qualitative methods conducted the 20- to 30-minute interviews in early 2013. All interviews were audio-recorded and transcribed, with the exception of one wherein the audio recording failed. In this instance, interview summary notes were created immediately after the interview. Because summary notes were not conducive to further coding, we analyzed 11 interviews for this study.

## Analysis

Researchers trained in qualitative methods (coauthors SM and SL) reviewed and coded interview transcripts using a deductive, consensus-based directed content analysis approach to strengthen the trustworthiness of the analysis [35,36]. Guided by the CFIR model, a coding scheme was developed that outlined each of the constructs to represent either a barrier or facilitator to implementation of the mobile recovery support tool. The coders independently coded each transcript using the coding scheme to document presence of given constructs throughout the narrative and whether a barrier or facilitator. The coders met frequently to ensure that coded text segments were consistent with code definitions; inconsistencies were resolved through discussion to achieve consensus. Coding discrepancies were primarily related to perceived conceptual overlap of CFIR constructs.

# Results

Results are described first in terms of the implementation process for each agency, followed by description of contextual facilitators and barriers to implementation that emerged across agencies and stakeholders. Represented CFIR coding themes across agencies and stakeholders are depicted in Multimedia Appendix 1. Multimedia Appendix 2 includes code conceptualizations and representative quotes.

# **Implementation Process**

# Veteran Substance Use Treatment Center

This agency offered a set of integrated services to clients including A-CHESS, naltrexone, individual therapy, and a recovery coach. At the time of the interviews, 45 of 50 eligible clients were using A-CHESS. The agency fostered engagement through creation of a dedicated implementation team that included the following: (1) a nurse case manager who identified and trained eligible clients and (2) the information technology director who set up the technology infrastructure, oversaw all internal technical assistance and troubleshooting, and managed the data collected through A-CHESS.

Implementation of A-CHESS was marked by detailed planning before the launch, including: (1) identifying strategies for recruitment of clients, obtaining consents, and training of all agency providers and clients, (2) identifying the types of mobile phones and data plans that would be most compatible with the agency service area (working with a local phone vendor), and (3) determining processes for monitoring and maintaining online app features (eg, discussion board) and for how to effectively use data to inform implementation. Clearly defined roles, regular meetings, and open communication between team members and with clients allowed for adaptability during implementation to improve compatibility with agency and client needs.

We saw actually a tipping point...one veteran had reached out on the discussion board and there was radio silence...the member of our team managing A-CHESS had a talk with the veterans and the next week, the same veteran sent out a distress signal and 20 vets descended upon the cellphone, and that was the tipping point. Now it's instant support. [Medical Director]

Ongoing collaboration with the UW app development researchers to address technical issues and adaptations as needed to improve fit with the agency and clients also facilitated implementation, as did routine reviews of data to evaluate implementation and client engagement.

... our CEO, he is definitely the one who is...taking the numbers and talking to other places where he thinks this could be beneficial...It could be a grant, it could become a VA benefit...trying to show the VA that it's gonna cost them a lot less to keep these people in the A-CHESS program than paying for five detoxes a year...inpatient stays are always more expensive. [Director IT]

# Drug Court

A-CHESS and mobile phones were offered to all drug court participants. A dedicated team was created that included a certified change leader, a caseworker, and a peer recovery coach. At the time of the interviews, 40 clients were using the recovery support app. Familiarity with A-CHESS from a prior pilot facilitated preimplementation activities. Careful planning of client training, execution of implementation, and tailoring of the app to meet client needs facilitated implementation. The agency worked closely with the UW researchers and their IRB to address concerns about features that could compromise client privacy and confidentiality (with potential legal implications) to ensure protection of clients, including prohibiting probation officers from accessing client information.

Regular team meetings, open communication between team members and with clients, close attention to client needs, and ongoing review of data to monitor client usage, risk, and outcomes all helped to create an organization culture that valued use of A-CHESS and made it a routine aspect of treatment. Client-centered implementation strategies to promote engagement included staged introduction to new clients and use of peer recovery coaches, establishing contracts with clients to set clear expectations about app usage, encouraging clients to try the app before committing to use it, using consistent client-centered messaging about the app, and supporting peer-driven management of app features (eg, discussion board).

It is client-to-client...our staff step back...and we let the peers run it. They police it...Because we don't dominate it, they own it. They feel very empowered... [Change Leader]

The more people you have using the app, the more benefits others get out of it...You have to encourage clients to use it. Once they start using it...the clients will start encouraging the other clients to use it...Make sure clients know it's for their benefit, it's for them. The minute they think it's for your benefit you will find they are resistant... [Peer Recovery Coach]

# Addiction Treatment Center

The team at this agency offered the A-CHESS app to alumni clients of the inpatient treatment program as one of several postdischarge resources. Access was available only to those with a compatible mobile phone. Inpatient alumni were targeted owing to disinterest in the A-CHESS project among outpatient treatment clinicians. The focus on this client subgroup also allowed for a more manageable implementation process. At the time of the interviews, approximately 40 clients were using the app.

The agency engaged a dedicated team that included the alumni services coordinator, the inpatient administrator for clinical outreach, and the training director. The team paid careful attention to planning implementation rollout, including designing a course of action for training clients with the app, tailoring implementation for client subgroups (eg, older clients, those with learning disabilities), setting expectations for use of the discussion board, and identifying response strategies to "Panic"

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outreach. Clients were oriented to the app as part of inpatient discharge planning to build awareness and interest in use of the app as a postdischarge resource.

We always talk about the alumni stuff, and we always talk about the app and just kind of put it in their head that there is this app out there and it's really cool...After they've been there a few weeks, that's when I start meeting with them and talking about aftercare...and just letting them play around with the app on my phone...Before their discharge we meet again to discuss if they want to get [the app] and then I will actually download [Inpatient Administrator]

Other process facilitators included working collaboratively with the UW app development researchers on adaptations to improve client engagement (eg, notification feature for discussion board) and ongoing use of data to monitor client engagement and implementation progress. For example, early review of client usage data and time spent in relapse suggested that relapse times were shorter for those clients more actively using the app, i.e. agency staff was able to intervene quickly because of notification about relapse. Agency stakeholders used this information to promote engagement of clients and to highlight the value of the mobile phone app to administrators to promote ongoing adoption.

# Community Behavioral Health Agency

This agency offered A-CHESS as an ancillary posttreatment support for clients with a substance use disorder who had compatible mobile phones. At the time of the interviews, 5 clients had been set up to use the recovery support tool. A clinical supervisor was in charge of implementation efforts. The agency was familiar with the app from successful participation in prior projects wherein clients were given mobile phones. In this study, there were challenges recruiting clients with mobile phones.

Recruitment strategies shifted to target younger college-aged clientele, with limited success. The clinical supervisor also described general plans to make A-CHESS a more central component of treatment planning for clients. Stakeholders did not elucidate specific planning strategies for implementation of A-CHESS, ways in which data could inform implementation, or whether they engaged the UW researchers to promote implementation.

## **Facilitators and Barriers to Implementation**

Salient barriers and facilitators to implementation of the app across settings and stakeholders are described in the following section (see Multimedia Appendices 1 and 2 for detail).

## **Inner Setting (Agency Characteristics)**

## Compatibility: Facilitators

Across settings and stakeholders, perceived compatibility of A-CHESS with client needs emerged as a salient facilitator to implementation. Themes associated with the perceived compatibility included the ability to communicate when clients needed it the most (eg, "clients reach to their phones as a way to interrupt a bad moment" [Veterans Substance Use Treatment]), and to promote client empowerment (eg, "...it puts

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the power of recovery in the hands of the individual. It is the quintessential strength-based, person-centered model." [Behavioral Health]

#### Compatibility: Barriers

Noted barriers included app features that were incompatible with client populations. For example, stakeholders from the veterans' treatment setting noted that the name of the outreach feature (Panic Button) was not compatible with military training (ie, "Soldiers don't panic"), and was thus a feature this client subgroup was ambivalent about using. Drug Court stakeholders noted that the location-tracking feature could be used to violate client privacy and result in additional legal issues.

Agency-level compatibility barriers included concerns about lack of reimbursement for use of the mobile phone app in the care process, provider resistance to use of technology with clients (eg, concerns about therapeutic boundaries and 24/7 liability), and organization policies restricting use of mobile phones.

# **Other Agency-Level Facilitators**

Implementation readiness marked by clear leadership support and availability of resources to support implementation (eg, training, dedicated team) facilitated implementation of A-CHESS with clients. Clear and consistent messaging to staff about the relative priority of the mobile phone app, open communication among staff, and a positive learning climate that supported workflow adaptation to improve implementation all facilitated implementation.

## **Intervention Characteristics**

Characteristics of the A-CHESS app itself were salient for implementation. Design quality and packaging and evidence of strength and quality were the two most referenced characteristics.

## Design Quality and Packaging: Facilitators

Design quality and packaging is defined as how the intervention is bundled, presented, and assembled [23,24]. In this analysis, we interpreted "bundling" as the app being inseparable from the mobile phone. The phone itself was a significant perceived benefit ("There is a huge incentive for our clients to have a free phone…" [Drug Court]). Other facilitators included the ability to preprogram important client support contacts to foster easy outreach when needed ("To just be given a phone to say dude, my number is in there, press a number and call me, the ease of access…it just sort of freed them…" [Drug Court]), the online discussion board ("It's giving them a place to reach out to, a place to vent, a place to feel supported when maybe they can't get to meetings" [Addiction Treatment]) and features to aid those with literacy challenges, including speech-to-text functionality.

## Design Quality and Packaging: Barriers

Accessibility was a significant barrier to implementation in agencies that did not issue mobile phones both by virtue of clients not owning mobile phones or having phones that were incompatible with the A-CHESS android app (ie, iPhone or Blackberry). A number of clinical barriers were noted. For

example, drug court staff were concerned about adverse effects of relapsing clients' posts on other clients in the online community.

A stakeholder from the addiction treatment setting expressed concern about potential iatrogenic triggering of relapse by the location-based alert feature that makes a user "aware of every liquor store in your area." Liability issues were also noted, including concern about the need for ongoing monitoring and response to client postings on the discussion board in the event of actionable incidents (eg, suicide threats). Other noted barriers included limited flexibility of the online administrative feature for providers, navigation challenges (eg, duplicate login areas) and sporadic technical problems with features that required wireless access (particularly in rural areas), and the influence of rapidly changing technologies.

# Evidence of Strength and Quality: Facilitators

Positive perceptions about the quality of the mobile phone app as a recovery support tool facilitated implementation across care settings (ie, "We've found this to be a great tool to stay connected, and it's all recovery-based, which is great" [Addiction Treatment]). As a drug court stakeholder noted,

The relapse prevention model of A-CHESS itself is really well demonstrated with clients...the fact that clients can reach out 24/7 to peers...that interrupts the moment...the relapse prevention moment, they had something to do instead of sitting in their own head...it really does play out that clients reach to their phone as a way to interrupt a bad moment.

True to the mobile phone app's purported mandate—to improve continuing care for individuals with substance use disorders by offering ongoing emotional and instrumental support—these quotes all reference contributions to adaptive functioning.

# Evidence of Strength and Quality: Barriers

Salient barriers with regard to strength and quality of the app included limited longer term client engagement with the app ("Like a lot of other apps, you use it for a month...and then you start losing touch with it" [Addiction Treatment]) and questions about impact with dissemination to a broader client base ("I think if you have too many people on this...you kind of get lost in the whole cyberspace thing of who is this person—anybody could be on there...you want to keep it small so people feel comfortable actually interacting and putting messages on there...you get more interaction when people know each other" [Addiction Treatment]).

## **Relative** Advantage

Perceptions of relative advantage of the recovery support app over usual care also facilitated implementation across service sites, particularly with regard to ongoing client support:

A lot of people who deal with drug issues are pretty solitary people...so it's hard to get them to open up. When you're doing it through the application, it's somewhat anonymous...you're not standing face-to-face...and it makes it a little bit easier to develop friendship. [Drug Court] Stakeholders generally did not indicate perceived relative advantages of the app with regard to their own workflow (eg, "Does it save me...on paperwork or phone calls? I would not say either. It's probably just the same" [Addiction Treatment]).

# Ease of Use

Perceived ease of use of the app was a facilitator to implementation across settings (eg, "It is a very safe app; anything you press it easily directs you to go right back to it" [Addiction Treatment]).

# Trialability and Adaptability

The ability to try the app and adapt it to improve workflow and client use emerged as important implementation facilitators. For example, to overcome usability barriers with the discussion board due to duplicate login navigation, the implementation teams worked with UW development researchers to improve access to the discussion board and create notifications to alert clients to new material.

# Cost

Cost was a perceived barrier to sustained implementation in the Veteran Substance Use Treatment Center, Drug Court, and Community Behavioral Health agency. Long-term sustainability of providing mobile phones to clients and paying for technical assistance from the UW development team were the most salient cost concerns.

# **Individual Characteristics**

Providers' treatment philosophy and beliefs about the use of technology influenced implementation (eg, "this is not how I work with people"). Individual differences in clients' technology and reading literacies, and degree of learning disability impacted the level of training required for implementation. The intuitive ease of use of the app aided in self-learning.

Once they got the hang of it they really don't need more instruction. They loved it once they got playing with it. It was a surprise; people we thought would not use it much did use it [Veterans Substance Use Treatment]

# **Outer Setting**

Overall agency awareness of patient needs and resources was positively associated with implementation. Agencies that modified implementation strategies to improve compatibility with clients' needs experienced implementation success. The behavioral health agency, which had positive experience with A-CHESS in a prior pilot, referenced unawareness of patient needs and resources, specifically with regard to clients' relative lack of access to mobile phones. This factor contributed significantly to the agency's challenges with client recruitment to use the app.

External policies and regulations regarding technology use also introduced barriers to implementation. For example, in the drug court, concerns about client privacy and regulations prohibiting mobile phone use were only circumvented through IRB study provisions and a plan to exclude probation officers from access to client information from the mobile phone app. Such exclusion could be more difficult outside a research context.

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Textbox 1. Summary of Implementation Process Strategies

#### Planning

- Identify what mobile phones to use (if providing phones) to maximize compatibility with clientele and agency needs
- Develop client recruitment strategies, when and how to introduce the app to clients, and training protocol
- Create clear plans for monitoring program features to ensure client safety and privacy
- Identify indicators of implementation success and develop plan for consistent monitoring and use of data to inform implementation and agency practices

#### Engagement

- Create a dedicated internal team with clear role and responsibilities to lead implementation
- Identify staff with positive attitudes toward the mobile phone recovery support approach to serve as champions to promote buy-in among clinicians and clients
- As possible, collaborate with the mobile phone app development team to address technical issues and create adaptations to improve client engagement and fit with agency and client needs
- Work with technology vendors to ensure that mobile phones to be issued are compatible with the mobile phone app software, the local service area, and the technology infrastructure of agency
- Orient clients to the app early to build awareness and interest (eg, as a postdischarge resource during inpatient care)
- Use contracts with clients to set mutual expectations about mobile phone app use
- Seed discussion forums with conversation content to build client engagement

#### Execution

- Scale rollout to work out implementation challenges
- Meet regularly to review implementation and adjust workflow as needed
- Obtain client feedback regarding app experiences to guide implementation adaptations

#### Reflection/evaluation

- Conduct ongoing review of data to monitor client usage, risk, and client outcomes
- Use data to adapt workflow processes to promote implementation



#### Textbox 2. Summary of Implementation Strategies by CFIR Context Domains

Inner Setting Characteristics

- Adapt technology and implementation plans to maximize compatibility with agency workflow and needs
- Train clinicians and staff to promote awareness about the mobile phone app and emphasize priority of the app as routine part of care
- Develop and clearly communicate standards and practices to ensure protection of clients and clinicians with regard to use of the mobile phone recovery support app
- Communicate clear indicators of implementation success to all staff to build perceptions of relative advantages of the technology-based approach and elicit staff engagement to help overcome implementation barriers

#### Intervention characteristics

- Provide mobile devices to foster standardization of client experience and technical support
- Preprogram important client support contacts to foster easy outreach when needed
- Seek funding (eg, donations, minigrants) and leverage state Medicaid billing codes to subsidize hardware and software purchases
- Trial the mobile phone app with end users to promote buy-in

#### Characteristics of individuals

- Provide ongoing technical assistance and education to staff and clinicians to increase perceptions of the app as compatible with client needs and effective care
- Train clients individually to accommodate differences in technology literacy and learning disabilities
- Tailor the app to meet client needs
- Tailor implementation for client subgroups
- Highlight features to aid those with literacy challenges (eg, speech-to-text functionality)

#### Outer setting characteristics

- Maintain client-centered approach to care that prioritizes client needs and resources
- Assess technology ownership and use among an agency's client base to provide foundation for planning of technology-based service delivery initiatives
- Use data from successful implementation to inform administrative policy decisions
- Change agency policies if necessary to accommodate use of mobile care approaches

Textbox 1 summarizes successful implementation process strategies. Textbox 2 summarizes strategies within each of the CFIR context domains that facilitated implementation.

# Discussion

The CFIR conceptual framework provided a valuable lens through which to identify key barriers and facilitators to implementation of A-CHESS with clients from 4 service settings. Results of the study contribute to the field in 3 substantive ways: (1) informing practice for implementation of mobile phone technology approaches for addiction treatment and behavioral health care more broadly, (2) informing development of mobile phone apps to optimize implementation success, and (3) informing directions for implementation science research with regard to use of mobile phone technologies for behavioral health care.

# **Informing Practice**

Successful implementation of the recovery support app was marked by careful attention to planning for implementation before launch, including what mobile phones to use, what client populations could benefit the most from program use, when to

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introduce the app to clients, processes for training staff and clientele, how to monitor program features most effectively in terms of staff time and expertise, and how to effectively use data to inform implementation. A key component to planning was early engagement of a dedicated, appropriately trained internal team to foster implementation buy-in among agency providers and clients and facilitate implementation. Iterative and ongoing technical assistance from the app development team to improve the fit of A-CHESS with the agencies and their respective clientele also facilitated implementation. One agency also worked with a local technology vendor to ensure that the mobile phones to be issued to clients were compatible with the mobile app software, the local service area, and the technology infrastructure of the agency. This pre-implementation preparation paved the way for standardization of client experience and internal technical assistance. The use of internal change agents and external supports to promote implementation in systems of care is central to a number of implementation models [25-27]. This study provides a lens on how agencies used internal staff and outside supports to improve client and agency experiences with the mobile phone recovery support app.

Consideration of client needs was central to implementation and informed adaptations to address subgroup needs (eg, learning disability, literacy, drug court involvement), as well as strategies to support client engagement, such as training all staff about the app so that they would be better prepared to respond to clients' questions regarding their own experiences with the app. The most successful implementation occurred in agencies that actively created a culture that positioned the mobile phone app as a routine part of relapse prevention care. The community behavioral health agency had the most challenges with implementation in large part due to lack of awareness about the technology resources of its clientele. As the only participating agency that did not focus exclusively on addiction treatment, competing service demands may have made it more difficult to prioritize the mobile phone recovery support app as a central part of care. Assessing technology ownership and use among an agency's client base would create a foundation from which to plan technology-based service delivery initiatives.

#### **Facilitators and Barriers to Implementation**

#### Agency Level

Perceptions of A-CHESS as compatible with client needs were central to stakeholders' assessment of implementation. Such compatibility was noted across substance use diagnostic categories, that is, alcohol disorders as well as other substance use disorders (eg, drug court). Compatibility, or fit, of interventions with client and organizational needs is a key aspect of many implementation models [25-27] and is associated with implementation of substance use care in community service settings [37]. Replication studies with clients with primary substance use disorders other than alcohol would strengthen generalizability of the results found here.

Consistent with other research with provider stakeholders in behavioral health care settings [34], perceived compatibility barriers such as concerns about billable time, therapeutic boundaries, privacy, and liability (ie, response to suicide threats after hours) are all important issues to address in planning implementation of technology-based care approaches. As would be the case with introduction of any service innovation, these issues should be addressed according to best practices for clinical care at the agency. Strategies to address concerns include ongoing training and support of clinical staff, clear communication about standards and practices with regard to protection of clients and providers, and ongoing collection and sharing of data regarding implementation success [34]. Ongoing provision of clear indicators of implementation success (and barriers) to staff can foster positive perceptions about the relative advantages of technology-based care approaches and elicit staff engagement to help overcome implementation barriers [23,24]. Establishing an organizational climate that emphasizes the relative priority of the mobile phone approach to care promotes collaboration, communication, and flexibility to adjust course and adapt as challenges emerge.

# Intervention Level

The potential of mobile phones for enhancing continuing care was salient across agencies and stakeholders. Access to mobile phones was a powerful motivator to client buy-in to use the app

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in agencies that offered phones for A-CHESS implementation. Cost was a barrier to sustained ability to provide mobile phones to clients. In agencies that did not provide phones, accessibility to the A-CHESS app was limited to those clients that owned app-compatible mobile phones. Fortunately, mobile phone ownership continues to increase across demographics [20]. Still, this study highlights the real continued disparity in mobile phone ownership, particularly among disadvantaged, rural populations.

Strategies to promote sustainable client access to evidence-based mobile apps such as A-CHESS are essential. When possible, agencies can seek funding (eg, donations, mini-grants) and leverage state Medicaid billing codes to subsidize hardware and software purchases [38]. Alternatively, agencies have successfully integrated A-CHESS into their service line and overall business model, establishing a reputation in the field and demand among consumers [38]. Another strategy to reduce costs is to lend mobile phones with the app preinstalled to clients entering treatment and recycle those phones to new clients as previous clients begin to experience diminishing returns from the app. Setting clear expectations with clients at the outset and thoroughly debriefing on retrieval of the phone to outline a clear plan for continued recovery support would be important with this approach. Changing policies in health care could eventually support "prescribing" mobile phones with the installed app as a covered cost.

The online peer discussion forum was the most popular feature of A-CHESS for clients, as reported by stakeholders across the 3 agencies that successfully implemented the mobile phone app. This feature empowered clients and fostered active engagement in their recovery process through opportunities to both receive and offer support to others. The online forum created a way for individuals to connect with others and overcame traditional barriers to in-person recovery support groups, including difficulty finding meetings or inability to attend at scheduled times, and perceived stigma or discomfort with in-person meetings.

There were differences between agencies in the level of monitoring and seeding of the forum by the care teams. Stakeholders from the drug court set expectations for forum use and client privacy protection and encouraged client ownership of the forum; stakeholders from the Veterans and addiction treatment settings were more involved in seeding the forum to encourage client engagement. One way to address concerns that A-CHESS communities might get too large is to create multiple groups as volume increases based on obvious delineations within the community-at-large (ie, separate forums for probationers and post-probationers or for younger and older adults). Research is needed with clients in addiction recovery to broaden our understanding of the role and benefits of online support communities, such as those offered in A-CHESS, for recovery outcomes. Key research questions include when and for whom these online support networks are most helpful and how online communities compare with inperson self-help groups in terms of mechanisms of influence on client outcomes (eg, bonding and support, goal direction and structure, promotion of non-drug–using norms, fostering self-efficacy and coping skills) [39].

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# Individual Characteristics

Variability in implementation was primarily due to provider attitudes regarding use of technology with clientele and to individual differences in technology literacy of clients who required different levels of training. Although achieving buy-in for service innovations from all clinical staff is unlikely at the outset, agencies can optimize buy-in by carefully selecting internal champions as part of implementation team that will promote use of the mobile phone app by clients. Ongoing sharing of data that supports implementation success among clients can help persuade others about the relative advantages of the technology. The intuitive interface design and ease of use of the A-CHESS app allowed clients to easily learn to use the app with practice.

# **Outer** Context

Agency policies prohibiting client use of mobile phones and more stringent privacy regulations for particular subpopulations (ie, drug court-involved) can introduce barriers to implementation of mobile substance use treatment technologies. In some cases, liabilities related to specific technology features, such as location tracking, may need to be turned off to proceed with use of the tool for other capacities. In many cases, agency policies can also be changed. Thinking systemically, an innovation can be adapted to improve fit during implementation; organizations can also adapt to accommodate the innovation [40,41]. Key to any policy change is use of data to demonstrate value, such as improving clients' health and wellbeing and promoting health service quality and efficiency. Furthermore, organizations are encouraged to adapt the innovation to the needs of the agency and client subgroups. Although efforts should be made by people at adoption sites to maintain the core elements of the intervention [42], scholars are increasingly rejecting the assumption that an intervention will yield diminished benefit for clients after being modified to fit real-world delivery settings [43].

# Postlude: Sustainability

The focus of this implementation process study was a single point in time relatively early in implementation. In a separate study of A-CHESS sustainability among consortium members, 3 agencies had sustained use of the recovery support tool at 24 months, 2 of which were agencies studied here (Veterans Substance Use Treatment and Addiction Treatment) [38]. It may be that the salient barriers noted in implementation for the 2 nonsustaining agencies (Drug Court: cost, client privacy, mobile phone use policies; Behavioral Health: mobile phone accessibility, cost) reduced perceptions of value added by the mobile recovery support tool in an ongoing service package. Issues of sustainability were foremost on the minds of stakeholders in the Veterans' agency from the outset of implementation. This agency integrated the cost of mobile phones for clients into their overall business model, which contributed to sustainability. The addiction treatment agency experienced early implementation success with a carefully targeted client subgroup.

# **Informing Development**

Study results can guide developers to create mobile applications to optimize implementation success. A-CHESS was developed based on evidence-based relapse prevention practices, and evidence of these elements promoted implementation. To optimize adoption, features should be developed to align with evidence-based practices, target audience needs and characteristics, and organizational workflow. To the degree possible, apps should be developed to be cross-platform and Web-accessible. User-centered design practices that include iterative feedback from target end users during the development process help ensure that the app is easy to use and can promote client engagement. Ongoing evaluation of data collected from technology-based approaches can help agencies monitor client engagement related to their care and implementation progress. The way in which important implementation data from technology-based care approaches are displayed to stakeholders is often underappreciated. Improving visualization of data to make it accessible and meaningful to stakeholders is critical.

# **Informing Implementation Science**

This study also highlights directions for future research with regard to implementation frameworks for technology-based care approaches. A challenge to achieving code consensus using the CFIR framework largely reflected overlap of constructs within and between domains as applied to the mobile phone recovery support app (eg, compatibility of the mobile app for clients as a characteristic of the intervention; compatibility with provider practices as characteristic of the organization). The CFIR model also positions implementation as a traditional unidirectional process-an intervention is delivered to clients by providers or clinicians in a given setting. However, in the case of mobile treatment approaches, the mobile phone itself is a context for implementation, as is the sociocultural environment in which mobile apps are used. Implementation frameworks such as the CFIR need to be expanded or adapted to align with the capacities and multidimensional, dynamic nature of technology-based treatment approaches that actively engage clients at various stages of motivation and treatment and expand care beyond clinic walls [44]. Research in the application of the CFIR model as it pertains to technology-based behavioral health treatment tools more broadly is needed.

# Conclusions

Moving science to service is inherently an active process and the implementers, those people who put an innovation to use, are active recipients of these innovations [45]. In the case of mobile phone interventions, such as A-CHESS, there are a number of implementers. Clients literally have the intervention in the palm of their hands to use as they wish , and agency leaders and clinicians are in the important role of facilitating implementation by offering the tool to clients, supporting their use of it, and identifying ways that the technology can be sustainably integrated into care delivery more broadly.

There are several limitations to this implementation process study. First, the study was conducted in 4 settings, the sample size was small and only reflected the perspectives of provider and staff stakeholders, and data were collected at a single point

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in time. Future efforts to explore implementation would benefit from longitudinal data collection from a larger, more diverse range of settings and stakeholders, including those who decided not to use the technology. Second, although providers and staff provide a valuable lens on implementation from the perspective of the larger client base and organization, clients' experiences with the app would lend valuable perspective on strategies for implementation and ongoing engagement with the app and should be a focus of future research. Finally, it is possible that the relationships between the consortium participants and the UW-Madison team may have inflated the overall impressions of the tool owing to the collective investment in the consortium itself. This possibility is countered by the fact that 2 of the 4 agencies did not sustain use of A-CHESS as demonstrated in later work. Despite these limitations, the study yielded important findings that may generate further research and aid in practice-based efforts to implement mobile substance use treatment approaches.

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# **Authors' Contributions**

AR conducted the qualitative interviews. SM and SL coded and analyzed the transcribed interviews. KJ and SD led the consortium study, facilitated site recruitment for the study described in this paper, and provided valuable feedback on the paper.

# **Conflicts of Interest**

Dr. Johnson and Ms. Dinauer are shareholders in CHESS Mobile Health, a company that markets A-CHESS. The remaining authors have no conflicts of interest to declare.

# **Multimedia Appendix 1**

[PDF File (Adobe PDF File), 79KB - mental\_v3i2e24\_app1.pdf]

# Multimedia Appendix 2

[PDF File (Adobe PDF File), 62KB - mental\_v3i2e24\_app2.pdf]

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# Abbreviations

A-CHESS: Addiction-Comprehensive Health Enhancement Support System CFIR: Consolidated Framework for Implementation Research CHEC: Comprehensive Health Enhancement Support System Health Education Consortium IRB: institutional review board

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# Original Paper

# Direction to an Internet Support Group Compared With Online Expressive Writing for People With Depression and Anxiety: A Randomized Trial

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# Abstract

**Background:** Depression and anxiety are common, often comorbid, conditions, and Internet support groups for them are well used. However, little rigorous research has been conducted on the outcome of these groups.

**Objective:** This study aimed to evaluate the efficacy of an Internet support group in reducing depression and anxiety, and increasing social support and life satisfaction.

**Methods:** A randomized trial compared direction to an existing Internet support group for depression and anxiety with an online expressive writing condition. A total of 863 (628 female) United Kingdom, United States, and Canadian volunteers were recruited via the Internet. Online, self-report measures of depression, anxiety, social support, and satisfaction with life were administered at baseline, 3, and 6 months.

**Results:** All four outcomes – depression, anxiety, social support, and satisfaction with life – improved over the 6 months of the study (all P<.001). There was no difference in outcome between the two conditions: participants responded similarly to the expressive writing and the Internet support group. Engagement with the Internet support group was low, it had high 6-month attrition (692/795, 87%) and low adherence, and it received mixed and often negative feedback. The main problems reported were a lack of comfort and connection with others, negative social comparisons, and the potential for receiving bad advice. Expressive writing had lower attrition (194/295, 65%) and participants reported that it was more acceptable.

**Conclusions:** Until further evidence accumulates, directing people with depression and anxiety to Internet support groups cannot be recommended. On the other hand, online expressive writing seems to have potential, and its use for people with depression and anxiety warrants further investigation.

**Trial Registration:** Trial Registration: Clinicaltrials.gov NCT01149265; https://clinicaltrials.gov/ct2/show/NCT01149265 (Archived by WebCite at http://www.webcitation.org/6hYISINFT)

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# KEYWORDS

depression; anxiety; Internet support; online support; expressive writing

# Introduction

Internet support groups (ISGs) covering health and well-being are undoubtedly popular: tens of millions of people have joined

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them in the United States alone [1,2]. Barak et al. [3] estimate that there may be several hundred thousand of these groups. Many focus on mental health problems, particularly depression and anxiety, which are prevalent and persistent disorders. A

review of European studies estimated that the 1-year prevalence of major depressive disorder was 5.7% [4], and it is frequently comorbid with anxiety [5]. However, for various reasons, people with depression and anxiety may be reluctant to seek formal psychological help [6], and so ISGs represent a potential additional source of informal help for them [7].

Given the prevalence of depression and anxiety and the popularity of online support, it is important that studies be carried out to estimate the overall outcome of ISGs, and to understand the mechanisms that may account for any beneficial effects. Evidence from these studies will help people with depression and anxiety decide whether an ISG is worth joining, and help professionals decide whether ISGs might benefit their patients. ISGs could potentially be an adjunct to other types of more intensive psychological treatment like cognitive-behavioral therapy or be a standalone low-intensity intervention in their own right.

There has been relatively little work on the outcome of ISGs for common mental health problems. Griffiths et al [7] reviewed studies of ISGs that measured depression as an outcome (not necessarily in ISGs primarily for people with depression). The majority of the 17 studies reviewed found positive effects on depression, although only two [8,9] were of depression-specific ISGs. Griffiths et al's randomized controlled trial (RCT) [10] compared a purpose-built ISG for depression with a computerized cognitive behavioral therapy condition, and found that the ISG participants had generally better outcomes at 6 and 12 months (but not 3 months).

The present study investigated the effectiveness of directing individuals to an existing ISG for depression and anxiety. It was partly motivated by the National Institute for Clinical Excellence (NICE) guidelines [11], which recommend the development of accessible help and support for people with common mental health problems. The design was a 6-month RCT. Participants in the experimental condition were facilitated to join the forums on a specific ISG, chosen because it had a constructive atmosphere and high traffic. Such an intervention mimics the approach that health care professionals or online resources can take, of directing those interested to existing groups, rather than the approach taken in some studies [10,12] where a group is created for the purposes of the study.

The selection of a comparison group for a naturalistic ISG study is problematic. Traditional waitlist control groups are difficult to maintain, as participants, prompted by their involvement in a study, can simply find and use other Web-based resources. We therefore chose an active control group, consisting of an online expressive writing intervention [13,14], which involves asking participants to write about "a traumatic experience" for between 15 and 20 minutes per day over a period of 3 to 5 days. A meta-analysis [15] found that expressive writing was effective in reducing psychological distress and increasing physical health, although the aggregated effect size was very small: 0.075. There are also similarities between expressive writing and the interactions between ISG users: both involve the expression of upsetting thoughts and emotions, although in expressive writing the writing is addressed to the self, whereas in an ISG it is addressed to the online community. However, there are additional therapeutic benefits potentially present in an ISG but not in expressive writing, such as receiving both information and emotional support from fellow group members, plus the sense of normalization of one's difficulties and the instillation of hope [16].

The main hypothesis was that participants randomized to the ISG condition would accordingly show greater improvement on the primary outcome measures (depression and anxiety) than those in the expressive writing condition. Secondary outcomes were perceived social support and satisfaction with life. Because increased social support is one of the mechanisms by which ISGs are thought to benefit their users, in accordance with Houston et al [9] it was hypothesized that social support would improve over time. Following Freeman et al [12], we hypothesized that a successful intervention would not only decrease depression and anxiety, but also increase satisfaction with life. These latter two outcome variables, social support and life satisfaction, have also been found to be correlated among users of social network sites [17].

In addition, a word count analysis was conducted to examine the associations between the language used in ISG postings and changes in depression over time. Following Pennebaker and Francis [18] and Riessman [19] respectively, we hypothesized that participants who (1) expressed more positive and negative emotions, and (2) used more other-focused pronouns would tend to have a greater reduction in depression.

# Methods

The study was a CONSORT-R compliant RCT [20]. The protocol was registered with clinicaltrials.gov, a database of clinical trials run by the US National Institute of Health [trial ID: NCT01149265].

## Design

The design was a 6-month RCT with participants randomized to either (1) direction to an ISG, or (2) an expressive writing condition. Measurement points were baseline, 3, and 6 months. Participants were randomized in a 2:1 ratio in favor of the ISG condition (because a pilot study found that attrition was twice as great in that condition).

## Recruitment

To recruit a Web-based sample, adverts were placed on a popular website, PsyBlog [21], run by the first author. Other individuals and organizations also publicized the study through websites, Facebook, and Twitter. Table 1 shows how participants located the study. Recruitment occurred between April and July 2010.



Table 1. How participants located the study.

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Source	N (%)		
Twitter	412 (48%)		
PsyBlog	187 (22%)		
Google search	58 (7%)		
Facebook	56 (6%)		
Discussion forum	36 (4%)		
Other	116 (13%)		
Total	863 (100%)		

The inclusion criteria were that participants were (1) over 18, (2) able to access the Internet, (3) English-speaking and living in the United Kingdom, the United States, or Canada, (4) experiencing self-defined depression or anxiety, and (5) computer literate. There were 1192 participants who met the inclusion criteria (see the Results section for their characteristics). Applicants who did not meet the criteria were sent an email thanking them for their interest.

The study was approved by the University Research Ethics Committee. Web-based informed consent was obtained from all participants.

## Interventions

## **Internet Support Group Condition**

Participants were randomized to either direction to an ISG or to the expressive writing condition. Participants in the ISG condition were asked to take part in the existing groups hosted at Psych Central [22], and given instructions on how to register and choose a username, password, and screen name. They were instructed to not use a screen name that personally identified them. They were shown the frequently asked questions page at the Psych Central forums and asked to familiarize themselves with the terms and conditions, and were provided with a list of hints and tips produced by the researcher, which outlined the potential benefits and issues that they may face in the ISG. They were told that they could contact the researcher at any stage if they were having any problems. Participants were encouraged to post an introductory message in the ISG and to try to take part in the ongoing discussions or start their own threads. Participants entered the group in batches over several weeks.

# **Expressive Writing Condition**

The expressive writing paradigm, developed by Pennebaker and Beall [14], involves participants writing about their thoughts

and feelings, often upsetting ones, for a short period of time. In the current study, participants were asked to write about an upsetting experience for a minimum of 5 minutes, every 2 weeks, over the 6 months of the study. They were asked to carry out this task any time during the 2-week period and submit it securely through a study website.

# Email Reminders

In both conditions, participants were each sent a reminder email every 2 weeks. In the ISG condition it reminded them to take part in the ISG as well as asking how much they had used it in the last 2 weeks. In the expressive writing condition, it reminded them to carry out the expressive writing task and contained instructions on how to submit it online.

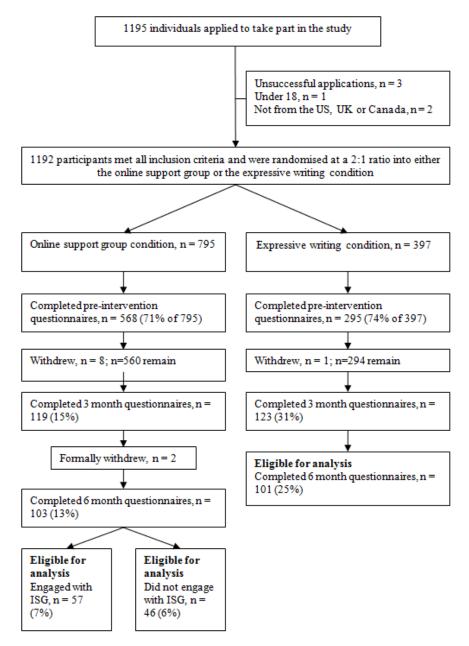
# Sample Size and Randomization

A power calculation suggested that 51 participants per group would provide sufficient power to detect a medium between-groups effect size (Cohen's d=0.5). It was carried out on the Center for Epidemiologic Studies Depression Scale (CES-D) using the G\*Power 3 computer program [23], specifying alpha at 5% and desired power at 80%. To reach a minimum of 51 participants per group, however, a much larger number of participants had to be recruited. Pilot work yielded expected attrition rates of approximately 90% in the ISG group and approximately 70% in the expressive writing group. Therefore, 1200 participants were recruited. Because of the greater attrition in the ISG group in the pilot study, randomization was carried out at a 2:1 ratio in favor of the ISG condition. It was carried out remotely by the second author, a statistician, using random numbers generated in Excel.

Of the 863 participants in both conditions who completed the initial measures, 24% (204/863) completed the final measures after 6 months (see Figure 1).



Figure 1. CONSORT-R participant flow chart.



#### **Outcome Measures**

All measures were administered online using the Opinio software [24]. The primary outcome measure was the 20-item CES-D [25]. Items (eg, "[in the last week] I was bothered by things that usually don't bother me") are rated on a 5-point scale from 1 = "Rarely or none of the time (less than 1 day)" to 5 = "Most or all of the time (5-7 days)". It has been validated for online use [26]. Cut-offs for depression vary between scores of 16 and 27 [25,27,28].

The General Anxiety Disorder Questionnaire (GAD-7) [29] is a 7-item anxiety scale. It asks how often in the last 2 weeks the respondent has felt worried or tense (eg, "Worrying too much about different things"). It is rated on a 4-point scale from 0 = "Not at all" to 3 = "Nearly every day". It has good psychometric properties (Cronbach's  $\alpha = 0.92$ ) [30].

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The Medical Outcomes Study Social Support Survey (MOSSSS) [31] is a 19-item scale that assesses perceived functional social support. The items ask how often someone is available to give certain types of support (eg, "Someone to give you good advice about a crisis"), rated on a 5-point scale from 1 = "None of the time" to 5 = "All of the time". It has five subscales: emotional support, informational support, affection, tangible support, and positive interaction, with high internal consistency [31].
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The Satisfaction with Life Scale (SWLS) [32] measures global satisfaction with life. It has five items (eg, "In most ways my life is close to ideal") rated on a 7-point scale, from 1 = "Strongly disagree" to 7 = "Strongly agree." It has good reliability and validity [33,34].

A slightly modified version of the Brief Illness Perception Questionnaire (IPQ) [35] was used to assess participants' expectations. The standard scale has nine items, five of which

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assess cognitive illness representations, two assess emotional representations, one assesses illness comprehensibility, and one assesses causal representations. Only five of these were used in the current study, in a slightly modified form to make them relevant for the study's participants. The items (eg, "How much does your condition [eg, depression, anxiety] affect your life?") were rated on an 11-point scale, from 0 = "No effect at all" to 10 = "Severely affects my life." The IPQ has good reliability and validity [36].

Participants' level of satisfaction with the ISG was measured at the end of the study using the Online Support Group Questionnaire [37], a nine-item scale, which measures satisfaction across three areas: comfort-connection, relevance, and support. Items (eg, "I felt satisfied with being part of the group") are rated on a seven-point scale ranging from 0 = "Not at all" to 7 = "Very much." Good internal consistency and reliability has been reported for this measure [37].

## **ISG Process Measures**

## Engagement

Participants' engagement with the ISG was assessed by asking them to report their usage every 2 weeks. First, they were asked how often they had accessed the ISG in the last 2 weeks. Responses were categorical, ranging from 0 = "Not in the last two weeks" to 5 = "More than 5 times." Second, they were asked how long they had spent accessing the ISG on each occasion on a scale ranging from 0 = "Not applicable/never" to 5 = "More than 20 minutes." Third, they were asked to report the number of messages they had posted in the last 2 weeks, on a scale ranging from 0 = "Nore" to 4 = "More than 5 times."

## **ISG Posts**

The text that participants wrote was collected from the ISG, with their permission, by using their anonymous usernames to search the ISG's forums. Although 57 participants were classified as engagers with the ISG based on self-reported use, it was only possible to collect data from 48, because nine participants' usernames could not be matched with usage. For the 48 users for whom posts were available, a total of 1659 messages were posted across the 6 months of the study. However, a large number of posts were written by three participants, one of whom posted over 250 times. With these outliers included, the mean number of posts was 34.6. To avoid these three participants being too strongly represented, for those participants who had posted more than 32 times, their messages were randomly sampled to make 32 the maximum number of posts analyzed. This method led to a mean number of posts analyzed of 15 for each participant. In addition, some posts were excluded from the analysis: (1) posts to one of the forums on the ISG called 'Games', which consisted of word games, and (2) short replies to simple questions, such as "What is your favorite song?"

The text was cleaned up in Microsoft Word for analysis in the word counting software, Linguistic Inquiry and Word Count, version 1.08 (LIWC) [38]. The software uses a dictionary containing 86% of the words commonly used in speech and writing, placed into one or more of 64 categories, only a handful of which are relevant to the present study. These were positive

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and negative emotion words and the pronouns denoting either the first person (singular or plural) versus those denoting the second and third person (singular or plural). LIWC outputs the total number of words (as a percentage) that match the categories.

#### **Qualitative Data**

After taking part in the study, as part of the final measures, which were collected online, participants were asked: "Finally, this last question is optional. If you like you can let us know what you thought of the online support group (expressive writing) and the study in general. You might like to tell us about both good and bad points. You might also like to suggest changes or improvements." There was a single free-text box for responses. Data were analyzed thematically [39]; coding was carried out using the Web-based software package Dedoose [40].

# Results

## **Participants**

At baseline, 863 participants (628/863 female; 73%) completed measures; of these 204 (157/204 female; 76%) completed the final measures at 6 months. Characteristics are given in Multimedia Appendix 1. The overall 76% (659/863) attrition rate was high, but it is comparable with similar Web-based studies [41]. Most participants did not indicate why they left the study. The attrition rate in the ISG condition was 85% (676/795) at 3 months and 87% (692/795) at 6 months; in the expressive writing condition it was 58% (172/295) at 3 months and 65% (194/295) at 6 months. The CONSORT-R flowchart [20] is given in Figure 1.

#### **ISG Engagement**

ISG usage decreased markedly over time. The average frequency at which the ISG was accessed declined from twice every 2 weeks at the start down to less than once every 2 weeks by the end of the study. The average amount of time spent accessing the ISG declined from approximately 5 minutes in the first week to less than 1 minute toward the end. The number of posts participants made declined from approximately two in the first 2 weeks, down to almost zero by the week 12.

To analyze the characteristics of those who engaged with the ISG, an engager was defined as a participant who used the ISG on more than two occasions over the 6-month period. There were no differences on demographic variables between engagers and nonengagers. In particular, participants from the United States were no more likely to engage than those from the United Kingdom or Canada ( $\chi^2(2) = 0.70$ , *P*=0.71, N=103). Similarly no differences for engagement were seen for gender, age, ethnicity, education, whether participants were seeing a therapist or taking medication, and whether they had previously taken part in an online or face-to-face support group.

In terms of baseline outcome measures, engagers were more anxious (M=11.1, SD = 4.9) than nonengagers (M=7.8, SD = 5.6; t(101) = 3.2, *P*=0.002). For depression there was a similar trend with engagers' CES-D scores marginally higher (M=30.3, SD = 11.8) than nonengagers (M=25.7, SD = 13.1; t(101) = 1.9,

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P=0.064). There were no differences for social support or satisfaction with life.

# **Outcome: ISG Versus Expressive Writing**

Following the study protocol, the initial analysis included all participants in the ISG and expressive writing conditions who completed the outcome measures at 6 months. Means and SDs for the four outcome measures are shown in Table 2. To assess the effects of using the ISG compared with carrying out the expressive writing task, a series of 3 (time, within groups)  $\times 2$  (condition, between groups) mixed analysis of variance

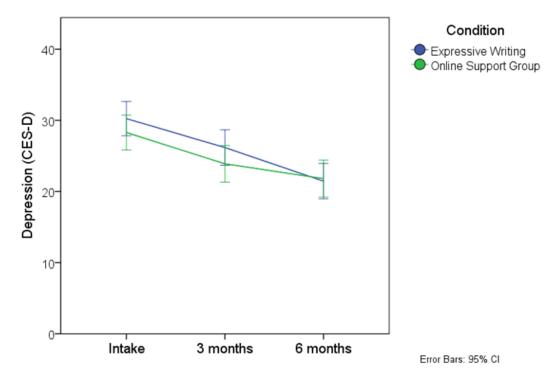
(ANOVAs) were conducted. All four outcome variables showed a significant effect of time (depression:  $F_{2,201}$ = 35.00, P<.001; social support:  $F_{2,201}$ = 12.29, P<.001; satisfaction with life:  $F_{2,201}$ = 16.67, P<.001; anxiety:  $F_{2,201}$ = 13.39, P<.001) but none of the interaction effects was significant, suggesting there were no differences in the treatment effects between conditions (depression:  $F_{2,201}$ = 1.57, P=0.21; social support:  $F_{2,201}$ = 0.59, P=.56; satisfaction with life:  $F_{2,201}$ = 0.19, P=.91; anxiety:  $F_{2,201}$ = 1.09, P=.34). The marginal means for the CES-D are depicted in Figure 2; the other outcome variables showed a similar pattern.

Table 2. Outcome measures by condition.

Measure	Baseline	3 months	6 months	Baseline-3 months	Baseline-6 months, effect
	M (SD)	M (SD)	M (SD)	effect size (95 CI)	size (95 CI)
Depression (CES-D)					
Expressive writing (n=101)	30.2 (12.2)	26.2 (12.7)	21.5 (12.7)	0.3 (0-0.6)	0.7 (0.4-1.0)
ISG (n=103)	28.3 (12.5)	23.9 (13.2)	21.8 (13.3)	0.3 (0.1-0.6)	0.5 (0.2-0.8)
Engagers (n=57)	30.3 (11.8)	26.1 (13.2)	23.6 (13.7)	0.3 (0-0.7)	0.5 (0.2-0.9)
Nonengagers (n=46)	25.7 (13.1)	21.2 (12.7)	19.6 (12.7)	0.4 (0.1-0.8)	0.5 (0.1-0.9)
Social support (MOSSS)					
Expressive writing (n=101)	50.9 (16.5)	52.1 (18.2)	54.3 (19.0)	-0.1 (-0.3-0.2)	-0.2 (-0.5-0.1)
ISG (n=103)	55.1 (17.6)	57.4 (18.6)	60.4 (18.0)	-0.1 (0.4-0.2)	-0.3 (-0.6-0)
Engagers (n=57)	52.4 (17.3)	54.8 (18.4)	59.5 (18.4)	-0.1 (-0.5-0.2)	-0.4 (-0.8-0)
Nonengagers (n=46)	58.4 (17.6)	60.6 (18.6)	61.4 (17.6)	-0.1 (-0.5-0.3)	-0.2 (-0.6-0.2)
Satisfaction with life (SW	'LS)				
Expressive writing (n=101)	14.7 (6.9)	15.7 (7.7)	17.0 (7.0)	-0.1 (-0.4-0.1)	-0.3 (-0.6 -0.1)
ISG (n=103)	15.8 (7.5)	16.9 (8.2)	17.8 (8.0)	-0.1 (-0.4-0.1)	-0.3 (-0.5-0)
Engagers (n=57)	15.5 (8.0)	16.9 (8.8)	17.8 (8.4)	-0.2 (-0.5-0.2)	-0.3 (-0.7-0.1)
Nonengagers (n=46)	16.2 (7.0)	16.8 (7.4)	17.9 (7.5)	-0.1 (-0.5-0.3)	-0.2 (-0.6-0.2)
Anxiety (GAD-7)					
Expressive writing (n=101)	9.8 (5.0)	9.0 (5.4)	7.6 (5.0)	0.2 (-0.1-0.4)	0.4 (0.2-0.7)
ISG (n=103)	9.6 (5.5)	8.4 (5.5)	7.9 (5.8)	0.2 (0-0.5)	0.3 (0-0.6)
Engagers (n=57)	11.1 (4.9)	9.4 (5.1)	8.6 (5.5)	0.3 (0-0.7)	0.5 (0.1-0.9)
Nonengagers (n=46)	7.8 (5.6)	7.1 (5.7)	7.2 (6.1)	0.1 (-0.3-0.5)	0.1 (-0.3-0.5)



Figure 2. Mean CES-D scores at baseline, 3, and 6 months for all participants.

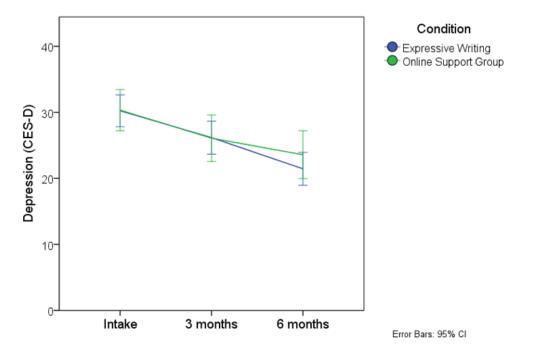


# **Outcome: Engagers Versus Expressive Writing**

A secondary analysis excluded nonengagers, comparing the 57 engagers in the ISG with all 101 expressive writing participants. A series of 3 (time, within groups) × 2 (condition, between groups) mixed ANOVAs were conducted. The pattern of results was the same as with the previous analysis. All four outcome variables showed a significant effect of time (depression:  $F_{2,155}$ = 26.80, *P*<.001; social support:  $F_{2,155}$ = 14.70, *P*<.001; satisfaction

with life:  $F_{2,155}$ = 14.05, P<.001; anxiety:  $F_{2,155}$ = 15.74, P<.001) but none of the interaction effects were significant, suggesting there were no differences in the treatment effects between conditions (depression:  $F_{2,155}$ = 0.78, P=.46; social support:  $F_{2,155}$ = 1.88, P=.16; satisfaction with life:  $F_{2,155}$ = 0.12, P=.88; anxiety:  $F_{2,155}$ = 0.77, P=.46). The marginal means for the CES-D are depicted in Figure 3; the other outcome variables showed a similar pattern.

Figure 3. Mean depression scores on the CES-D at baseline, three, and six months excluding those who did not engage with the ISG.





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#### **Intention-to-Treat Analysis**

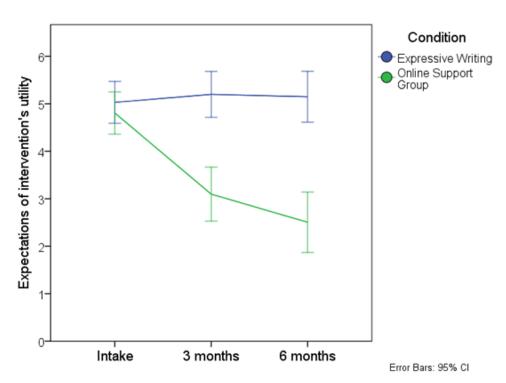
Finally, an intention-to-treat analysis was also carried out, for all participants with baseline scores, using the last observation carried forward procedure. The results are not reported in detail as they showed a similar pattern to the previous analyses. There was no evidence that participants in the ISG condition experienced improved outcomes over the expressive writing condition.

#### **Expectations Analysis**

Changes in expectation of the intervention's usefulness over time, were analyzed in a series of 3 (time, within groups)  $\times$  2 (condition, between groups) mixed ANOVAs. There were effects of time on expectations of "the condition's influence on life" ( $F_{2,201}$ = 6.1, P=.003), "control over the condition" ( $F_{2,201}$ = 8.24, P<.001) and "expectations of the intervention's use" ( $F_{2,201}$ = 13.21, P<.001), but not on "expected longevity of the condition" ( $F_{2,201}$ = 1.98, P=.14), or "understanding of condition"  $(F_{2,201}= 1.49, P=.23)$ . Two of the effects were in a psychologically positive direction (ie, toward more control and lower effect of the condition on life but expectations of the intervention's usefulness declined). The interaction was only significant for expectations of the intervention's use  $(F_{2,201}= 16.69, P<.001)$ , suggesting expectations changed differentially in each group, so this was further explored.

A plot of the means (Figure 4) for expectations of the intervention's usefulness suggested that the source of the interaction was a drop in expectations over time in the ISG condition and not the expressive writing condition. A one-way ANOVA conducted on the expectation scores on the ISG group suggested that expectations had changed over time ( $F_{2,608} = 8.69$ , P < .001). Post-hoc tests using the least significant difference (LSD) correction for multiple comparisons revealed a drop in expectations between baseline (M=4.9, SD = 2.2) and 3 months (M=4.1, SD = 2.9; P=.04) and between baseline and 6 months (M=3.8, SD = 3.2; P < .001).

Figure 4. Expectation of the intervention's utility at baseline, three and six months for all participants eligible for analysis.



#### **Satisfaction Data**

Table 3 shows the means for each of the nine items of the OSGQ [37]. The satisfaction levels in each of the categories for engagers are clustered around the midpoint of the scale, except for anonymity, which is higher. The satisfaction of the nonengagers was significantly lower on every variable, but, again, the importance of anonymity is underlined.

# Word Count Analysis

Forty-eight participants who engaged with the ISG and who provided matchable username information were included in the linguistic analysis. In total, they posted 1659 messages across the full 6 months of the study. As described above, messages

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from three prolific posters were randomly sampled, leaving a total of 722. Messages ranged in length from 38 to 6124 words, with the total analyzed being 91,084.

To analyze the associations between ISG language use and improvement, correlations were carried out between the improvements on the outcome measures and the features of language use. Improvement was calculated by the difference between baseline scores and those at 3 and 6 months. The categories of language use tested were positive and negative emotions and the use of first-person singular pronouns and second- and third-person pronouns. The aim was to test the degree to which participants were talking about themselves, compared with interacting with others. Spearman correlations were carried out as the word count data were not normally

distributed. For the 3-month data, only one of the correlations was significant: that between improvement on depression scores and the expression of positive emotions (Table 4). For the 6-month data, only one correlation was significant, that between improvement in social support and use of the "I" pronoun (Table

Table 3. Satisfaction with the ISG.

epression scores directional hypothesis and no support for the second hypothesis that improvements in depression would be associated with higher use of second-person pronouns.

5). There was, therefore, only weak evidence for the first

	Engagers (n=57)	Non-engagers (n=46)	t(101)	Р
Variable	M (SD)	M (SD)		
Felt supported	3.60 (2.62)	0.78 (1.85)	6.16	<.001
Felt listened to	3.40 (2.52)	0.67 (1.96)	6.02	<.001
Relevance of discussion	3.81 (2.19)	0.54 (1.39)	8.79	<.001
Others addressed my issues	3.39 (2.39)	0.39 (1.37)	7.56	<.001
Comfortable raising issues	3.33 (2.63)	0.78 (1.76)	5.63	<.001
Connection to other members	2.44 (1.84)	0.61 (1.47)	5.48	<.001
Satisfied with group membership	2.95 (2.26)	0.70 (1.72)	5.57	<.001
Importance of anonymity	5.12 (2.56)	2.20 (3.14)	5.20	<.001

 Table 4. Spearman correlations between improvement on outcome measures and facets of language use in the ISG over the first 3 months.

Outcome	Positive emotion	Negative emotion	"I"	"We, you, he, she, and they"
Depression	.38 <sup>a</sup>	.02	.25	.09
Social support	.27	25	13	.11
Satisfaction with life	.21	07	04	.15
Anxiety	.27	11	17	.13

\*P=.009

Table 5. Spearman correlations between improvement on outcome measures and facets of language use in the ISG over the full 6 months of the study.

Outcome	Positive emotion	Negative emotion	"I"	"We, you, he, she, and they"
Depression	.01	13	.25	.09
Social support	09	.04	.31*	.11
Satisfaction with life	.06	15	.08	03
Anxiety	0	21	02	.15

\*P=.03

# **Qualitative Data**

In the ISG condition, 73 participants wrote free-text comments after the intervention

The analysis yielded four main themes: (1) comfort and connection, (2) social comparisons, (3) needing guidance, and (4) advice. Overall, the responses were quite negative for most of the themes, with people pointing out more problems than beneficial aspects (see Textbox 1 for subthemes and illustrative quotations).

In the expressive writing condition, 69 participants provided comments. The analysis yielded two main themes: (1) emotional effects and (2) task tweaks. The feedback was predominantly positive, with many participants pointing out the beneficial aspects of the writing task (see Textbox 2).

In Textboxes 1 and 2 a typical theme is one which applies to more than one-half of the participants, a variant theme applies to up to one-half of participants, and a rare theme applies to less than one-tenth of participants.



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Textbox 1. Themes and subthemes in participants' ISG feedback

Themes and subthemes (frequency) with an illustrative quote:

Comfort and connection

- Negative: the ISG is too big (variant): "I found it overwhelming trying to settle into a place to go, and then how to respond. There was an overload of people, problems and information." (P48)
- Negative: unsupportive (variant): "I think not getting involved was healthier for me as, frankly, most of the threads I read were people winding each other up and making each other more anxious." (P55)
- Positive: warm and supportive (variant): "The forum used for this study was very friendly and usually answered my posts and seemed appreciative of my responses." (P8)

Social comparisons

- Negative: they are not like me (variant): I was afraid to talk about my problems because it felt like nobody else had ever dealt with the same thing. It almost felt like talking about it in the group was worse than dealing with it on my own." (P45)
- Negative: triggers (variant): "*Reading posts by other people often triggered a negative feeling for me, and made me feel more anxious about myself.*" (P11)
- Negative: my trivial problems (variant): "It seemed that the majority of the regular posters on Psych Central went way beyond a tad anxious or a bit blue. A lot of the members had severe mental illnesses or told stories about going through horrendously traumatic experiences. I felt a little over my head in the community." (P22)
- Positive: putting it into perspective (rare): "I do appreciate that this group exists for people with a much more severe "condition" than mine and it is good to know it is here." (P51)

Need guidance using the site (rare)

• "I had no idea how to start as I was depressed." (P2)

Advice

- Negative: bad advice (variant): "There seemed to be a hell of a lot of ill-informed rubbish posted, which could in the case of medication or treatment be dangerous." (P55)
- Positive: good advice (rare): "There were some very interesting discussions raised over the last few months, which have helped me look at my illness and recovery in a different way." (P62)

#### Textbox 2. Themes and subthemes in participants' expressive writing feedback

Themes and subthemes (frequency) with an illustrative quote:

Emotional effects

- Positive: feeling better (typical): "The activity itself was very uplifting. I felt I had gotten a huge weight off my shoulders. I feel that this was a very effective way of alleviating what I feel was a moderate (but still significant) level of depression and anxiety due to a combination of genetics, environment, and the usual lark." (P55)
- Negative: feeling worse (rare): "Sometimes doing the writing and the questionnaires made me feel more depressed and anxious than if I wasn't thinking about those things." (P60)

Task tweaks

- Lack of feedback (rare): "I felt I was still totally on my own, there was no response, there was no indication that anyone was even interested in my thoughts let alone reading them." (P34)
- Writing prompts (rare): "I would have preferred boxes with headings to fill in I think-a blank box to ramble on in to be read by unknown people didn't feel very constructive." (P36)
- Positive writing (rare): "While expressive writing was helpful, and I do think it's important to explore the bad, it might be more helpful to also explore the good. To remind myself that it's not always bad." (P21)

# Discussion

# **Principal Findings**

The study aimed to test the effectiveness of an ISG for depression and anxiety by comparing it with an expressive writing intervention, thereby extending previous research, which

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has not involved a comparison group. When all participants eligible for analysis were included, all four outcomes – depression, anxiety, social support, and satisfaction with life – improved over the 6 months of the study. However, there were no differences in outcome between the ISG and the expressive writing conditions, although the expressive writing group had lower attrition, better engagement, and more positive user

feedback. We must therefore conclude that the ISG intervention provided no additional benefit to that obtained by expressive writing. That may be because the ISG intervention was weaker than predicted, or because the expressive writing condition was stronger than predicted. We explore both possibilities below.

The low rate of engagement and high rate of attrition suggest that the ISG intervention was not a strong or attractive one. Either our direction to participants was insufficient to motivate their engagement with the ISG, or the ISG did not suit our participants, a possibility which the qualitative data seem to support. It is likely that its impact was diluted by this lack of engagement. However, an analysis only including engagers still showed no differences between the conditions. We set our definition of engagers quite low, but the number of high engagers in the study was small. It is possible that the ISG selected for the study was not typical or in some way less effective, at least for our participants. However, we put considerable effort into choosing an existing ISG for the study, and Psych Central appeared then, and appears now, to be one of the best available.

The second possibility is that the expressive writing task had a stronger than expected impact. We picked expressive writing to be a plausible comparator, but we did not expect it to be of as much benefit as the ISG. However, it was certainly more attractive to participants, with notably lower attrition and more positive user feedback. The effect size found for expressive writing over time in this study is above the average reported by Frattaroli [15], although it is within the range of some of the studies reviewed there. The major difference in the current study was the greater length of the intervention. The average study length reported by Frattaroli involved four sessions over 4 days. The current study had 12 sessions spread over 6 months. In addition, in contrast to the studies reviewed by Frattaroli [15], there was no maximum limit set on the length of the expressive writing session that participants undertook. This is a considerable difference and may have contributed to a larger than expected effect in the expressive writing condition. The use of expressive writing over a longer period like this warrants further investigation.

If the expressive writing condition was unexpectedly powerful, then perhaps a comparison with a waitlist control or a weaker intervention would have shown gains for both conditions. In order to test this possibility, we reviewed other studies that used the CES-D to look at change in a control group, in order to see whether the improvement shown over time was a result of a natural tendency for conditions to improve over time. To identify suitable comparison control groups, a systematic review of computer-based psychological treatments for depression was consulted [42]. This identified 19 RCTs and, among these, six studies that used the CES-D, with similar exclusion criteria and recruitment methods to the current study (see Table 6).

Table 6. Control group outcomes in studies of computer-based psychological treatments for depression which have used the CES-D.

Study	Follow-up	CES-D at baseline	CES-D at follow-up	Cohen's d
Baikie et al [13]	4 months	30.86 (13.06)	22.02 (14.30)	0.65
Christensen et al [ 43]	6 weeks	21.6 (11.1)	20.6 (11.4)	0.09
Clarke et al [44]	16 weeks	31.2 (11.7)	22.7 (12.6)	0.70
Clarke et al [44]	32 weeks		23 (14)	0.64
Clarke et al [45]	16 weeks	28 (13.6)	22.3 (13.1)	0.43
Van Straten et al [46]	4 weeks	29.9 (9.2)	26.2 (10.5)	0.37
Warmerdam et al [ 47]	12 weeks	32.1 (9.3)	25.8 (10.4)	0.64

Other than Christensen et al [43], all of the control groups had similar mean initial CES-D scores of approximately 30, as in the present study. At 6-month follow-ups, and mostly over shorter periods, the mean scores in the control groups had dropped to approximately that seen in the current study: 22. The Christensen et al [43] study is slightly different in that participants had lower baseline levels of depression and an attempt was made to control for placebo effects, which was not the case in the other studies.

Thus, the change in CES-D scores seen in the current study in both conditions is likely to reflect a tendency to improve naturally over time, without treatment. The improvements are comparable to the majority of the control groups from other studies cited here. Therefore, while the effect sizes seen in the expressive writing and ISG conditions were medium in size, it is likely that this is the type of effect size that would be seen even in a waitlist control condition. This evidence weakens the notion that either the expressive writing or the ISG condition had any additional effect.

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Overall, therefore, there is no evidence that the ISG was effective in ameliorating the symptoms of depression or anxiety. In addition, the ISG had worse attrition and less engagement in comparison to the expressive writing.

#### **Attrition and Engagement**

Attrition rates are frequently high in Web-based studies and, in eHealth interventions, attrition curves are often logarithmic [41]. Still, the attrition rate seen here was especially high in the ISG group. Of the 568 participants randomized to the ISG condition who completed preintervention questionnaires, only 10% (57/568) were classified as engaging with the ISG, and many of these did not use the group much. This may well be a function of the sample, which differed somewhat from those in previous studies. Houston et al [9], for example, who found use of an ISG to be beneficial, recruited existing members of a support group. In the current study, participants were not existing members of an ISG and were asked to take part in forums that were new to them. Because 85% (736/863) of

participants had never used an ISG before and 78% (672/863) had never taken part in a face-to-face support group before, they were probably not very aware of what ISGs would be like. This accords with the findings of a naturalistic study, which found similar problems in engaging new users to the same ISG [48], and echoes Eysenbach et al's [49] warning against 'recruiting from the street'.

In comparison to the ISG condition, the expressive writing condition had an attrition rate closer to those found in previous Web-based studies [41]. The increase in attrition over the study was also less slow in the expressive writing condition. At 3 months it was 58% (172/295), while at 6 months it was 65% (194/295). The equivalent figures in the ISG were 85% (676/795) and 87% (692/795). It is also worth noting that engagement with the expressive writing tasks was essentially a binary process, participants either engaged or they did not, whereas engagement in the ISG was a more complex process: participants could either contribute by posting material themselves, or they could be actively involved with the group by simply reading other group members' posts.

The high attrition rates compared with the expressive writing condition was not the only indication that participants were unenthusiastic about the ISG. Across the first 4 to 6 weeks of the study, engagement with the ISG dropped from a mean of once a week to less than once every 2 weeks, remaining at this level or lower for the rest of the study. The same picture came from the data on the amount of time spent accessing the ISG and particularly from the number of posts made. Across all participants in the ISG condition, after the first 2 weeks, even those classified as 'engaged' with the ISG were only posting a mean of approximately one message every 2 weeks.

There are many potential reasons for the low levels of engagement with the ISG, but one that stood out was participants' expectations. Before the study began, and at every measurement point, participants were asked about their expectations of the intervention's usefulness, using the IPQ [35]. Although the other IPQ factors, such as the condition's influence on life, the expected longevity of the condition, and control and understanding of it changed little, expectations of the intervention's usefulness dropped markedly in the ISG group, in comparison with expectations in the expressive writing condition, which remained largely stable over the 3 months. This difference was clear from both baseline to 3 months and between baseline and 6 months. As might be expected it was even clearer when comparing engagers to the ISG with nonengagers. After only 3 months, mean expectations of the intervention's usefulness for nonengagers had dropped to two on the 11-point scale, indicating that they thought it was close to worthless. It is hard to ignore this message that many of the participants in the study expected the ISG to do little for them.

It may have been the case that we underestimated the difficulty of joining an established ISG. It was probably hard for participants to find their way in what to a newcomer is quite an unusual social system. We attempted to mitigate this by briefing participants about the group beforehand and encouraging them to contact the researcher if they were having problems, but this may not have been sufficient to ease their transition into the ISG.

Engagement with the ISG was not predicted by demographic variables, although those reporting higher anxiety were more likely to engage with the ISG and there was a trend in the same direction for depression. However, the expectations in both the engaging and nonengaging groups began at the same level and only dropped after the start of the study. This again suggested that participants did not know what to expect from the ISG and some quickly wrote off the chance of any potential benefits from it. Much the same message came from the satisfaction data. Although engagers were moderately satisfied with the ISG, those who did not engage gave very poor ratings to it.

# Word Count Analysis

The final part of the study examined associations between the type of language used in the ISG and outcome. Of particular interest were positive and negative emotion words and the pronouns used. Only one of the expected correlations was significant, supporting previous findings [50] that the expression of positive emotions was associated with improved psychological health (although this was only found after 3 months, but not after 6 months). Because this part of the research was correlational, it may well be that the use of positive emotion words is a result rather than a cause of lower levels of depression. Nevertheless it may be a useful linguistic marker to assess how participants are reacting in an ISG.

No correlations were found for pronoun use, providing no support for the theory that helping others is beneficial [19] or for the idea that focusing on the self may be detrimental to psychological health in the context of ISGs [51].

## Limitations

The main limitation of the study was the lack of a wait-list control group. We took the view that this would be difficult to implement, as participants could not ethically or practically be prevented from seeking help elsewhere. We instead used previous research on our main outcome variable, the CES-D, to construct a post-hoc quasi-experimental control.

The study involved one particular ISG, PsychCentral, and it is possible that it was not typical of ISGs in general. However, as discussed above, we put considerable effort into its selection, and it appeared to us to be one of the best mental health ISGs available at that time. However, it is remotely possible that PsychCentral might have had some undetected problematic aspects and, in retrospect, it would have been better to offer participants a choice from a shortlist of ISGs that we had approved.

The sample was more highly educated than a typical community sample experiencing depression or anxiety. The greater proportion of women (628/863, 73%) was broadly representative of the higher levels of depression among women.

Engagement was measured using retrospective self-report, which is well known to be subject to potential sources of bias, such as distortions of memory [52]. However, the picture from the self-report data was similar to that from other data sources (ie,

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the attrition rates and the qualitative comments), all pointing to low levels of engagement with the ISG.

## Conclusions

The findings present a paradox. On the one hand, ISGs for depression and anxiety are thriving, as are those for many physical conditions, which suggests that their many users are benefitting from their experiences. PsychCentral and many other sites maintain high traffic from users who appear to be engaged with and supportive of one another. Some outcome research has found positive results with ISGs for depression [7,10].

On the other hand, the present study, as well as that done by Breuer and Barker [48], found no evidence that ISGs were effective or attractive for potential users who were directed to the groups, in terms of standard outcome variables, and little evidence of benefits in other areas. However, it is important to re-emphasize that our ISG participants were directed by us to the group, rather than seeking it out themselves, and that their engagement was low. So our conclusion that the ISG group showed no evidence of benefit is limited to such 'recruited from the street' users [49].

It may well be that people vote with their feet, and that the current satisfied users of anxiety and depression ISGs are a small percentage of the general population. That would mean that interventions by health care professionals or public health campaigns directing individuals to ISGs offer little benefit, unless one can target those who do benefit from ISGs. It may also be the case that even those who engage and presumably appreciate ISGs are not actually benefitting in terms of reduced morbidity.

However, that conclusion does not immediately explain those studies that have found positive results with ISGs for depression, and a larger literature finding positive results for ISGs more broadly. Such heterogeneity in study results may have many explanations. One possibility is that what makes for a successful online intervention and individual experience is subtle and contingent. The effects of technology in health are often not readily determined [53] and an intervention like an ISG depends on a range of complex factors including usability, sociability [54], and the nature of therapeutic relationships.

Until further evidence accumulates, we cannot at present recommend generally directing people with anxiety and depression to internet support as an effective additional intervention. On the other hand, online expressive writing [13] seems to have potential, and its use for people with depression and anxiety warrants further investigation, particularly to examine who engages with it, and who benefits from it, under what conditions.

# Acknowledgments

The authors thank Dr. John Grohol for permission to use PsychCentral for the purposes of this study.

## **Conflicts of Interest**

None declared.

# Multimedia Appendix 1

Demographics for all participants who (1) completed the baseline measures, and (2) were eligible for analysis, by condition.

[PDF File (Adobe PDF File), 37KB - mental\_v3i2e12\_app1.pdf]

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# Abbreviations

ANOVA: analysis of variance CES-D: Center for Epidemiologic Studies Depression Scale GAD-7: General Anxiety Disorder Questionnaire IPQ: Illness Perception Questionnaire ISG: Internet support group LIWC: Linguistic Inquiry and Word Count LSD: least significant difference MOSSSS: Medical Outcomes Study Social Support Survey RCT: randomized controlled trial SWLS: Satisfaction with Life Scale



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# **Original Paper**

# Validating Machine Learning Algorithms for Twitter Data Against Established Measures of Suicidality

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# Abstract

**Background:** One of the leading causes of death in the United States (US) is suicide and new methods of assessment are needed to track its risk in real time.

**Objective:** Our objective is to validate the use of machine learning algorithms for Twitter data against empirically validated measures of suicidality in the US population.

**Methods:** Using a machine learning algorithm, the Twitter feeds of 135 Mechanical Turk (MTurk) participants were compared with validated, self-report measures of suicide risk.

**Results:** Our findings show that people who are at high suicidal risk can be easily differentiated from those who are not by machine learning algorithms, which accurately identify the clinically significant suicidal rate in 92% of cases (sensitivity: 53%, specificity: 97%, positive predictive value: 75%, negative predictive value: 93%).

**Conclusions:** Machine learning algorithms are efficient in differentiating people who are at a suicidal risk from those who are not. Evidence for suicidality can be measured in nonclinical populations using social media data.

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## **KEYWORDS**

suicide; social media; twitter; machine learning

# Introduction

Suicide claims more than twice as many lives each year as compared with homicide, and is the 10th leading cause of death in the United States (US). It is found that the suicide count rises above 33,000 every year [1] and more than 30 people attempt suicide following each death [1]. This eventually results in emotional and financial burdens on their families and loved ones. The World Health Organization [2] recently endorsed several universal interventions to prevent suicide, of which two

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promising strategies were to target vulnerable groups and individuals and then facilitate their access to crisis helplines. Timely identification of these vulnerable groups and individuals [3], and the balance of identifying high-risk cases without too many false positives [4,5], however, remains a challenge. This has led to increasing efforts in clinical settings, which further increase financial and time-related costs [6]. Due to these reasons, the public health priority is to explore novel approaches and identify individuals at risk for suicide without increasing costs or adding burdens to the already present clinical system.

This effort may benefit from the introduction and proliferation of emerging social media technologies.

Social media has provided researchers with new avenues to employ automated methods for analyzing language and to better understand individuals' thoughts, feelings, beliefs, behavior, and personalities [7]. Studies of language-using computational data-driven methodologies have demonstrated utility for monitoring psychological states and public health problems such as influenza [8,9], heart disease mortality [10], drinking problem [11], prescription drug abuse [12,13], and tobacco use [14]. Infodemiology or infoveillance is an emerging field related to computational data-driven methodologies and other studies, that use social media to understand and monitor health problems efficiently [15,16].

Twitter is a social media application that allows users to broadcast news, information, and personal updates to other users (followers) in tweets or statements of 140 characters or less. Speech is considered to be an important marker for both depression and suicide risk assessment [17], and Twitter provides a novel social media avenue for exploring these major public health concerns. Initial studies confirmed the role of infodemiology or infoveillance for social media data to track health trends [8-14], something beyond its original purpose. However, these early studies are limited as they failed to prove that the observed trends reflect the actual values. The advanced research in several studies has focused on confirming social media observations, which increases our collective confidence in these data values that act as a source for monitoring health issues and trends [18-20]. Most relevant to the work presented here, recent studies have used Twitter, Sina Weibo (Sina Weibo is a Chinese social media and microblogging site similar to Twitter), and Reddit specifically to tackle suicidality [21-25]. An annual workshop series commenced in 2014 on Computational Linguistics and Clinical Psychology: From Linguistic Signal to Clinical Reality, has attracted a host of social media data-driven work on suicide, as well as other mental health issues, including depression, schizophrenia, dementia, and posttraumatic syndrome disorder (eg, see [26-30]). Additional research remains warranted to demonstrate the safety and efficacy of social media prevention activities [31], and methodological issues need further refinement especially in terms of specificity and sensitivity of suicide risk. The purpose of this study was to validate the use of machine learning for Twitter data against empirically validated measures of suicidality in the US population with an eye for suicide prevention.

### Methods

#### **Recruitment and Procedure**

The participants for this study were selected through Amazon's Mechanical Turk (MTurk, www.mturk.com). Participants in the US who were frequent Twitter users and above 18 years of age were invited to participate in a "Survey for Twitter users (~10 min)." Only those who had completed more than 500 Human Intelligence Tasks (HITs)—the name MTurk gives to online tasks, including surveys, transcriptions, categorization of receipt items, etc.—with an approval rate of > 95% (ie, requesters found their work was acceptable for more than 95%

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of tasks they had undertaken) were allowed to complete the survey. Participants were informed that this survey was for Twitter users and that "Only those who are active Twitter users with public, personal Twitter accounts may participate, we will not approve any workers who do not meet these qualifications." To ensure the eligibility of participants, they had to complete a screening questionnaire before accepting the HIT. The screening questionnaire questioned whether they had an active, public Twitter account, how long the account had been active, and how often they tweeted. Our survey was published during the early summer of 2014 and republished during the early fall of 2015. Participants were paid according to the current MTurk market rates (ie, between 30 and 50 cents). The authors' university institutional review board approved all the study procedures and measures.

#### Stimuli: Human Intelligence Tasks

Participation in the study consisted of providing a Twitter handle and completing a set of questionnaires that assessed psychosocial functioning. A Twitter handle is a username that takes the form @username. The questionnaires examined in the present study are the Depressive Symptom Inventory-Suicide Subscale (DSI-SS), The Interpersonal Needs Questionnaire (INQ), and Acquired Capability for Suicide Scale (ACSS). The DSI-SS, a 4-item screening tool for suicidal symptoms assesses suicidality in a reliable and valid manner. In addition to an established clinical cutoff, it assesses for resolved plans and presuicidal actions, which are absent in most suicidal cases [32]. The INQ and ACSS scales assess facets of Joiner's Interpersonal Theory of suicide: thwarted belongingness, perceived burdensomeness (INQ), and the acquired capability for suicide (ACSS) [33]. These scales have demonstrated good reliability and construct validity [34].

#### **Participants**

In Summer 2014, we decided to obtain a sample of 100 participants. Beginning with 489 potential participants, we dropped 251 participants that did not actually provide data (most of these were likely bots, which are computer programs designed to generate responses to HITs in hopes of receiving payment). Researchers studying MTurk data collection recommended involving high reputation participants (those with a high number of completed and approved HITs) and including attention control checks [35]. We included control questions to ensure that those who responded were providing reliable data. Our control questions were designed to discern whether the participant was paying attention to each question (eg, "In the last month how often have you showed that you were paying attention by selecting 'Sometimes'"). We included five control questions; participants who failed two or more were excluded. About 46 participants who failed to answer the control questions were excluded. Finally, five participants attempted the survey more than once, in some cases with variable answers. Since, it was impossible to decide which of their answers was valid, we removed these respondents and their duplicates (17 participants in total), resulting in 175 participants. To validate the Twitter handles provided by the corresponding MTurk participants, we used the Twitter API via Twitter4J, and queried the last status by the handle. We removed all users who could not answer the

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query as it indicates that either the user does not exist or the user's account is not public. As individuals sometimes find it funny to mention a celebrity handle as their own, we verified that the user was not a celebrity. If an account was verified as a celebrity account, we removed the corresponding user. In addition, to ensure that the MTurk participants had some activity on Twitter and that they would have a sufficient number of tweets for our analysis, we removed all users who posted less than two posts per month on an average. To find the average number of posts per month, we divided the total number of tweets that the user posted by the number of months, since the user's account was created. Finally, we removed all users whose last tweet was more than 1 month old. In total, there were 101 MTurk workers with both permissible responses and exploitable Twitter accounts. In Summer and Fall 2015, we repeated the above data collection procedure to extend the size of our sample. We began with 111 more potential candidates, excluded 77 of them, resulting in an additional 34 exploitable Twitter accounts for a final sample of size N=135. Participant characteristics are shown in Table 1. For all valid user accounts, we again queried the Twitter API to collect the latest 200 tweets of the user.

Table 1. Participant characteristics

Ethnicity	
African American	19 (14.1%)
Asian	5 (3.7%)
Latino	6 (4.4%)
Mixed/Biracial	9 (6.7%)
Caucasian (White)	95 (70.4%)
Native American	1 (0.7%)
Education	
Graduate of professional degree	14 (10.4%)
Bachelor's degree	48 (35.6%)
Some college	60 (44.4%)
High school or equivalent (eg, GED)	9 (6.7%)
Less than high school	4 (2.9%)
Income	
Over \$150K	2 (1.5%)
\$100K-\$150K	4 (3.0%)
\$75K-\$100K	12 (8.9%)
\$50K-\$75K	28 (20.7%)
\$25K-\$50K	41 (30.3%)
Under \$25K	46 (34.1%)
None	2 (1.5%)
Twitter account creation date	
2008	14 (10.4%)
2009	39 (28.9%)
2010	17 (12.6%)
2011	23 (17.1%)
2012	20 (14.8%)
2013	13 (9.6%)
2014	8 (5.9%)
2015	1 (0.7%)

<sup>a</sup>GED General Educational Development

### **Analysis of Tweets**

For each participant, the textual content of all of the retrieved tweets was aggregated into a single file. Each file was then

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analyzed with the updated 2015 version of Linguistic Inquiry and Word Count software (LIWC) [36]. LIWC is a language analysis tool that extracts information from text in three main forms. The first, new in the 2015 version, consists of four

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variables that capture global high-level properties of the text as percentiles, namely, analytical thinking, clout, authenticity, and emotional tone. The second consists of 71 variables that represent the relative use of predefined word categories, from linguistic forms, such as pronouns and verbs, to psychological, social, emotional, and cognitive mechanisms, such as family, anger, sadness, certainty, leisure, religion, and death. The third focuses on the relative use of 17 language markers (eg, swear words, netspeak) and punctuation categories. For each of its 88 base categories, LIWC computes the percentage of total words in that category within the body of text being analyzed. For example, if a text sample has 125 words, and 3 of these words belong the pronoun category, LIWC gives a score of 2.4 (3/125) to that category. LIWC has been validated in a number of studies in the context of social media data [37,38] and has been previously proved to correlate in meaningful ways with suicidality [39-41]. LIWC has also been used to annotate tweets as showing signs of distress, where distress is regarded as a risk factor for suicide [42], as well as to analyze language differences across ten mental health issues [43].

### **Description of Sample**

Our sample consists of 85 females and 50 males with an ethnic composition largely consistent with the US population, with a slight under-representation of Latino, and overrepresentation of mixed/biracial individuals. The distribution level of education and income suggests that our sample consists of generally more educated and affluent individuals than the national average, consistent with the findings of other researchers [44]. About 7 (5.2%) individuals were identified as homosexual, 18 (13.3%) as bisexual, and 110 (81.5%) as heterosexual. The proportion of individuals who were not heterosexual is higher than that expected from population norms, perhaps because social media provides readier access to lesbian, gay, bisexual, and transgender (LGBT) populations than traditional methods of sampling [45]. All Twitter accounts were listed as English accounts, and most users had been active for several years as shown by the distribution of account creation dates in Table 1. Almost half of the users (64 of 135) had posted over 2000 tweets at the time of data collection. About 17 individuals in our sample could be confidently considered as clinically significantly suicidal, since their DSI-SS score was greater than 2; the remaining 118 individuals were deemed nonsuicidal.

### **Machine Learning**

For each participant, we built a feature vector consisting of the LIWC variables, together with a target class label: suicidal, nonsuicidal (as determined by the DSI-SS). The set of 135 vectors form a training data set that can be used by classification learning algorithms to induce a predictive model of suicidality. We implemented the predictive analysis in Python, using the scikit-learn library [46].

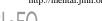
Various classification learning algorithms are available. For this study, our aim was to build not only a model with good accuracy but also one that would potentially provide insight into its predictions. Hence, decision tree learning was selected as it empirically produced accurate models for a large number of applications, and the models it built are easily interpretable [47]. Decision tree learning implements a kind of divide-and-conquer approach to learning. At each stage, a feature is selected and becomes the root of a subtree whose branches are the values, or ranges of values, of the selected feature. The training data are partitioned along these values, and sent down the corresponding branch. The process is then applied recursively to each partition until all training examples in the partition have the same label or there are no more features to select; at this point, a leaf node is created and labeled with the most prevalent label in the partition. A new example is classified by starting at the root of the tree, and following a path to a leaf node such that at each internal node the example takes the branch corresponding to its value for the feature at that node. The leaf node label is the predicted label for the new example. Note that the prevalence computed for a leaf node during training may in turn serve as a measure of confidence in its predictions. During learning, feature selection is affected by maximizing gain of information or the difference between the entropy of the training data before and after partitioning. Entropy measures the purity of a set of training examples with respect to the class label. A set where all of the examples have the same label has minimum entropy, while a set where the examples are spread uniformly over all labels has maximum entropy. Hence, at each stage, the attribute that is best at discriminating among the training examples at that stage is selected.

We estimate the accuracy of our decision tree learning approach using leave-one-out cross-validation (loo-cv), wherein, a decision tree is induced from all but one of the participants' feature vectors and tested on the out-of-training participant. The process is repeated N times, until each participant has been left out for testing. For each participant, we record whether the prediction was correct and aggregate over all participants to obtain an overall accuracy value.

### Results

Analysis of responses to the INQ across the entire group and for each subgroup (suicidal and nonsuicidal, as defined by the DSI-SS cut-point) revealed significant differences. Suicidal individuals endorsed significantly less belongingness (one-tailed independent sample t (133) = -5.84, p<.001; Cohen's d=-1.52, 95% CI [-2.05, -0.97]), and significantly higher burdensomeness (t (133) = -8.41, p<.001; d=-2.18, 95% CI [-2.75, -1.61]). Those indicating significant suicidality reported a slightly higher acquired capability for suicide (t (133) = -1.91, p=.03; d=-0.49, 95% CI [-1.00, 0.19]). These results offer additional support for the validity of the INQ and provide converging evidence of the suicidality of those who were above the cutoff on the DSI-SS.

If the DSI-SS cutoff identifies 17 individuals in our sample as suicidal, then the default accuracy of a predictive model, obtained by indiscriminately predicting the most prevalent class (here, nonsuicidal), is 87.4% (118/135). The decision tree's loo-cv accuracy was 91.9%. The confusion matrix, shown in Table 2, gives rise to the following values.



	Suicidal	Not suicidal		
Suicidal	9	8		
Not suicidal	3	115		

- Sensitivity: 0.53 (8 suicidal individuals were wrongly labeled as nonsuicidal)
- Specificity: 0.97 (only 3 out of 118 nonsuicidal individuals were wrongly labeled as suicidal)
- Positive predictive value: 0.75 (only 3 of the 12 individuals labeled as suicidal were actually not suicidal)
- Negative predictive value: 0.93 (only 8 of the 123 individuals labeled as nonsuicidal were actually suicidal)

The pruned decision tree induced from the complete sample is shown in Figure 1. It is included here for its explanatory power.

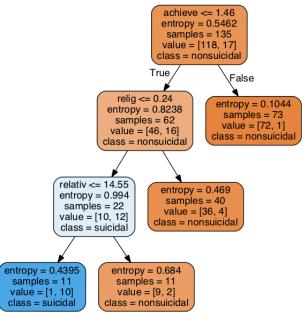
We note that there were minor differences in deeper parts of the unpruned trees induced over various runs, as increased depth tends to lead to overfitting. However, the macrostructure of the pruned tree depicted in Figure 1 remains consistent across runs, suggesting that the results should generalize.

The structure of the tree is rather consistent with intuition as well. The tree first splits on the "achieve" category of LIWC, such that if an individual's usage rate of achievement-related words exceeds 1.46, that individual is labeled as nonsuicidal. It is striking that the corresponding leaf node has very low entropy, indicating that 72 of the 73 individuals in our sample

Figure 1. Result from Decision Tree Learning Algorithm.

satisfying the condition are indeed nonsuicidal. A noted fact is that a value of 1.46 for the "achieve" category is larger than the mean "achieve" values of most genres of writing analyzed using LIWC, as reported in the LIWC documentation [36]. This suggests that relative to others, these individuals' tweets have a higher proportion of achievement-related words, and that this high degree of achievement talk covaries with nil levels of clinically significant suicidality.

The next node where the tree splits (left branch) contains the "religion" category of LIWC. If an individual's rate of usage of religion-related words exceeds 0.24, then that individual is labeled as nonsuicidal. As seen above, it is striking that the corresponding leaf node has rather small entropy, giving relatively high confidence to the prediction (90%; 36 of 40). This seems to confirm other studies suggesting that religiosity may act as a protective factor against depression, social isolation, and suicidality. If the rate of religion-related words is low, the prediction of suicidality jumps to just about 50% (12 of 22). The final split of the pruned tree contains the "relativity" category, which is related to notions of motion, space, and time. It provides a rather clean separation between suicidal and nonsuicidal individuals.



### Discussion

### **Principal Findings**

Suicide continues to be one of the leading causes of death in the US [1] and new methods of assessment capable of tracking suicide risk in real time are required. Our findings reveal that machine learning algorithms can help differentiate between those who are at suicide suicidal risk and those who are not.

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Below we discuss these findings in light of theories of suicide, implications for public health intervention, and future directions for using social media to reduce suicide.

The notion of using ML approaches to make interpretations of large data has been explored previously. Poulin et al. demonstrated the capacity for an algorithm to identify suicide risk by analyzing clinical notes [48]. Provided the clinical context of the notes, which included specific references to

suicidality, their findings may be somewhat expected. Another step beyond, then, is the analysis of data, which were not intended for a professional audience and to identify the user at suicidal risk. It is believed that text in social media includes technical jargon or official diagnoses indicative of suicidal risk. Only a handful of studies have examined measurement of suicidality in social media data using a variety of methodological approaches. One showed that simply tweeting the phrases "want to commit suicide" or "want to die" were predictive of suicidal ideation and behavior [49]. At least two studies have employed machine-learning algorithms to assess suicide risk. One compared level of agreement between humans and algorithms on three categories of suicide risk, finding rates of agreement between 76-80% [22]. Jashinsky and colleagues compared Twitter derived assessment of suicide risk with rates of suicide from the Centers for Disease Control and Prevention (CDC) and showed the correlation between their method and the actual suicidal rates by state across the US [19]. Our study advanced this line of research by validating Twitter data against already validated measures of suicidality at the individual level. This is an important step forward, because the most effective interventions target individuals who are mostly at risk, ideally with an approach that is tailored to their specific needs [50]. Efforts to target individuals at risk would not need to discuss suicide explicitly, but could simply be a directed tweet mentioning, "In moments of crisis, 1-800-273-TALK is a great resource staffed with trained professionals who care." It is possible that an individual may feel upset at being targeted with such message. However, this is only a speculation and future research could explore tolerance for such messaging approaches and ultimately inform health communication strategies that are nonobtrusive, yet effective.

The fact that tweets including themes of achievement differentiated respondents so well may at first seem surprising in light of theories of suicide. The interpersonal theory of suicide predicts that suicide is most likely when a sense of thwarted belonging and burdensomeness are coupled with an acquired capability for suicide through repeated exposure to painful and provocative experiences [33]. Other prominent theories focus on hopelessness [51] and escape from the self [52]; none include achievement as a key theoretical component. Further, previous research on achievement as a predictor of suicide generally shows no association while controlling depressive symptoms and other common covariates [53-56].

However, it is likely that achievement helps us to rule out suicide rather than to rule it in. Our algorithm appeared to go through two major steps. First, ruling out those who are clearly nonsuicidal (using achievement) and then ruling suicidality in using themes of death and emotional intensity. Traditional assessment of suicide risk has implicitly focused on discerning severe suicidality among populations that often present with thoughts of suicide (eg, individuals seeking treatment for depression or posttraumatic stress disorder); traditional approaches do not typically assess which variables rule out suicide. Our attempt to measure suicidality using social media data in a nonclinical population is distinct from typical methods because it does not ask people to report on symptoms, instead the algorithm monitors a broadcast of comments intended to be shared with anyone who will listen. Hence, achievement likely emerged as a strong differentiating factor because the forward thinking and optimistic nature of achievement is antithetical to suicide. Future research should continue to explore whether a similar "rule out" followed by "ruling in" approach occurs in other machine learning algorithms of social media data.

### **Limitations and Strengths**

Our study has a number of limitations as well as strengths. First, although self-report measures have an element of socially desirable responding influencing scores, it is possible that social desirability may also play a role in Twitter data. However, when themes predictive of suicide emerge in social media, and thus go against the typical scripts of social media chatter, they could represent a major cry for help that may be more informative than other methods of assessing suicidal risk; we propose that future research should explore this issue. We also encourage examination of other forms of online media (eg, Facebook, blogs, etc) because they may serve a slightly different function than Twitter and thus generate different algorithms for detecting suicide risk. Second, as suicide is a rare event, only limited amounts of clinically significant suicidality was analyzed. Although we cross-validated our own sample, we encourage other researchers to replicate our work in other samples to provide even stronger converging evidence of these machine-learning algorithms. We would especially encourage replication using samples recruited via means other than MTurk, since it is possible that MTurk participants are different from the general population of social media users in ways that influenced the themes we observed in our research (eg, themes of achievement). On the other hand, our study is the first to validate machine-learning algorithms in Twitter data against psychometrically validated measures of suicidality. Moreover, our multimodal assessment of suicidality took place within a sample that is known to be more attentive [57] and representative than college student populations [58], where novel research ideas are often tested. Further, our results provide strong evidence that we are reliably able to differentiate those who are clinically significantly suicidal from those who are not.

#### **Public Health Significance**

Regarding public health approaches to suicide, Twitter offers an unprecedented stream of data connecting individuals to society; our study suggests that there might be a very tangible way we can leverage this phenomenon to do something beneficial. As we further refine our ability to identify suicide risk in real time, our ability to reduce risk for suicide will increase. This may augment existing programs attempting to reduce suicide. For example, suicide hotlines have staff that wait for individuals in crisis to call in; we may enhance these efforts using social media data to proactively identify those who may benefit from their services. When an individual's public twitter stream indicates clinically significant suicidality, simple interventions such as sending them a private message directing them to 1-800-273-TALK is almost effortless to do, but may have a significant impact. Simple interventions that foster belongingness or connect people to reach-out-and-talkto-someone resources are likely to help anyone virtually. An important study showed that simply sending follow-up letters

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to individuals who had been previously hospitalized for suicide or depression reduced the rate of subsequent suicide compared to those who received no such contact[59]. We believe that expanding our portfolio of approaches to include surveillance of social media in order to identify and prevent suicide across the entire population of those who use social media has the potential to substantially reduce the incidence of suicide in the US. The White House has indicated that suicide prevention is a top priority and has funded a number of initiatives attempting to reduce suicide [60]. However, many attempts to reduce suicide are marked by good intentions but lack a strong empirical base and reach only a limited number of people. In order to extend our reach in a way that can commensurate with the problem of suicide, we need to move beyond status quo approaches that wait for people to seek treatment when they are in deep distress and instead seek them out before they reach the point of crisis.

### **Conflicts of Interest**

None declared.

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**Original Paper** 

# A Thematic Analysis of Stigma and Disclosure for Perinatal Depression on an Online Forum

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### Abstract

**Background:** Perinatal mental illness is a global health concern; however, many women do not get the treatment they need to recover. Some women choose not to seek professional help and get no treatment because they feel stigmatized. Online forums for various health conditions, including perinatal mental health, can be beneficial for members. Little is known about the role that online forums for perinatal mental illness play in reducing stigma and subsequent disclosure of symptoms to health care providers and treatment uptake.

**Objective:** This study aimed to examine stigma and disclosure in forums and describe any potential disadvantages of forum use.

**Methods:** An online forum for mothers was examined and 1546 messages extracted from 102 threads from the antenatal and postnatal depression section. These messages were subjected to deductive systematic thematic analysis to identify common themes regarding stigma and disclosure of symptoms and potential disadvantages of forum use.

**Results:** Two major themes were identified: *stigma* and *negative experiences of disclosure*. Stigma had 3 subthemes: internal stigma, external stigma, and treatment stigma. Many women were concerned about feeling like a "bad" or "failed" mother and worried that if they disclosed their symptoms to a health care provider they would be stigmatized. Posts in response to this frequently encouraged women to disclose their symptoms to health care providers and accept professional treatment. Forum discourse reconstructed the ideology of motherhood as compatible with perinatal mental illness, especially if the woman sought help and adhered to treatment. Many women overcame stigma and replied that they had taken advice and disclosed to a health care provider and/or taken treatment.

**Conclusions:** Forum use may increase women's disclosure to health care providers by challenging their internal and external stigma and this may strengthen professional treatment uptake and adherence. However, a few posts described negative experiences when disclosing to health care providers.

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### **KEYWORDS**

perinatal; online; Internet; depression; eHealth

### Introduction

Perinatal mental illness is a global health concern and includes antenatal and postnatal depression and anxiety disorders, post-traumatic stress disorder after childbirth, and adjustment

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disorders. Perinatal depression has a prevalence of 12%-20% [1] and perinatal anxiety affects 2.6%-39% of women [2]. Post-traumatic stress disorder after childbirth affects 3.17% of new mothers and 15% in high-risk groups [3]. If these illnesses are not treated, there are well-documented adverse outcomes

for women, infants, and families [4]. Detrimental maternal outcomes include substance abuse and suicide [5] and untreated antenatal depression is associated with postnatal depression [6]. Negative infant outcomes include developmental and cognitive delays [7,8], preterm delivery [9], and an increased risk of behavioral and attachment problems [10].

Women with perinatal mental illness often fail to receive treatment despite treatment being available [11]. Often this is because women choose not to disclose and seek help from their health care provider. Poor knowledge of medical conditions is one reason some people may be less likely to recognize they are ill and therefore less likely to seek help [12]. Some women have poor health literacy about perinatal mental illness and problems relating professional health information to how they experience the illness [13]. In addition, there can be a misconception about what perinatal mental illness is, and women may find it difficult to distinguish what is a healthy emotional reaction to the transition to motherhood and what emotions may indicate a mental illness [14]. These issues can contribute to stigma.

Stigma is an extreme disapproval of someone or group of people because of a certain characteristic; it can present as external stigma where the general public holds a stigmatizing attitude. It can also present as internal stigma where the stigmatized individual believes this negative appraisal and applies it to themselves. There are high levels of external stigma in the general population and internal stigma has been identified in approximately a third of people with severe mental illnesses [15,16]. There are well-documented negative outcomes for individuals with mental illness because of external stigma such as social exclusion, discrimination, and fewer life opportunities [17]. Similarly, internal stigma has been associated with low self-esteem, reduced disclosure, and reluctance to seek treatment [17,18].

Thus, some women may think others will view them negatively for having a mental illness (external stigma) and may also feel bad about themselves for having a mental illness (internal stigma). Stigma is a major barrier to disclosure and help-seeking in the perinatal period [14,19]. Some women feel stigmatized not only because they have a mental illness but principally because they are a mother with a mental illness. This two-fold stigma means they are concerned about feeling like, and being seen by others as, a "bad mother" [20]. Women with perinatal mental illness have unique concerns related to their maternal identity; they may worry that having a mental illness would result in negative consequences such as social services involvement, loss of custodial rights, and hospitalization [21-23]. These features of stigma can contribute to reluctance to disclose symptoms [24]. A systematic review and meta-synthesis identified stigma and concerns about child custody as a key barrier to care for postnatal women [25]. Many women avoided disclosing symptoms to health care providers, as they did not want to be diagnosed as having a mental illness. They wanted to be seen as coping and were worried they would lose custody of their child should they disclose.

People suffering from stigmatized illnesses are more likely to turn to the Internet for help [26,27]. Studies have detailed the

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benefits of using online social support for a variety of health issues [28,29]. The Internet could provide a unique avenue to reduce stigma in terms of knowledge and attitude. It could provide information about perinatal mental illness that women could relate to. This could aid disclosure by increasing women's health literacy about perinatal mental illness and enable them to recognize that they have a problem.

There are thousands of websites dedicated to perinatal mental health and many online support groups or forums, but little is known about how members engage with them [30,31]. A content analysis by Evans et al [32] of an online support group for postnatal depression reported it was nonjudgmental. The forum provided emotional, informational, and some instrumental support. Posts encouraged users to contact a health care provider and take medication; there were no posts containing negative experiences with health care providers. Similarly, another content analysis documented how online support forums for lesbians with postnatal depression provided social support [33]. Many women were reluctant to disclose and seek help because of the stigma of being seen as an unfit mother and fear of the child being taken away. In addition to the stigma around their mental illness, women felt stigmatized because they were homosexual. The dichotomy of "good mother" "bad mother" deterred help-seeking behavior; it is plausible that this may be because it increases internal and external stigma. To some women the idea of a "good mother" is not compatible with mental illness; similarly, having symptoms of perinatal mental illness such as bonding problems or thinking of harming your child can make women feel like a "bad mother" [20].

A discourse analysis of an online forum for postnatal depression reported how it provided a place for mothers to confess their shame about having perinatal mental illness [34]. This enabled many women to overcome the stigma of being mentally ill and not meeting the expectations of a good mother. Women found that no one talked about this offline, so they constructed an online dialogue with other forum users that expressed negative feelings around motherhood. Nevertheless, it is important to note that some recent research suggests online support groups may not challenge stigma enough to affect or change help-seeking behavior [35]. Excessive participation in online support groups could also be a form of social avoidance and prevent disclosure and foster over reliance on forums [36]. Internet forums for perinatal mental health have yet to be researched to see how using forums may increase disclosure of symptoms and help-seeking behavior. Forums may challenge stigma by providing a unique source of experiential information and a space for women to disclose and seek advice anonymously without fear of being stigmatized. Posts on forums may challenge stigma and provide positive discourse about perinatal mental health. Posts may also provide encouragement for women to seek and adhere to professional treatment by challenging external stigma.

This study aimed to investigate if and how perinatal mental illness forums might overcome the barriers stigma presents to some women with perinatal mental illness when seeking help from health care providers and to see if there are possible disadvantages of using forums regarding disclosure and stigma.

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### Methods

### Sample

Forums were identified using the three most popular UK search engines (Google, Bing, and Yahoo) that are used by 98.83% of Web users [37]. The text searches were "postnatal depression," "postnatal forum," "postnatal anxiety," and "birth trauma" and entered into each of the search engines. The first 25 websites and their hyperlinks were assessed for inclusion in the study. Inclusion criteria were as follows: (1) they had a forum or message board dedicated to antenatal and/or postnatal mental health, (2) they had been active for the last 6 months, (3) the forum had more than 50 members, (4) messages could be viewed by nonmembers of the group, and (5) moderators gave permission to research their forums. Nine forums were contacted but only 1 forum moderator gave permission to research posts. The forum moderator was from "Mumsnet," one of the largest websites for parenting advice and has active forums with between 1.2 and 1.7 million members [38]. There were 28 "talk topics" that contained between 1 and 273 forums. The forum section for antenatal and postnatal depression was dedicated to perinatal mental health and was used to draw the data for analysis.

### Procedure

Nineteen forum moderators were contacted and written permission from 1 moderator was obtained. Visitors were informed of the nature of the research and their right to withdraw their data via a prominent disclaimer on the forum. A link from the site provided details about what data were taken from the site and how the information was used. The study was retrospective to avoid influencing the participants' interactions. Confidentiality was maximized by ensuring the anonymity of participants by replacing their user names with pseudo names.

### **Data Selection**

All messages on the antenatal and postnatal forum between January 2013 and June 2013 were included for analysis. This comprised 1546 messages retrieved from 102 threads. The average number of posts in a thread was nearly 28. These threads and messages were copied into Microsoft Word files and stored securely for data protection purposes and because forums can terminate at any time.

### **Ethical Considerations**

The study received ethical approval from the School of Health Sciences Research Ethics Committee, City University London. Precautions were taken to ensure the safety, dignity, and rights of participants in accordance with the 2007 "Guidelines for Ethical Practice in Psychological Research Online" as outlined by the British Psychological Society [39]. Consideration was given to the nature of online private and public spaces, anonymity, confidentiality, valid consent, and the right to withdraw from the study [40].

### Analysis

Discussion threads were examined using deductive systematic thematic analysis from a realist stance [41]. Threads were copied into the qualitative data analysis computer software NVivo 10

and threads were read and reread before generating initial codes [42]. Themes were generated from patterns in the codes and were included when they were frequent, appeared important to posters, and were related to the research aims. The principal researcher had experience in qualitative analyses and met regularly with a senior health researcher (SA) to discuss analysis, thus increasing reliability of codes and themes. The whole dataset was recoded when themes were defined and codes were organized to address the research questions of stigma, disclosure, and messages that could potentially hinder women seeking help. The principal researcher developed the interpretation of themes and final interpretations were agreed by consensus of all authors.

### Results

Two major themes were identified: stigma and negative experiences. Stigma had 3 subthemes: internal stigma, external stigma, and treatment stigma.

### Stigma

The majority of women disclosed their symptoms on their first post and often sought advice on diagnosis, whether or not they should contact a health care provider, healthcare providers' attitudes to illness and treatment. Nearly all the replying posts urged women to contact their healthcare providers and often reassured women who had concerns about approaching health care providers. Women were frequently encouraged to honestly disclose their symptoms to health care providers and take professional treatment offered.

### **Internal Stigma**

Internal stigma was coded when women wrote about their stigmatized attitudes towards themselves, such as feelings of inadequacy as a mother. Many women used the forum to disclose shameful feelings often hidden from others such as feeling like a failure as a mother, wanting to leave the baby or family, intrusive thoughts of self-harm and child-abuse. They felt that there was no place offline to talk about the negative side of pregnancy and motherhood and valued the nonjudgmental space offered by forums. Replies were often reassuring and challenged internal stigma by stressing that these feelings were part of the illness and not indicative of failure as a mother:

I'm not very compassionate towards myself or accepting of the fact that I was ill (rather than just being crap). [R] You haven't failed!!! The illness is making you think

You haven't failed!!! The illness is making you think this way. [R]

### **External Stigma**

External stigma comprised of the concerns many women had about how health care providers would think that they were inadequate mother if they disclosed symptoms.

Members perpetuated a strong culture of advice that urged women to contact a general practitioner, midwife or health visitor even if they did not ask for it. Half of all women who had not disclosed to a health care providers when they first

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posted replied that they had sought professional help following others' encouragement (n=15):

# Thank you have rung the doctor. Think I just needed someone else to tell me to do it. [I]

Nearly half of women who posted did not reply to say if they had taken members advice, and one woman refused to disclose to a health care provider. Women were often reluctant to disclose to their health care providers as they feared being seen as a bad mother and their baby would be taken away or social services would intervene:

I have seen the perinatal team and dr previously but kind of played down my feelings as I am scared that if I show I am not coping with my moods then they might look down on me, see me as an unfit mother and pass me over to social services. [I]

Anyone got any experience with this - what did u say to the DR? What was their approach? Were you made to feel like a bad mum/mum to be? Were you strictly monitored/referred to social services after? [I]

Most replies to these posts were reassuring, shared positive experiences of disclosing, and stressed getting help from a health care provider was the best course of action:

If you are seeking help and trying to sort it that's good. There's no reason to take your baby. I was honest with my gp. Nothing bad happened. I got better. [R]

### **Treatment Stigma**

Treatment stigma was related to women's concerns about seeking and adhering to professional treatment. It extended concepts of internal and external stigma described above.

Often posters emphasized the importance of professional help in recovery; women who started threads and posed questions were often reassured that they had *done the right thing* when they had disclosed to health care providers.

It is the people who are not seeking help and not being honest with themselves that are in the most danger, You are doing the right things, you are being objective, and seeking help. [R]

Treatment was largely discussed in terms of antidepressants. Some women felt like a failure for having to take medication, which added to feelings of *weakness* for having a mental illness and being a *failure* as a mother. This stigma often centered on guilt for thinking they would harm the baby, inability to cope as a mother, and needing to rely on medication.

I still feel guilty and worried I am causing my baby harm and being selfish if I ask for drugs - did any of you guys who have taken meds struggle with this before asking? [I]

Replies were embedded in a dialogue of social support and most were pro-antidepressants and encouraged women to work with health care providers. These posts often challenged stigma by promoting an alternative "good mum" discourse that challenged external and internal stigma. Posts reconceptualized what a good mother is, namely, a good mother gets help and takes treatment:

And don't worry about not being a good mum, the very fact that you posted what you did and are worried about the possible effects on the baby show that you're already a very caring mum. [R]

I feel like there's a stigma attached to taking meds for a mental illness, which doesn't exist for physical illnesses...And I don't think I'm going to do DD (darling daughter) any favours by trying to prove I can be a good mum off my medication. [R]

### **Negative Experiences**

Negative experiences with health care providers included disclosure and treatment experiences. This theme extended feelings of internal and external stigma and the majority of subsequent posts challenged stigma by promoting health care providers and treatment.

Very few posts outlined any negative experiences when women disclosed to health care providers (n=3). One woman who started a thread rebuked replies encouraging help-seeking as she had previous negative experiences with the social services and did not trust health care providers. Two women started threads to talk about bad events with health care providers:

My midwife said, and I quote, 'if you suffer from psychosis we could take your child away'. For someone feeling vulnerable this was really scary and I have not been able to relax with the pregnancy. [I]

Subsequent posts condemned the midwife's approach and said how there are good and non-judgemental healthcare providers. Replies to unhelpful health care provider experiences strongly urged women to engage with health care providers and stressed that treatment was essential for recovery.

### Discussion

### Principal Findings

This study increases our knowledge of the stigma women with perinatal mental illness may experience. In particular, it offers unique insights into how women are expressing different types of stigma on an online forum, online discourse that challenged this stigma, and the potential outcomes for help-seeking behavior. Women frequently expressed internal stigma and were concerned about external stigma from health care providers. Both were noteworthy barriers to help-seeking behavior and reply posts often challenged this stigma by sharing positive experiences of disclosure and treatment. Posts challenged some women's beliefs that health care providers would think of them as an unfit mother or social services would take their baby. Women were consistently encouraged to seek professional help.

Treatment stigma was often expressed as stigma about having a mental illness and having a mental illness as a mother. Some women felt they had failed at their role as a mother because they had to rely on medication to cope and feared treatment would harm their unborn child. Subsequent posts challenged this stigma promoting a different discourse that advocated good mothers seek help and take treatment. Many women who sought

advice on whether they should disclose to a healthcare provider reported that they followed the advice of reply posts and sought help. There were 3 instances of negative experiences when disclosing symptoms to health care providers.

### **Comparisons With Prior Work**

Consistent with previous studies [25,43], the stigma attached to mental illness was a salient barrier to treatment and women were able to "test out" disclosing symptoms and concerns in online conversations. Like previous research, many women spoke about the stigma attached to antidepressants that contributed to a reluctance to engage in treatment [44]. This study extends our knowledge of how a forum provided an anonymous place where women could explore their understanding of perinatal mental illness and where they got encouragement to seek help and accept treatment. If women recognize that they may have a mental illness, they may be more motived to seek help like many women in this study. Women frequently expressed internal and external stigma often describing feeling like and/or being seen as a "bad mother," an "unfit mother," or a "failure."

Internal, external, and treatment stigma discourse was met by replies of encouragement to get help and praised acts of disclosure to health care providers. Posts often promoted a "good mother" discourse that included the ideas that a good mother discloses and gets treatment and health care providers will not think them inadequate or take their baby away. These posts challenged the distressing dissonance between the concept of a good mother, and that of a bad mother, present in some mothers' posts and thus reconciled that a "good mother" can have perinatal mental illness.

Unlike previous research on perinatal mental health forums, there were 3 posts that shared negative experiences of disclosing to health care providers [32-34]. Despite the vast majority of posts presenting positive experiences, the potential effect of negative posts should be considered. Some women who experience stigma can suffer with intense feelings of inadequacy and worry that health care providers will not understand or social services will become involved [20]. Future work should investigate if negative posts reinforce these anxieties and if in turn this inhibits disclosure and help-seeking behavior. The culture of discussions and attitudes to disclosure may be very different in other online communities, for example, a birth trauma support group may include many posts describing negative experiences with health care providers. This group gives women an opportunity to voice their concerns that they may not be able to do offline, however, there is potential for conversations to negatively impact healthcare decisions.

Concerns are warranted, especially if the forum is unmoderated and lacks encouragement to engage with health care providers.

### Limitations

This is the first study of messages on a perinatal mental illness forum that explores stigma and disclosure and suggests potential concerns for users. Unfortunately, this study only considered one online forum as all other moderators either did not give consent or failed to reply to requests for consent. Future research should observe other forums to ensure the validity and generalizability of findings. Messages reported that half of women sought help as a direct consequence of using the forums. We do not know if there was an effect on the women who did not reply or those who read forums without posting. Users who read without posting are also known as lurkers and account for the majority of forum users [45,46]. Therefore, future research should aim to explore both posters' and lurkers' experiences and survey women with various levels of participation in different forums.

### **Clinical Implications**

This study provides further insights into the stigma women with perinatal mental illness may experience and how they communicate online. This could be used to develop targeted interventions to help women disclose to health care providers and get treatment, for example, forums could be developed to offer this support to at risk women and their subsequent disclosure could be measured against a control group. Future theoretical models could draw on this evidence and investigate if online forum use for perinatal mental illness impacts the stigma experienced by some women and if this affects disclosure to health care providers.

### Conclusions

Forum posts often expressed internal and external stigma from health care providers and treatment stigma as major barriers to disclosure and help-seeking behavior. Forum replies challenged this stigma and provided a place to discuss stigma. Forum discourse reconstructed the idea of a good mother as compatible with perinatal mental illness, especially if the woman sought help and adhered to treatment.

The vast majority of posts encouraged women to engage with and trust in health care providers, and consequently some women sought help and engaged in treatment. This study showed that this forum has the potential to increase women's disclosure to health care providers and strengthen professional treatment uptake and adherence. However, there are possible concerns when using forums. Health care providers should exercise discernment when directing their clients to online forums.

### Acknowledgments

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### **Conflicts of Interest**

None declared.



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## Mobile Phone and Web-based Cognitive Behavior Therapy for Depressive Symptoms and Mental Health Comorbidities in People Living With Diabetes: Results of a Feasibility Study

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### Abstract

**Background:** Depression is often comorbid with diabetes; however, undertreatment of depressive symptoms in people affected is common.

**Objective:** We studied preliminary acceptability and effectiveness of a fully automated, mobile phone, and web-based public health intervention, myCompass, for reducing depressive symptoms and improving mental health comorbidities in people with diabetes.

**Methods:** In this single-group feasibility study, 89 volunteers with type 1 (n=34) or type 2 (n=55) diabetes and at least mild depressive symptoms used myCompass for 7 weeks. Web-based measures of depressive and anxious symptoms, functional impairment, diabetes-specific variables, and user satisfaction were completed at baseline, postintervention, and 3-month follow-up.

**Results:** Retention rates were 54% (n=48) at postintervention and 36% (n=32) at follow-up. Depressive symptoms were significantly improved at postintervention (P<.001; within-group effect size d=1.05), with gains persisting at follow-up. Mental health comorbidities, including anxiety (P<.001), functioning (P<.001), and diabetes-specific distress (P<.001), also showed significant and sustained improvement. Satisfaction with myCompass was high, with convenience and ease of program use, and relevance of program content rated positively by participants.

**Conclusions:** The myCompass program shows promise as an acceptable and effective treatment for depression and comorbid mental health problems in people with diabetes. The program is broadly available, free to use, and may benefit patients with diabetes who do not access services and/or wish to manage their mental health themselves. Replication of these findings in a controlled study is warranted.

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### **KEYWORDS**

diabetes; depression; Internet interventions; eHealth; CBT

### Introduction

Depression is frequently comorbid with diabetes, affecting 10% to 30% of the estimated 415 million people with the disease [1], and contributes independently to poorer daily management of diabetes regimen tasks or "self-care," higher rates of microvascular and macrovascular complications, elevated health

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service costs, and increased mortality [2]. Evidence-based treatments for comorbid depression are available, including face-to-face cognitive behavior therapy (CBT) and antidepressant medication, and evidence supports the utility of these approaches for improving self-management of diabetes and glycemic control [3,4]. Psychotherapeutic approaches are particularly beneficial as they lack the side effects of medication

[5], and there is evidence that treatment gains in CBT are maintained for up to 1 year past cessation of treatment [6].

The existence of effective treatments means that the adverse consequences of depression for people with diabetes are not inevitable [3,7]. Nevertheless, it is estimated that only one-third of people with diabetes and depression receive appropriate treatment for both disorders [8]. In the primary care setting, where medical support for most patients with diabetes is provided, only a minority of patients who screen positive accept a referral for face-to-face support [9]. At the same time, barriers to help seeking, including lack of psychological services (especially in rural and remote areas), financial cost, concerns about confidentiality and stigma, and time and lifestyle constraints [10], compromise access to satisfactory care for many patients. There is, therefore, considerable opportunity to improve diabetes management and to intervene with disease progression by increasing patient access to effective depression treatments that reduce structural and patient barriers to care and offer the advantages of user privacy and 24-hour availability.

The Internet is a popular, clinically effective and cost-efficient means of increasing access to empirically supported psychological treatments, and diabetes-specific Internet-delivered programs targeting depressive symptoms are available [11-13]. Nevertheless, a public health-focused intervention that is delivered through the Internet and generic in its therapeutic content (ie, capable of targeting depressive symptoms across a range of physical health conditions) may have a number of benefits over disease-specific approaches. In addition to facilitating broader treatment reach, a generic treatment program delivered through the Internet would assist increasing number of individuals experiencing the multimorbidity, for whom depression co-occurs with somatic symptoms of multiple illnesses (eg, diabetes, heart disease, hypertension, and kidney disease [14,15]). Related to this, a generic intervention is likely to be more efficiently and easily disseminated in the primary care setting, where treatment of multimorbidity and undifferentiated physical and mental health symptoms are particularly relevant.

We have previously demonstrated the effectiveness of a fully automated public health intervention, myCompass, for improving symptom and functional outcomes for people with mild-to-moderate depression, anxiety, and stress [16,17]. Grounded in CBT, myCompass provides 24/7 access to psychotherapeutic support and real-time monitoring of thoughts, feelings, and behaviors using mobile phone and Web technology. Compared with active control and waitlist conditions, use of myCompass for 7 weeks reduced symptoms to within the near-normal range, with benefits persisting for 3 months [16].

This study was largely exploratory and aimed to assess initial acceptability and effectiveness for a larger randomized controlled trial of myCompass as an intervention for depression in diabetes. Depression and anxiety often co-occur [18,19], and as both increase the functional burden of chronic disease (eg, more days of missed work; [20]), we expected that myCompass would have important collateral advantages for patients with diabetes over and above the amelioration of depressive

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symptoms. Specifically, we hypothesized that people with diabetes and at least mild depression would show a pattern of symptom and functional gains consistent with the improvements observed for participants in our earlier trial.

Our secondary aim was to examine whether the benefits of myCompass extended beyond affective symptoms and general functional impairment to include disease-specific cognitions that correlate with depression and mediate diabetes outcomes. In particular, we were interested in whether the intervention would increase diabetes self-efficacy, that is, people's confidence in their ability to perform diabetes self-care tasks [21] and reduce diabetes-related distress, that is, a person's emotional adjustment to the various chronic stressors of diabetes (eg, fear of complications, feelings of isolation, distress associated with insulin, and frustration with daily self-care; [22]). Both diabetes self-efficacy and diabetes-related distress are clinically relevant variables with direct links to performance of diabetes regimen tasks (including blood glucose monitoring, healthy eating, exercise, taking medication, and foot care) and glycemic control [21-23]. Whereas previous studies have documented the benefits for these variables of disease-specific interventions (eg, [11,24]), we wanted to learn whether improvement in diabetes-specific cognitions might be possible using a CBT-based public health intervention with no disease-relevant content.

### Methods

### Recruitment

Participants were recruited nationally between March and November 2013 via advertisements placed on social media (Facebook and Twitter); Websites of the Black Dog Institute and diabetes associations in Victoria, New South Wales, and Queensland and in radio and print media. Those interested were invited to visit a study-specific Website to access information about the study, a Web-based consent form, and a screening survey.

Eligibility criteria included: diagnosed with type 1 (T1D) or type 2 (T2D) diabetes by a general practitioner (GP) or endocrinologist; Australian resident aged 18 to 75 years; has access to the Internet via mobile phone and computer; has a valid email address; reports symptoms of at least mild depression (score > 4 on the Patient Health Questionnaire (PHQ-9; [25]); and has no previous experience with myCompass. Individuals who endorsed psychotic symptoms on the Psychosis Screening Questionnaire (PSQ; [26]) were excluded from the study.

### **Procedure and Design**

A within-subject, prepost design was used for this study that was conducted entirely online. Eligible participants completed a baseline questionnaire and were automatically registered with the myCompass program. Because existing efficacy data for myCompass are based on a 7-week intervention period [16], study participants were provided access to the full program for 7 weeks and encouraged to use it *ad libitum* during this time. At the end of 7 weeks and again at week 20, participants completed the Web-based postintervention and follow-up questionnaires, respectively.

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The study was approved by the University of New South Wales' Human Research Ethics Committee (HREC12616) and registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12613000172707).

### Intervention

The myCompass program [27] is a fully automated public health intervention (no therapist input) that is accessible from any Internet-enabled mobile phone, tablet, or computer (see Figures 1-5). The program assesses user symptoms and provides a personalized intervention that facilitates round-the-clock self-monitoring of moods and behaviors (via mobile phone, tablet, or computer) and provides interactive evidence-based learning modules (via tablet and computer). Each module contains 3, 5- to 10-minute sessions, each with an assigned homework task. Users are encouraged to complete 1 module session per week, with the aim of completing 2 full modules during the intervention period.

In addition, users can schedule text messaging (short message service, SMS) or email reminders to facilitate self-monitoring;

Figure 1. Screenshot of myCompass landing page (1).

receive and print graphical feedback about their self-monitoring (including contextual information) on their mobile phone or computer (to monitor change and assist identification of triggers); and elect to receive helpful facts, mental health care tips or motivational statements by SMS text messaging or email. Registering to use the program is free, and users are not billed for the SMSs they receive. A detailed description of the myCompass intervention is provided in the study by Proudfoot et al [16].

Providing feedback to program users improves adherence with Web-based interventions [28], and so we enhanced the functionality of myCompass in this study to send automated and personalized email messages to participants (at 4 weeks) about their use of the program's self-monitoring and module functions. Messages were designed to be motivating: infrequent users were reminded of the benefits of regular program use; and frequent users were encouraged to continue self-monitoring and explore additional program modules.





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Figure 5. Screen from myCompass Breathing and Relaxation module.

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	Now please answer the fo	llowing questions:	
	Did your breathing change	e when you thought about your ten	se episode?
1 2 3 1 5 1 M	●Yes ◎No ◎Not Sure		
-	Was there any area of you episode?	r body (neck, back, tummy etc.) tha	at tensed up as you were recalling the
A Sie	●Yes ◎No ◎Not Sure		
	●Yes        ●No        ●Not Sure         I felt tension in my		
	I felt tension in my		
	I felt tension in my		
	I felt tension in my		
	I felt tension in my		
	I felt tension in my		
	I felt tension in my		
Back	I felt tension in my		Next
Back EXPLORE	I felt tension in my	INFORMATION	Next SHARE myCOMPASS

### Measures

Participants provided sociodemographic (age, gender, highest educational qualification, and employment status) and disease-related information (age at diagnosis, treatment modality, and diabetes complications status) at baseline. At each assessment point, participants completed the following standardized and psychometrically sound measures.

### **Primary Outcomes**

Depression and anxiety were measured by the PHQ-9 [25] and the Generalized Anxiety Disorder 7-item scale (GAD-7; [29]), respectively. The scales are well validated [30], used widely as screening tools in primary care settings, and frequently included as outcome measures in studies of Web-based interventions [31,32]. Scores of 5, 10, and 15 are used as cutoff points for mild, moderate, and severe symptoms, respectively, on both the scales. Mental health self-efficacy was assessed using the Mental Health Self-Efficacy Scale (MHSES; [17]), which measures people's confidence in managing mental health issues using six 10-point Likert scale items. Scores are summed to obtain an overall measure, with higher scores indicating greater mental health self-efficacy.

The Work and Social Adjustment Scale (WSAS; [33]) measured the impact of mental health problems on daily functioning in 5 domains: work, social leisure activities, private leisure activities, home management, and personal relationships [33,34]. Scores range from 0 to 40, with higher scores indicating poorer adjustment.

#### Secondary Outcomes

Emotional adjustment to diabetes was measured using the 20-item Problem Areas in Diabetes scale (PAID; [35,36]) Items are rated on a 5-point Likert scale (0-4) and assess distress caused by treatment, food, diet, social support, and emotional



issues. Total scores on the PAID are multiplied by 1.25 to yield a score within the range of 0 to 100, with scores greater than 40 indicating elevated diabetes-related distress [37].

Diabetes self-efficacy was measured using the 8-item Diabetes Self-efficacy Scale (DSES; [38]), which asks about people's beliefs in their ability to perform a range of diabetes self-care activities. Scores on the DSES are the average response to scale items and range from 1 to 10, with higher scores indicating greater diabetes self-efficacy.

The Summary of Diabetes Self-Care Activities Scale (DSCAS; [39]) measures diabetes self-management across 4 regimen areas: diet, exercise, blood glucose testing, and foot care. Mean scores are calculated for each area and range between 0 and 7, with higher scores representing better self-care.

Glycemic control was measured indirectly by asking participants to report on recent symptoms of hypoglycemia (eg, headaches, light-headedness, weakness) and hyperglycemia (eg, increased thirst, dry mouth, decreased appetite) using the scales developed by Piette [40]. Scores for each symptom domain range from 0 to 7, with higher scores reflecting more symptoms.

A combined quantitative and qualitative method was used to investigate participant's views of the program and its utility. The postintervention questionnaire included 8 items that asked users to rate (0-4) their satisfaction with the usability, content, flexibility, and functionality of myCompass [16]. Scores ranged between 0 and 32 with higher scores reflecting a more positive user experience. In addition, data indicating extent of user engagement with myCompass were extracted from the program, including frequency of logins, number of modules completed, and self-monitoring frequency.

Quantitative data were supplemented with information obtained from brief telephone interviews with a subset of participants about their experience with the myCompass program. A standard "sampling to saturation" recruitment method yielded a total of 18 interviews that were audiotaped and later transcribed to identify emergent themes.

### **Statistical Analyses**

Statistical analyses were completed using SPSS 21.0 software. Descriptive statistics were calculated for baseline data, and independent *t*-tests, chi-square tests, and bivariate correlations were used, as appropriate, to examine: (1) differences between people with T1D and T2D on the demographic and disease-related characteristics; (2) relations between demographic and disease-related variables and scores on the outcome measures (to identify potential covariates); and (3) possible biases in study attrition.

Postintervention and follow-up treatment effects were examined based on the intention-to-treat sample using linear mixed modeling (LMM; [41]). In LMM, incomplete cases are included in the analysis, and all available data are used to obtain parameter estimates. Restricted maximum likelihood was used to estimate model parameters, and Satterthwaite's approximation was used to obtain degrees of freedom. Analyses assumed a compound symmetric structure [42] and included all identified covariates in addition to baseline scores on the outcome variable of interest. Significant effects were tested using separate contrasts to compare scores at baseline and postintervention, and postintervention and follow-up. All effects were tested at the P<.05 level, with adjustment for the number of contrasts.

Cohen's *d* was calculated to obtain estimates of treatment effects using estimated marginal means for within-group changes on all outcome measures (based on the pooled standard deviation—SD).

### Results

### **Participants**

Of the 161 people who consented to screening, 91 were eligible to participate (Figure 2). Reasons for ineligibility included: screening questionnaire incomplete (n=26, 38%); no Internet-enabled mobile phone (n=20, 29%); symptoms in the normal range (n=7, 10%); psychotic symptoms (n=3, 4%), used myCompass previously (n=5, 7%), not an Australian resident (n=4, 6%), no diabetes (n=2, 3%), and no mobile phone (n=2, 3%). Two people subsequently withdrew from the study, and their data were excluded from the analyses.

Demographic and disease-related data for the study participants are summarized in Table 1. Most participants had T2D (n=55, 61.8%) were female (n=62, 69.7%), tertiary educated (n=41, 46.1%), married (n=46, 51.7%), employed at least part-time (n=57, 64%), nonsmoking (n=79, 88.8%), with a mean age of 48 years (SD=12 years). Mean age of diabetes onset differed significantly for people with T1D and T2D, being 18 years (SD=12 years) and 52 years (SD=10 years), respectively [t(87)=-5.45, P<.001]. Insulin therapy was more common in people with T1D [ $X^2(1)=42.91$ , P<.001], and tablet therapy was more common in T2D [ $X^2(1)=42.71$ , P<.001]. Half of the sample reported no diabetes-related complications (n=45, 50.6%), with diabetes-related eye, health, and sexual problems being the most frequently reported complications for both T1D and T2D participants.



Table 1. Demographic and disease-related characteristics.

Demographic characteristics		Type 1 diabetes (n=34)	Type 2 diabetes (n=55)
Age (mean, SD <sup>a</sup> )		39.91 (11.72)	52.78 (10.21)
Gender (n, %)			
	Male	8 (24)	19 (35)
	Female	26 (76)	36 (65)
Marital status (n, %)			
	Single	9 (26)	9 (16)
	Married	16 (47)	30 (55)
	Other	9 (26)	16 (29)
Educational level (n, %)			
	Secondary school or lower	8 (24)	6 (11)
	Trade certificate or diploma	8 (24)	26 (47)
	University undergraduate degree or higher	18 (52)	23 (42)
Employed (n, %)		24 (71)	33 (60)
Treatment type $(n, \%)^{b}$			
	Insulin <sup>c</sup>	34 (100)	17 (31)
	Tablets	3 (9)	44 (80)
	Diet or exercise	6 (18)	33 (60)
Age of onset of diabetes (mean, SD) <sup>c</sup>		18.4 (11.8)	52 (10.2)
Diabetes complications (n, %) <sup>b</sup>			
	Eye problems	7 (21)	14 (26)
	Kidney problems	0 (0)	3 (6)
	Heart problems	4 (12)	11 (20)
	Foot problems	3 (9)	11 (20)
	Sexual problems	3 (9)	12 (22)
	None	21 (62)	24 (44)

<sup>a</sup>SD: standard deviation.

<sup>b</sup>Participants can select more than one option.

<sup>c</sup>Groups differ, *P*<.001.

Table 2 summarizes baseline scores on the outcome measures. When the recommended cutoffs were applied, depressive symptoms were in the moderate range (M=12.79, SD=4.7; [25]), anxiety symptoms were in the mild range (M=9.48, SD=4.04; [29]), and scores on the WSAS indicated significant functional impairment (M=17.44, SD=8.41; [33]). Scores on the diabetes (M=5.57, SD=2.1) and mental health (M=30.14, SD=11.11) self-efficacy measures indicated moderate levels of confidence

in managing diabetes regimen demands and mental health issues, respectively, and diabetes-related distress was elevated (M=52.71, SD=18.28; [37]). Overall, symptoms of hypoglycemia (M=2.14, SD=1.37) and hyperglycemia (M=2.70, SD=1.47) were infrequent, and diabetes self-care was variable, with adherence greatest for blood glucose monitoring (M=4.32, SD=2.75) and poorest for foot care (M=1.90, SD=2.05).

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Table 2. Observed scores on the outcome measures at baseline, postintervention, and follow-up.

			Baseline (n	=89)	Postinterve	ention $(n=48)$	Follow-up	( <i>n</i> =32)
		Mean	SD <sup>a</sup>	Mean	SD	Mean	SD	
Primary out- comes								
	Depression (PHQ-9 <sup>a</sup> )		12.79	4.70	7.94	4.20	9.03	4.51
	Anxiety (GAD-7 <sup>a</sup> )		9.48	4.04	6.93	3.34	7.41	3.89
	Work and So- cial Function- ing		17.44	8.41	14.63	8.22	13.06	7.53
	Mental Health Self-Efficacy		30.14	11.11	33.48	11.52	33.78	10.91
Secondary outcomes								
	Diabetes-dis- tress (PAID <sup>a</sup> )		50.71	18.28	30.10	17.42	30.15	21.62
	Diabetes self- efficacy		5.57	2.08	6.12	2.10	6.23	1.99
	Diabetes self- care							
		Foot	1.90	2.05	2.33	2.34	2.45	2.48
		Diet	3.63	1.55	3.74	1.36	3.85	1.32
		Blood glucose monitoring	4.32	2.75	4.45	2.67	4.56	2.35
		Exercise	2.19	2.27	2.05	2.02	2.20	2.25
	Glycemic con- trol							
		Hypoglycemia	2.14	1.37	2.42	1.32	2.31	1.44
		Hyper- glycemia	2.70	1.47	1.92	1.33	1.97	1.59

<sup>a</sup>SD: standard deviation; GAD: generalized anxiety disorder; PHQ-9: Patient Health Questionnaire; PAID: Problem Areas in Diabetes scale.



#### Figure 2. Screenshot of myCompass landing page (2).

#### YOUR MENTAL HEALTH TOOLKIT



Figure 3. Screenshot of myCompass self-monitoring.

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How energetic have you bee last logged on/in the last 24		0 1 Not at all	2	© 3	© 4	© 5	© 6	© 7	© 8	9 10 Extremely			
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Figure 4. Screenshot of myCompass user home page.

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### **Identification of Covariates**

Participants with T1D reported greater diabetes self-efficacy [t (86)=4.47, P<.001], more regular blood glucose monitoring [t (85)=4.51, P<.001], fewer hypoglycemic symptoms [t (86)=-2.39, P=.019], and reduced depressive symptoms [t (87)= -2.11, P=.037], compared with T2D participants. Length of diagnosis was positively correlated with diabetes self-efficacy [r (89)=0.36, P=.001], negatively correlated with depressive symptoms [r (89)=-0.22, P=.01], and scores were higher for women than men on the hyperglycemia scale [t (86)=-2.77, P=.007]. The influence of identified covariates on study outcomes was controlled in subsequent tests of treatment effects.

### **Study Attrition**

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The attrition rate for the total sample at postintervention was 46% (*n*=41) and 64% (n=57) at follow-up (Figure 1).

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Participants who did and did not complete the postintervention and follow-up assessments were indistinguishable at baseline on the basis of their demographic and disease-related characteristics and scores on the outcome measures.

#### **Postintervention Outcomes**

Observed mean scores on the study outcomes at postintervention and follow-up are summarized in Table 2. Results of the LMM analyses for the primary study outcomes are summarized in Table 3, which show a consistent pattern of sustained improvement for depressive and anxious symptoms, mental health self-efficacy, and work and social functioning. Improvement was also observed for some secondary outcomes including diabetes-related cognitions, diabetes foot care, and hyperglycemic symptoms (see Table 4).

Table 3.	Results	of LMM <sup>a</sup>	analyses	for p	rimary	outcomes:	test o	f repeat	effect (	(time).
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Effect			Contrast esti- mate	df	F, t statistic	Р	95% CI
Depression							
	Time			2, 132	38.14	< .001	
	Contrasts						
		Baseline vs postintervention	4.68	1, 127	8.30	< .001	3.31-6.04
		Postintervention vs follow-up	-1.28	1, 127	-1.76	.081	-3.0- 0.48
Anxiety							
	Time			2, 135	16.46	< .001	
	Contrasts						
		Baseline vs postintervention	2.51	1, 131	5.36	< .001	1.38-3.65
		Postintervention vs follow-up	-0.60	1, 129	-1.02	.311	-2.04- 0.83
Work and Social Functioning							
	Time			2, 132	12.96	< .001	
	Contrasts						
		Baseline vs postintervention	3.33	1, 129	3.87	< .001	1.25-5.40
		Postintervention vs follow-up	1.18	1, 125	1.07	.289	-1.50- 3.87
Mental Health Self-Efficacy							
	Time			2, 134	7.56	.001	
	Contrasts						
		Baseline vs postintervention	-4.52	1, 130	-3.39	.001	-7.751.29
		Postintervention vs follow-up	0.10	1, 129	0.06	.955	-4.00- 4.19

<sup>a</sup>LMM: linear mixed modeling.



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Table 4. Results of LMM analyses for secondary outcomes: test of repeat effect (time).

Effect				Contrast esti- mate	df	F, <i>t</i> statis- tic	Р	CI
Diabetes distress								-
	Time				2, 131	88.58	<.001	
	Contrasts							
		Baseline vs postinter- vention		20.51	1, 128	11.51	<.001	16.20- 24.82
		Postintervention vs fol- low-up		0.15	1, 125	0.07	.947	-5.33-5.64
Diabetes self-effica- cy								
	Time				2, 128	5.96	.003	
	Contrasts							
		Baseline vs postinter- vention		-0.47	1, 125	-2.80	.006	-0.88- -0.06
		Postintervention vs fol- low-up		-0.09	1, 123	-0.40	.692	-0.62-0.44
Diabetes self-care								
	Foot							
		Time			2, 128	4.09	.019	
		Contrasts						
			Baseline vs postinter- vention	-0.60	1, 126	-2.42	.017	-1.21- -0.00
			Postintervention vs fol- low-up	-0.03	1, 121	-0.08	.933	-0.78-0.7
	Diet							
		Time			2, 133	0.28	.760	
		Contrasts						
			Baseline vs postinter- vention	0.03	1, 131	0.20	.844	-0.33 -0.3
			Postintervention vs fol- low-up	-0.13	1, 128	-0.72	.476	-0.59 - 0.32
	BGT <sup>a</sup>							
		Time			2, 126	0.79	.458	
		Contrasts						
			Baseline vs post inter- vention	-0.15	1, 125	-0.85	.399	-0.58 - 0.28
			Postintervention vs fol- low-up	-0.08	1, 119	-0.38	.708	-0.63 - 0.46
	Exercise							
		Time			2, 131	0.44	.647	
		Contrasts						
			Baseline vs postinter- vention	0.21	1, 129	0.89	.377	-0.36 - 0.79
			Postintervention vs fol- low-up	-0.21	1, 125	-0.70	.483	-0.93 - 0.51
Physical symptoms								



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Effect				Contrast esti- mate	df	F, <i>t</i> statis- tic	Р	CI
	Hypoglycemia							
		Time			2, 89	1.52	.224	
		Contrasts						
			Baseline vs postinter- vention	-0.32	1, 90	-1.59	.116	-1.00 - 0.36
			Postintervention vs fol- low-up	0.02	1, 82	0.10	.924	-0.85 - 0.90
	Hyperglycemia							
		Time			2, 130	12.99	<.001	
		Contrasts						
			Baseline vs postinter- vention	0.80	1, 128	4.79	<.001	0.40-1.21
			Post intervention vs follow-up	-0.18	1, 124	-0.86	.389	-0.70 -0.33

<sup>a</sup>BGT: blood glucose testing.

Within-group effect sizes at postintervention and follow-up ranged between moderate and large for the measures of depression and mental health comorbidities (Table 5). Effect

sizes for the diabetes self-care and hypoglycemia and hyperglycemia scales were small, an exception being the moderate effect observed for diabetes foot care.

**Table 5.** Within-group effect sizes (Cohen's d) at postintervention and follow-up.

Study outcome			Postintervention (d)	Follow-up $(d)$
Primary outcomes				
	Depression		1.05	0.74
	Anxiety		0.68	0.48
	Work and Social Func- tioning		0.40	0.57
	Mental Health Self-Efficacy		0.40	0.40
Secondary outcomes				
	Diabetes Distress			
	(PAID <sup>a</sup> )		1.15	1.04
	Diabetes Self-Efficacy		0.22	0.27
	Diabetes Self Care			
		Foot	0.28	0.28
		Diet	0.02	0.07
		Blood glucose monitoring	0.06	0.09
		Exercise	-0.10	0.00
	Physical symptoms			
		Hypoglycemia	-0.24	-0.21
		Hyperglycemia	0.57	0.40

<sup>a</sup>PAID: Problem Areas in Diabetes scale.

### **User Experience**

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Overall, mean ratings for the items assessing user experience were at or above the midpoint, suggesting that participants were

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largely satisfied with the program (Table 6). A total of 32 (67%) participants who returned postintervention questionnaires reported that they would recommend myCompass to other

people with diabetes, and 28 (58%) indicated that they would happily use the program again.

Table 6.	Descriptive statistics	for items on the myCo	mpass satisfaction survey	(range 0-4).

No.	Question ( <i>n</i> =48)	Mean	SD <sup>a</sup>
1	myCompass was easy to use	2.93	1.10
2	myCompass was convenient to use	2.96	1.10
3	The information was easy to understand	2.91	1.30
4	The program kept my interest and attention	2.27	1.18
5	The program helped improve my stress, low mood, and/or anxiety	2.50	0.91
6	The program taught me skills that will help me handle future problems	2.42	1.14
7	The program has helped me to feel more in control of my stress, low mood, and/or anxiety	2.29	1.00
8	The program has helped me feel more in control of my diabetes	2.10	0.93

<sup>a</sup>SD: standard deviation.

On average, participants who returned postintervention questionnaires used the myCompass program 16 times (SD=20.47; range 0-84), self-monitored 26 times (SD=28.1; range 2-93), and completed almost 1 psychotherapeutic module (M=0.81, SD=1.05, range 0-4) during the 7-week intervention period.

Thematic analysis [43] was used to identify salient themes and ideas that emerged from interview responses regarding participant's experience with myCompass. When asked what they liked about myCompass, interviewees generally agreed that the program was accessible (24/7) and convenient (mobile phone and computer) to use, with content that was engaging and useful for skill building and self-reflection.

"The fact that you could do it in your own time. You could go to it when you felt like it and when it was gonna [sic] do you the most good." [Male, 50]

"Some of the activities I had never tried. I've done a lot of counselling and psychology and stuff but I hadn't actually tried those methods so they were quite useful." [Female, 56]

"It works well in that it's a prompt to get you to think about things." [Male, 42]

The main criticisms of the myCompass program related to connectivity issues, including slow downloading speed, and difficulties understanding program features due to insufficient instructions.

"I pretty much went on there every day, until I just got frustrated with it because it was taking so long." [Male, 63]

# "There were too many names of things, you know. It confused me." [Female, 41]

When asked about the usefulness of myCompass for people with diabetes, many users reported noticing improvement in their mood over the intervention period and acknowledged that myCompass may be a useful first step to accessing mental health support for people with diabetes.

"If you really didn't want to go and do anything else, it would be quite suitable for the short-term. However

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you may then need to talk to someone professional." [Male, 60]

Some participants also reported an indirect effect of the program on their ability to manage their diabetes.

"It helped with my mood, and if everything was calm the sugars were much easier to control." [Male, 50]

### Discussion

### **Principal Findings**

Depressive symptoms were significantly reduced in people with diabetes after using the myCompass intervention for 7 weeks. The effect size at postintervention was large (d=-1.28), with treatment gains maintained for 3 months. Significant and persistent improvements were also seen in anxiety symptoms, work and social functioning, and mental health self-efficacy. These preliminary data concur with previous controlled investigations of myCompass [16,17] and Internet-delivered treatments generally [44-47] and are in line with findings for guided disease-specific interventions and face-to-face CBT in people with diabetes [48,49]. Satisfaction with myCompass was in line with the community sample [16], with convenience and ease of program use and relevance of program content rated positively by participants. Psychotherapy delivered via mobile phone and Web technology without human support seemingly shows promise as an effective and acceptable treatment option for people with diabetes.

Interestingly, we also found significant and sustained improvements (with large effect sizes) in diabetes self-efficacy beliefs and diabetes-related distress; results that are striking considering that myCompass is a public health intervention with no diabetes-specific content. Of course, depressive symptoms correlate strongly with these cognitive variables [50], and treating depression alone may reduce the perceived demandingness of the disease and improve self-confidence (by reducing the negative bias that characterizes information processing in depression [51]). Alternatively, myCompass may have a direct effect on psychological constructs that underlie both depressive symptoms and diabetes-related distress (eg, emotional distress; [22]), and/or core cognitive and behavioral skills that are beneficial for people with one or both conditions.

The mechanisms whereby a generic intervention produces diabetes-specific benefits need to be explored further. Nevertheless, our preliminary efficacy data suggest that a fully automated and generic public health intervention may have therapeutic benefits for patients with diabetes that extend beyond common mental health symptoms to include clinically important disease-specific cognitive, behavioral (eg, self-care) and physical symptom (eg, hyperglycemia) outcomes.

### Implications

International guidelines emphasize the importance of identifying and addressing emotional problems in the context of diabetes care [52], yet comorbid depression and distress are frequently untreated. Development of diabetes-specific Web-based interventions is an emerging paradigm that offers a possible solution [11-13], nevertheless, competition for funding for development and testing of eHealth solutions is fierce. At the same time, urgent action is required to immediately improve the well-being of people with diabetes and reduce the broader economic impact of depression in this high-risk group. Our findings suggest that myCompass, a public health intervention that is already broadly available and deliverable at minimal cost [53], may be a clinically and cost-effective and timely treatment option; a possibility that we are investigating more rigorously in a recently commenced placebo-controlled study.

At the primary care level, the opportunity to prescribe to patients a generic, low-intensity, and readily available psychotherapeutic intervention is likely to assist practitioners who encounter depressive symptoms within the context of multimorbidity [14,15], have difficulty discussing mental health issues with their diabetic patients (for fear of inadvertently making matters worse [52]), and/or struggle to disentangle depressive from diabetes-specific emotional and physical symptoms [15,54]. Furthermore, because myCompass can be efficiently disseminated to GPs in a single education session (as opposed to multiple sessions for different disease-specific programs), it is potentially an attractive, realistic, and cost-effective training option for practitioners negotiating the competitive demands and time pressures of primary care [55].

Privacy and stigma concerns can be major barriers to help seeking, and there are many people with diabetes who avoid confiding in health professionals for fear that their efforts and experiences will be misunderstood or patronized [56,57]. Others talk openly about their problems with their GP, but nevertheless refuse a referral for ongoing face-to-face care [37]. For these groups, a fully automated self-help program that is private, free to use, available 24/7, and able to screen symptoms and provide a tailored intervention may be a more palatable treatment alternative.

### Limitations

Caution is required in attributing symptom improvements to the intervention as our uncontrolled findings may reflect the natural course of symptom remission [58], or perhaps even regression toward the mean. Nevertheless, the improvements observed in this study are similar to those of controlled studies of Internet-delivered interventions (including myCompass; [16]), and reviews suggest a time course for recovery from mild-to-moderate depression of between 4 and 12 months [58,59]. Further study is required to clarify whether myCompass accelerates symptom alleviation for people with diabetes.

As data were derived from an older, highly educated, and predominantly female group of community volunteers, our findings may not generalize to other diabetic patient groups, including young people with T1D (a group at particularly high risk of mental health problems [60]), and patients recruited in primary care clinics. Consistent with other studies of self-guided Internet-delivered interventions, study attrition was also high (eg, [61-63]). Although our statistical methods accounted for dropout attrition and noncompletion, the potential for attrition bias remains. For example, it is not clear whether dropouts; (1) were less satisfied with the intervention; (2) experienced fewer symptom benefits than nondropouts, or (3) experienced symptom improvements early and dropped out because they no longer believed the intervention was required. Our placebo-controlled study will help shed light on relations between program usage, symptom outcomes, and attrition rates.

Finally, the large number of outcomes resulted in numerous statistical tests and possible inflation of the type 1 error rate (ie, mistakenly claiming significant effects in their absence). However, feasibility and exploratory studies generally have higher tolerance for type 1 errors [64], and most of our significant findings would have remained as such had more stringent control of the type 1 error rate been applied.

### Conclusions

Depressive symptoms were reduced in people with diabetes after use of a fully automated, mobile phone, and Web-based, public health intervention that is freely available. Importantly, significant and sustained improvement was also observed in comorbid anxiety and functional impairment with treatment gains extending to clinically relevant diabetes-specific cognitions, behaviors, and physical symptoms. Although an uncontrolled study, these preliminary results are encouraging and warrant further controlled investigation. myCompass shows promise as an intervention for depression and mental health comorbidities in people with diabetes and may overcome accessibility difficulties and other barriers to help seeking for people who might otherwise not access the psychological support they need.

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### **Authors' Contributions**

JC conceived and designed the study, undertook data collection, performed the statistical analysis, and drafted the manuscript; JP was involved in the design of the study, supervised the data collection and carried out critical revision of the manuscript for intellectual content; HM conducted the brief telephone interviews and performed the thematic analysis under the supervision of JC and JP. All authors read and approved the final manuscript.

### **Conflicts of Interest**

The myCompass program was developed at Black Dog Institute, Sydney, Australia, where all the authors are based.

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### Abbreviations

**CBT:** cognitive behavior therapy

DSES: Diabetes Self-efficacy Scale
T1D: type 1 diabetes
T2D: type 2 diabetes
GP: general practitioner
LMM: linear mixed modeling
PAID: Problem Areas in Diabetes scale
PHQ-9: Patient Health Questionnaire
SD: standard deviation
SMS: short message service
WSAS: Work and Social Adjustment Scale

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**Original Paper** 

# New Tools for New Research in Psychiatry: A Scalable and Customizable Platform to Empower Data Driven Smartphone Research

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### Abstract

**Background:** A longstanding barrier to progress in psychiatry, both in clinical settings and research trials, has been the persistent difficulty of accurately and reliably quantifying disease phenotypes. Mobile phone technology combined with data science has the potential to offer medicine a wealth of additional information on disease phenotypes, but the large majority of existing smartphone apps are not intended for use as biomedical research platforms and, as such, do not generate research-quality data.

**Objective:** Our aim is not the creation of yet another app per se but rather the establishment of a platform to collect research-quality smartphone raw sensor and usage pattern data. Our ultimate goal is to develop statistical, mathematical, and computational methodology to enable us and others to extract biomedical and clinical insights from smartphone data.

**Methods:** We report on the development and early testing of Beiwe, a research platform featuring a study portal, smartphone app, database, and data modeling and analysis tools designed and developed specifically for transparent, customizable, and reproducible biomedical research use, in particular for the study of psychiatric and neurological disorders. We also outline a proposed study using the platform for patients with schizophrenia.

Results: We demonstrate the passive data capabilities of the Beiwe platform and early results of its analytical capabilities.

**Conclusions:** Smartphone sensors and phone usage patterns, when coupled with appropriate statistical learning tools, are able to capture various social and behavioral manifestations of illnesses, in naturalistic settings, as lived and experienced by patients. The ubiquity of smartphones makes this type of moment-by-moment quantification of disease phenotypes highly scalable and, when integrated within a transparent research platform, presents tremendous opportunities for research, discovery, and patient health.

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### KEYWORDS

mental health; schizophrenia; evaluation; smartphone; informatics

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# Introduction

The theoretical physicist Freeman Dyson, who was recently quoted by Dr Thomas Insel, the Director of the National Institute of Mental Health (NIMH) 2002-2015, has argued that "new directions in science are launched by new tools much more often than by new concepts" [1,2]. Smartphone and sensor technologies have recently emerged as novel tools in many fields of medicine, and there is growing literature in mental health on their potential to increase access to care [3], reduce stigma [4], improve diagnosis [5], and enable remote monitoring [6]. Despite the recent attention and interest in the potential of such data, less has been written about how to study, collect, store, analyze, and reproduce results of smartphone studies.

In this paper, we report on the development and early testing of Beiwe, a research platform designed and developed by the Onnela Lab at the Harvard TH Chan School of Public Health. The Beiwe platform is intended for biomedical research use, and it includes a study portal, smartphone app, database, and data analysis and modeling tools. Our aim is not the creation of yet another app per se but rather the establishment of a platform to collect research-quality smartphone raw sensor and usage pattern data. Our ultimate goal is to develop statistical, mathematical, and computational methodology to enable us and others to extract biomedical and clinical insights from smartphone data. In this paper, we focus on the app component of the platform.

We also introduce the term "digital phenotyping" to refer to the "moment-by-moment quantification of the individual-level human phenotype in-situ using data from smartphones and other personal digital devices." The data from these devices can be combined with electronic medical records and with molecular and neuroimaging data. In this sense, digital phenotyping can be viewed as a variant of deep phenotyping. Digital phenotyping is also closely aligned with the goals of precision medicine, which links new types of phenotypic data with genome data in order to identify potential connections between disease subtypes and their genetic variations [7]. Note that our definition of digital phenotyping is distinct from the "digital phenotype" that was introduced recently [8].

The data generated by increasingly sophisticated smartphone sensors and phone use patterns appear ideal for capturing various social and behavioral dimensions of psychiatric and neurological diseases. Given that the majority of the adult population in developed nations now owns and operates a smartphone, the act of measurement no longer needs to be confined to research laboratories but instead can be carried out in naturalistic settings in situ, leveraging the actual real-world experiences of patients.

While smartphones can be harnessed to offer medicine a wealth of data on disease phenotypes, the majority of existing smartphone apps are not intended for biomedical research use and, as such, do not generate research-quality data. While several commercial platforms collect similar data streams as Beiwe, they rarely allow investigators to access the raw data. Most offer only proprietary summaries of the data. This approach is problematic not only from the data analysis

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perspective, but it also makes it harder to replicate research. In a typical biomedical research setting, one first formulates the scientific question of interest, then determines what data are needed to address that question, and finally decides on a statistical approach needed to connect the collected data with the research question. This approach seems incompatible with platforms that do not allow access to raw data.

Finally, while many apps are able to collect data, without a research platform to support these data, results are difficult to analyze and reproduce. Because the Beiwe platform includes a flexible study portal, customizable app, scalable database, as well as an evolving suite of modeling and data analysis tools, researchers can use it for a diverse set of studies. Equally important, results can be re-analyzed and studies recreated and validated using the same data collection settings and the same data analysis tools as those in the original study, thus significantly enhancing the level of reproducibility and transparency in mobile health research.

In this paper, we document the development of the inaugural version of the Beiwe platform focusing on the app component, including implementation of its encryption, privacy, and security features. In addition to discussing features of the app, we also report on our ongoing testing and development of the platform to better understand its present capabilities and limitations. Digital phenotyping requires great concern for patient privacy and data security, and we discuss the medical risks and benefits for patients that we can foresee at this early state of the app in patients with schizophrenia and discuss how this line of research is able to inform the ongoing Research Domain Criteria Project of the NIMH [9].

#### Background

The year 2014 marked a decisive moment in the history of mobile phones. For the first time, there were more active smartphone subscriptions globally than people on the planet [10]. Connected to this development, the rate of smartphone ownership has been steadily increasing over the past few years, and at present approximately 64% of the US adult population has a smartphone. Young adults between ages 18-29 now own smartphones at a rate of 85%, and ownership is expected to continue to increase across all populations with the majority of new phones sales being smartphones instead of technologically less advanced feature phones [11]. Smartphone ownership has also been investigated among psychiatric patients, and early findings based on a relatively small sample size suggest that psychiatric patients are no less likely to own a smartphone than the average person and are not opposed to using their own phones to monitor their mental health [3].

The final aspect that makes it feasible to collect sensor and usage data is that smartphones can be programmed using third-party apps. Thousands of mental health apps have become available to consumers in the past few years, and they have usually been positioned within the quantified-self or mHealth movements. These apps have various functionalities, but very few of them are intended for research use. We can draw an analogy here between digital phenotyping and DNA sequencing based on the intended use of these technologies. Next-generation

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DNA sequencing methods have made it inexpensive for anyone to learn about their ancestry, but research-quality sequencing typically requires much greater sequencing depth and remains more costly to perform. Like genetic research tools that sequence each nucleotide in a gene, chromosome, or an entire genome, smartphone apps intended for research use need to record and store all relevant data. They also need to be customizable to the needs of any given study by allowing the researchers to specify what data are collected and how they are collected, such as the sampling frequency of the accelerometer. Finally, they need to incorporate data analysis and modeling as clinical insights come from combining data with analytical methods. The goal of many of the existing mHealth apps is to collect and report summaries of either user-reported data or data collected from some of the phone's sensors.

Both psychology and psychiatry have a history of quantifying human behavior in situ. Briefly, ecological momentary assessment (EMA) refers to a collection of methods used in behavioral medicine research for participants to report on symptoms and behaviors close in time to experience and in the participant's natural environment [12]. It is related to the experience sampling method (ESM) [13]. Both EMA and ESM rely on self-reported accounts of behavior, and both have traditionally required the use of specialized tools from notebooks to electronic devices for the duration of the study. For example, some studies used personal digital assistants, but since this technology never really took off, subsequent studies have not been able to exploit it. While laudable in their inventiveness, traditional EMA/ESM approaches do not lend themselves to long-term follow-up due to the burden to the patient of carrying an additional device that may not have any direct functionality. They also scale poorly to large cohorts because that would require access to a large collection of study devices. Because both psychiatric and neurological disorders can be long-term illnesses and show significant variation in their symptomatology from person to person, there are clear benefits to being able to monitor a large group of patients over extended periods of time without any additional instrumentation. Some recent implementations of EMA/ESM make use of smartphones, but so far, it is with the apparent goal to replicate more traditional forms of EMA/ESM in a more convenient way.

Given these developments, how is smartphone-based digital phenotyping distinct from EMA/ESM? The short answer is that the purpose of digital phenotyping is not to implement surveys (although surveys can be incorporated into it) but to collect and analyze large quantities of various types of social and behavioral data that capture the subjects' lived experiences and their interactions with people and places. Among others, digital phenotyping encompasses the collection of spatial trajectories (via global positioning system [GPS]), physical mobility patterns (via accelerometer), and audio samples (via microphone).

# Beiwe Research Platform

#### Overview

The Beiwe platform was designed with the philosophy that every clinical or biomedical study starts with specific research questions and has its distinct data collection and analysis requirements. The workflow on the platform consists of several steps (see Figure 1) and reflects the natural flow of a research project. Our current set-up makes it possible to customize the app for a given study using a Web-based study portal. Among other things, this allows the investigators to set up any number of surveys, specify the content of the app, specify which sensors are used for data collection, and how they are sampled. This results in the generation of a new study specific app. Collected data are immediately encrypted and buffered on the device until a Wi-Fi connection becomes available, at which point the data are uploaded to a database on the study server. The data can be analyzed using an evolving suite of software, to be released at a future date to the public domain, which combines more traditional biostatistical analyses with machine learning techniques capable of dealing with millions of observations.

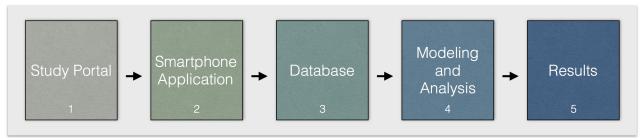
The online study portal (see Figure 2) is used to create new studies and to manage existing ones. As part of the process of creating a new study, investigators customize all aspects of phone data collection, including what sensor data are collected and how frequently they are sampled. This is also where investigators can program any number of smartphone-based surveys, specify their timing and content, and enter any informational text that appears on the app screen (eg, text used to solicit audio samples and text describing study objectives). As a consequence, each study has its own version of the app with its own unique features.

Once a study has been created, investigators can generate unique participant IDs for subjects and perform basic administrative operations, such as remove a subject or reset a password. The only identifier linking subjects to their data in the platform is the participant ID. When a subject downloads the app, the platform uses the participant ID to determine which virtual version of the app to download and install. Beiwe uses a store-and-forward architecture for managing data, meaning that data are buffered on the device until Wi-Fi becomes available, at which point the data are uploaded to the server database and expunged from the device. Direct identifiers in the collected data are hashed, and data are always encrypted, as discussed in more detail below.

The Beiwe platform is currently available to only a small group of researchers. However, to stimulate further research into digital phenotyping and to promote transparency and replicability of that research, we envision releasing both Beiwe and a software suite for analyzing data collected by Beiwe to the public domain at a future date. Finally, for those curious, Beiwe is the name of the solar deity of the Sami people, an indigenous Finno-Ugric people. The name references the complex yet powerful relationship between personal experiences, physical environment, and mental health—all different aspects of the lived experiences that the Beiwe platform seeks to bridge.



Figure 1. Workflow on the Beiwe platform.



#### Surveys

Surveys have a long history in the social sciences, psychology, and medicine, in particular psychiatry. Paper has been the traditional medium of delivering surveys, and only more recently have Web-based online surveys become more common [14]. Smartphone-based surveys, like Web-based surveys, make it possible to record the exact start and end time of surveys, but smartphones can also capture the physical location of the subject via GPS at the time the survey was taken [15]. Given that human behavior is highly context sensitive [16], being able to localize the surveys in both time and space would seem to generate new research opportunities. Previous attempts to have patients conduct EMA using pencil-and-paper methods have noted high rates of backfilling and unreliable data [17]. Current research has instead underscored not only the feasibility, but also utility of having patients, including those with schizophrenia, complete surveys on smartphone platforms [18,19].

Beiwe implements several different types of surveys that can be customized using its Web panel. The responses to survey questions can take any of the following forms: (1) checkbox: multiple options can be selected from a list, (2) radio buttons: one option is selected from a list, (3) numerical slider: a numerical slider bar can be moved along a line, and (4) free response: text can be entered directly into the survey field.

Currently Beiwe implements any number of surveys on any schedule, which allows for maximal flexibility. For example, one could implement a short daily survey and a more detailed weekly survey. Whenever a new survey is available, the app notifies the subject by bringing up a survey prompt, and Beiwe also quantifies the amount of time that passes between the survey notification and the time the survey is actually taken. While Beiwe does not give any feedback to subjects based on their passive data streams, it does display a simple graph of the subject's responses to numerically quantifiable questions from the previous week.

# Characteristics of Research Platform and Research Data

The characteristics of scientific research platforms like Beiwe are quite distinct, on multiple levels, from the existing commercial mHealth apps. The research app component of Beiwe functions primarily as a data collection engine, meaning that it attempts to collect the specified data streams using the specified sampling scheme as accurately as possible. Second, the data analysis is not done in real time on the phone but instead takes place on a dedicated server, which enables the use of sophisticated data analysis techniques that are not possible to

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perform on the phone itself. Third, Beiwe stores data on the phone only temporarily, and whenever a Wi-Fi connection is established, it uploads the data to the server and expunges the data from the device. Fourth, while many commercial and research applications attempt to give subjects feedback, Beiwe attempts to construct social and behavioral phenotypes with minimal user interference and is not at present intended for behavioral interventions. In order to minimize the impact of measurement on what is measured, Beiwe gives only very minimal feedback to the subject in order to avoid behavior change that could result from this feedback.

Arguably the most important aspect of a research platform is the collection of raw sensor and phone use data. Reliance on data summaries, especially on proprietary data summaries, is problematic for two reasons related to data analysis and replicability of research. First, smartphone data are high dimensional, longitudinal, exhibit interstream and temporal correlations, and are typically sampled at adaptive rates depending on the state of the phone (active vs sleep). This has the implication that one needs to exercise extreme care when considering different data summaries and different data analytic strategies. Proprietary data summaries rely on undisclosed assumptions, and they are fixed before either the scientific questions or the statistical approach have been formulated. In the best case, this compromises the validity of the statistical analyses, and in the worst case, it leads to research that is driven by what data summaries happen to be available rather than research driven by authentic research questions. Second, aside from analytical challenges, collection of raw data means that results can be re-analyzed retroactively and studies can be replicated and validated using the same data collection settings and the same data analysis tools as those in the original study. This aspect significantly enhances the level of reproducibility and transparency in research carried out using mobile devices. The fact that proprietary data summaries can be changed at whim without disclosure means that even using the same summary from the same vendor is no guarantee that the metric is the same.

We divide all data collected by Beiwe into two categories: active data and passive data. We define active data as data that require active participation from the subject for its generation, such as surveys and audio samples (more below). In contrast, we define passive data as data that are generated without any direct involvement from the subject, such as GPS traces and phone call logs (more below). We also use the term "data stream" to jointly refer to all the different types of continuously sampled smartphone passive data.

We note that there are at least three factors in any given study that might influence the decision regarding what type of data to collect and how to collect it. First, the decision regarding what types of data to collect and what specific parameter values are optimal for each type of data should be driven by the scientific questions at hand. Second, in order to protect patients' right to privacy, it is pertinent to collect only the type of data that can be brought to bear on the specific scientific questions that are being investigated. Third, collection of active and passive data increases the phone's consumption of electricity. If the phone sensors are sampled too frequently, the app can drain the phone battery in a short time.

### Data Encryption, Security, and Privacy

Beiwe was designed to collect large quantities of social and behavioral data and as such, both security and privacy are high priorities. Yet privacy in the digital world can be complex as much data may actually be outside the legal protection of the Health Insurance Portability and Accountability Act (HIPAA) [20], and clinicians may have a difficult time keeping up to date on security and privacy policies. For these reasons, Beiwe was designed on the premise that identifying data, such as phone numbers, should be protected through hashing and that, in addition, all data should be encrypted at all times. Beiwe uses a store-and-forward architecture for managing data, meaning that data are buffered on the device and as soon as a Wi-Fi connection is available, all data are securely transmitted in a HIPAA-compliant manner (details below). Using Wi-Fi for data transfer has the obvious benefit that it does not use up a subject's 3G/4G data plan, which is important given the large quantities of data collected. Delays in data transfer, until a subject is connected to Wi-Fi, will not alter data collection or quality.

During study registration, the platform provides the smartphone with the public half of a 2048-bit RSA (Rivest-Shamir-Adleman) encryption key. With this key the device can encrypt data, but only the server, which has the private key, can decrypt it. Thus, the Beiwe app cannot read its own data, so even if a phone is lost or stolen, no information is compromised. The RSA key is then used to encrypt a symmetric Advanced Encryption Standard key for bulk encryption. These keys are generated as needed by the app; therefore, they are not stored anywhere and must be decrypted by the study server before any data can be recovered. Our current set-up does not use local servers but instead relies on cloud computing from Amazon Web Services, where at present we use an Amazon EC2 instance as the study server and an Amazon S3 instance for data storage. In our current configuration, data received by the EC2 server are re-encrypted with a master key provided for the given study and then stored on an Amazon S3 instance, an industry-standard secure storage platform housed in guarded data centers.

The main identifying information collected by Beiwe is phone numbers and the unique media access control (MAC) addresses of Wi-Fi and Bluetooth devices. The app uses the industry standard SHA-256 algorithm to carry out a one-way hash from a phone number or MAC address to a surrogate key. This mapping is always the same, meaning that a given phone number or MAC address will always be replaced by the same surrogate key. Importantly, it is impossible to undo a hash (in mathematical terms, the hash function is not invertible), which ensures that identifying information remains secure.

Finally, unrelated to data itself, but closely related to patient safety more generally, the app includes an easy-to-use, in-case-of-emergency feature that enables the patient to request immediate help from a medical professional. These emergency numbers and the numbers of clinical research coordinators are customizable for each study and are entered into the Beiwe app during a subject's registration in a study.

## **Features of Beiwe App Data**

The following provides a description of some of the active and passive data types collected by Beiwe 1.0 running on a Samsung Galaxy S4 running Android 5.0. Of note, a version of the Beiwe app that will run on Apple's iPhone is currently under development and will be completed early 2016. Given the differences across the operating systems, the data streams collected on these two platforms will not be identical, but every effort will be made to standardize them. One notable difference is that, at the time of writing, Apple's iOS does not allow the extraction of phone call and text message logs, so the data streams collected from Android platforms will be somewhat richer. Apart from these differences, both the Android and iOS versions use the same Web study portal, database, and modeling and data analysis tools.

#### **Global Positioning System and Accelerometer**

Beiwe uses the GPS chip to record the spatial location of the phone over time. GPS sampling is typically periodic, occurring at pre-specified regular intervals, but the operating system may not always allow for the GPS query to be implemented in order to prevent battery drainage (eg, if the phone is inferred to be stationary). Beiwe also records the phone's accelerometer data to produce a history of the phone's movement, specifically a trajectory of its acceleration, which can be used to quantify movement and mobility patterns. For both GPS and accelerometer data (see Figures 3 and 4), the optimal sampling rates will depend on the specific scientific questions, as well as how much battery drainage is acceptable in any given study, which is why the sampling schedule for both sensors is fully customizable. More specifically, the durations of the time intervals when each sensor is on and off can be specified precisely. When the phone is in motion, the operating system samples GPS at approximately one data point every second, or at 1 Hz. GPS longitude and latitude data are most often accurate to within 30-50 feet. While battery drainage is always a concern with GPS as well as accelerometer, in our internal testing, the battery life still lasted an entire day for various sampling settings. The accelerometer chip in most smartphones has a sampling rate between 5-100 Hz, depending on the device model and the mode the device is in (eg, screen on or off). The accelerometer records acceleration along the x, y, and z axes and reports acceleration in units of meters per second squared  $(m/s^2).$ 

Using schizophrenia as an example, it is possible to envision GPS and accelerometer data having significant clinical potential. Recent studies have collected GPS data from patients with alcohol use disorder to better support patients [21], and others

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have underscored the correlation of GPS data with depressive symptoms [6]. It is possible that certain states of schizophrenia, such as paranoia, may be correlated with decreased or altered patterns of movement. Of note, these two studies utilizing GPS data did not report significant battery issues related to GPS use. Accelerometer data could be useful in helping monitor for neurological side effects of medications, such as tremors present when the subject is holding the phone to make a call and also in understanding activity states (eg, running vs walking) [22].

A visualization of a spatial trajectory is available, constructed from GPS samples over a 5-minute interval, collected by Beiwe [23] (figure and animation were created with software from CartoDB).

Figure 2. The Beiwe research administrator panel allows researchers to add new patients to a study (top) and create surveys and customize survey deployment (bottom).

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fln5wm	Un-Register Smartphone Reset Password	
qk2gtn	Un-Register Smartphone Reset Password	
snoyuo	Un-Register Smartphone Reset Password	
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Survey ID #55f08300970136	le6e9376e057	
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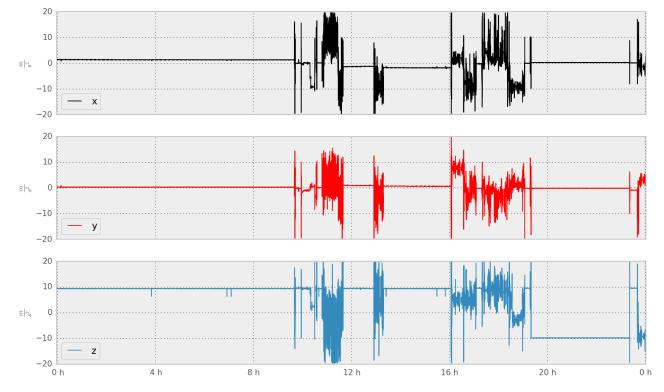


Figure 4. Sample GPS data collected by Beiwe over a 5-minute interval.



# Phone Call and Text Message Logs

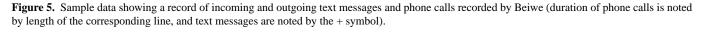
Mobile phone data, in the format of anonymized call detail records obtained directly from phone operators, have now been used for about a decade to study social and communication networks, communication dynamics, spatial mobility, and more [24-29]. Although collecting phone call and text message logs via a smartphone app would at first seem to add little to this burgeoning literature, the fact that they can be combined with other types of sensor data makes them increasingly valuable from a research point of view.

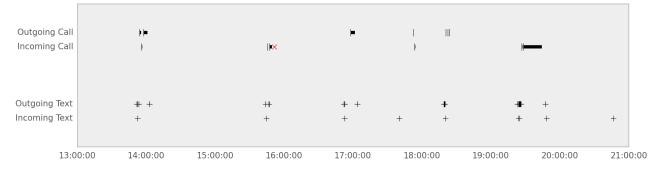
The Android version of the Beiwe app collects phone call and text message (SMS) logs detailing communication events between subjects and their social contacts (see Figure 5). The phone numbers are one-way hashed to render them non-identifiable (see Data Encryption, Security, and Privacy for more details). The communication logs contain only communication metadata, that is, data pertaining to the communication events themselves, but no actual content of communication, either auditory or textual, is stored by the app. The text message log includes the date, time, indicator for whether the text was sent or received by the subject, hashed phone number of the other party, and message length quantified

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in number of characters. The phone call log includes the date, time, hashed phone number, call type (incoming, outgoing, missed), and duration in seconds for each call.

Considering schizophrenia, it is possible to envision that information from these anonymized call and text messages logs may be a potential marker for social activity. Negative symptoms in schizophrenia can often blunt social activity and the Beiwe platform may offer early detection of worsening symptoms as well as response to treatments targeting negative symptoms.





#### Wi-Fi and Bluetooth

The Beiwe app scans both Wi-Fi and Bluetooth signals that are used to improve estimation of its spatial location, especially while indoors, and to determine whether the subject is nearby other people (see Figures 6 and 7). The Wi-Fi scans cover both the 2.4 GHz and the 5 GHz frequency bands, whereas Bluetooth operates on the standard 2.4 to 2.485 GHz frequency band. Each Wi-Fi and Bluetooth device has its unique identifier, the MAC address, which Beiwe hashes using the approach described above (see Data Encryption, Security, and Privacy). Signal strength data (in dBm) are collected for both data streams, which can be used to estimate the physical proximity of the subject to the transmitting device. The rate of both Bluetooth and Wi-Fi scanning can be adjusted depending on the research goals of the study, but as default settings, we sample Bluetooth for 1 minute every 5 minutes and Wi-Fi networks are recorded (instantaneously) every 5 minutes. A future version of Beiwe will have the capability to use Bluetooth to incorporate

additional study instrumentation, such as wearable wristbands, to complement the smartphone-based measurements. However, the current version uses Bluetooth solely to learn about the proximity of other Bluetooth devices, such as smartphones.

Taking schizophrenia as a use case, Bluetooth and Wi-Fi data offer several potential uses. One can envision instrumenting an entire family with a schizophrenic family member with the Beiwe app. Smartphone Bluetooth transmitters could provide new levels of detail on how an individual with schizophrenia spends time with various family members. In addition, Bluetooth beacons—small devices that send out frequent pings using the Bluetooth frequency band—could be placed in different rooms of the home to give a new level of detail on how these individuals use their personal space and whether changes in space use may be correlated with illness. Similarly, Wi-Fi can provide precise information on specific venues that the subject visits, such as bars, and this information, with the patient's consent, could be used to investigate whether time spent at these venues is correlated with symptoms.

Figure 6. Sample Bluetooth data collected by Beiwe demonstrate its ability to detect and log nearby signals over the course of a day.

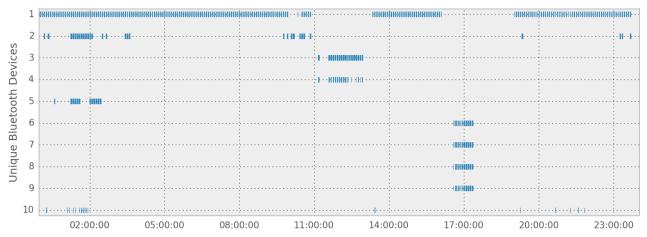
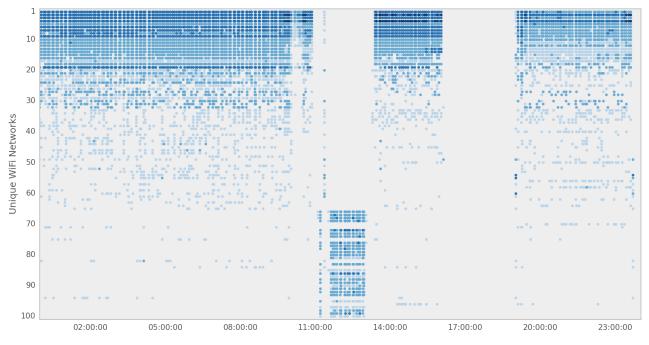




Figure 7. Beiwe scans for nearby Wi-Fi signals throughout the day and records their hashed MAC addresses and signal strengths.



#### Audio

Beiwe can also record audio samples from subjects (see 8). The investigator specifies the maximum duration of the recording, at which point the recording terminates, but the subject can also stop the recording at any time before reaching the end. After completing the recording, the subject has the option to play back the recording, to do the recording again, to discard the recording, or to accept the recording. If accepted, the recording is immediately encrypted on the phone for awaiting subsequent transfer to server. Because Beiwe uses asymmetric encryption, once the recording has been accepted, whether it was played back or not, it is no longer available for playback to the subject.

There is increasing evidence of the clinical value of voice data in schizophrenia in predicting conversation from prodromal state [30], and there is also much literature on the value of correlating such data with changes in symptoms [31,32]. The ability to have subjects record their audio using their smartphones, at a time and place of their choosing, appears to have significant potential to enrich the clinical literature on voice data.

# **Phone and Screen Status**

Beiwe records the power state of the phone (screen on/off, power connected/disconnected, and shutdown/restart/boot) and also records all screen touch events, not only those taking place when the subject uses the Beiwe app itself. The latter can be useful for making inferences about subject behavior. For example, data on screen touches can be used to monitor survey response times and to learn whether the subject uses the phone at night to infer coarse sleep duration and quality metrics. See Figure 9 for sample screenshots from the platform.

The clinical significance of such data is broad and one interesting use case is related to cognitive functioning. Knowing how long it takes for a subject to take a survey, something that can be easily quantified from screen touch events, provides novel clinical data about the subject's cognitive state, and hence about the survey's validity, that is unavailable from paper-and-pencil scales. Speed of responses to smartphone surveys may be correlated with attention and a useful marker for cognition in many illnesses including schizophrenia or ADHD.



Figure 8. Voice samples are captured in MP4 file format or as raw uncompressed audio data depending on the intended use case.

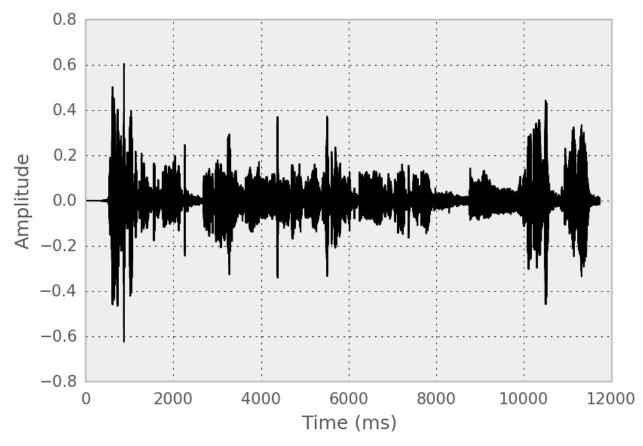
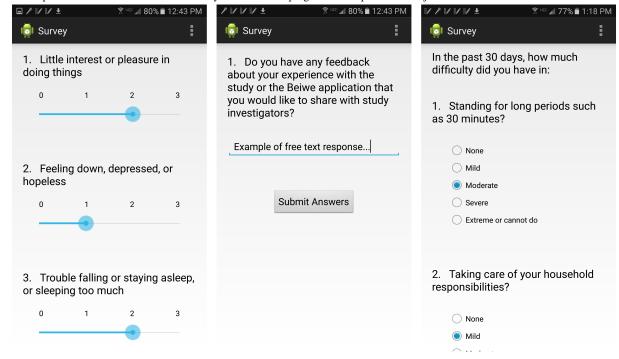


Figure 9. Sample screenshots of customizable surveys that Beiwe is programmed to present to subjects.



# Discussion

# From Data to Biomedical Insights

While we have focused here on the Beiwe smartphone app, it is important to stress that the app is just one of the many

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components of the Beiwe platform. From our perspective, the key component of the platform is its modeling and data analysis component, which we discuss here only briefly. The development of new biostatistical tools for making sense of smartphone data in the context of digital phenotyping is one of our two main research areas, and we will be documenting our

progress in this area in much more detail in journals that focus on the methodology of statistical learning. As we develop and refine these methods, we plan to make the code that implements them open source and accessible to investigators as part of the Beiwe platform, with the ultimate goal of seamlessly integrating data collection and data analysis on a single platform. Transparency in both data collection and data analysis are critical for scientific progress, and Beiwe has been designed specifically for these goals, which differentiates the platform from numerous commercial apps.

Equally important, the Beiwe platform will facilitate re-analyses of existing data and reproducibility of clinical studies. While reproducibility is fundamental to research, it remains a challenge with many existing app platforms. Using Beiwe, it is possible to create validation studies that use the exact same surveys, user prompts, and sensor settings as the original study. This is possible because the platform stores not only the collected raw data, but also the configuration file that specifies all of the app settings. Once the data analysis platform is released more broadly, it will be possible to analyze the data using the same analytical tools that were used in the original. As the analytical tools evolve, we will maintain a complete version history of the software that implements in a Web-based Git repository hosting service, which enables an investigator to match the data with the version of the data analysis modules used in the original study.

Google Flu Trends offers a cautionary tale about lack of reproducibility from a field of research that uses search engine queries to learn about the prevalence of influenza. Although the original study [33] appeared to offer strong support for the use of this approach as a public health surveillance tool, the paper was found to suffer from a lack of reproducibility. This was in part because Google updated its proprietary search algorithm numerous times, up to 86 times in a 2-month period, making even monthly comparisons across studies impossible [34].

The term big data is often used to refer to data that are high velocity (generated continuously), high variety (multiple types of data), and high volume (large quantities of data). Given that the Beiwe app collects data continuously, its data types vary from surveys to audio data, and the net result is a million observations of longitudinal multivariate data being collected per subject per day, it fits squarely within the criteria for big data. We anticipate that the most productive way of analyzing such data might consist of a mixture of more traditional models for longitudinal multivariate data with dimensionality reduction of predictors achieved using machine learning techniques. While at present there is very limited research on big data methods specifically for psychiatric data, there are many promising leads and existing methods and tools that can be applied to such data today [35].

## Outline for Initial Study in Patients With Schizophrenia Spectrum Illness

To better explore the capabilities of the Beiwe platform, assess the app, and produce novel data to fuel the modeling and analytical components of Beiwe, we are in the process of starting a clinical study in patients with schizophrenia. This study has been approved by the Institutional Review Board at Beth Israel

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Deaconess Medical Center, and it underscores the how the Beiwe platform can be used in clinical research. Schizophrenia is a chronic mental illness characterized by periods of exacerbation of core features including delusions, hallucinations, and disorganized speech and thoughts [36]. The disease has a global impact, afflicting 1.5% of the world's population [37] and remains one of the most severe illnesses in terms of personal disability [38], suffering [39], economic impact [40], and caregiver burden [41].

Although antipsychotic medications remain the first line treatment for schizophrenia, research suggests that up to 40% of patients discharged from the hospital on an antipsychotic medication may still relapse within 1 year [42]. Common causes of relapse include non-adherence to medications, substance abuse, stress, and disengagement with treatment. The negative consequences of relapse in schizophrenia include decreased quality of life, with relationships and employment often in jeopardy [43], as well as likely neurotoxic effects [44], cognitive decline [45], and often a return to an overall lower level of baseline functioning than prior to relapse [46]. However, there is evidence that early recognition of warning signs of symptom exacerbation and early treatment may mitigate or even prevent relapse [47]. However, because the early warning signs of relapse in schizophrenia may be abrupt [48] and often occur outside of the health care environment, they are often noticed too late when the patient is already psychotic or requires hospitalization [49].

Smartphones and mobile apps offer a novel means of identifying the early signs of symptom exacerbation in schizophrenia outside of the clinic in real life and in real time. Prior research has identified the potential of paper-and-pencil-based EMA in schizophrenia, with an early study noting that half of patients using EMA techniques were able to identify noticeable symptoms of relapse 1 week prior to actual relapse [50]. However, the cumbersome nature of paper-and-pencil EMA, as well as concern for inaccuracy through backfilling [51], has limited its application. Smartphones offer a new means to collect EMA data more easily, and recent research has demonstrated the feasibility of smartphone-based EMA in patients with schizophrenia. Patient feasibility using smartphone apps to self-report symptoms of psychosis has been demonstrated in several studies [19,52,53]. A recent study of 33 patients with schizophrenia noted that patients found the experience of using a smartphone app to provide on-demand psychoeducation in response to self-reported data to be very positive [18]. A survey study of a state mental health clinic serving a majority of patients with psychotic disorders noted that nearly 65% of patients under age 30 may own a smartphone and that overall ownership for all age groups is 33% [3]. Thus, research suggests that patients with schizophrenia are able to use smartphones to monitor their mental health, and many may own smartphones capable of running symptom-monitoring apps.

At present, there is a considerable lack of data regarding the clinical utility of smartphone-based passively collected data streams, like the ones that Beiwe can capture, and their correlations with traditional clinical metrics. Thus, the main objective of our study is to investigate any correlations between active data (here, surveys and audio data), passive data (here,

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GPS, accelerometer, call and texts logs, and screen event data), and traditional metrics collected in-clinic, with a focus on relapse as well as positive and negative symptoms. There is also a lack of long-term adherence data, with most studies ending after 6 weeks, and consequently little known on how patients learn to use or accept new apps in studies with longer follow-up times [54]. Our secondary objective is thus to study adherence and patterns of app adoption and use over a 3-month period.

In this observational pilot study, we will enroll 20 patients with schizophrenia with inclusion criteria being that they are in current treatment for schizophrenia at the study hospital and own specifically, a smartphone. Age, sex, gender, medication status, or comorbidities will not be exclusion factors. Eligible patients will first be given an in-person assessment consisting of the following validated psychiatric scales: Mini-International Neuropsychiatric Interview (MINI) [55], Patient Health Questionnaire 8 (PHQ-8) [56], General Anxiety Disorder Questionnaire 7 (GAD-7) [57], Pittsburgh Sleep Quality Index (PSQI) [58], and the Warning Signals Scale (WSS), which assess for risk of relapse in schizophrenia [59]. After completing these questionnaires with study staff, patients will be educated on how to download, launch, and use the Beiwe app. Then they will be asked to use it for the next 30 days. The app will be programmed to generate the following surveys: daily WSS and biweekly PHQ-8, PSQI, and GAD-7. The app will also prompt subjects for a daily audio sample. Passive data collection will include GPS, accelerometer, voice call logs, text message logs, and screen event data.

After 30 days, subjects will be invited back to the clinic for another round of in-person assessment scales identical to those presented at the beginning of the study. Subjects will then be asked to continue using the app for another 30 days and to return at the end of Month 2 for another in-person assessment. Finally, subjects will be asked to continue the use of the app for a yet another 30 days and to return for a final in-person assessment at the end of Month 3. As this is a pilot study, subjects who drop out or leave the study for any reason will not be replaced. See Figure 10 for a schematic of the study design.

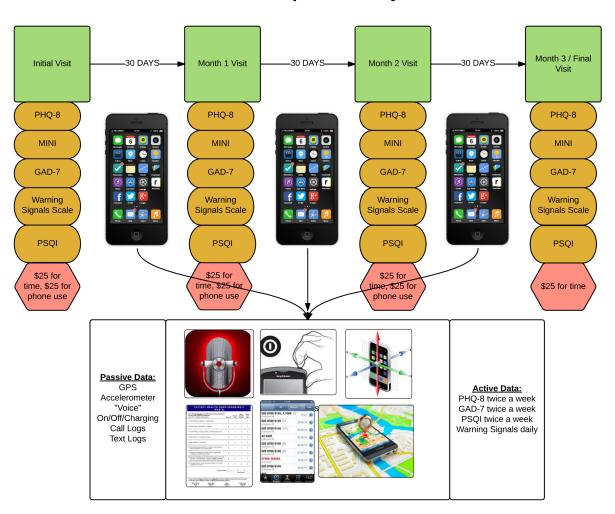
We stress that neither Bluetooth nor Wi-Fi data will be collected in this study; although the Beiwe app has the ability to collect these data, these data streams are not central to the clinical question at hand and they do not have an early clinical evidence base yet, unlike the other passive data streams that are included. The customizability of the platform ensures that unnecessary data are not collected and studies can be conducted in as minimally invasive a manner as possible. Just as a study making use of blood samples would collect only the number of samples necessary to run the relevant lab tests, here we also plan to collect only the digital data necessary for the purposes of our study.

Having subjects use their own phones in the study offers several advantages. First, it may likely reduce bias and the Hawthorne effect, as studies of psychiatric patients have reported patients being more comfortable with their own devices [19,60]. Second, using subjects' own smartphones reduces study costs. In this pilot study, subjects will be paid only for their time for completing in-person clinical assessments and will be reimbursed a flat rate for using their own smartphone in the course of the study. Note that the patients do not have to be compensated for cell phone data use as all data uploads happen through Wi-Fi. Third, for mobile mental health interventions to be scalable and impactful, especially in the long term, they will likely have to rely on patients' own smartphones, and thus it makes sense to have patients use their own phones also in our pilot. Of note, in our internal testing of the Beiwe platform customized for this study, we did not notice any considerable drain on battery or change in the phone's performance or speed based on the daily feedback of numerous healthy volunteers. While in principle it is possible that a subject never connects to a Wi-Fi network and thus data collection would be limited by the phone's internal storage space, in practice this has never happened in either test use or in our other ongoing studies that use the same platform.

This methodology of collecting patient self-reported symptoms in the form of smartphone surveys complemented with behavioral data from smartphone sensors, which includes physiological data related to sleep patterns and voice features, matches the NIMH's Research Domain Criteria (RDoc) model, which encourages the simultaneous examination of multiple levels of the system. The results from this study could provide novel insights to the utility of big data in psychiatry and demonstrate how digital phenotyping more broadly may contribute to our understanding of schizophrenia.



Figure 10. A schematic of the proposed pilot study for patients with schizophrenia using the Beiwe platform.



# Schematic of Smartphone Study Protocol

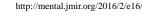
# Conclusion

With Beiwe, we introduce a new platform that will enable digital phenotyping in a scalable, customizable, transparent, and reproducible manner. The platform consists of a Web-based study portal used to manage studies, a smartphone app customized to the needs of any given study, backend database for storing study data and metadata, and a suite of software to be used to model and analyze the data collected using the platform. At the time of writing, the first version of the data analysis and modeling component is being developed, with all other components being fully functional. While there are other smartphone apps that are used to collect both active and passive data from patient cohorts, the Beiwe platform features the collection of high-quality raw data from smartphones and couples this with appropriate statistical learning tools that can be readily applied to the collected data. Because both data collection and data analysis are carried out using tools that will be released to the scientific community, we expect this open design paradigm to foster a more productive and more

sustainable approach to digital phenotyping than reliance on proprietary black box tools.

While at this stage we are studying the clinical utility and validity of Beiwe in patients with schizophrenia, and in this paper have focused on the app component of the platform, we are in the process of evolving and expanding out the data analysis and methods component to match the nature and demands of complex data generated by the platform. We are currently using Beiwe in several other clinical studies in the Boston metropolitan area and exploring new avenues, such as incorporating wearable sensor data and DNA sequencing data, to realize the full potential of digital phenotyping.

We hope that this brief introduction to the Beiwe platform will be a step to directing the present discussion about smartphone and mobile apps as data collection tools toward a discourse centered on the new kinds of science that they may enable and the new kinds of data analytical approaches that will be needed to redeem their full potential.



# Acknowledgments

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# **Conflicts of Interest**

None declared.

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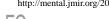
# Abbreviations

EMA: ecological momentary assessment **ESM:** experience sampling method GAD-7: General Anxiety Disorder Questionnaire 7 NIMH: National Institute of Mental Health PHQ-8: Patient Health Questionnaire 8 PSQI: Pittsburgh Sleep Quality Index **RSA:** Rivest-Shamir-Adleman WSS: Warning Signals Scale

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**Original Paper** 

# Digital Technology Use Among Individuals with Schizophrenia: Results of an Online Survey

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# Abstract

**Background:** Despite growing interest in the use of digital technology by individuals with schizophrenia, little is known about how these individual relate to, own, and use technology in their daily life and in the context of their symptoms.

**Objective:** The goal of this study is to better characterize technology use in those with schizophrenia.

**Methods:** A Web-based survey of individuals' use of and attitudes toward technology for those 18 years and older self-identifying as having schizophrenia, schizoaffective disorder, or schizophrenia spectrum disorders was conducted. Consumer input was sought in the design of the survey.

**Results:** In total, 457 individuals responded to this Web-based survey. Ninety percent owned more than one device (personal computer, landline telephone, tablet, public computer, mobile phone without applications or Internet, or smartphone), with many reporting high utilization of multiple devices, and 61% having 2 devices. The respondents reported that Web-based technology helped with support from family and friends, as well as in gathering information. Many respondents used Web-based technology to help identify coping strategies (24% very often or often) including music to help block or manage voices (42%), while others used technology to set alarms/reminders for medication management (28%). Younger respondents in particular anticipated the role of technology growing over time with respect to their recovery.

**Conclusions:** Survey respondents reported that technology access was common, with utilization involving coping, reminders for medications and appointments, and connection. Overall, attitudes were largely positive. Overuse was a concern for 30% of respondents. The study is limited in its generalizability as the population was highly engaged in mental health treatment (87%), self-identified as living with the disorder, and had awareness of their illness. This survey demonstrates high engagement for a subset of technology-oriented individuals living with schizophrenia. It is not known what percent of individuals with schizophrenia are represented by these technology-oriented survey respondents.

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**KEYWORDS** Schizophrenia; Computers; Technology; Internet; Coping; Recovery

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# Introduction

Mobile health (mHealth) has emerged as a movement to harness connected, digital tools such as computers, tablets, mobile phones, and wearables with an aim to advance health care. Such digital devices have the potential to decrease health care costs, increase access to care, and offer novel diagnostic, monitoring, and treatment options across a broad range of diseases [1].

Mental illness is a crucial target for mHealth. mHealth can directly address a number of the devastating characteristics of mental illness, including its chronic nature, stigma, dynamic symptoms, and lack of easy access to treatment. In addition, mHealth can assist individuals in managing their conditions and help empower them to be active participants in their own recovery, a key to improved outcomes.

Schizophrenia is a mental illness for which mHealth offers a tremendous opportunity to deliver personalized, innovative, and accessible solutions. Schizophrenia is a health condition impacting approximately 1% of the population worldwide, afflicting men and woman with equal prevalence, often beginning in the late teens or twenties, and frequently characterized by chronic symptoms including delusions, hallucinations, and disorganization [2]. While outcomes can be poor for some [3], with early interventions [4], psychosocial support [5], judicious medication management [6], and appropriate medical care [7], individuals with schizophrenia can lead rich and fulfilling lives.

However, individuals with schizophrenia remain at risk of relapse, which can be difficult to predict, may struggle with more difficulty accessing appropriate care than others with chronic conditions, and often face tremendous social and emotional obstacles in their recovery [8]. Since their inception, digital technologies have been explored as tools to offer better mental health care. Twenty-three years ago, researchers were using the first mobile phones to help patients with anxiety disorders [9]. With the rise of mobile handheld technologies such as personal digital assistants, clinical studies suggested that those with serious mental illness were able to use and adhere to mobile interventions [10], even when experiencing negative symptoms [11], and that they generally found such technology helpful and easy to use. However, the advantages of such early mobile technological solutions involved practical limitations such as high cost and limited ownership.

However, the situation has changed in the last several years, as connected and mobile technologies are becoming more prevalent and affordable. Along with the rest of the population, those with schizophrenia are increasingly owning mobile technological devices such as mobile phones [12] and are using them to digitally connect. A recent meta-analysis of mobile phone ownership among those with symptoms of psychosis revealed that the rate of phone ownership was rapidly increasing, with 81.4% ownership among those surveyed in 2014 and 2015 [13]. Individuals with schizophrenia not only own connected devices, but are also able to use them for their mental health care. A recent systematic review of mobile phone studies and schizophrenia found no evidence of any adverse events related to technology use and rather overall strong support, interest,

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and adherence among those with schizophrenia [14]. There is also emerging data on how those with schizophrenia engage with digital technology; one recent study of 80 individuals reports that just over half of respondents used text messaging (short message service, SMS), nearly half had email accounts, and over a quarter used social networking websites [15].

Yet, despite the increasing potential of digital technologies for the treatment of schizophrenia, little is known about how individuals with schizophrenia use, interact with, and feel about these mobile health tools. While previous studies have examined serious mental illness and technology [16,17], less is known about how people with schizophrenia actually use connected devices. Just as "early adopters" of consumer electronics are an important segment in market research, important lessons may be learned about technology use in schizophrenia from even the more engaged individuals. mHealth technologies now offer the potential for advanced personalized care; however, that potential starts with understanding how people are actually using these technologies. In this paper, we present results from a Web-based survey on mobile technology that captures a subset of those with schizophrenia who are more engaged with technology.

# Methods

In 2014, the National Alliance on Mental Illness (NAMI) commissioned Harris Poll to conduct a survey on technology use among those self-identifying as having schizophrenia. Harris Poll is an international market research firm, which in part specializes in Internet-based polls. Harris Poll conducted 457 interviews via a Web-based survey that averaged 15 minutes in length from August 25 to September 8, 2014.

The survey was developed and distributed to assess the role and use of technology among a subset of individuals who self-identified as having schizophrenia, schizoaffective disorder, and schizophrenia spectrum disorder.

The survey was designed to elicit individual responses to questions about technology use. Survey questions focused on access to digital devices, frequency of use, purposes of use including coping strategies, experience of technology use including risks of overuse, and perceptions of the possible role of technology in the future. Inclusion criteria were the following: 18 years or older, living in the United States, and self-reporting having been diagnosed with schizophrenia, schizoaffective disorder, or another schizophrenia spectrum disorder. Subjects were recruited from a sample obtained by Harris Poll (65%), NAMI's mailing list (15%), and NAMI's website (20%).

To help adjust for attitudinal and behavioral differences between those who use the Internet versus those who do not, those who join Web-based panels versus those who do not, and those who responded to this survey versus those who did not, results were weighted using a propensity score. This propensity weighting is proprietary to Harris Poll and its parent company, Nielsen, and used frequently in their international survey work. This propensity score, used to minimize the sociodemographic, attitudinal, and behavioral differences between Web-based and phone respondents, was calculated using a logistic regression model, based on the theory of individual choice. This weighted

data set was then used to create a profile for those meeting the full qualification criteria, and was applied to the entire sample using the attitudinal and behavioral variables listed above. The weight also included a variable to account for the frequency of visiting the NAMI website [18]. Both Harris Poll and NAMI analyzed the data. Of note, results presented in this paper are based on this weighting score, although NAMI will offer the raw data to mental health researchers upon request. This study was approved by the University of Southern California Institutional Review Board.

# Results

A complete copy of the survey is accessible at the NAMI website [19]. These results are weighted as explained in the methods section

# **Survey Respondents**

As indicated in Table 1, 457 subjects completed the survey. Thirty-nine percent of subjects (179/457) were aged 18-34, 23% (107/457) were aged 35-46, 30% (136/457) were aged 47-64, and 8% (35/457) were older than 65. The median age of respondents was 41.3 years and 46% were female. Seventy-one percent of respondents were white and 48% reported a household income less than \$24,999. The mean age of onset of schizophrenia in respondents was 25.5 years. Eighty-seven percent of respondents were in current treatment for schizophrenia. Details of demographics are shown below in Table 1.



Table 1. Demographics

Variable		n (%) or mean (SD)
Gender (n=457)	Male	247 (54)
	Female	210 (46)
Age (n=457)	18-34	179 (39)
	35-46	107 (23)
	47-64	136 (30)
	65+	35 (8)
	Mean	41.3 (13.96)
Ethnicity (n=457)	White	324 (71)
	Hispanic	32 (7)
	Black/African American	64 (14)
	Asian or Pacific Islander	14 (3)
	Native American or Alaskan Native	5 (1)
	Mixed race	1 (0)
	Other race	5 (1)
	Declined to answer	14 (3)
Highest Level of Education (n=457)	High school or less	165 (36)
	Job specific training program(s) after high school	50 (11)
	Attended college or college degree	215 (47)
	Attended graduate school or graduate degree	27 (6)
Household Income (n=457)	Less than \$24,999	219 (48)
	\$25,000 - \$49,999	91 (20)
	\$50,000 - \$99,999	77 (17)
	\$100,000 or more	41 (9)
	Declined to answer	31 (7)
Employment Status (n=457)	Full time	86 (19)
	Part time	55 (12)
	Self-employed	18 (4)
	Not employed, but looking for work	32 (7)
	Not employed and not looking for work	18 (4)
	Not employed, unable to work due to a disability or illness	151 (33)
	Retired	41 (9)
	Stay-at-home spouse or partner	32 (7)
	Student	23 (5)
Health Insurance Status (n=457)	Covered	411 (90)
	Not covered	46 (10)
Type of Health Insurance Among Those Covered (n=415)	Health insurance or HMO <sup>a</sup> through work or union or someone else's work or union	54 (13)
	Health insurance or HMO bought directly by me or another member of my family	50 (12)
	Medicare or a Medicare HMO	158 (38)
	Medicaid, Medicaid HMO, or medical assistance	133 (32)
	Health insurance from another source	20 (5)

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Variable		n (%) or mean (SD)
Region (n=457)	East	101 (22)
	Midwest	118 (26)
	South	137 (30)
	West	101 (22)

<sup>a</sup>Health Maintenance Organization

### **Access to Digital Devices**

When asked about access to personal computers, smartphones, landline phones, tablets, public computers, and mobile phones without Internet capabilities, 90% (411/457) had access to more than one of the items listed, 61% (279/457) had access to 2 or 3 devices, and 29% (133/457) had access to 4 or more. Eighty-nine percent (407/457) had access to a personal computer, 54% (247/457) to a smartphone, 52% (238/457) to a landline, 35% (160/457) to a tablet, 32% (146/457) to a public computer, and 31% (141/457) to a mobile phone without applications or Internet accessibility. Access to technology also varied by age with 68% (122/179) of those aged 18-34, 48% (52/107) of those aged 35-46, 44% (59/136) of those aged 47-64, and 37% (13/35) of those older than 65 possessing a smartphone.

# **Frequency of Use**

In examining time spent on devices per day, results indicated that 89% (407/457) of those living with schizophrenia spent one or more hours per day on their personal computer, and 18% (82/457) spent 10 or more hours per day. For mobile phones, results suggested that 85% (388/457) spent one or more hours per day on the device, while nearly half, 48% (219/457), spent 3 or more hours per day. Sixty-six (302/457) percent of respondents anticipated that technology would become a bigger part of their recovery in the coming years.

# **Purpose of Use**

The most common activities during device use were surfing the Internet (2.7 hours), visiting social networking sites (2.0 hours), playing Web-based games (1.4 hours), and sending text messages (1.3 hours). Thirty-six percent (165/457) reported using Web-based technology to cope with schizophrenia "often" or "very often." Twenty-four percent (110/457) reported using technology "sometimes," and 40% (183/457) reported using technology "rarely" or "never" to cope with their illness.

Respondents reported using technology to cope with their illness "often" or "very often" with respect to music or audio files to block or manage auditory hallucinations (42%, 192/457); information about mental health on the Internet (38%, 174/457); calendar reminders for appointments or setting alarms (37%, 169/457); transportation, GPS, and map needs (32%, 146/457); medication management (28%, 128/457); providing support for others (26%, 119/457); developing relationships with others who have lived experience of schizophrenia (26%, 119/457); monitoring symptoms (25%, 114/457); and identifying coping strategies (24%, 110/457). Response rates varied by age: 34% (61/179) of those aged 18-34, 24% aged 35-46 (26/107), 14% aged 47-64 (19/136), and 8% of those aged 65 or older (3/35)

reported that they would use various technologies for coping with symptoms of schizophrenia.

Twenty-three percent of respondents (150/457) "often" or "very often" avoided offline activities in order to stay on the Internet, and 18% (82/457) reported "often" or "very often" neglecting responsibilities because of Internet use.

For those who reported having the following relationships, respondents used their devices to communicate "often" or "very often" with family (51%, 233/457) and friends (48%, 219/457) and least often with case managers (23%, 105/457), professors (22%, 101/457), their doctors (22%, 101/457), or peer supporters (22%, 101/457).

# **Experiences of Using Digital Devices**

Respondents rated the helpfulness of various activities that they engaged in via digital devices. Surfing the Internet was reported to be the most helpful activity for 42% (192/457) of respondents, followed by talking on a landline, mobile phone, or smartphone (39%, 178/457), sending personal emails (31%, 142/457), text messaging (31%, 142/457), spending time on social networking sites (29%, 133/457), online gaming (26%, 119/457), and participating in online chat rooms or discussion groups (21%, 96/457).

When asked about computer, tablet, or mobile phone use, survey respondents were more likely to report positive feelings about their device usage (75%, 343/457). Participants felt connected (58%, 265/457), happy (47%, 215/457), inspired (47%, 215/457), hopeful (45%, 206/457), peaceful (44%, 201/457), motivated (43%, 197/457), and empowered (33%, 151/457), "often" or "very often" during their digital device usage.

Negative feelings were reported "often" or "very often" 56% (255/457) of the time, including feelings of being unable to stop (27%, 123/457), frustration (25%, 114/457), paranoia (24%, 110/457), worry (20%, 91/457), sadness (20%, 91/457), anger (19%, 87/457), mania (16%, 73/457), or envy (16%, 73/457).

Respondents also indicated that they were more likely to use technology when feeling well (58%, 265/457, reported "often" or "very often") as compared to when they were experiencing many symptoms (30%, 137/457). Respondents indicated that surfing the Internet, talking to others on the phone, spending time on social networking sites, and sending emails and text messages were helpful activities in managing their illness. To better understand how views differed between those who had versus had not used technology, we compared how nonusers versus users rated the helpfulness of various technologies. In Table 2, "perceived" helpfulness refers to the views of those who had used it.

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Table 2. Mean helpfulness ratings (actual vs. perceived) of activities on a scale from 1 to 10, where 10 was the most helpful and 1 was the least helpful.

	Actual	Perceived
Surfing the Internet	6.1	4.2
Talking on the telephone including on a landline, mobile phone, or smartphone	5.8	3.7
Using social networking sites	5.3	2.4
Text messaging	5.3	2.8
Sending personal emails	5.1	3.3
Joining or participating in online chat rooms or discussion groups	5	3.3
Online gaming	5	2.7
Video chatting	4.7	2.9

# Discussion

# **Principal Findings**

This is the largest study to date examining ownership and use of technology among those with schizophrenia. While conducting this study via a Web-based survey created a response bias (respondents are likely to be more technology savvy), the results offer crucial insights into how those with schizophrenia engage and connect with technology, suggesting potential targets for further study and possible considerations for clinical care.

# Access to Digital Devices and Frequency of Use

As expected in a Web-based survey, access to connected devices was high in the surveyed population-although results were similar to early smaller studies. This study demonstrates that many individuals living with schizophrenia have access to connected devices with results suggesting that the majority (61%, 279/457) actually have access to two or three devices. Rates of access to technology in this survey sample were similar to such rates in the general population, with 54% (247/457) of respondents having access to a smartphone compared to 64% of Americans currently owning one [20]. Although 54% is also similar to the rate of ownership of 58% reported in a survey study at a state clinic treating those with serious mental illness [12], it is higher than the rate of ownership of 37% reported in another recent survey study of those with serious mental illness at a community health center [21]. The fact that this study was not limited to a single clinic and was conducted as an Internet survey may explain the higher ownership rates reported here. Results also showed that ownership of technology was biased toward younger individuals with schizophrenia, which is in line with national general population trends [20] and earlier survey studies on technology use in patients with mental illness [13,22]. This suggests that technology use in clinical care may be more fruitful when targeted toward younger individuals, such as those with prodromal or first episode symptoms; recent survey research supports this population's strong interest in technology as part of their care [23].

Survey results also indicated that digital device utilization among people with schizophrenia as similar in manner to that of the general population—individuals with schizophrenia spent the most time with their connected devices talking to others,

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followed by surfing the Internet, browsing social networking sites, gaming, and text messaging. A recent Pew survey of the general population showed that the four most common uses of mobile phones were texting, voice calls, Internet browsing, and text messaging [20].

Individuals living with schizophrenia may face a double stigma when using digital devices. Beyond the stigma often associated with schizophrenia itself [24], there may be bias that those living with schizophrenia do not own, cannot use, are not interested in, or will become more paranoid and agitated when using technologies like mobile phones [25]. Our survey indicates that there is a subset of individuals with schizophrenia who challenge the assumptions of low access and low frequency of use. While our methodology of a Web-based survey excludes many who do not like or use technology, our results highlight a subset of those with schizophrenia who not only are well connected, but also use technology in a similar manner to the general population.

The nature of this survey administered on the Internet also allowed us to capture information on those who may be too connected. Results revealed that 18% (82/457) of respondents reported using their personal computer and 14% (64/457) reported using their mobile phone for 10 hours or more per day. Therefore, rather than being "underconnected," some in this sample of individuals living with schizophrenia may have overused digital devices. Twenty-three percent (105/457) of respondents "often" or "very often" avoided activities to stay on the Internet, and 18% (82/457) neglected responsibilities because of the Internet. Future work will need to examine the causes and effects of digital device overuse in populations with schizophrenia; exploring how they use the Internet has the potential to reveal important insights. While we often consider those who are not connected and not using technology, ensuring that we also understand those who may be overconnected is also important, especially given how little we know about the impact of excessive digital device use on the symptoms and course of schizophrenia.

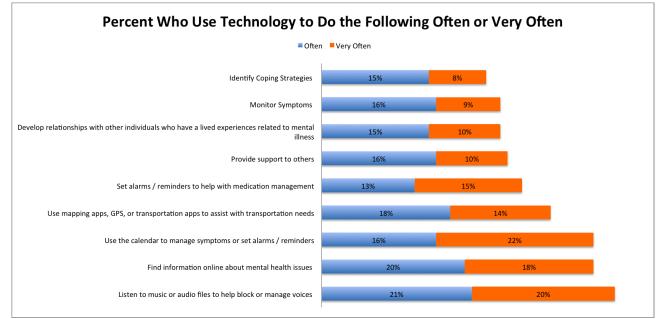
#### **Purpose of Use and Coping Strategies**

As shown in Figure 1, the survey results suggest that many people with schizophrenia already use their mobile phones to manage their illness and promote their recovery. However,

nearly half (48%, 219/457) of respondents reported that they "rarely" or "never" used their devices to communicate with others when experiencing symptoms, raising concerns about the ability of various technology interventions to deliver assistance when it may potentially be helpful. Results indicating that the highest use of technology for coping was among younger individuals suggests that such tools may be best

accepted among a younger population; however, those who are older should not be excluded from use. Finally, considering again the bias of our survey toward more connected individuals, the reported reluctance to use technology when in crisis is especially concerning and underscores the importance of not overrelying on technology for crisis planning and intervention.

Figure 1. Reported use of technology in coping based on 457 responses to Question 4: Aside from telephone calls, how frequently do you use a computer, tablet, or cell/smartphone to do the following?



#### **Experiences of Using Digital Devices**

While positive feelings toward mobile devices were more common, our study results indicate that individuals with schizophrenia have both positive and negative feelings toward their mobile devices. However, these results are not unique to individuals with schizophrenia: 77% of the general population reported that their mobile phones made them feel "happy," 57% reported they felt "distracted, 36% "frustrated," and 15% "angry" because of their devices [17]. Of the survey respondents with schizophrenia, 25% (114/457) reported feeling "frustrated," 24% (110/457) "paranoid," and 19% (87/457) "angry," suggesting that the feelings caused by use of technology are similar between the general population and those living with schizophrenia. The lack of any strong signal regarding negative experiences with technology is also in line with a recent systematic review of the literature on mobile phone interventions in those with schizophrenia, which also found no evidence of adverse events such as increased paranoia, fear, or anger [13]. However, some who are afraid of technology may not have taken this Web-based survey, so it is difficult to generalize these results.

#### Limitations

While this is the largest study to date examining technology use specifically in people living with schizophrenia, several serious limitations exist. Because this was a Web-based survey, there was a strong sampling bias toward those who had access to the Internet. The respondents of the survey represented a population that was highly engaged in treatment (87%, 398/457), which is

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above the average nationally. In addition, the survey respondents were not representative of the demographic distribution of individuals living with schizophrenia, since Caucasians were overrepresented in our sample (71%, 325/457). Furthermore, the majority of survey respondents were younger; due to the low sample size of those over age 65, the results for older people with schizophrenia must be interpreted with caution. This survey may be considered to have included a subpopulation of individuals who self-identified as having schizophrenia, were engaged in treatment at a high level, and were technology oriented. These results cannot, therefore, be generalized to the broader population of individuals with schizophrenia; however, they do still represent a segment of those engaged in their recovery and treatment. The fact that our results, especially in regards to device ownership, were similar to prior surveys of technology use in schizophrenia is encouraging. While the study design did not allow us to ascertain if technology use itself was correlated with higher rates of treatment adherence or general functioning, such an analysis is possible and will be an important topic for future research. Our finding that at least some individuals with schizophrenia are well connected digitally underscores the importance of conducting further studies to examine those who are not as connected and why such differences exist. While our survey focused on those who may be more connected, the results are also important in countering assumptions and stigma around those with mental illness and schizophrenia.

#### Conclusion

There is a subset of individuals living with schizophrenia who often have access to several mobile and Internet-connected devices such as mobile phones and personal computers. They use them in a similar manner as the general population: to make phone calls, browse the Internet, and send text messages. Our results suggest that they use technology in positive ways—for coping, appointments and medication reminders, and connection to family, friends, and peers. For some there is the suggestion of a risk of overuse, as in the general population. While our survey indicates that there is a digitally engaged subset of those with schizophrenia, it does not tell us how we can best leverage technology to improve outcomes, or suggest methods to reach less-connected individuals to better utilize technology to improve outcomes. What our survey does tell us is that these are important questions to be explored, and that we can realize and leverage mHealth solutions in schizophrenia.

As technology continues to be a growing force in modern life and in health care practice, our results demonstrate that opportunities exist to further engage some individuals with schizophrenia in support of their recovery. While our survey does not inform us about those who are not connected and online, understanding those who are connected underscores that schizophrenia should not be considered a barrier to mHealth innovation and the use of digital health tools. Our survey also suggests that technology alone is not a panacea and that there are potential risks associated with technology use. As technology and mHealth continue to expand, it is critical we that we study and understand how mobile devices and Internet tools can be used to further promote recovery in individuals living with schizophrenia.

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# **Conflicts of Interest**

None declared.

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# Abbreviations

mHealth: mobile health

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**Review** 

# Consensus Among International Ethical Guidelines for the Provision of Videoconferencing-Based Mental Health Treatments

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# Abstract

**Background:** Online technologies may reduce barriers to evidence-based mental health care, yet they also create numerous ethical challenges. Recently, numerous professional organizations and expert groups have produced best-practice guidelines to assist mental health professionals in delivering online interventions in an ethically and clinically sound manner. However, there has been little critical examination of these international best-practice guidelines regarding appropriate electronic mental health (e-mental health) service delivery via technologies such as videoconferencing (including Skype), particularly for specific, vulnerable populations. Further, the extent to which concordance exists between these guidelines remains unclear. Synthesizing this literature to provide clear guidance to both mental health professionals and researchers is critical to ensure continued progress in the field of e-mental health.

**Objective:** This study aims to review all currently available ethical and best-practice guidelines relating to videoconferencing-delivered mental health treatments in order to ascertain the recommendations for which international consensus could be found. Additionally, this review examines the extent to which each set of guidance addresses several key special populations, including children and young people, and populations living with illness.

**Methods:** This systematic review examined guidelines using a two-armed search strategy, examining (1) professional organizations' published guidance; and (2) MEDLINE, PsycINFO, and EMBASE for the past ten years. In order to determine consensus for best-practice, a recommendation was considered "firm" if 50% or more of the reviewed guidelines endorsed it and "tentative" if recommended by fewer guidelines than these. The professional guidelines were also scored by two raters using the Appraisal of Guidelines for Research and Evaluation II (AGREE-II) criteria.

**Results:** In the study, 19 guidelines were included, yielding 11 specific "firm" and a further 123 "tentative-level" recommendations regarding the appropriateness of e-mental health, competence, legal and regulatory issues, confidentiality, consent, professional boundaries, and crisis management. International consensus yielded firm guidance across almost all areas except professional boundaries and some aspects of determining the appropriateness of e-mental health. Few guidelines specifically addressed special populations. Overall guideline quality varied; however, 42% (8/19) of the guidelines scored at least 5 out of 7.

**Conclusions:** This synthesis of guidelines provides a foundation for clinicians and researchers utilizing e-mental health worldwide. The lack of specific guidance relating to special populations is an area warranting further attention in order to strengthen mental health professionals' and researchers' capacity to ethically and effectively tailor e-mental health interventions to these groups.

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#### **KEYWORDS**

Internet; videoconferencing; Skype; mental health; cognitive therapy; ethics, professional; guidelines as topic; professional practice; societies; standards

# Introduction

The increasing burden of mental health disorders has focused attention on the need for evidence-based psychological services [1]. Internationally, there remain numerous barriers to accessing evidence-based, specialist mental health interventions, including distance, financial access and/or cost, and stigma [2]. Electronic mental health (e-mental health) strategies have significant potential to address these issues through reducing or removing these barriers [3,4]. Building on previous definitions [5], e-mental health refers here to the provision of mental health services delivered or enhanced by Internet-related technologies; including email, chat, videoconferencing (for example, via Skype), and websites. E-mental health services may be synchronous with two or more parties interacting in real-time (eg, videoconferencing), asynchronous where there may be delays between two parties' communications (eg, email), or involve no clinician interaction whatsoever (eg, self-guided modules). E-mental health can be used as an alternative to traditional face-to-face (FTF) support or as an adjunct to routine practice - for example, for follow-up sessions, or as initial treatment within a stepped care model [6]. In this way, e-mental health has significant potential to increase the accessibility of evidence-based interventions in increasingly cost-constrained health settings [7].

Early evidence across case studies, randomized controlled trials (RCTs), and meta-analyses point to e-mental health's potentially equivalent therapeutic benefits to FTF formats [8-12]. Therapist-assisted models show the strongest effects [13,14]. Qualitative and quantitative evaluations of e-mental health's acceptability, feasibility, safety, and process elements such as working alliance are also promising [8,15]. Both child and adolescent [16-19], and adult [1] clients have indicated that e-mental health methods are as satisfactory as FTF, and reduce the burden of travel.

Despite this burgeoning literature, many recent critical examinations argue that there is a lack of high-level, gold-standard evidence to support the efficacy of e-mental health. Most studies have compared e-mental health interventions to waitlist controls, rather than the gold-standard attention, in vivo control [9,20,21]. A recent review of videoconference-delivered treatment for anxiety disorders in last delivered the decade indicated that videoconference-delivered treatment is effective in reducing symptoms of anxiety, and that the outcomes are comparable with those found in FTF formats. However, this evidence does not exist for all mental health issues, and the general uncertainty regarding the management of ethical quandaries in e-mental

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health forms a significant barrier to generating further high-quality research [2,9], and may also add to clinicians' hesitance to try this mode of delivering therapy. This has contributed to a lag in the uptake of these technologies, even in settings where they are readily available [3,22,23].

While a range of e-mental health modalities exist, each with unique clinical applications and ethical implications, videoconferencing has emerged as an especially promising modality with growing research and clinical use. Videoconferencing has already been employed for many years [10-12], in both practitioner-patient and supervision areas, and has a rapidly growing evidence base [24]. That videoconferencing most closely mirrors a traditional FTF session may also mean that it is the modality that professionals are most likely to integrate into their routine practice.

#### **Ethical Implications of E-Mental Health**

As e-mental health interventions become increasingly advanced, researchers have begun to consider their vast ethical implications [2,9]. While the ethical issues relevant to FTF services still apply to e-mental health, there are unique issues to consider with this new modality. Because of the use of technology, there are additional legal (confidentiality, obtaining consent, licensing, and record keeping) and professional issues (privacy and maintaining professional boundaries) to address. Pertaining to the provision of services remotely, the issues to be considered include crisis risk management and appropriateness of the service for the client. The practitioner must also be competent in delivering the service via this modality [25]. More specifically, videoconferencing requires careful consideration of ethical issues relating to confidentiality (of the session, other correspondence, and patient notes), competence, and consent [25].

However, the rapid expansion of online interventions has somewhat outpaced regulatory bodies' capacity to provide guidance around their provision [9,26,27]. Although several professional bodies have issued guidelines relevant to e-mental health, it remains unclear whether there is international consensus regarding how potential ethical issues should be managed in practice [9,21]. The capacity for online interventions to be accessed by consumers across state and country lines, in conjunction with possible jurisdictional differences, speaks to the need for the reconciliation of available guidelines [2,9]. Identifying consensus among ethical practice guidelines is critical for ensuring the efficacy of online interventions and for the protection of both client and psychologist [28]. The availability of e-mental health has the potential to increase the reach of psychological services to consumers, however, with

this there are new ethical issues and risks. As with any area of mental health service, there may be great risk with the provision of services without proper ethical guidance. Perhaps this is even more pertinent in the online arena, where for example in telepsychology, there is an increased risk of confidentiality breaches [29]. It is critical that the ethical issues unique to this new modality of videoconferencing are discussed and addressed. Special consideration also needs to be given to how these ethical codes might apply within different settings and to special populations [9,30].

# **Special Populations**

Mental health professionals may require additional, tailored guidance regarding the provision of e-mental health services to populations regarded as high risk, including individuals with psychosis or suicidal tendencies [31]. Other special populations with unique considerations include individuals with co-morbid serious or chronic illness, as well as children and young people [32-35]. Specialized mental health support tailored to the needs of these groups may be difficult to access outside of metropolitan regions. Individuals with a chronic illness show an estimated 10% higher incidence of mental disorders relative to healthy individuals [36], and the burden of physical symptoms may make the accessibility afforded by e-mental health especially relevant to this group. Similarly, e-mental health may address the barriers of stigma and geographic isolation in young people accessing evidence-based interventions from mental health professionals [32,35,37], and may even promote further help-seeking [38,39].

# The Present Review

This review focuses on guidelines for delivering videoconferencing-based treatments (for example, via Skype), because this modality requires the active participation of a mental health professional in real-time, in the same way as a FTF session. Focusing on this modality allowed this review to generate more specific recommendations that were more easily applicable to practice. Discussions of the ethics of other forms of e-mental health are available elsewhere [40,41].

This systematic review aims to identify consensus among current best-practice guidelines and synthesize the recommendations regarding the ethical delivery of mental health treatments using videoconferencing technology. The review aims to answer the following two key research questions: (1) what areas of consensus in recommendations can be identified from international best-practice guidelines to guide clinicians in the ethical provision of videoconferencing-based mental health treatments? (2) What recommendations are made in best-practice guidelines regarding special populations including high risk, unwell, and young people?

# Methods

The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews [42].

# **Search Strategy**

In order to integrate research evidence with best-practice guidelines and capture the broadest set of current guidance, a two-armed approach was adopted involving systematic searches of (1) guidelines disseminated by international mental health-related professional bodies; and (2) the recent peer-reviewed literature for best-practice guidelines and recommendations published in scientific journals.

# Search One: Professional Bodies and Organizations

We searched the websites of peak professional bodies in countries where videoconferencing-based mental health interventions are known to be occurring; as informed by a recent review [8]. The websites of other international professional bodies affiliated with the American Psychological Association (APA) were also identified through their website [43] and subsequently searched. These organizations were individually searched for the presence of an English-language website, and the availability of ethical guidelines specific to e-mental health and videoconferencing-based interventions. Guidelines publicly available in draft format were also included where no more recent document existed.

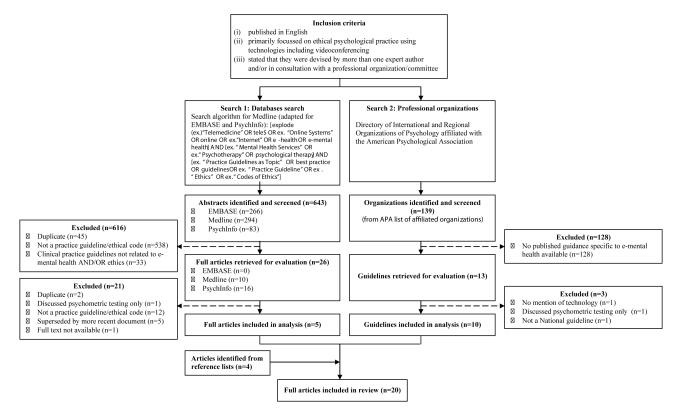
# Search Two: Published Expert Recommendations

We also undertook a targeted search of the peer-reviewed scientific literature for published recommendations generated by expert groups. Three electronic databases were searched (Medline, EMBASE, and PsychInfo), for human studies published in English between 2004 and 2014. The search and selection process, with detailed exclusion criteria is depicted in Figure 1. Search terms were informed by recent reviews [8,16], and included terms defining online interventions, psychology and mental health, and best-practice-recommendations or guidelines. We did not specify videoconferencing as a search term to avoid missing relevant papers in an emerging research field, where at present most guidelines are general to a variety of forms of e-mental health. Reference lists of reviews retrieved were also screened to identify additional relevant guidelines. An initial abstract review identified potentially eligible articles, in addition to a subsequent full-text review by two independent reviewers (ER and MB). Here, articles including best-practice guidance and clinical recommendations relevant to videoconferencing were included. Reviewer disagreements regarding article inclusion were discussed further to achieve consensus, remaining disagreements were resolved through consultation with the other authors.



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Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart of the search and selection process of guidelines included in the review.



#### **Inclusion Criteria**

Best-practice guidelines were included if they (1) were published in English; (2) focused on ethical practice recommendations to deliver therapeutic mental health services using online technologies (including videoconferencing); and (3) stated that they were devised by more than one expert author and/or in consultation with a national professional organization and/or committee.

#### Data Synthesis and Method for Establishing Consensus

The inter-rater reliability for the guideline search was acceptable (83%). The following data was extracted from guidelines: organization/lead author, year of publication and review, country of origin, guideline type, technological focus, target audience, and peer-reviewed status or involvement of consumer input (Multimedia Appendix 1). In order to be considered peer-reviewed, guidelines needed to explicitly state that they underwent a process during development whereby recommendations were reviewed by colleagues, other relevant organizations or stakeholders. Ethical recommendations from each guideline were extracted and collated by content (ie, ethical issue) by two authors (USD, HW). Each individual recommendation was read for specific intent and guidance, with recommendations with the same essential intent collapsed across guidelines (Multimedia Appendices 2-8). In seeking to establish consensus where possible, this review applied a graded rating each recommendation. We considered scale across recommendations made by 50% or more of the expert groups be firm recommendations, the highest level of to evidence-consensus (described as "was recommended"). As this is a new area of research, a consensus seen across half (50%)

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or more of the existing expert groups was considered representative of consistent recognition of a particular issue, particularly given the varying scope of the 19 international guidelines included. We categorized recommendations proposed by fewer groups than this as tentative ("may be recommended").

#### **Quality Assessment**

The quality of guidelines published by professional organizations (identified through Search Two) was also assessed by two researchers (USD and HW) using the Appraisal of Guidelines for Research and Evaluation (AGREE-II) instrument [44]. The AGREE-II tool assesses the methodological rigor of guidelines using 23 items rated across six domains: scope and purpose, stakeholder involvement, rigor of development, clarity of presentation, applicability, and editorial independence (including bias). Guideline quality was not a criterion for review inclusion.

# Results

#### **Guidelines and Position Papers**

The guideline selection and inclusion process are depicted in Figure 1. We included 19 different guidelines or position papers (Multimedia Appendix 1), originating from seven countries, with the majority from USA (53%, 10/19). All guidelines included information on videoconferencing-based mental health treatments. Most were targeted towards psychologists (74%, 14/19) (Multimedia Appendix 9). As online psychological therapy should be conducted by an appropriately trained, accredited mental health professional [27], this review does not include recommendations for para-psychology or other

professionals (eg, teachers, nurses). The qualitative assessment did not reveal any issues of bias across studies.

# **Quality Assessment**

There was significant variation between guidelines in the breadth and depth of topics covered across guidelines (Multimedia Appendix 9). The AGREE-II [44] tool highlighted significant variation in the quality of the 14 guidelines produced by professional organizations, often due to guidelines failing to explicitly address certain elements. Mean overall quality scores ranged from 2-6 out of 7 (scale ranges from 1 "lowest possible quality" to 7 "highest possible quality"), with 64% (9/14) professional guidelines recommended for use on the basis of these scores [45-54]. The domain relating to guidelines' Scope and Purpose showed the highest overall quality, with a mean score of 76.6% across guidelines (range 33-100%), while the domain of Editorial Independence appeared the least well addressed across guidelines (mean score 2%; range 0-33%), which could reflect the methods of review used by professional organizations in publishing their guidelines. As previously mentioned, the AGREE-II assessment was not used as criteria for inclusion or exclusion. In addition to the AGREE-II criteria, guidelines were also examined in terms of whether their development had involved peer-review and consumer involvement. Only 32% (6/19) guidelines explicitly described processes of seeking peer-review from expert colleagues as part of their development [27,28,48,51,53,55], while only one set of guidelines reported involving consumers as part of their expert committee (Multimedia Appendix 1) [51].

# **Research Question One**

# What Recommendations can be Drawn From the Guidelines?

All of the guidelines reviewed indicated that mental health professionals overarching ethical obligations do not change when services are being delivered using online modalities. A summary of the ethical issues addressed across guidelines is shown in Multimedia Appendix 9. A detailed summary of specific firm recommendations for which consensus was found (across 10 or more of the 19 guidelines), as well as tentative recommendations is presented in Multimedia Appendices 2-8 , grouped by the following general ethical domains: the appropriateness of e-mental health, legal considerations, confidentiality, consent, professional boundaries, and crisis management. In total, 11 specific firm recommendations could be drawn from the reviewed guidelines, relating to areas such as determining the appropriateness of e-mental health, competence to deliver e-mental health interventions, legal and regulatory issues, confidentiality, consent, and crisis interventions and distress management. No firm recommendations could be drawn relating to professional boundaries. A further 123 tentative-level recommendations were drawn across all domains. An overview of the recommendations with key practice recommendations highlighted is shown in Multimedia Appendix 10.

# Appropriateness of e-Mental Health

#### **Client-Related Factors**

Although several sets of guidelines identified particular groups or individuals for whom e-mental health may be contraindicated, they differed in terms of how strongly they advised against providing e-mental health interventions to such individuals. The most strongly endorsed recommendation indicated that mental health professionals should incorporate an assessment process to determine the appropriateness of e-mental health services for an individual client (58%, 11/19 guidelines) (see Multimedia Appendices 2-8). However, of these, only four sets of guidelines provided more concrete recommendations as to how professionals could undertake such an assessment [46,52,54,55].

### Service-Related Factors

No firm recommendations emerged regarding the ethical implications of the psychological service type being offered (Multimedia Appendices 2-8). Several recommendations received tentative-level endorsement; however, the most strongly endorsed of these suggested that psychological tests designed to be implemented FTF may not be possible or ethical to conduct online. Only three sets of guidelines commented on the appropriateness of delivering other psychological services using e-mental health (eg, couples, family, or group-based therapy), however, few specific recommendations were generated [46,52,56].

# Competence

Regarding general professional competence, three firm recommendations emerged. The two most strongly endorsed of these indicated that mental health professionals should provide online services within the boundaries of their competence, with an understanding of the limits and applications of different technologies (58%, 11/19 guidelines), and that they should also assist clients to readily assess their competence by verifying their identity and making available their qualifications and professional endorsements (58%, 11/19 guidelines) (Multimedia Appendix 3). Regarding technical competence, one firm recommendation emerged indicating that professionals should acquire skills to manage the technology they are using and to navigate core interpersonal, therapeutic processes using e-mental health services (53%, 10/19 guidelines). No firm recommendations could be drawn regarding competence to assess the suitability of an e-mental health service for a particular client or group. However, the strongest tentative-level recommendation indicated that mental health professionals should be culturally competent to deliver online services to different populations, including considerations of clients' ethnic/racial, cultural, linguistic, gender/sexual orientation, geographic, and socioeconomic backgrounds (42%, 8/19 guidelines).

# Legal and Regulatory Issues

Guidelines highlighted recommendations related to the psychologist's accreditation, record keeping, billing, and establishing a client's age to determine their (legal) capacity to consent (Multimedia Appendix 4). Two firm recommendations emerged relating to mental health professionals' registration/accreditation; these indicated that professionals

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should know and comply with all relevant laws and regulations (from both their and their client's jurisdiction; 79%, 15/19 guidelines), and should ensure that their licensing board approves the provision of online services, and obtain site-specific credentialing across jurisdictions where necessary (63%, 12/19 guidelines). No firm-level recommendations emerged regarding record keeping and electronic records; however, the strongest tentative-level recommendation highlighted that professionals delivering e-mental health interventions should adhere to the usual laws and professional standards applicable to record keeping, particularly where the intervention diverges from usual practice (47%, 9/19 guidelines). Regarding billing, no firm recommendations emerged; the strongest tentative-level recommendation highlighted that mental health professionals should clarify up-front the nature and security of payment for sessions (21%, 4/19 guidelines). Finally, in determining a client's legal capacity to consent to e-mental health interventions, no firm recommendations emerged. However, the two strongest tentative-level recommendations highlighted that professionals should take steps to determine the age of potential clients to establish the appropriateness of e-mental health interventions, and should ensure that a parent/guardian's consent is obtained for all minors before services proceed (both 21%, 4/19 guidelines).

# Confidentiality

Guidelines examined several aspects of confidentiality, including privacy during the online session, client anonymity and establishing identity, and appropriate use and storage of electronic material (Multimedia Appendix 5). One firm recommendation emerged, indicating that mental health professionals should take all up-to-date precautionary efforts to protect clients' confidentiality using e-mental health services (63%, 12/19 guidelines). Further tentative-level guidance emerged pertaining to the issues of ensuring privacy during e-mental health sessions, client anonymity and establishing identity, and confidentiality in the use and storage of electronic materials (Multimedia Appendix 5).

#### Consent

Guidelines regarding consent addressed the limits to confidentiality across technologies, the need to clarify expected psychologist-client contact, and a client's capacity to legally consent (Multimedia Appendix 6). Two firm recommendations emerged regarding *limits to confidentiality*, highlighting the importance of undertaking and documenting thorough consent processes consistent with relevant laws and regulations (58%, 11/19 guidelines). A second recommendation further suggested that these consent processes should address numerous issues unique to e-mental health services including privacy and confidentiality in the online domain, security steps taken, technological equipment and skills requirements, limits to communication, and reliability of the connection (63%, 12/19 guidelines). No firm recommendations emerged regarding clarifying contact times, though the two strongest tentative-level recommendations indicated that professionals should clarify contact information, as well as the nature of and expectations around therapeutic contact at the commencement of e-mental health interventions (47%, 9/19 guidelines), and that

XSL•F() RenderX professionals should additionally clarify expected timeframes for their client receiving a response from them, as well as processes around emergency contacts (47%, 9/19 guidelines). No firm recommendations emerged regarding *capacity to provide consent*.

### **Professional Boundaries**

Recommendations regarding professional boundaries emerged in two key areas: preventing boundary crossings, and social media, though no firm recommendations emerged (Multimedia Appendix 7). The two strongest tentative-level recommendations indicated that mental-health professionals consider the increased potential for boundary issues to arise using e-mental health (21%, 4/19 guidelines) and use the same level of professional language across all media as they would in person (21%, 4/19 guidelines).

#### Crisis Intervention and Distress Management

Recommendations surrounding the assessment and management of acute distress and mental health crises were addressed across most guidelines (79%, 15/19 guidelines) (Multimedia Appendix 9). The only firm recommendation related to crisis management strategies, and highlighted that professionals should establish in-person clinical supports in the client's geographic location prior to initiating e-mental health services, in case of emergency 10/19 guidelines) (Multimedia Appendix 8). (53%, Tentative-level guidance was also available relating to the communication of crisis management strategies, and mental health professionals' responsibilities regarding crisis management in the context of e-mental health. The strongest tentative-level guidance in these areas indicated respectively that professionals inform clients of alternative means of communication should the technology fail (42%, 8/19 guidelines), and that professionals be familiar with mandatory reporting and involuntary hospitalization laws both for their, and their client's jurisdictions (21%, 4/19 guidelines).

# **Research Question Two : What Recommendations** Were Made Regarding Special Populations?

Few guidelines discussed applications to particular special populations. Only six discussed providing e-mental health services to clients with high risk features such as psychosis. Populations noted as being higher risk across guidelines included clients with cognitive impairments (21%, 4/19 guidelines) and psychotic disorders (16%, 3/19 guidelines). Although several guidelines indicated that it may be preferable to exclude these individuals from e-mental health services (Multimedia Appendices 2-8), one set of guidelines noted that there is no concrete evidence indicating which populations may benefit most, or may be harmed by, psychological therapy delivered via videoconferencing [54]. One set of guidelines mentioned conducting e-mental health with illness populations [46], but no recommendations were made regarding adaptations to suit these groups.

A minority of guidelines (32%, 6/19 guidelines) discussed the appropriateness of e-mental health services for young people, with only two explicitly noting its potential acceptability and capacity to increase access to appropriate services [48,52]. However, more guidance was available regarding the importance

of ensuring capacity to consent with young people (42%, 8/19 guidelines) (Multimedia Appendix 9), as well as useful strategies to obtain consent when sessions occur online. Given that minors may be highly computer literate (and may present as adult), professionals were advised to explicitly check young people's age and the required consent prior to services proceeding. All guidelines noted that the requirement for parent/guardian legal consent remained in e-mental health interventions (Multimedia Appendix 6), and one set of guidelines noted that in some circumstances it may be important to engage with and support a young person, even if this consent is not possible [52]. In this case, the guidelines emphasized that identifying real-world support services around the young person would be a key element to therapeutic intervention, as well as discussion and thorough documentation around risk management [52]. Guidelines did not address tailored strategies for young people with regards to managing the following issues: anonymity and verifying identity, safety and risk management, or maintaining professional boundaries.

# Discussion

This review examined and synthesized available guidelines to guide mental health professionals in ethically delivering e-mental health services, with a particular focus on videoconferencing. A total of 19 guidelines were reviewed from seven countries/regions. Across guidelines, consensus supported 11 firm ethical practice recommendations. To our knowledge, this is the first time ethical and best-practice guidelines regarding e-mental health have been synthesized on an international scale. The resulting firm recommendations indicate that despite numerous, distinct best-practice documents, there is emerging agreement across jurisdictions.

Despite this, no firm guidance could be drawn in several key areas, including how professionals should assess the suitability of e-mental health services to their client (Multimedia Appendices 2-8), record-keeping, electronic records and billing (Multimedia Appendix 3), client anonymity, establishing identity and ensuring confidentiality in the use and storage of electronic materials (Multimedia Appendix 5), clarifying contact times and a client's capacity to consent (Multimedia Appendix 6), how professionals should negotiate preventing boundary crossings and social media (Multimedia Appendix 7), and a professional's responsibilities with relation to crisis management strategies in e-mental health interventions (Multimedia Appendix 8). This lack of specific and consistent guidance could be due to the aforementioned outpacing of the uptake of telepsychology with the establishment of professional guidelines for use, and with it a smaller pool of experience to draw from in producing these guidelines. In addition, the lack of uptake by some professionals due to the absence of clear guidance on how to approach the ethical issues unique to telepsychology may also be contributing to the lag in the production of guidelines. Achieving consensus in these areas will be critical to providing professionals with the confidence to deliver services online and may also contribute to providing a robust practice framework against which more rigorous research in this area may be undertaken.

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Discordance between recommendations was rare; although in some instances guidelines differed in how strongly they discouraged certain practices. The delivery of e-mental health services to high risk populations was one such area. Although there was some (tentative-level) guidance regarding how identifiable electronic data relating to client material should be managed, there was less consensus around the appropriateness of mental health professionals recording material from their sessions (eg, audio-visual recordings of a videoconferencing session) [57]. More rigorous guidance is needed given that there may be new benefits (eg, using recordings in professional development, supervision, or as medico-legal documentation) as well as risks (eg, confidentiality) [27].

Regulatory issues in providing e-mental health to clients in different jurisdictions pose ongoing challenges for the field. The firm recommendations that mental health professionals be appropriately registered across their own and their client's jurisdiction may be difficult to enforce in practice [52]. One set of guidelines noted that "If you enter the state or country via technology, you may be deemed to be practicing in that country" [52], and indicated that complaints made against a clinician would likely be heard in the client's jurisdiction. Some work appears to have been undertaken for North American psychologists, with the development of a chart summarizing temporary and guest licensure across 50 states [58]. The future resolution of such issues internationally is likely to be critical to professionals' confidence in delivering these services.

#### **Special Populations**

#### "High Risk" Populations

Of the few guidelines that directly addressed special populations some discordance was evident as to whether this constituted a contraindication. One group noted that currently there is no convincing evidence identifying any populations for whom e-mental health services would be especially harmful, and cited emerging evidence that in some circumstances e-mental health could be successfully implemented with psychotic patients [54]. Evidence is mixed regarding whether or not high risk groups should be excluded or whether in some cases there is merit in including them with appropriate precautions [31,59].

The issue of crisis and risk management was comprehensively addressed across 15 guidelines (Multimedia Appendix 9), and offered numerous concrete strategies professionals may use to continually monitor and ensure the safety of their client. Based on these guidelines, thorough assessment, collaboration with local services, and partnership with the client's support person may be integral to the management and safety of clients using e-mental health. Useful data may come from emerging e-mental health programs targeted at individuals with suicidal thoughts [60].

#### **Illness Populations**

Only one guideline highlighted the applicability of e-mental health strategies to illness populations, but no guidelines addressed how (if at all) the proposed recommendations should be tailored to these groups' needs. Despite this, the convenience of e-mental health may be especially helpful in removing barriers to care for clients experiencing significant physical

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symptoms, such as fatigue or pain, which may hinder access to a FTF session [32,34]. E-mental health may facilitate more specialized support tailored to illness-specific issues [2], and connect otherwise dispersed individuals living with the same illness. This in turn could address the documented unmet need to access peer-support (eg, in cancer patients) [61-63].

Though firm recommendations regarding illness populations could not be drawn from this review, emerging literature indicates the acceptability, feasibility, and potential efficacy of videoconferencing-based psychological support among individuals with illness [64,65]. Despite the added complexities involved in delivering psychological support to multiple distressed unwell individuals concurrently, we have recently developed an intervention with adolescents and young adults with cancer, and documented rigorous protocols to successfully navigate challenging ethical issues surrounding consent, confidentiality, and crisis management [33,66]. Further work in this area will strengthen the evidence base for these unique groups.

#### **Children and Young People**

Online psychological therapy programs for children and young people involve the same core components as for adults [67], and are gaining evidence [8,16]. However, there is a gap in understanding how ethical and best-practice recommendations in the online space apply to young people [9]. Determining capacity to consent, and arranging for appropriate parental consent if needed, are important issues to consider. Some guidelines propose incorporating a FTF contracting session prior to the commencement of any online services [2,50-52]; this would enable the psychologist (or a proxy) to ascertain the age of the young person and obtain informed consent.

In cases where the referral or presenting problem itself makes parental or guardian consent difficult or inappropriate (eg, physical or sexual abuse involving their parent or guardian), an initial risk assessment should involve consideration of the young person's vulnerability, and access to any other forms of appropriate evidence-based supports in the absence of online services [52]. Choosing to leave a vulnerable young person without any appropriate FTF supports due to online services being deemed too risky without parental consent does not avoid any ethical risks, but rather appears to make a choice as to which risk is preferable.

An issue not addressed by the reviewed guidelines is that young people may have limited access to e-mental health platforms due to their limited autonomy, particularly around finances. For example, some young people may not have independent access to the Internet or to computers in private locations to enable confidential conversations.

Although guidelines tentatively suggested that routine practice should involve clients being identifiable (Multimedia Appendix 5), several groups noted that maintaining anonymity may be reasonable under some circumstances. A desire for anonymity may lead an individual to provide a pseudonym, obscure their face, or to not use a Web camera at all. This issue may be particularly relevant to young people who report being especially concerned about the stigma related to consulting with mental

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health professionals [37]. Several existing community-based e-mental health platforms provide anonymous psychological services to adolescents and young adults (eg, Headspace [68] and CanTeen [69] in Australia; Blah Therapy [70] and Teen Line [71] in the United States).

In adapting e-mental health guidelines to children and young people, maintaining appropriate professional boundaries appears crucial. Due to the developing nature of their cognitive, emotional and social competencies, and their lack of exposure to mental-health services, young people may not necessarily understand the concept of professional boundaries. The reviewed guidelines tentatively indicated ways in which professionals can maintain boundaries, including monitoring what information is available about them online, maintaining professional language across all media (eg, in short message service [SMS] text messages), and avoiding interactions on social media.

#### Gaps in Translation of Guidance to Practice

Despite predictions that online methods will soon form an integral part of mainstream psychological practice [30], gaps remain between ethical best-practice and the development of the competencies mental health professionals require to follow these guidelines [72]. For example, consensus indicated that professionals must practice within their area of competence, and need to learn the unique skills involved in delivering interventions online. One recent Canadian guideline proposed competency standards for professionals delivering e-mental health [72], however, little other guidance exists. This is a critical issue in need of resolution [21,72]. Recognized standards as to what would constitute adequate preparatory training do not yet exist [53]. These gaps are likely to need to be bridged through professional development integrally related to each practice setting at a local, jurisdictional level [9,21,72]. Professional development would need to incorporate both how practice may be modified to suit unique aspects of videoconferencing, and how clinicians can balance competing ethical demands in this space [9,22,28].

Another critical issue in translating videoconferencing-based methods into practice is ensuring increased exposure to the medium. Even when mental health professionals gain familiarity with videoconferencing and when it is shown to result in equivalent outcomes, higher client satisfaction and lower costs, professionals still report preferring FTF methods [73]. Lack of practice-based exposure has been identified as a contributing factor here [22]. Several specific practice issues that have been noted within videoconferencing, such as additional anxiety on the psychologist's part, lack of feedback, and increased demands to ensure client engagement [22,74]; training addressing these issues may increase professionals' skills, and lower their resistance to incorporating videoconferencing-based methods into routine practice. Previous reviews have noted mental health professionals' concerns that videoconferencing methods might phase out FTF treatments [1,22]. However, one of the greatest benefits to professionals will likely be its capacity to supplement FTF - for example as an adjunct to FTF sessions [6,75].

There are currently few training opportunities in e-mental health methods [76], yet standardized specialized graduate training programs will become crucial to the field as it continues to

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become part of standard psychological care [77,78]. One recent reported, example has been Australian where videoconferencing-based training clinics were built into tailored postgraduate clinical psychology programs [79]. Videoconferencing has also been used to disseminate evidence-based professional development for mental health professionals [80]. The development of similar opportunities for practice and supervision in e-mental health methods is an important area for future development [2].

#### **Strengths and Limitations**

This review represents the first time best-practice recommendations for the delivery of e-mental health interventions using videoconferencing have been evaluated for consensus across internationally-available literature. The review's two-armed methodology enabled a synthesis of available guidance generated both by professional bodies as well as expert groups' published recommendations. This was critical to ensure that consensus was drawn across the broadest set of currently-available guidance; this also increases the applicability of this review to future clinical practice and research endeavors in e-mental health.

Nevertheless, some limitations must be acknowledged. Guidelines currently in development may have been missed, and guidelines not published in English were excluded. The need to draw consensus across guidelines precluded the inclusion of great detail here, which may be useful to the clinician wishing to implement ethical guidance in their practice (though see Multimedia Appendices 2-8). In addition, guideline quality was only assessed for best-practice guidelines published by professional organizations, in keeping with the AGREE-II framework [44]. Nonetheless, professional guidelines varied significantly in their quality as well as their coverage of topics, an issue common to other guideline reviews [81].

Further, this review drew from a broader literature that is acknowledged to be in its infancy: a literature that suffers from several limitations itself. The ethical guidelines that do exist are not prescriptive but rather recommendations [21], with considerable gaps in how these recommendations might be adopted in varying contexts and populations [9]. In addition, one set of guidelines noted that while many ethical best-practice documents are somewhat abstract in nature, they require clinical, practical, or administrative guidance to be attached to them in order to be clinically useful [51].

For example, while many guidelines emphasized the importance of professionals continuously evaluating their competencies in delivering e-mental health interventions, including seeking ongoing training, few specific recommendations were made clarifying what precise interpersonal, therapeutic, or technical skills might be uniquely relevant to a clinician's capacity to competently deliver e-mental health, or how this should be evaluated (either by professionals themselves or an external evaluator). This has implications for the future training of professionals in this field. National professional organizations' capacity to create practice-based guidance for clinicians, as well as their capacity to develop and integrate practical materials into postgraduate training courses and accreditation and/or registration examinations as relevant, may be critical. As the literature base in this area develops, so too will clarity around what constitutes ethical best-practice for mental health professionals.

#### **Future Research**

This exciting area of development offers numerous fruitful areas for future research. There is scope for international bodies to jointly participate in a Delphi consensus process [82] regarding best-practice e-mental health. Further work is needed to concretely determine the efficacy of videoconferencing-based services in larger populations, different disorders (including those classed as high risk), minority groups, using different therapy formats (eg, group-based), and compared to attention control groups. Future research should also consider more rigorously reporting on navigating consent in practice, as well as documenting clinical issues and adverse events that arise in the delivery of online services [27]. More detailed reports on what practical and technical logistics are required for implementation of these technologies are also needed, as many studies still do not report training, costs, and use of equipment within their interventions [8].

Online therapies have been heralded as a way to overcome perceived stigma around mental health [1,37]. Yet clients may be less likely to enter into a professional relationship with a psychologist if they have not had the opportunity to meet them FTF and evaluate their suitability for themselves [51]. Future research could explore whether e-mental health models show different rates of uptake and/or attrition relative to FTF therapy [1,37,51,83]. Some evidence also indicates that there is a higher rate of clients not returning for their second session in e-mental health [83]. Questions surrounding the ability to establish the therapeutic alliance as well as the quality and importance of this alliance in e-mental health interventions remain unanswered [27]; the cost-effectiveness of e-mental health services also needs to be established. A final question is whether e-mental health methods do in fact increase access to evidence-based services among vulnerable clients who are socio-economically or geographically disadvantaged, younger, or unwell.

# Conclusion

This review aimed to determine the consensus among international ethical guidelines regarding the provision of videoconferencing-based mental health services. Though different regulatory bodies across jurisdictions have unique local parameters within which professionals need to practice, consensus emerged across current international guidelines to inform how mental health professionals can effectively and ethically deliver their services using e-mental health platforms. Innovations in delivering mental health services online involve numerous trade-offs and the balance of different ethical risks, but if managed carefully may have significant benefits to a variety of vulnerable client groups.



# Acknowledgments

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# **Authors' Contributions**

USD, CW, BM, and PP conceived of the review and developed its concepts. All authors participated in the study design. USD, BM, and HW conducted the literature search and data collection. USD and HW developed study tables and figures. All authors participated in data analysis, interpretation, and writing of the manuscript.

# **Conflicts of Interest**

None declared.

# **Multimedia Appendix 1**

Characteristics of the reviewed ethical guidelines and best-practice recommendations.

[PDF File (Adobe PDF File), 40KB - mental v3i2e17 app1.pdf]

# Multimedia Appendix 2

Specific recommendations for which consensus emerged regarding appropriateness of e-mental health.

[PDF File (Adobe PDF File), 56KB - mental\_v3i2e17\_app2.pdf]

# Multimedia Appendix 3

Specific recommendations for which consensus emerged regarding competence.

[PDF File (Adobe PDF File), 80KB - mental\_v3i2e17\_app3.pdf]

# Multimedia Appendix 4

Specific recommendations for which consensus emerged regarding legal and regulatory issues.

[PDF File (Adobe PDF File), 86KB - mental\_v3i2e17\_app4.pdf]

# **Multimedia Appendix 5**

Specific recommendations for which consensus emerged regarding confidentiality.

[PDF File (Adobe PDF File), 73KB - mental\_v3i2e17\_app5.pdf]

# Multimedia Appendix 6

Specific recommendations for which consensus emerged regarding consent.

[PDF File (Adobe PDF File), 66KB - mental\_v3i2e17\_app6.pdf]

#### Multimedia Appendix 7

Specific recommendations for which consensus emerged regarding professional boundaries.

[PDF File (Adobe PDF File), 67KB - mental\_v3i2e17\_app7.pdf]

# Multimedia Appendix 8

Specific recommendations for which consensus emerged regarding crisis intervention and distress management.

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[PDF File (Adobe PDF File), 82KB - mental\_v3i2e17\_app8.pdf]

# **Multimedia Appendix 9**

Overview of ethical practice issues addressed across guidelines.

[PDF File (Adobe PDF File), 51KB - mental\_v3i2e17\_app9.pdf]

# **Multimedia Appendix 10**

Most highly-endorsed recommendations across each ethical issue.

[PDF File (Adobe PDF File), 45KB - mental\_v3i2e17\_app10.pdf]

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#### Abbreviations

AGREE-II: Appraisal of Guidelines for Research and Evaluation II e-mental health: electronic mental health FTF: face-to-face

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#### **Review**

# Finding Web-Based Anxiety Interventions on the World Wide Web: A Scoping Review

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# Abstract

**Background:** One relatively new and increasingly popular approach of increasing access to treatment is Web-based intervention programs. The advantage of Web-based approaches is the accessibility, affordability, and anonymity of potentially evidence-based treatment. Despite much research evidence on the effectiveness of Web-based interventions for anxiety found in the literature, little is known about what is publically available for potential consumers on the Web.

**Objective:** Our aim was to explore what a consumer searching the Web for Web-based intervention options for anxiety-related issues might find. The objectives were to identify currently publically available Web-based intervention programs for anxiety and to synthesize and review these in terms of (1) website characteristics such as credibility and accessibility; (2) intervention program characteristics such as intervention focus, design, and presentation modes; (3) therapeutic elements employed; and (4) published evidence of efficacy.

**Methods:** Web keyword searches were carried out on three major search engines (Google, Bing, and Yahoo—UK platforms). For each search, the first 25 hyperlinks were screened for eligible programs. Included were programs that were designed for anxiety symptoms, currently publically accessible on the Web, had an online component, a structured treatment plan, and were available in English. Data were extracted for website characteristics, program characteristics, therapeutic characteristics, as well as empirical evidence. Programs were also evaluated using a 16-point rating tool.

**Results:** The search resulted in 34 programs that were eligible for review. A wide variety of programs for anxiety, including specific anxiety disorders, and anxiety in combination with stress, depression, or anger were identified and based predominantly on cognitive behavioral therapy techniques. The majority of websites were rated as credible, secure, and free of advertisement. The majority required users to register and/or to pay a program access fee. Half of the programs offered some form of paid therapist or professional support. Programs varied in treatment length and number of modules and employed a variety of presentation modes. Relatively few programs had published research evidence of the intervention's efficacy.

**Conclusions:** This review represents a snapshot of available Web-based intervention programs for anxiety that could be found by consumers in March 2015. The consumer is confronted with a diversity of programs, which makes it difficult to identify an appropriate program. Limited reports and existence of empirical evidence for efficacy make it even more challenging to identify credible and reliable programs. This highlights the need for consistent guidelines and standards on developing, providing, and evaluating Web-based interventions and platforms with reliable up-to-date information for professionals and consumers about the characteristics, quality, and accessibility of Web-based interventions.

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#### **KEYWORDS**

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Anxiety; mental health; web-based interventions; internet; technology; consumer; access to health care

## Introduction

The National Comorbidity Survey Replication showed that 28.8% of people in the United States suffer from an anxiety disorder in their lifetime [1]. Reviews suggest that anxiety disorders are the most frequently occurring class of mental health disorders [2-4] and are considered chronic and disabling conditions worldwide [5]. Despite effective treatments being available, anxiety disorders are still widely underdiagnosed and undertreated [4,6]. The adverse effects of anxiety disorders on psychological and somatic health, as well as high economic costs [2,6-8] mean that treatment is a significant public health issue.

Lack of help-seeking behavior and perceived barriers to accessing treatment contribute to underdiagnosis and undertreatment. Generally, individuals with anxiety display a tendency not to seek help for their disorder [9,10]. Identified treatment barriers include lack of awareness of the presence of a disorder and available services, financial burden, and the stigma associated with disclosing mental health disorders [10,11].

Research has shown that many individuals use the Internet to find information or help for health-related topics [12], especially for topics that they experience as difficult to talk about [13,14]. A survey demonstrated that 18% of all surveyed Internet users had searched the Internet for mental health-related information, with higher prevalence for those who had a history of mental health issues and those who at the time stated that they were experiencing psychological distress [15]. Similarly, nationally representative surveys from the Pew Internet and American Life Project found that 26-39% of individuals who sought Web-based health information looked at mental health information [14,16]. When searching the Internet for mental health information, individuals may come across Web-based interventions.

A Web-based intervention has been defined as "a primarily self-guided intervention program that is executed by means of a prescriptive online program operated through a website." (p. 5) [17]. Advantages of Web-based approaches include accessibility, affordability, and anonymity of mental health interventions [18,19]. Web-based interventions can be accessed anytime and anywhere from devices such as computers, laptops, tablets, and mobile phones and large audiences and rural areas can be reached in a cost-effective manner [20-22]. Web-based interventions also offer anonymity and privacy, which may attract individuals who experience difficulties with disclosing mental health disorders [23-24].

The efficacy of Web-based mental health intervention programs is well established. Meta-analyses of Web-based mental health interventions have shown that those interventions were as effective as face-to-face treatments and superior to control groups with substantial effect sizes [25,26]. With regard to anxiety disorders specifically, a meta-analysis concluded that computerized- and Internet-based cognitive behavioral therapy (CBT) for anxiety disorders had improved outcomes compared to waitlist and placebo assignments and these effects were equal to face-to-face treatment [27,28]. Another meta-analytic review concluded that computer-aided psychotherapy was as effective

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as face-to-face therapy and that the effects did not differ across various anxiety disorders and types of delivery [29]. Similarly, a recent review reported moderate to large effect sizes for Internet-based CBT for a range of anxiety disorders ranging from 0.30 to 2.53 [30].

Despite an extensive body of literature evaluating the effectiveness of developed Web-based interventions, little research has examined the range and characteristics of publically available Web-based intervention programs for individuals with mental health issues. Research has started to identify, describe, and evaluate the range and characteristics of mental health mobile phone apps [31,32] and e-therapy or e-counselling services [33,34]. However, e-therapy is different from Web-based programs, as in e-therapy mental health professionals use text- or video-based formats (eg, email, chat, Skype) for delivering therapy. There is also a clinical online directory of Web-based mental health programs called Beacon available, which lists among others, intervention program websites for phobias, generalized anxiety disorder, social anxiety disorder, and panic disorder [35]. However, this website is not updated very often and is clinically directed rather than a systematic review of programs that are publically available. A few publically available Web-based programs were briefly discussed in a review; however, this was restricted to four programs available in Australia (FearFighter, Beating the Blues, Online Anxiety, CRUfAD) and included only a short overall description of the main program characteristics [36]. In addition, the programs were not identified by a systematic Web search. Recently, a scoping review has identified and evaluated currently available interactive Web-based interventions for depression [37]. However, to our knowledge no study has conducted a similar review for Web-based intervention programs for anxiety.

In summary, despite the clear advantages of Web-based anxiety interventions, there is only limited systematically identified and up-to-date information available on the characteristics of publically available Web-based interventions for anxiety and the quality of these services is currently unknown. This information would be helpful and important for consumers and practitioners interested in Web-based interventions for anxiety, as well as researchers developing and evaluating those interventions. Therefore, this study conducted a replicable Web search to identify freely available Web-based anxiety intervention programs and review these in terms of (1) website characteristics such as origin, accessibility, and credibility; (2) Web-based program characteristics, such as intervention focus, design, delivery, and features; (3) intervention characteristics such as the overall therapeutic approach and intervention features; as well as (4) published evidence of efficacy.

### Methods

#### Search Strategy

Using the 3 most popular Web search engines, Google, Bing, and Yahoo [38,39], a keyword search for Web-based intervention programs for anxiety was performed in March 2015. UK versions of the search engines were used (.co.uk). Before starting the search, existing search history and cookies were deleted and future tracking and cookies were disabled in

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the browser. A list of the 9 search term combinations used can be found in Textbox 1. Primarily simple and lay keywords were used to simulate a Web search that was relatively likely to be conducted by an individual searching for Web-based programs. It has been shown that most individuals rarely consider more

Textbox 1. Search terms used in Google, Bing, and Yahoo.

- 2. Internet treatment anxiety
- 3. Internet cognitive behavioural therapy anxiety
- 4. Online therapy anxiety
- 5. Online treatment anxiety
- 6. Online cognitive behavioural therapy anxiety
- 7. Web therapy anxiety
- 8. Web treatment anxiety
- 9. Web cognitive behavioural therapy anxiety

**Program Identification** 

All 675 hyperlinks were screened for eligible Web-based programs for anxiety by the first author. The screening process consisted of two stages. The first stage involved screening all 675 hyperlinked websites to eliminate clearly irrelevant websites. All hyperlinks were screened and organized into 1 of the following 3 categories: websites with Web-based programs, websites linking to websites with Web-based programs, and websites with irrelevant content. Irrelevant content included, among others, e-counselling websites, mental health information websites, support groups/forums, online mental health screening/assessment, therapist or mental health clinic websites, scholarly articles, blogs, Facebook pages, Wikipedia, videos, and broken links.

For all websites categorized as "websites of Web-based programs" and "websites linking to websites of Web-based programs," duplicates were removed. All remaining websites entered the second stage of screening and were screened according to the following criteria by the first author: (1) designed for anxiety symptoms (although they did not need to be focused on anxiety only), (2) currently publically accessible on the Internet (via registration, application, General Practitioner (GP) referral), (3) online component, (4) structured treatment plan (information only), and (5) available in English. Programs were excluded if they were (1) not publically accessible; (2) Web-based counseling only (Skype, email, or instant message contact with a counselor only, with no structured program associated); (3) purely informational (psychoeducation only); or (4) exclusively part of a research study.

than the first 20 links generated by a search engine [40]. As

featured links placed at the top and bottom were also considered,

we chose to assess the first 25 links. This resulted in 675

hyperlinks being screened (3 search engines  $\times$  9 search terms

#### Data Extraction

 $\times$  25 hyperlinks).

A data extraction form was created containing 4 main categories and 9 subcategories. Table 1 provides an overview of the items in each main category and subcategories. The 4 main categories are based on the 4 specified study interests (website characteristics. characteristics. program intervention characteristics, and empirical evidence). The 9 subcategories of the 4 main categories were established by incorporating the 12 key facets of a framework designed for evaluating and reporting Internet intervention studies [41]. The extraction was undertaken by the first author in March 2015. Screenshots of all programs and websites were taken in case the program changed during the rating period. To ensure that the programs could be evaluated thoroughly, all program authors were contacted to request free access.



Table 1. Data extraction categories and subcategories.

Main Category	Subcategory	Item
Website characteristics	Origin	Country of origin
	Accessibility	Registration (yes/no-if yes, how?)
		Log-in available on website (yes/no)
		Access fee (yes/no-if yes, how much? Free trial available? Refund period? Length of subscription)
		Mobile phone rendering (yes/no)
	Credibility	Advertisements (yes/no-if yes, relevant vs irrelevant)
		Presented contact details (yes/no)
		Specified authorship (yes/no)
		Terms of use specified (yes/no)
		Privacy notice specified (yes/no)
Program characteristics	Intervention focus	Target anxiety issue
		Target audience
	Intervention design	Therapist support (yes/no-if yes, specify)
		Suggested or set treatment length
		Number of modules
	Intervention delivery	Presentation format
Intervention characteristics	Therapeutic approach	CBT <sup>a</sup> ; others (specify)
		Other therapeutic elements
	Intervention features	Worksheets (yes/no-if yes, specify format)
		Mood or symptom monitoring (yes/no)
		Diary (yes/no)
		Forum (yes/no)
		Other features (yes/no—if yes, specify)
Empirical evidence	Empirical evidence for program efficacy	Scrutinized program website for relevant information, contacted the author, and checked the Beacon <sup>b</sup> directory

<sup>a</sup>CBT: cognitive behavioral therapy

<sup>b</sup>Beacon: Australian clinical Web-based platform that describes different Web-based self-help treatment programs [49].

#### **Program Evaluation**

Several validated and widely accepted scales are available to evaluate the methodology of published studies. However, there are currently no validated criteria available for evaluating actual Web-based interventions as found on the web. Renton et al [31] created a program scoring system to evaluate Web-based depression interventions. With permission from the authors, the scale was adapted to fit the 4 specified study interests. The adapted version consists of 16 yes or no close-ended questions that are outlined in Table 2. Consistent with the scoring system used by Renton et al [31], a score of 1 was awarded if the answer was yes, and a score of 0 if the answer was no or the question could not be evaluated. Scores were converted into percentages, with higher scores indicating a larger number of met criteria on the scale.



#### Table 2. Program evaluation criteria.

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Main Category	Question
Website characteristics	1. Was country of origin stated?
	2. Was a unique user name or password provided to users?
	3. Were the names and credentials of authors present?
	4. Were contact details provided?
	5. Were the Terms of Use specified?
	6. Was a Privacy Notice specified?
	7. Was evidence for the program provided to the user (ie, attrition data/success rate/completion rate/# of users in the program/testimonials)?
Program characteristics	8. Were the primary focus/goals/objectives of the intervention stated?
	9. Was the patient group or target mental health issue specified?
	10. Was the number of modules or time to complete each module stated?
	11. Was the intervention tailored to the user or was it generic for all users?
	12. Did the program offer multimedia content delivery (ie, a combination of text, video, graphics, and audio formats)?
	13. Was the program easy to navigate?
Intervention characteristics	14. Was the model of change (ie, type of therapy utilized) defined/stated?
	15. Was information on what is covered in the intervention modules provided (ie, names of modules or a short description)?
Empirical evidence	16. Has the program been empirically validated?

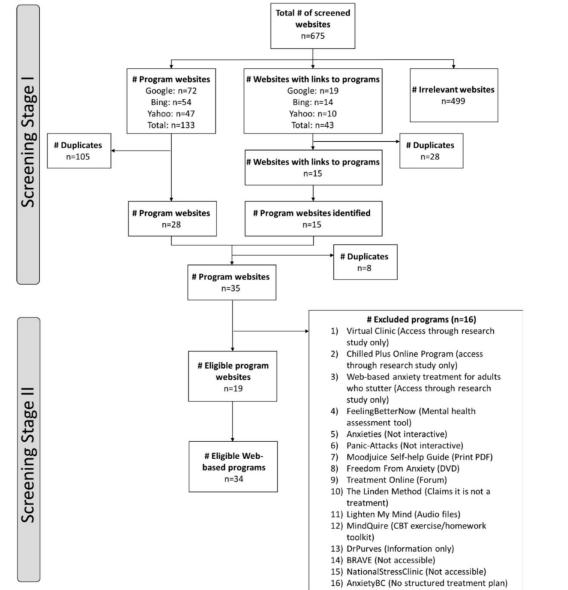
# Results

#### **Program Selection**

A search log outlines the number of hits per search, as well as the number of included and excluded hyperlinks (see Multimedia Appendix 1). Most program websites were identified when the search terms "online treatment anxiety" (Program websites: n=14, websites with links to program websites: n=2) and "online cognitive behavioural therapy anxiety" (program websites: n=12, websites with links to program websites: n=4) were entered into Google. "Web therapy anxiety" entered in Yahoo did not identify any program websites. All 675 links were assessed for inclusion. Figure 1 displays the flowchart for the two-stage selection process of included programs and reasons for exclusion. In total, 176 of the 675 (25.3%) assessed hyperlinks led either directly to program websites (133/675, 19.7%) or to websites containing links to program websites (43/675, 6.4%). The first stage of the screening identified 35 potentially eligible program websites that were subsequently assessed for inclusion. Of those, 19 websites and 34 programs met the inclusion criteria. For 5 programs, the authors did not grant access and some aspects of those programs could therefore not be evaluated (Beating the Blues, Changing States, eCentreClinic, FearFighter, Social Anxiety Institute).



Figure 1. Flow diagram of program selection.



#### Website Characteristics

#### **Country of Origin**

Programs identified in this review originated from 4 different countries. The majority of programs were developed in Australia (16/34, 47%), followed by the UK (9/34, 28%) and the USA (8/34, 24%), and Sweden with one program.

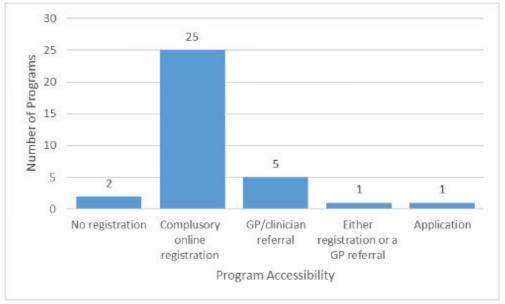
#### Accessibility

Out of the 34 programs evaluated, 25 (74%) had a compulsory online registration process to access the program, 5 (15%) required GP/clinician referral, 1 (3%) was accessible through either registration or GP referral, 1 (3%) through application, and 2 (6%) did not require registration to access the program (see Figure 2). Excluding the 2 programs that did not require registration, 29 (85%) had a log-in feature on their website. For 3 programs (9%), no log-in feature was found and it was unclear how users would log in after buying the program. For programs requiring registration, consumers had to enter personal information to set up a profile. Registration allowed tracking and saving of entered information. This was not possible for programs that required no registration.

Over half of programs (24/34, 71%) required an access fee, while 3 were free if signing up for a research trial. Costs varied from £14.99 (Changing States) for 1 module to £197 (FearFighter) for 9 modules and therapist support. Most programs that required a fee had either a free trial period, or a 100% refund period and were either weekly/monthly subscriptions or only valid for 1 to 6 months. Out of the 34 programs, 9 (28%) were accessible in a mobile phone version, while 3 (9%) could not be evaluated in this respect, as the authors did not grant access to the program.

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Figure 2. Access to evaluated programs.



#### Credibility

All programs specified authorship and all programs presented contact details either via a contact form and phone number (9/34, 28%), email address (7/34, 21%), email address and live chat (6/34, 18%), contact form (5/34, 15%), email address and mailing address (3/34,9%), email address and phone number (2/34, 6%), phone number (1/34, 3%), or email address and contact form (1/34, 3%) (see Figure 3). Thirty out of 34 (88%) programs specified their terms of use and 32 (94%) had a privacy notice. All programs with a privacy notice also included

information about browser cookies, data collection, and data management. Thirty-one programs (91%) displayed no advertisements. One program's advertisement was deemed relevant (mental health self-help books) and the other two were deemed irrelevant (BBC news link and Google Ads).

### **Intervention Program Characteristics**

An overview of intervention program characteristics for each program can be found in Table 3 and screenshots of all programs can be found in Multimedia Appendix 2.



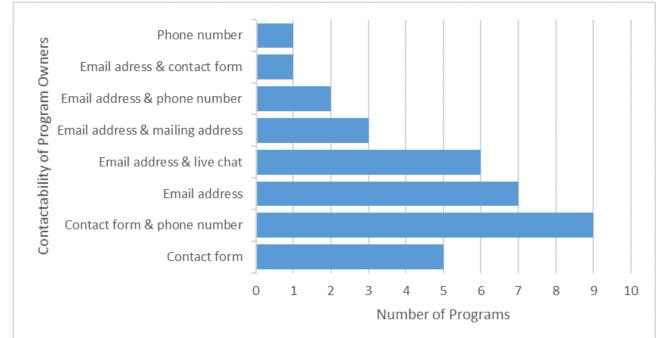




Table 3. Intervention program characteristics of included Web-based intervention programs for anxiety.

Program (Ref#)	Target Anxiety Is- sue & Population	Therapist-Assisted	Structure & Length	Presentation For- mat	Therapeutic Approach	Intervention Features
AI-Therapy (#1)	Social anxiety	No	7 modules (1-2 modules per week)	<ul> <li>Text chapters with figures</li> <li>Audio features with every chapter</li> <li>Video features</li> </ul>	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Email reminders</li> <li>Knowledge quizzes</li> <li>Personalized eBook</li> </ul>
Beating the Blues (#2)	Anxiety & depres- sion	No	8 sessions (over 8 weeks)	- Image slides with audio & video - In- teractive slides	CBT <sup>a</sup>	<ul><li>Worksheet printouts</li><li>Email reminders</li></ul>
Blues Begone (#3)	Anxiety & depression	No	30 modules (8 weeks)	- Text chapters with figures and images - Audio with every chapter - Cartoon videos	CBT <sup>a</sup>	<ul> <li>Worksheets</li> <li>Symptom tracking</li> <li>Diary</li> </ul>
Changing States - The Stress and Anxiety Manager (#4)	Anxiety & stress	No	1 module divided in 4 main sections	<ul><li>Slides with images, text, accompanied by audio</li><li>Notes for printing</li></ul>	Hypnothera- py & CBT <sup>a</sup>	- Relaxation technique audio files
CBT 7 Step Self Help Course (#5)	Anxiety, depres- sion, & anger	Option of receiving paid email guid- ance and personal- ized formulation	7 modules	<ul> <li>Text chapters with figures</li> <li>Audio features (need to be pur- chased separately)</li> </ul>	CBT <sup>a</sup>	- PDF worksheet - Wiki
CCBT Limited – FearFighter (#6)	Panic and phobia	Via telephone (if purchased)	9 steps (recom- mended 9 weeks)	- Video text and image slides	CBT <sup>a</sup>	<ul><li>Worksheet printouts</li><li>Progress monitoring</li><li>Emails with further tips at the end of each step</li></ul>
eCentreClinic - Mood Mechanic Course (#7)	Depression, social anxiety, panic at- tacks, & general- ized worry; Aus- tralian adults aged 18 to 24	Weekly contact with clinician via email and tele- phone (depends on trial)	4 lessons (5 weeks)	- Text chapters and images	CBT <sup>a</sup>	<ul> <li>Online questionnaires and worksheets</li> <li>Symptom tracking</li> <li>Diary</li> <li>Knowledge tests</li> </ul>
eCouch - Anxiety & Worry Program (#8)	Anxiety & worry; Aged over 16	No	3 main sections (arm chair: 15 sec- tions, tool kit, workbooks)	<ul> <li>Text chapters with figures and animated pictures</li> <li>Audio features</li> </ul>	CBT <sup>a</sup> & IPT <sup>b</sup>	<ul> <li>Online questionnaires and worksheets</li> <li>Symptom tracking</li> <li>Diary</li> <li>Knowledge tests</li> </ul>
eCouch - Social Anxiety Program (#9)	Social anxiety; Aged over 16	No	3 main sections (arm chair: 16 sec- tions, tool kit, workbooks)	- Text chapters with figures and animated pictures - Audio features	CBT <sup>a</sup> & IPT <sup>b</sup>	<ul> <li>Online questionnaires and worksheets</li> <li>Symptom tracking</li> <li>Diary</li> <li>Knowledge tests</li> </ul>
Learn to Live (#10)	Social anxiety	No	8 lessons (8 weeks recommended)	<ul> <li>Animated slides with audio, images, and text</li> <li>Videos</li> <li>Slides require in- put from users</li> </ul>	CBT <sup>a</sup>	<ul> <li>Online and printable worksheets</li> <li>Forum</li> <li>Symptom tracking</li> <li>Online calendar</li> <li>Questionnaires</li> </ul>
Livanda - Free from Anxi- ety (#11)	Panic disorder, so- cial phobia, & gen- eral anxiety	Through messag- ing system within the program (if paid for)	8-10 sections (12- 15 weeks)	<ul><li>Text chapters and slides</li><li>Audio features</li></ul>	CBT <sup>a</sup>	- Online worksheets - Symptom tracking

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Program (Ref#)	Target Anxiety Is- sue & Population	Therapist-Assisted	Structure & Length	Presentation For- mat	Therapeutic Approach	Intervention Features
Living Life to the Full (#12)	Anxiety, stress, & life skills	User can designate a support practition- er	12 modules	- Text slides with figures - Audio with every slide	CBT <sup>a</sup>	<ul> <li>Alert emails for incomplete modules</li> <li>Symptom tracking</li> <li>PDF worksheets</li> <li>Online books</li> <li>Online questionnaires</li> </ul>
Mental Health On- line - Generalised Anx- iety Disorder (#13)	Generalized anxi- ety disorder; Aged over 18	Weekly eTherapist emails, monitor progress, answer questions and pro- vide support via email	12 modules (12 weeks)	<ul> <li>Text chapters with figures</li> <li>Audio and video features</li> </ul>	CBT <sup>a</sup>	<ul> <li>PDFs worksheets</li> <li>Online worksheets</li> <li>Symptom tracking</li> <li>Diary</li> </ul>
Mental Health On- line - Social Anxiety Disorder (#14)	Social anxiety dis- order; Aged over 18	Weekly eTherapist emails, monitor progress, answer questions and pro- vide support via email	12 modules (12 weeks)	<ul> <li>Text chapters with figures</li> <li>Audio and video features</li> </ul>	CBT <sup>a</sup>	<ul><li> PDF worksheets</li><li> Online worksheets</li><li> Symptom tracking</li><li> Diary</li></ul>
Mental Health On- line - Panic Disorder with or without Agoraphobia (#15)	Panic disorder with or without agora- phobia; Aged over 18	Weekly eTherapist emails, monitor progress, answer questions and pro- vide support via email	12 modules (12 weeks)	<ul> <li>Text chapters with figures</li> <li>Audio and video features</li> </ul>	CBT <sup>a</sup>	<ul> <li>PDF worksheets</li> <li>Online worksheets</li> <li>Symptom tracking</li> <li>Diary</li> </ul>
Mood Control (#16)	Anxiety & depres- sion	No	12 modules (13 weeks)	- Video for every chapter with an in- troduction text	CBT <sup>a</sup>	<ul> <li>PDF worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Forum</li> <li>Bonus material (sessions for personal development and life change)</li> <li>Additional worksheets</li> </ul>
MoodGym (#17)	Anxiety & depres- sion; Aged over 16	No	5 modules	- Text chapters with images	CBT <sup>a</sup> & IPT <sup>b</sup>	<ul> <li>Quizzes</li> <li>Worksheets</li> <li>Downloadable relaxation audio</li> <li>Symptom tracking</li> </ul>
myCompass (#18)	Anxiety, depres- sion, & stress; Aged over 18; Mo- bile phone function for Australian resi- dents only	No	12 modules (6-8 weeks)	- Text chapters with figures	CBT <sup>a</sup> , IPT <sup>b</sup> , & positive psychology	<ul> <li>PDF worksheets</li> <li>Online worksheets</li> <li>Symptom tracking</li> <li>Diary</li> <li>Wiki</li> <li>SMS &amp; email reminders</li> <li>Real-life experience stories</li> </ul>
Online Therapy – Anxiety (#19)	Anxiety; Aged over 18	Live support and email	8 sections (8 weeks)	- Text chapters with figures and images	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Diary</li> <li>Forum</li> <li>Chatroom for general help</li> </ul>

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Program (Ref#)	Target Anxiety Is- sue & Population	Therapist-Assisted	Structure & Length	Presentation For- mat	Therapeutic Approach	Intervention Features
Online Therapy - Generalized Anxi- ety Disorder (#20)	Generalized anxi- ety disorder; Aged over 18	Live support and email	8 sections (8 weeks)	- Text chapters with figures and images	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Diary</li> <li>Forum</li> <li>Chatroom for general help</li> </ul>
Online Therapy - Panic Attacks (#21)	Panic attacks; Aged over 18	Live support and email	8 sections (8 weeks)	- Text chapters with figures and images	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Diary</li> <li>Forum</li> <li>Chatroom for general help</li> </ul>
Online Therapy - Agoraphobia (#22)	Agoraphobia; Aged over 18	Live support and email	8 sections (8 weeks)	- Text chapters with figures and images	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Diary</li> <li>Forum</li> <li>Chatroom for general help</li> </ul>
Online Therapy - Social Anxiety (#23)	Social anxiety; Aged over 18	Live support and email	8 sections (8 weeks)	- Text chapters with figures and images	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Diary</li> <li>Forum</li> <li>Chatroom for general help</li> </ul>
Online Therapy - Speech Anxiety (#24)	Speech anxiety; Aged over 18	Live support and email	8 sections (8 weeks)	- Text chapters with figures and images	CBT <sup>a</sup>	<ul> <li>Online worksheets</li> <li>Online questionnaires</li> <li>Symptom tracking</li> <li>Diary</li> <li>Forum</li> <li>Chatroom for general help</li> </ul>
Serenity Program - Anxiety Program (#25)	Stress, generalized anxiety disorder, social anxiety, & panic disorder; Aged over 18	No	9 modules (9 weeks)	<ul> <li>Text slides with figures and animat- ed images</li> <li>Interactive con- tent on slides</li> <li>Audio feature</li> </ul>	CBT <sup>a</sup>	- PDF worksheets
Social Anxiety In- stitute (#26)	Social anxiety	No	25 modules	- Audio sessions - Video features - Hand-outs	CBT <sup>a</sup>	None
This Way Up Clin- ic – Worry (#27)	Generalized anxi- ety disorder; Aged over 18	Supervised by clin- ician	6 modules (8 weeks)	- Comic slides	CBT <sup>a</sup>	<ul> <li>Online questionnaires</li> <li>Downloadable homework</li> <li>Symptom tracking</li> <li>Recovery stories</li> <li>Online calendar (set up email reminders)</li> <li>Downloadable extra activ- ities and information</li> </ul>

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Program (Ref#)	Target Anxiety Is- sue & Population	Therapist-Assisted	Structure & Length	Presentation For- mat	Therapeutic Approach	Intervention Features
This Way Up Clin-	Depression & anxi-	Supervised by clin-	6 modules (8	- Comic slides	CBT <sup>a</sup>	- Online questionnaires
ic	ety; Aged over 18	ician	weeks)		021	- Downloadable homework
-Worry and sad-						- Symptom tracking
ness (#28)						- Recovery stories
						- Online calendar (set up email reminders)
						- Downloadable extra activ- ities and information
This Way Up Clin-	Panic/agoraphobia;	Supervised by clin-	6 modules (8	- Comic slides	CBT <sup>a</sup>	- Online questionnaires
ic – Panic (#29)	Aged over 18	ician	weeks)		CDT	- Downloadable homeworl
						- Symptom tracking
						- Recovery stories
						- Online calendar (set up email reminders)
						- Downloadable extra activities and information
This Way Up Clin- ic	Social phobia; Aged over 18	Supervised by clin- ician	6 modules (8 weeks)	- Comic slides	CBT <sup>a</sup>	- Online questionnaires - Downloadable homework
- Shyness (#30)						- Symptom tracking
						- Recovery stories
						- Online calendar (set up email reminders)
						- Downloadable extra activ- ities and information
This Way Up Self-	Social phobia;	No	3 modules (3	- Comic slides	CDT	- Online questionnaires
help	Aged over 18	110	weeks)	- conne snues	CBT <sup>a</sup>	- Downloadable homework
- Shyness (#31)	-					- Symptom tracking
• • •						- Recovery stories
						- Online calendar (set up email reminders)
						- Downloadable extra activ- ities and information
• •	Depression & anxi-	No	3 modules (3 weeks)	- Comic slides	CBT <sup>a</sup>	- Online questionnaires
help - Worry and Sad-	ety; Aged over 18		weeks)			- Downloadable homework
ness (#32)						- Symptom tracking
						- Recovery stories
						- Online calendar (set up email reminders)
						- Downloadable extra activ ities and information
This Way Up	Social anxiety;	No	6 modules (6	- Comic slides	CBT <sup>a</sup>	- Online questionnaires
School	grade 11 and 12		weeks)			- Downloadable homework
-Overcoming So-	high school					- Symptom tracking
cial Anxiety (#33)						- Recovery stories
						- Online calendar (set up email reminders)
						- Downloadable extra activities and information

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Program (Ref#)	Target Anxiety Is- sue & Population	Therapist-Assisted	Structure & Length	Presentation For- mat	Therapeutic Approach	Intervention Features
This Way Up School -Anxiety and De- pression Preven- tion for Adoles- cents (#34)	Anxiety & depres- sion; grade 9 to 11 high school	No	6 modules (6 weeks)	- Comic slides	CBT <sup>a</sup>	<ul> <li>Online questionnaires</li> <li>Downloadable homework</li> <li>Symptom tracking</li> <li>Recovery stories</li> <li>Online calendar (set up email reminders)</li> <li>Downloadable extra activ- ities and information</li> </ul>

<sup>a</sup>CBT: Cognitive behavioral therapy

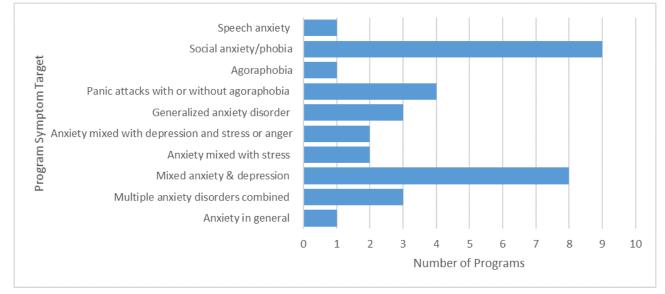
<sup>b</sup>IPT: Interpersonal Therapy

#### **Intervention Focus**

Programs were designed for a range of issues including specific anxiety disorders; anxiety combined with depression and stress, or anger; various anxiety disorders combined; or anxiety in general. Figure 4 shows that the majority of programs were designed for social anxiety/phobia (9/34, 28%) or for mixed anxiety and depression (8/34, 24%). The remaining programs focused on anxiety in general (1/34, 3%); multiple anxiety disorders combined (3/34, 3%); anxiety mixed with stress (2/34,

6%); anxiety mixed with depression and stress or anger (2/34, 6%); or other specific anxiety disorders such as generalized anxiety disorder (3/34, 9%), panic attacks with or without agoraphobia (4/34, 12%), agoraphobia (1/34, 3%), and speech anxiety (1/34, 3%). Concerning the target audience, the majority of programs were designed for an adult population (aged over 16 or 18 years) (20/34, 59%), 2 were targeted at teenagers of high school age, 1 specifically for young adults aged 18-24 years, and 11 programs (32%) did not specify an age group, but based on content seemed to be designed for adults.

Figure 4. Intervention target of evaluated programs.

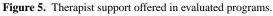


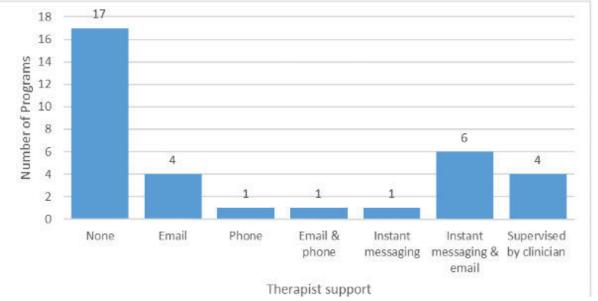
#### Intervention Design

In total, 17 programs (50%) offered therapist support, either by email, instant messaging, or phone. See Figure 5 for a summary of the different forms of therapist support. Therapist support always required a fee; for the majority of these support programs (10/17, 59%), there was an option of paying only for the

self-guided version or paying extra for support. For one free program (Living Life to the Full), consumers could invite a professional to access their account and provide support within the program (support practitioner). The recommended length of the programs varied from 1 to 15 weeks (mean 8.85 weeks, SD 4.10) and the number of modules offered ranged from 1 to 30 (mean 9.38, SD 5.97).





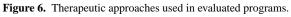


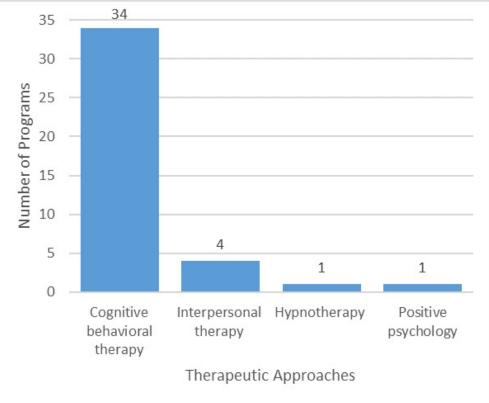
#### Modes of Therapy Presentation

All programs used a combination of different modes of presentation (eg, text, images, audio, video, text entry-fields, and animation). Content was most frequently presented as text chapters with images or diagrams (23/34; 68%). Other identified modes of presentation included animated slides or pictures, comic slides, ebooks, and video sessions. In total, 15 programs (44%) incorporated audio components and 9 included video components (26%).

#### General Therapeutic Approach

All 34 programs claimed to be CBT-based and at least one cognitive and behavioral therapeutic element was employed for each program based on the examined module content. Some programs stated that they also incorporated other therapeutic approaches, such as interpersonal therapy (4/34, 13%), hypnotherapy (1/34, 3%), and positive psychology (1/34, 3%) (see Figure 6).





#### **Other Therapeutic Elements**

Other popular therapeutic elements included psychoeducation modules, goal-setting features, features to create case conceptualizations for oneself, skills training exercises, various forms of relaxation exercises, mindfulness-based exercises, experience stories, sleep hygiene, and relapse prevention.

#### Intervention Features

All except for one program (33/34, 97%) provided the user with worksheets during the session or homework in PDF or online forms. Mood or symptom monitoring/tracking was part of the majority of programs (29/34, 85%). Most programs allowed the user to see results and access a result history either in a numerical or diagram format. In total, 12/34 programs (35%) offered an online diary and 9/34 programs (27%) incorporated a user forum. The review also revealed a great variety of other program features. One feature was the set-up of email or text message reminders for unfinished or future sessions (AI-Therapy, Beating the Blues, Living Life to the Full, myCompass) and an online treatment calendar to schedule the next session and set up alerts (Learn to Live, This Way Up programs). Other features included bonus material (eg, personal development offered in Mood Control), additional resources (ie, more worksheets to be used between sessions or after the end of treatment, offered in Mood Control, This Way Up), treatment items voted most useful by users, to-do-list maker,

personal note section, awards, commitment checks (Blues Begone), knowledge tests at the beginning and information about medication (AI-Therapy, e-couch), personalized eBooks (AI-Therapy), printable session recap and homework cards in wallet format (Mental Health Online), and a teammate function, which allowed the nomination of friends or family members for optional support (Learn to Live).

#### **Empirical Evidence for Program Efficacy**

A summary of the types of published research evaluations for each program and the respective references can be found in Table 4. For 3/34 programs (9%), indirect research evidence was identified. The two e-couch programs are based on the MoodGYM program, for which research evidence is available; however, the e-couch program's efficacy was not specifically empirically evaluated. The AI-Therapy program has only been evaluated for social anxiety in adults who stutter using a pre-post study without a control group. For 17/34 programs (50%), empirical studies evaluating efficacy or effectiveness were found. Studies ranged from case series and small to mid-sized pre-post interventions without comparison groups to controlled and randomized controlled trials (RCT). Both MoodGYM and This Way Up have been evaluated through 9 RCTs each. The efficacy of Beating the Blues was demonstrated by 2 RCTs, FearFighter by 2 RCTs, and myCompass by 1 RCT. For 14/34 programs (41%), no research evidence of the efficacy or effectiveness of the intervention was found.



Table 4. Types of research evaluations of included Web-based interventions

Program (Ref#)	Type of Research Evaluation Studies
AI-Therapy (#1)	- Pre-post intervention for social anxiety in adults who stutter [42]
	- Case study [43]
	- Feasibility & acceptability [44]
	- 2 RCTs <sup>a</sup> [45, 46]
	- Cost-effectiveness [47]
Beating the Blues (#2)	<ul> <li>Pre-post intervention without comparison group [42, 49]</li> <li>Implementation [50- 52]</li> </ul>
Blues Begone (#3)	- Pre-post intervention without comparison group [53]
Changing States - The Stress and Anxiety Manager (#4)	Website: not specified; Beacon <sup>b</sup> : no research evidence
CBT 7 Step Self Help Course (#5)	Website: not specified; Beacon <sup>b</sup> : not reviewed
CBT / Step Sen help Course (#3)	•
	<ul> <li>Acceptability study [54]</li> <li>Pre-post intervention pilot [55]</li> </ul>
	- Case studies without comparison group [56]
	- Implementation study [57]
CCBT Limited – FearFighter (#6)	- 2 RCTs <sup>a</sup> [58, 59]
eCentreClinic - Mood Mechanic Course (#7)	Website: nothing for this specific program; Beacon <sup>b</sup> : not reviewed
eCouch - Anxiety & Worry Program (#8, #9)	Adapted from MoodGYM
Learn to Live (#10)	Website: not specified; Beacon <sup>b</sup> : not reviewed
Livanda - Free from Anxiety (#11)	Website: not specified; Beacon <sup>b</sup> : no research evidence
Living Life to the Full (#12)	Website: not specified; Beacon <sup>b</sup> : no research evidence
Mental Health Online - Generalized Anxiety Disorder (#13,	- Participant choice trial [60]
#14, #15)	- Implementation [61]
	- Predictors of pre-treatment attrition and treatment withdrawal [62]
Mood Control (#16)	Website: not specified; Beacon <sup>b</sup> : no research evidence
MoodGym (#17)	- Nine RCTs <sup>a</sup> [63- 71]
	- School and class-based trials [72, 73]
	- Implementation [74] - Program usage analysis [75]
	- Frogram usage analysis [75] - Follow-up outcome analysis [76]
	- Compliance of community users and predictor of outcomes analysis [77]
myCompass (#18)	- RCT <sup>a</sup> [78, 79]
Online Therapy (#19, #20, #21, #22, #23, #24)	Website: not specified; Beacon <sup>b</sup> : not reviewed
Serenity Program - Anxiety Program (#25)	- Pilot pre-post treatment without comparison group [80]
Social Anxiety Institute (#26)	Website: not specified; Beacon <sup>b</sup> : not reviewed
This Way Up Clinic (#27, #28, #29, #30) This Way Up Self-	Generalized anxiety disorder:
help (#31, #32)	- 3 RCTs <sup>a</sup> [81- 83] - Implementation study [84]
	Panic: - 1 RCT <sup>a</sup> [85]
	- Pre-post intervention trial without comparison group [86] Social phobia:
	- 5 RCTs <sup>a</sup> [87- 91]
	- Implementation study [92]
This Way Up School (#33, #34) Anxiety	- Cost-effectiveness, acceptability, and follow-up analysis [93]

#### <sup>a</sup>RCT: randomized controlled trial

<sup>b</sup>Beacon: Australian clinical online platform that describes different Web-based self-help treatment programs [35]

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Results were examined for programs for which anxiety symptoms were evaluated in RCTs. Beating the Blues was found to lead to a significant reduction of anxiety both at the end of treatment and at 6 months' follow-up compared to treatment as usual [45]. For FearFighter, both the face-to-face and online program group had reduced anxiety at post-treatment and 1-month follow-up [59]. MoodGym was evaluated in adolescents and university students and levels of anxiety were found to be lower in the intervention group compared to the waitlist control group after the intervention [63,66]. In addition, combined face-to-face and online CBT was more effective in treating anxiety symptoms than either face-to-face or online as a standalone [70]. Compared to control subjects, participants in the myCompass intervention had reduced anxiety symptoms after the program and symptom scores remained at near normal levels at 3-month follow-up [78]. For This Way Up, a program targeted at generalized anxiety disorder, the intervention group participants showed significantly reduced symptoms of panic [81] and anxiety [82] at post-treatment compared to the control group. Symptom reduction was the same for technician and clinician-assisted versions of the treatment [83].

#### **Program Evaluation**

Program evaluation scores for each program and each evaluation criteria can be found in Multimedia Appendix 3. Scores for each program ranged from 69% (CBT 7 Step Self Help Course) to 100% (AI-Therapy) with an average score of 81% (SD 7%). Concerning the evaluation criteria, all program websites specified for which patient group or symptoms the program was designed, defined or stated the utilized model of change, presented program author names and credentials, and provided contact details. About half of the program websites had been empirically evaluated (19/34, 55.9%), specified which information was covered in the intervention modules (18/34, 52.9%), and provided evidence for the program to the user (eg, attrition data, success rate, completion rate, number of users in the program, testimonials) (14/34, 41.2%). Only 4 program websites (11.8%) specified whether the intervention was tailored to the user or generic for all users. This question could not be evaluated for one website (Social Anxiety Institute).

#### Discussion

#### **Principal Findings**

To our knowledge, this is the first review of publically available Web-based programs for anxiety that showcases what individuals seeking such treatment options might find if they search the Web. The review aimed at providing consumers, practitioners, and researchers with a summary of the availability, characteristics, and efficacy of currently freely available Web-based interventions for anxiety. The review identified a wide variety of programs for anxiety, specific anxiety disorders, or anxiety in combination with stress, depression, or anger with treatments based predominantly on CBT techniques. The majority of websites were found to be credible and accessible. Of the programs reviewed, the majority required that users register and/or pay a program access fee. Half of the programs offered some form of paid therapist or professional support. Programs varied in treatment length and number of modules

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and employed a variety of presentation modes. Relatively few were evaluated in terms of efficacy. In particular, this review highlights two key issues: the large number and diversity of program formats and the lack of empirical evidence of efficacy for many of the identified programs. These will be discussed in more detail and results will be compared with a similar review of Web-based depression programs available on the Web [37].

First, the great variety and large number of identified programs for anxiety is noteworthy. Programs differed in their level of support, accessibility, and presentation. A similarly great variability among identified programs was also found for Web-based depression interventions [37]. Concerning accessibility, more than half of the programs required an access fee. Considering the high costs and waiting times for psychotherapy in many countries, paid Web-based programs may provide an affordable alternative. However, programs often could only be purchased for a limited period. Many users may not be able to finish the program in the allotted time, and being able to receive treatment at one's own pace might be an important reason for choosing Web-based treatment over face-to-face therapy.

Overall, most programs used a multimedia presentation for the intervention delivery. With the current rapid pace of advances in technology, more engaging ways of translating therapeutic techniques into interactive techniques could be created for Web-based interventions to distinguish them from traditional self-help material. Increased engagement through interactivity may increase adherence and effectiveness [94,95], especially when considering reports of low utilization and high dropout rates of Web-based interventions [19,96]. As individuals may differ in their preferred style of therapy and time and resources available for treatment, trying different programs and considering the access period is recommended before choosing a program.

The number of identified anxiety programs was similar to the number listed in the Beacon directory [35]. In total, 33 distinct programs were found in the directory. About half of those programs were also identified by this review and some of those identified in this review were not listed on Beacon. It is important to note here that the Beacon website is not updated very often; for example, some reviews of anxiety programs were last updated in 2009. The difference may also be a result of the keywords used and the way search engines are designed and work. Search engines are often referred to as "information gatekeepers," as they are able to include and exclude websites and influence the ranking of websites in the search results [39]. These results suggest that even though a multitude of Web-based programs exists, it may be difficult for interested consumers to identify and compare all options. Having specialized services like the Beacon directory and keeping them up-to-date is therefore important to provide consumers with knowledge about program differences, credibility, and effectiveness. This will in turn help consumers to be able to compare programs and choose the one most suitable for them. A review of Web-based depression interventions identified a similar number (n=32) of programs on the Web and 12 of those programs were also included in this review [37]. Those were mostly programs that

offered interventions targeting both anxiety and depression issues.

To ensure that consumers access programs of appropriate quality and safety, national and/or international platforms are needed that provide consumers with reliable guidance on evidence-based and effective Web-based intervention options. For example, the E - Mental Health Strategy for Australia [97] outlines the development of an e-mental health portal that provides reliable information and accessible pathways for consumers and caregivers to navigate and use evidence-based Web-based mental health support. In addition, there is little consistent guidance on necessary quality standards, as well as legal and ethical issues regarding Web-based interventions for professionals. There is, for example, the Suggested Principles for the Online Provision of Mental Health Services by the International Society for Mental Health Online (ISMHO); however, this document mainly addresses online counselling and there are no guidelines specifically addressing Web-based programs. In the context of mental health apps, a review has also highlighted the need for standards and guidelines for developers to follow and frameworks for consumers to assess credibility and legitimacy [32].

Concerning the evidence base of the included programs, all were found to be based on CBT principles. This is consistent with prior reviews, which found that some form of CBT or other behavioral therapy was included in most Web-based interventions [98], as well as in publically available Web-based intervention programs for depression [37]. In general, research evidence indicates that CBT is an effective treatment for anxiety disorders (eg, [99,100]. This suggests that all reviewed programs were to some extent developed using an evidence-based approach; however, this does not guarantee that the evidence-based approach used is necessarily effective in the program.

In this context, another major finding was that several programs did not provide any research evidence or provided only limited evidence of the efficacy of the treatment. This is similar to findings from the review of Web-based depression interventions, which showed that 63% had not been evaluated using RCTs [37]. This finding is interesting considering the numerous systematic reviews and meta-analyses of Web-based interventions [25,30,101]. However, some may currently be in the process of being evaluated and not yet published. In addition, the absence of evidence of efficacy in terms of RCTs for a particular intervention also does not necessarily mean that the intervention does not work, especially if it is based on evidence-based approaches such as CBT. For treatment efficacy, the predominant model has been "empirically supported treatments" [102]. However, recently it has been proposed that clinical treatment decisions should be based on the best available research evidence, a clinician's expertise, and patient characteristics [103]. It has also been argued that RCTs evaluating interventions should focus on evaluating intervention principles rather than each actual implementation [104]. However, unlike therapists who require accreditation to practice an evidence-based approach such as CBT, no such accreditations currently exist for Web-based programs. Hence, any Web-based program can claim to be based on CBT, but may not fulfil all

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requirements and therefore not work, which is especially problematic for programs requiring an access fee. Therefore, programs should ideally undergo appropriate empirical evaluation before being made available online. The development of an accreditation service for Web-based interventions may help improve this issue and enable consumers to make more informed decisions. It is also important to acknowledge competing interests within the eHealth space. Developers with a commercial focus may not be as concerned about treatment efficacy and researchers developing programs may not have the resources to sustain a publically available program. For programs for which published empirical studies were identified in this review, there was a large variety of study designs and quality of evidence. Only This Way Up programs, MoodGYM, myCompass, Beating the Blues, and FearFighter underwent rigorous evaluation through RCTs.

#### Limitations

In regard to this study, a few limitations have to be noted. The representativeness and comprehensiveness of the search and identified programs may be affected by various characteristics of the Web, search engines, and search terms. First, the ranks of websites vary by location on commercial search engines. The search for this review was performed in the UK and it is likely that the same search in another country may have yielded different results. The Web and search engines are also dynamic. Results of search engines vary over time, meaning searches conducted several months before or after the current search could present a different set of programs. In addition, currently existing programs may change or be discontinued and new programs may be released. It is also possible that some individuals may not use the three search engines and would have therefore received different results. However, a considerable strength of this review is that the three most popular search engines were used.

Secondly, the first 25 hyperlinks from the search were included in this review. It is likely that more programs are available, which at the time did not have the page ranking to be identified by the search. This may especially be the case for recently created services [105]. However, it has been suggested that most people rarely consider more than the first 20 links [40]; thus the identified sample of this review is believed to be representative of what an average Internet user might discover when searching the Web for Web-based intervention options. Page ranking is also influenced by various search engine optimization techniques, algorithms of the search engines, as well as cookie settings of the browsers [106], and thereby impacts the results of the search. To combat this, we removed search engine histories and cookies were disabled on all three browsers. While this may not be a complete list of currently available Web-based programs for anxiety, it is a comprehensive snapshot of programs found in March 2015.

Third, the program evaluation scale used was an adapted version of the scoring system used by Renton et al [37]. However, the summative scores do not account for the fact that items within this scale may not be equivalent in terms of importance. Using different weightings based on importance would add great value to the rating. The development of such a scale was considered

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beyond the scope of this review; however, it would be important to develop a weighted scale for similar future reviews.

Lastly, it is important to acknowledge that the definition of Web credibility is complex and consists of multiple dimensions [107]. In the case of this paper, only a limited number of credibility dimensions that focused on trustworthiness rather than expertise, were assessed.

#### Conclusion

This review found that individuals searching for Web-based intervention programs for anxiety are presented with a large number and variety of potential programs to choose from. For consumers with limited knowledge about intervention quality criteria it may be challenging to choose an appropriate program. With the number of people using the Internet increasing, it is likely that more individuals will search for information about treatments options in general and, specifically, online interventions. It is therefore important for health professionals working with mental health clients to be aware of the diversity of Web-based interventions and that not all have had their efficacy tested in robust research trials. Directories such as Beacon can assist clinicians, as well as individuals in this task; however, it is important to keep services like these up-to-date. There is a definite need for consistent guidelines and standards on developing and providing Web-based mental health intervention programs for professionals and a platform with reliable up-to-date information for professionals and consumers about the quality and accessibility of Web-based interventions. This review is the first to identify and review Web-based anxiety interventions available on the Web. Therefore, research is needed in reviewing and evaluating Web-based intervention programs for other mental health related issues. There is also a need to develop standardized evaluation scales for publically available Web-based intervention programs to facilitate the rating process and ensure its rigor. For future research, it may also be interesting to explore health professionals' and consumers' experiences and perceptions of those programs.

#### Acknowledgments

We would like to thank all the authors of the interventions who provided us with free access to their Web-based interventions and additional information, such as relevant publications.

#### **Conflicts of Interest**

None declared.

#### Multimedia Appendix 1

Search log. [XLSX File (Microsoft Excel File), 490KB - mental\_v3i2e14\_app1.xlsx]

#### **Multimedia Appendix 2**

Screenshots of programs.

[PDF File (Adobe PDF File), 3MB - mental\_v3i2e14\_app2.pdf]

#### Multimedia Appendix 3

Program evaluation scores.

[XLSX File (Microsoft Excel File), 15KB - mental\_v3i2e14\_app3.xlsx ]

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#### Abbreviations

**CBT:** Cognitive behavioral therapy **IPT:** Interpersonal Therapy **RCT:** Randomized controlled trial **GP:** General Practitioner

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#### **Original Paper**

# Do Patients Look Up Their Therapists Online? An Exploratory Study Among Patients in Psychotherapy

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# Abstract

**Background:** The use of the Internet as a source of health information is growing among people who experience mental health difficulties. The increase in Internet use has led to questions about online information-seeking behaviors, for example, how psychotherapists and patients use the Internet to ascertain information about each other. The notion of psychotherapists seeking information about their patients online (patient-targeted googling, PTG) has been identified and explored. However, the idea of patients searching for information online about their psychotherapists (therapist-targeted googling, TTG) and the associated motives and effects on the therapeutic relationship remain unclear.

**Objective:** This study investigated former and current German-speaking psychotherapy patients' behavior and attitudes relating to TTG. In addition, patients' methods of information gathering, motives, and success in searching for information were examined. Furthermore, patients' experiences and perceptions of PTG were explored.

**Methods:** Overall, 238 former and current psychotherapy patients responded to a new questionnaire specifically designed to assess the frequency, motives, use, and outcomes of TTG as well as experiences and perceptions of PTG. The study sample was a nonrepresentative convenience sample recruited online via several German-speaking therapy platforms and self-help forums.

**Results:** Of the 238 former and current patients who responded, 106 (44.5%) had obtained information about their therapists; most of them (n=85, 80.2%) had used the Internet for this. Besides curiosity, motives behind information searches included the desire to get to know the therapist better by attempting to search for both professional and private information. TTG appeared to be associated with phases of therapy in which patients felt that progress was not being made. Patients being treated for personality disorders appear to engage more frequently in TTG (rphi = 0.21; P=.004). In general, however, information about their information searches.

**Conclusions:** Patients appear to engage in TTG to obtain both professional and private information about their psychotherapists. TTG can be viewed as a form of client-initiated disclosure. It is therefore important to include TTG as a subject in therapists' education and also to raise awareness within patient education. This investigation provides the first findings into TTG to begin debate on this subject.

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#### KEYWORDS

therapist-targeted googling; patient-targeted googling; Internet; patient-therapist relationship



# Introduction

The Internet has become firmly established as a source of information for health-related issues. According to the Internet user demographics published in 2014, an estimated 87% of US adults use the Internet. In 2012, 72% of US Internet users went online to search for health-related information [1]. Similar results were demonstrated in a national survey conducted in Germany, where more than two-thirds of Internet users had accessed health information online [2].

Research has also specifically focused on the use of the Internet among people who experience mental health difficulties, where common use of the Internet for health-related information was found [3]. Further research concentrating on attitudes has shown that more than 40% of people would use the Internet as a medium for seeking help in case of psychological distress [2].

The significant increase in Internet use within health care, in particular for information seeking purposes, is evident [4]. However, some behaviors relating to information seeking have received minimal research attention. One such area is how patients use the Internet to search for information about psychotherapists.

To date, online information seeking between patients and therapists has only been investigated from the therapist's perspective [5,6,7]. Previous studies have shown that despite the potential ethical complexities, 40% of therapists have used the Internet to search for various types of patient information (patient-targeted googling, PTG) [7]. The notion, however, of patients seeking information online regarding their therapists (therapist-targeted googling, TTG) has not yet been investigated. Furthermore, motivations for TTG and the potential effects on the therapeutic process remain unclear.

The psychotherapeutic process requires patients' openness when working with therapists. Patients disclose private emotions and share personal experiences often with the expectation that this type of information sharing will not be reciprocated. Nevertheless, the widely debated subject of therapist self-disclosure has highlighted that the sharing of information is not always unidirectional and that therapists have been shown to engage in different forms of disclosure [8]. Ziv-Beiman (2013) provides an extensive review of the varying and often opposing theoretical standpoints of therapist self-disclosure within the different schools of psychotherapy. According to Ziv-Beiman (2013), psychodynamic approaches have traditionally opposed self-disclosure on the grounds of preserving the correct setting for analysis, whereas humanistic approaches have encouraged self-disclosure to promote the therapist's authenticity [9].

The current acceptance or rejection of self-disclosure generally centers on the ethical implications and potential consequences of information sharing. Arguments in favor of self-disclosure claim that controlled information sharing can have potential benefits on the therapeutic process [10] and can be used successfully as a form of integrative intervention [9]. Patients have reported that therapist self-disclosure can help resolve imbalances of power within the therapeutic relationship and

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therefore empower the patient, provide reassurance, and offer new perspectives [11,12]. Positive effects of disclosure have also been found within Internet-based therapeutic relationships where occurrence of therapist self-disclosure was positively correlated to treatment outcome [13].

However, patients have also highlighted concerns including the need for therapists to maintain professional boundaries [11]. Arguments against self-disclosure underline ethical concerns, in particular the balance between beneficence and nonmaleficence as well as the dangers of inappropriate disclosures. The potential risks and implications of self-disclosure are particularly apparent when the individual circumstances of the patient and the therapists' motivations are not carefully considered [14]. For example, patients who display particular characteristics, symptoms, or vulnerabilities may be easily influenced by or indeed show a desire to accommodate the therapist's perspectives [8].

Research has also focused on identifying, categorizing, and investigating various types of self-disclosure. Zur (2008) identified 5 different types of self-disclosure such as deliberate, unavoidable, accidental, inappropriate, and client initiated [15]. Deliberate self-disclosure refers to the therapist's "intentional disclosure of personal information" (Zur, 2008, p. 82), for example, placing specific family photos in the office or empathic gestures such as a certain touch or sigh. In addition, the therapist may make unavoidable disclosures, for instance via physical attributes (tattoos, pregnancy, obesity, and so forth). Spontaneous verbal and even nonverbal encounters and occurrences can allow patients to gather information about their therapist, which Zur refers to as accidental disclosure. When patients are given greater access to information than necessary, it is regarded as inappropriate self-disclosure. Sometimes patients themselves start gathering information about the therapist, which Zur described as client-initiated self-disclosure, the subject of this study [15].

Zur et al (2009) later described 6 ways in which patients can potentially access information about their therapist online via the therapist's official Web page, information searches via search engines, by joining social networks, via professional list servers and therapist chat rooms, by paying for legal online background checks of the therapist (which rely on public access records), or by paying for illegal and highly invasive searches (such as trying to find financial and tax records, or sealed criminal records, through methods that contravene the law) [16].

This study aims to investigate to what extent both former and current patients initiate therapist self-disclosure by gathering information via TTG. Furthermore, this study aims to examine patients' perspectives on the potential effects of TTG. The following focus areas were established to investigate these aims: (1) various sources used by patients for gathering information about psychotherapists; (2) the type of information gathered; (3) reasons for gathering information and the success of information searches; (4) how gathered information is used; (5) patients' perceived consequences for the therapeutic process; and (6) patients' opinions on TTG and PTG.

### Methods

#### Recruitment

Participants for the study were recruited online via several German-speaking therapy platforms and self-help forums. Online surveys are increasingly used within psychological research and can be an effective method of data collection [17,18]. The Sigmund Freud University Ethics Committee approved the study. Participants were informed about the purpose and methods of the study and by completing the questionnaire indicated their consent. Participation in the survey was on a voluntary basis, and permission was attained from the forum moderators before posting the survey. The survey took around 10 minutes to complete. The forums were selected to best access a cross-section of both former and current patients, from a wide range of psychological conditions and from different age groups. For example, to target adolescent and young adult patients, self-harm forums were specifically selected

because of the high prevalence rates among this particular age group [19]. The sole inclusion criterion for participation in the study was that participants were either currently undergoing psychotherapeutic treatment or had received treatment within the past 5 years. Anyone who answered "no" to this item in the questionnaire was excluded from the analysis.

#### Sample

Data collection was conducted over a period of 4 weeks. At the end of this period, the nonrepresentative convenience sample comprised 238 former or current patients (189 women, 79.5%). The mean age was 34.9 (standard deviation = 13.8) years.

#### Questionnaire

The questionnaire included 32 items in total and was structured into a main section and an additional section (Table 1).

The questionnaire was Internet-based and generated with the online tool Unipark [20].

Table 1. Main and additional sections of the online questionnaire including example questions.

Topic (main section)	Example questions and/or type of data collected		
Sociodemographic data	Gender, age, family status, experience of psychotherapy		
Searching for information about therapists	Have you ever made enquiries about your therapist?		
	What type of information were you looking for?		
Using the Internet to conduct an information search about the therapist	How have you used the Internet to search for information about your therapist?		
Perceived therapists' reactions	Is your therapist aware that you searched for information about them online?		
	How did your therapist react when you told them? (open answer)		
Contact with therapists via social networks	Have you ever had contact with your therapist via social media?		
Perceived changes in the therapeutic relationship and therapy success as a result of online research	Did your relationship toward your therapist change after you performed an online search about them? (Yes/no/possibly, with opportunity for open answers)		
Attitudes and feelings relating to online research	What is your opinion on using the Internet to gather personal information about a therapist? (Positive/negative/neutral, with opportunity for open answers)		
Topic (additional section)	Data collected / Example questions		
Experience of patient-targeted googling (PTG)	Are you aware of your therapist having ever performed an online search about you?		
Attitudes toward patient-targeted googling (PTG)	Do you believe PTG influenced the therapeutic process? (No influence/positive influence/negative influence, with opportunity for open answers)		

#### **Statistical Analysis**

In addition to descriptive statistical methods, inferential statistical methods (correlation coefficient and chi-square distribution analysis) were used to analyze the closed questions. The open questions were evaluated using Mayring's Qualitative Content Analysis [21]. This intricate procedure ensures that answers are analyzed and interpreted paying particular attention to "origin and effect" (Mayring, 2014, p39). For the purpose of this study, the method of summarizing was used. Following Mayring's methodology, inductive categories were assigned to the open answers therefore creating a set of categories that were used for interpretation. The data were analyzed using the SPSS Statistical Package for the Social Sciences (IBM, version 19, Armonk, NY: IBM Corp) and PASW Predictive Analysis Software (version 18, Chicago: SPSS Inc.).

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# Results

#### **Patient Characteristics**

Of the 238 participants included in the study, 100 (42.0%) were single, 58 (24.2%) were married, 53 (22.4%) were in a live-in relationship, 24 (10%) were divorced, and 3 (1.4%) were widowed. The most common form of treatment was cognitive behavioral therapy (n=80, 33.8%), followed by psychodynamic psychotherapy (n=53, 22.4%) and psychoanalysis (n=19, 8.2%), whereas 25 (10.5%) did not know which form of therapy they were receiving. Combined therapies represented 29 (12.3%) of the patients. The self-indicated reasons for consultation included depression (n=140, 58.8%), anxiety disorders (n=55, 23.0%), personality disorders (n=52, 21.8%), and post-traumatic stress disorder and burnout syndrome (n=58, 24.2%).

#### To What Extent Did Former and Current Patients Obtain Information About Their Psychotherapist?

Almost half (n=106, 44.5%) of the respondents had already obtained information about their therapists, although not necessarily from the Internet. Based on the analysis of open questions, the central reason given by the remaining participants who had not sought additional information was the feeling that they could ask the therapist directly for information. Most of the participants (n=146, 61.4%) were in favor of using the Internet to access professional information concerning therapists; in contrast, 52 patients (21.9%) were against. The remaining 40 patients (16.7%) identified as ambivalent toward using the Internet in this way; on the one hand, the Internet was seen as a useful way to gain access to such information; however, handling this information required critical consideration. Searching for private details about the therapist had less support: 176 patients (74.0%) were strongly against this, 15 (6.3%) argued in favor, and the remainder argued that there were both advantages and disadvantages to searching for private information.

# Why Did Former and Current Patients Try to Gain Information About Their Therapists?

Evaluation of the answers to the open questions (where multiple answers were allowed) showed that the main reasons of those (n=106) who gained information about their therapists were curiosity (n=50, 47.2%), looking for the right kind of therapist (n=44, 41.5%), and trying to get to know their therapist better (n=39, 36.8%). Patients looked for information when their therapy was not progressing successfully (n=38, 35.8%) or when seeking a more personal relationship with the therapist (n=20, 18.8%).

#### To What Extent Did Former and Current Patients Use the Internet to Obtain Information About Their Psychotherapists? Was There Any Correlation between the Manner of Searching and Sociodemographic Data? Which Information Sources Did Patients Predominantly Use?

Of the participants who had obtained information about their therapist (n=106), most (n=85, 80.2%) had used the Internet for

this. Other methods for obtaining information (multiple answers were possible) included asking their general physician (n=19, 17.9%) and seeking help from fellow patients (n=15, 14.1%). The influence of sociodemographic variables on TTG was examined. After detailed analysis of the conditions, a weak correlation was found between being treated for personality disorder and searching for the information via the Internet (rphi = 0.21; P=.004). Nonsignificant variables included family status ( $\chi^2_{(4)}$ = 6.82, P=.15), form of therapy ( $\chi^2_{(4)}$ = 4.93, P=.29), age ( $r_s$ = -0.05, P=.67), and gender (r phi = 0.02, P=.85).

The most used method (multiple responses were permitted) for seeking online information about the therapist was via a search engine such as Google (n=68, 80.0%). Other common sources of information were the therapists' professional Web pages (n=40, 43.5%) and review sites of physicians (n=31, 36.4%); 15 patients (17.6%) said they had used social networks to find information about their therapist. There was a significant correlation between the age of respondents and the use of social networks for research ( $r_s$ = -0.26; *P*=.026): As might be expected, younger respondents (17-24 years) were more likely to use social networks for obtaining information about their therapist.

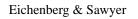
#### What Type of Information Did Former and Current Patients Seek on the Internet and With What Degree of Success?

Overall, 74 participants answered these 2 questions. As shown in Table 2, the most favored subjects for research were the therapists' professional experience followed by their curriculum vitae and professional development. This was followed by searches regarding personal information such as marital status, family and friends, pictures, private address, or phone number. Eleven patients (14.9%) indicated that they had viewed their therapist's house using Google Streetview (an interactive tool for viewing photographs of actual streets and buildings). The information actually found by the patients on the Internet deviated markedly from the information they were seeking (Table 2).

Table 2.	Types of information that former an	nd current patients searched	for and actually found.
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Type of information	Number (%) of patients who searched for the information (n=74)	Number (%) of patients who actually found the information (n=74)
Professional experience	54 (73.0)	28 (37.8)
Curriculum vitae and professional development	46 (62.2)	25 (33.8)
Recommendations and criticisms	46 (62.2)	15 (20.3)
Personal comments	24 (32.4)	8 (10.8)
Marital status	20 (27.0)	14 (18.9)
Hobbies	15 (20.3)	6 (8.1)
Family and friends	8 (10.8)	6 (8.1)
Private pictures	8 (10.8)	3 (4.1)
Private address and telephone number	5 (6.8)	2 (2.6)

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#### To What Extent Did Former and Current Patients Talk to Their Therapist About Their Online Research? What Did They Consider to Be the Consequences of Obtaining the Information for the Therapeutic Relationship and Therapeutic Success?

Few participants (n=7, 8.2%) had talked to their therapist about their online research beforehand or asked for the therapist's permission. A greater number (n=17, 19.9%) informed the therapist after their research; according to the participants' descriptions (n=9), most of the therapists reacted positively. With respect to the question of whether the research was helpful for the therapeutic process, 31 participants (36.5%) agreed that it was. Reading positive online reports by other patients about their therapist was cited as an important reason to feel more comfortable and secure in knowing that they had made the right choice of therapist.

Finding information about therapists' personal characteristics was seen as resulting in a positive increase in the therapeutic relationship. Furthermore, access to this information was perceived as beneficial to the therapeutic process. Some participants (n=15, 17.6%) reported that online research had affected the relationship between patient and therapist, indicating 4 major areas of change as follows: a feeling of greater security, greater confidence in their relationship with the therapist, a sense of being better informed about the therapy, and a sense of greater openness due to the information gained about the therapist's professional knowledge and skills. Overall, however, many participants (n=70, 82.4%) said that searching for information about their therapist.

### What Were the Attitudes and Experiences of Former and Current Patients Regarding the Possibility of Their Therapist Engaging in Ptg?

Most (n=219, 92.0%) of the participants who completed the questionnaire were not aware of PTG beforehand. In fact, only 13 (5.5%) had thought about their therapist potentially using the Internet to gain information about them. Content analysis of the open responses provided positive and negative perspectives of PTG (Textbox 1).

Textbox 1. Response categories and sample answers relating to patients' attitudes and feelings toward patient-targeted googling (PTG)

<b>Atbox 1.</b> Response categories and sample answers relating to patients' attitudes and feelings toward patient-targeted googling (PIG)
egative response categories and sample answers relating to PTG (n=74 open answers provided)
desire for self-controlled disclosure (n=25)
"I would like my therapist to ask me for information and not to search for it online."
"I want to decide when and who I tell things"
desire to protect privacy (n=18)
"My privacy would be violated"
"It is a private matter"
oncerns about therapists gaining a wrong impression due to available online information (n=7)
There may be rumors circulating online that could influence the therapist"
"The therapist should not create an impression of the patient beforehand"
breach of confidence (n=7)
"I think it is a betrayal of trust"
"I would feel spied upon"
reating a feeling of insecurity (n=7)
"It makes me feel insecure"
"I would not have a good feeling about it"
ther (n=10)
"I don't understand the sense in it"
"I prefer to remain anonymous"

# Discussion

### **Principal Findings**

This study aimed to investigate the extent to which patients engage in therapist–TTG, the various means of TTG, and patients' perspectives on the effects of TTG.

People are increasingly using the Internet for health-related purposes [2]. This increase has opened discussions surrounding how patients and clinicians use the Internet to seek information about each other. Although PTG has received research attention

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[5,6,7] the use of patients seeking information about therapists (TTG) has to date not been investigated. The notion of TTG is particularly relevant for client-initiated disclosure (patients gathering information about their therapist); however, it is also relevant for both accidental and deliberate self-disclosure (for example, therapists placing information on the Internet). All forms of therapist disclosure are widely debated within psychotherapy because of the potential positive and negative effects. As a consequence, TTG has the potential to be both beneficial and detrimental to the therapeutic process. For instance, patients accessing more information than necessary

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about their therapists via the Internet would represent an inappropriate disclosure.

Results from this study indicate that most patients who had researched therapists (80, 2%) did so online. The reasons for TTG are varied. Aside from curiosity and trying to find a suitable therapist, patients may engage in TTG to try to get to know their therapist better. This process can include searches for both professional and personal information. Results indicate that patients may look for information when their therapy is not progressing well or to foster a more personal relationship with the therapist. Furthermore, if patients have engaged in TTG, most of them refrain from disclosing this to their therapist.

The availability of information on the Internet affects the success of client-initiated disclosure. It appears that although patients may search for professional of personal information surrounding the therapist, in practice, they seem only to be partially successful as only some of the desired information is available online. This includes both professional and personal information. This may be because therapists have made arrangements to limit the success of online research by their patients [7]. However, therapists will only partially be able to control the available information about them, for example, it is difficult for them to influence the information other patients publish about them or what family and friends post in social networks. The same applies to work-related activities outside of the therapeutic practice, such as lecturing.

Therapists themselves have been shown to use self-disclosure as a form of intervention [22,9]. These deliberate disclosures can include the sharing of biographical information, personal experiences and insights, as well as opinions surrounding the therapeutic process [10]. Research to date has focused on how these deliberate disclosures take place within therapy sessions and the effectiveness of their implementation as a form of intervention, as opposed to the potential use of information found on the Internet as a form of intervention. Currently guidelines for psychotherapists' self-revelation exist, covering ethical aspects and clinical benefits [23]. Unfortunately, the guidelines provide no evidence or reflections on self-revelation via information on the Internet.

Similarly, empirical findings disagree about the effects of therapists' self-disclosure. Although numerous psychotherapy research studies have identified reasons, correlations with patients' characteristics, and in some cases, even moderator variables that determine positive or negative effects on patients [8], there has been no empirically based information reported about the effects of patients engaging in TTG. Results from this study indicate that one-third of patients who engaged in TTG reported positive effects from gathering personal information. Overall, most patients did not perceive any particular effect on the therapeutic relationship. However, these findings need to be complemented by studies that use established psychotherapy research methods (eg, the use of standardized scales to measure the quality of the therapeutic relationship in a longitudinal survey of patient-therapist dyads). Furthermore, more detailed consideration of patient demographics such as diagnosis needs to be considered within longitudinal studies.

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Results of this study also allow for comparisons to be made between PTG (conducted by therapists) [7] and TTG (conducted by patients). Both parties appear to share similar opinions relating to arguments for and against PTG. Arguments for PTG are seen as beneficial to the therapeutic relationship. In general, however, patients and therapists arguing against PTG suggest that undisclosed information that has been gathered nonconsensually has the potential to impact negatively on the therapeutic relationship. Regarding TTG, previous research shows that 54.6% of therapists were aware of being researched online or were content with the notion of TTG [7]. This study supports this result with similar findings; 44% of patients researched their therapists, 80.2% of these searches were conducted online. Furthermore, therapists have previously reported concerns about privacy violations from TTG and the control of information on the Internet. Some of these concerns, however, may be unwarranted as most patients disagreed with conducting TTG to seek private information.

#### Limitations

In general, TTG is rarely discussed and has not previously been subject of research. The present survey should therefore be understood and interpreted as an initial explorative study. The online methodology used for data collection means the present sample cannot be considered representative of all patients in receipt of psychotherapy. Recent demographic data does, however, suggest that 1 in 5 Internet users have gone online to engage in peer-to-peer health support, for example, via Internet forums and groups [24]. However, despite the growing use of the Internet among patients [1,2,3,4], further investigation conducted among non-internet-based clinical populations is essential before generalizations can be made. In addition, due to the fact that participants were recruited via the Internet, a theoretical bias toward participants particularly interested in Internet research may exist; a factor that may have influenced their decision to participate in the study.

Furthermore, although therapists' perspectives on patients retrieving personal information from the Internet about them has been explored in a parallel study [7], the patient-therapist dyad has not specifically been explored. This should be addressed in future studies.

#### Implications

It is important to provide consideration of PTG and TTG as a future subject within therapists' education and training [7] and as part of the information provided to patients. In general, if dealing with modern media in the context of psychotherapy arises explicitly in the initial therapy sessions (eg, if the therapist offers to the patient that he or she can be reached via email or short message service, the therapist integrates eMental Health applications into therapeutic practices, or the patient desires it), further discussion of the potential need for reciprocal Internet searches would be appropriate. In this context, the therapist should assure that information about the patient online would not be obtained without the patient's consent, and at the same time, convey to the patient that in certain phases of therapy, it is understandable that the patient may develop a desire to learn more about the therapist as a person. Creating a climate in which, through transparency, the therapeutic relationship is

strengthened so that appropriate desires and impulses are able to be discussed, would pave the way for both an open and constructive approach to this need and, in the case of PTG, to a discussion of the information about the patient gathered online. The fact that the therapist's private use of the Internet could lead to precarious situations within the therapeutic process (eg, through the therapist's use of online dating platforms) [25], may thus, at least to some extent, be approached.

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#### **Conflicts of Interest**

None declared.

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#### Abbreviations

**PTG:** patient-targeted googling **TTG:** therapist-targeted googling

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**Original Paper** 

# Community Structure of a Mental Health Internet Support Group: Modularity in User Thread Participation

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# Abstract

**Background:** Little is known about the community structure of mental health Internet support groups, quantitatively. A greater understanding of the factors, which lead to user interaction, is needed to explain the design information of these services and future research concerning their utility.

**Objective:** A study was conducted to determine the characteristics of users associated with the subgroup community structure of an Internet support group for mental health issues.

**Methods:** A social network analysis of the Internet support group BlueBoard (blueboard.anu.edu.au) was performed to determine the modularity of the community using the Louvain method. Demographic characteristics age, gender, residential location, type of user (consumer, carer, or other), registration date, and posting frequency in subforums (depression, generalized anxiety, social anxiety, panic disorder, bipolar disorder, obsessive compulsive disorder, borderline personality disorder, eating disorders, carers, general (eg, "chit chat"), and suggestions box) of the BlueBoard users were assessed as potential predictors of the resulting subgroup structure.

**Results:** The analysis of modularity identified five main subgroups in the BlueBoard community. Registration date was found to be the largest contributor to the modularity outcome as observed by multinomial logistic regression. The addition of this variable to the final model containing all other factors improved its classification accuracy by 46.3%, that is, from 37.9% to 84.2%. Further investigation of this variable revealed that the most active and central users registered significantly earlier than the median registration time in each group.

**Conclusions:** The five subgroups resembled five generations of BlueBoard in distinct eras that transcended discussion about different mental health issues. This finding may be due to the activity of highly engaged and central users who communicate with many other users. Future research should seek to determine the generalizability of this finding and investigate the role that highly active and central users may play in the formation of this phenomenon.

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#### **KEYWORDS**

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internet; support group; social network; modularity; mental health; super user

# Introduction

Online peer-support is a popular source of health information and social support. Findings suggest that in a 1-year period, 18% of the Internet users in the USA sought information online that was provided by a peer [1] and 8% actively sought a response or provided support to another peer by engaging in an online health community [2]. Annually, 28% of Internet users have sought mental health specific information online [3]. Consequently, Mental Health Internet Support Groups (MHISGs) can comprise thousands of users who are actively participating to varying degrees [4,5]. MHISGs are popular and have high potential to play a role in the management of mental illness. Research on MHISGs must address various questions concerning the nature of MHISGs such as "Who uses them?" and "How are they used?" in order to fully benefit from this potential [6]. Recent research on the demographic characteristics of MHISG users has identified differences in prevalence, engagement, and retention of users with different characteristics, such as age, gender, location and consumer or carer status [Personal communication by Kathleen M Griffiths, 2016]. This information is important in understanding to whom do MHISGs have greater appeal. The willingness to engage and the outcome of participating in the MHISG may be different for each user depending on whom they interact with, however, it is also important to understand the social dynamics of how users engage with each other.

From a sociological perspective, the principle of homophily suggests that those who group together, in this instance by communicating most often with each other, tend to share common characteristics [7]. If the premise of peer-support is a shared experience, then it is plausible that homophily may be an important underlying factor in the community structure of the MHISG, that is, the community structure of the MHISG may comprise various subgroups, each consisting of users with higher proportions of shared characteristics than in other subgroups.

Many characteristics may affect the formation of subgroups in the MHISG, with some being more relevant than others. The most commonly observed factors influencing the people in interaction are age, gender, and location [3]. These factors are also influential across large-scale online social networks [4]. Specifically, in the domain of MHISGs, there are other factors, which may be important. Different mental health conditions are characterized by different symptoms and experiences [8]. From a psychological perspective, these are fundamental distinctions and they form the basis for different treatments. One might hypothesize that users in the MHISG with similar health concerns would seek to interact with each other, that is, people with depression concerns would provide peer-support to other people with depression, and not anxiety. However, people engaging in peer-support through MHISGs have the autonomy to interact with whomever they choose. These naturally occurring dynamics are currently unknown and a greater understanding of this area is needed. This information may empower community managers to take informed decisions concerning the design of MHISGs. Understanding these natural inclinations also provides a basis for future research to design

studies and form hypotheses about relevant factors, which if altered, may affect the outcome of participation and subsequently the potential utility of these communities.

To determine user grouping among the social network of the MHISG, it is recommended to conduct an analysis of its modularity [9]. Modularity is a measure that identifies subgroups in a social network by applying an algorithm designed to find a structure, which optimizes the number of communications within each module compared with the number of communications between different modules. The result of such an algorithm is the assignment of nodes (users) to modules (subgroups), which have a greater density of edges (communications) between them compared with nodes in other modules. It may be possible to use this algorithm in order to determine subgroups of users who engage in higher amounts of peer-support with each other than other users. Using these groups as an outcome, it may be possible to determine whether certain user characteristics are associated with those groupings. To the best of our knowledge, no study has yet investigated modularity in the MHISG. This study aims to determine the community structure of the MHISG through modularity and to explore the user characteristics associated with the resulting structure.

## Methods

#### BlueBoard

The data used in this study were obtained from the publicly available Internet support group-BlueBoard (blueboard.anu.edu.au) established by the National Institute of Mental Health Research at the Australian National University. BlueBoard users must register and provide consent for their data to be used for research in order to participate in the MHISG. Peer-to-peer discussion on BlueBoard takes place anonymously via forum postings, which cover a range of topics, including depression (38.8% of posts), bipolar disorder (18.4%), generalized anxiety disorder (5.0%), chitchat and general discussion (22.1%), and other topics (15.7%). Posts dated between October 1, 2008, and May 23, 2014 were included in this study and were in a thread with posts given by two or more users (n=130,582 by 2652 users). BlueBoard is moderated by paid personnel who monitor content and enforce rules, for example, by editing posts to remove personally identifying information. BlueBoard moderators do not operate as facilitators of conversation, but post content occasionally regarding rules or other administrative matters. Moderator posts (n=352 by 10 moderators) were not included in the analysis. Data collection procedures were approved by The Australian National University Human Research Ethics Committee.

*Measures*. User characteristics included age (measured in 5 year brackets, eg, 25–29); gender (female, male); type of user (consumer, carer, other); location (capital city, other city, rural or remote region); registration date; and the number of posts in each of the subforums of BlueBoard (depression, generalized anxiety, social anxiety, panic disorder, bipolar disorder, obsessive compulsive disorder, borderline personality disorder, eating disorders, carers, general (eg, "chit chat"), and suggestions box).

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Age, gender, location, and type of user were self-identified at the time of registration on BlueBoard. The last recorded activity of users was not more than 1 month or 1 year post registration for 86 and 97% of users respectively, thus suggesting that the data likely remained accurate for the majority of users throughout the period of the study. Data on age was grouped into three categories (<25, 25-34, >34) for the analysis to eliminate singularities in the Hessian matrix occurring in brackets above 60 years, with low counts. The three age categories contained approximately one-third of the users each. The term "consumer" refers to a person with depression, anxiety, or other mental health problems, and the term "carer" refers to a nonprofessional carer. The frequency of the posts in each of the subforums was tallied during the entire study duration, that is, from October 1, 2008 to May 23, 2014 for all subforums except the obsessive compulsive, borderline personality, and eating disorder forums, which were established on the June 1, 2009, March 1, 2010, and July 30, 2012, respectively.

### **Data Analysis**

*Modularity.* Social network analysis was undertaken using Gephi 0.8.2. software [10]. Edges within nodes were defined as undirected communications between each user who had posted in the same thread. The modularity algorithm utilized was the widely-used Louvain method [11], which has the fastest computational time of any comparable algorithm and excellent performance in detecting communities [12]. The resolution was set to the default value 1.0 as this provided the highest modularity score (0.273).

*Multinomial Logistic Regression.* A multinomial logistic regression analysis was conducted to determine the user factors

Table 1. Module sizes

that were significantly associated with the modularity outcome. There were 449 individuals who left at least one of the demographic questions unanswered while registering for BlueBoard. Little's Missing Completely at Random test was not significant, indicating that the data was missing completely at random; accordingly, they were not included in the analysis.

*Visualization.* In order to explore the results patterns, graphs of the data underlying significant effects were created using pivot tables and charts in Microsoft Excel. To further explore the temporal factor associated with the registration date, a dynamic social network analysis was conducted. This required a timestamp to be associated with the creation of each edge in the social network. The time associated with the creation of each edge was the time a user first posted content in a thread. This edge was created only between the new user and users who had already posted in the thread. A visualization of the edges being created between nodes was generated using Gephi 0.8.2. software and TechSmith Jing screen recording tool [13].

# Results

# Modularity

The modularity algorithm produced 11 separate modules (See Table 1), out of which 6 modules contained less than 10 users. The latter modules were isolated from the giant component of the social network as they involved threads in which only new users not connected to the larger social network posted. The remaining 5 modules comprised between 328 and 954 users, which made 1977 and 67,590 posts, cumulatively. All subsequent analyses are concentrated on these five main modules as outcomes.

Module	N (%)	Posts	
1	434 (16.4)	1977	
2	954 (36.0)	15,954	
3	393 (14.8)	39,720	
4	525 (19.8)	67,590	
5	328 (12.4)	5300	
6	8 (0.3)	27	
7	2 (0.1)	2	
8	2 (0.1)	2	
9	2 (0.1)	5	
10	2(0.1)	3	
11	2 (0.1)	2	
Total	2652 (100)	130,582	

# **Multinomial Logistic Regression**

Multinomial logistic regression is used to finds the odds of being allocated to each of the different dependent variable outcomes based on a number of factors as predictors. In this analysis, the outcomes were the five different modules. One of the outcomes should be used as a reference category for comparison with the

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other outcomes. In this case, we chose to use Module 4 because its users had contributed the highest number of posts. This decision was made before obtaining any knowledge regarding the number order, we labeled them with. In multinomial logistic regression each of the factors are used to predict the relative odds of persons from the reference group and the comparison group being allocated to each of the two groups as the predictive

factors change. In this analysis, several significant effects were found and each of the parameter estimates is shown in Table 2. In this table, the odds ratios, which are the exponents of B, show the relative odds of being allocated to each outcome group as compared with the reference module (thus Module 4 is not included).

With respect to all independent variables in the analysis as predictors of the modularity outcomes, for each unit change, the odds of a person being allocated to the comparison group as opposed to the reference group changes by a factor of the odds ratio. As such, an odds ratio of < 1 indicates that as the

score of the predictor increases, the odds of a person being included in the comparison module decreases. An odds ratio > 1 indicates that as the score of the predictor increases, the odds of a person being included in the comparison module increases.

Overall, the final model fits the data significantly better than the null model (Chi square = 4146.4, p<.001). The classification accuracy of the model was 84.2% and the effect size was large (Nagelkerke  $R^2$ = 0.891). The addition of one variable, registration date, improved the model classification accuracy by 46.3%. Without this variable, the effect size was much smaller (Nagelkerke  $R^2$ = 0.119).

**Table 2.** Significant parameter estimates for the multinomial logistic regression of registration date, age, gender, location, type of user, and frequency of posts in the subforums on the dependent variable modularity.

Module <sup>a</sup>	Predictor	В	Standard error	Wald	p <sup>b</sup>	Odds ratio
1	Registration date	-0.033	0.001	620.975	<.001	0.968
	Subforum: depression	-0.048	0.018	7.063	.008	0.953
	Subforum: carers	-0.782	0.280	7.834	.005	0.457
2	Registration date	-0.022	0.001	403.895	<.001	0.978
	Subforum: generalized anxiety disorder	-0.082	0.028	8.402	.004	0.921
	Subforum: borderline personality disorder	0.069	0.026	7.272	.007	1.071
	Subforum: suggestions	0.437	0.217	4.061	.044	1.548
3	Registration date	-0.009	0.001	171.921	<.001	0.991
	Subforum: suggestions	-0.165	0.075	4.750	.029	0.848
5	Registration date	0.008	0.001	149.971	<.001	1.008

<sup>a</sup>Module 4 was used as the reference category

<sup>b</sup>All effects degrees of freedom = 1

*Registration Date.* There was a significant parameter estimate for the relationship between registration date and each of the module outcomes as shown in Table 2. For comparing Modules 1-3 with the reference group, the odds ratios of registration date have values < 1. This indicates that a person would be 0.968, 0.978, and 0.991 times as likely to be included in the groups 1-3, respectively, compared with the reference group (Module 4) for each day post registration. The opposite was true for Module 5 relative to the reference group. This indicates that a person would be 1.008 times more likely to be included in Module 5 than Module 4 for each day post registration.

*User Characteristics.* Across the three demographic variables and user type, there were no significant parameter estimates.

*Frequency of Posting in Subforums*. Based on the frequency of posts in the 11 different subforums, there were 6 significant parameter estimates across 5 different subforums. These are shown in Table 2. For the comparison of Module 1 with the reference group, the odds ratios reveal that posting more in either the depression subforum or the carers subforum indicated that a person was more likely to be included in the reference group, the odds ratios more in the generalized anxiety disorder subforum indicated that a person was more likely to be included that a person was more likely to be included that a person was more likely to be included that a person was more likely to be included that a person was more likely to be included in the reference group. The opposite was true

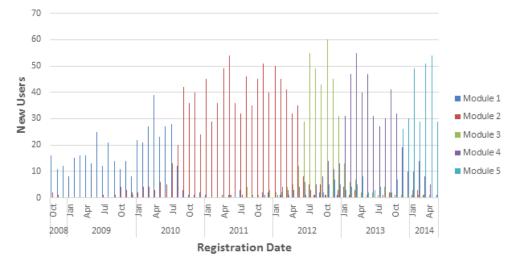
for posting in the borderline personality disorder subforum and suggestions subforum. For the comparison of Module 3 with the reference group, posting more in the suggestions subforum indicated that a person was more likely to be included in the reference group. There were no significant parameter estimates for the frequency of posts in subforums in Module 5.

### Visualization

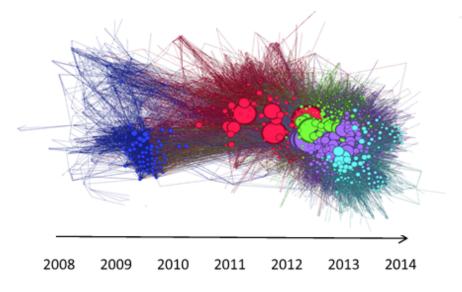
*Registration Date.* The graph shown in Figure 1 displays the number of users who registered with BlueBoard during each month from October 2008 to May 2014. Users are grouped by module. This graph supports the pattern of results found in the regression analysis. It shows that the five modules have five sequential time periods in which most of the users who signed up during that period were classified within that group. The distribution of new registrations in each of the four most recent subgroups loosely resembles a normal distribution.

A video showing the sequence in which edges were created between nodes is available as Multimedia Appendix 1: BlueBoard social network growth time lapse. A graph representing this dynamic visualization is displayed in Figure 2. Both show the progression of new communications occurring between users of BlueBoard, primarily between users of the same subgroup during each era progressing from 1 to 5.

Figure 1. Number of new users who registered each month between October 2008 and May 2014, grouped by module.



**Figure 2.** Graphical representation of the sequence of edges created between nodes. Each node is represented by a colored circle, and the nodes are colored according to their module. The size of each node corresponds to its degree (number of connections with other nodes). The layout was determined by the algorithm ForceAtlas 2 [15]. This algorithm places nodes, which have more edges between them, closer together. The arrow on the graph gives a general indication as to the order in which new edges are added to the network as time progresses.



#### **Further Investigation of Registration Date**

Since modularity was so strongly associated with registration date, we initiated further analyses to investigate the other factors associated with registration date that might explain the modularity pattern. Based on research, which suggests that online community development follows a life-cycle [14] and that certain "core users" play a vital role from the inception of that development [15,16], we hypothesized that there may be highly active and central users whose registration date is earlier than the majority of other users in each module. For this, we tested whether the top 10 users in each module, ranked by (1) total post frequency and (2) eigenvector centrality (a measure of network centrality, which identifies the most influential nodes [17]), registered significantly earlier than the median registration

date for each module. The results of these analyses are presented in Table 3. For total frequency of posts, we found that on average the top ranked users registered significantly earlier than the median registration time in all five modules ( $\alpha < .05$ ). The case for eigenvector centrality was similar, except for the first module. This occurred despite the fact that, across BlueBoard as a whole, there was no significant difference between the average registration date of the top 10 users and the median for either total post frequency (p=.40) or eigenvector centrality (p=.39). In addition, there was no correlation between total post frequency and registration date (Spearman rho = 0.01, p=.60). Contrary to the pattern in each module, there was a significant positive correlation between registration date and eigenvector centrality (Spearman rho = 0.37, p<.001).

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**Table 3.** T-tests of the mean difference (days) between the median registration date in each module and the average registration date of the top 10 users ranked by (1) total post frequency and (2) eigenvector centrality.

	Total post frequency			Eigenvector centrality		
Module	Mean difference (days)	t	p <sup>a</sup>	Mean difference (days)	Т	p <sup>a</sup>
1	272	-3.56	.006	140	-1.15	.28
2	317	-3.34	.009	293	-2.74	.023
3	145	-3.32	.009	123	-2.64	.027
4	347	-5.96	<.001	377	-8.56	<.001
5	55	-2.84	.019	137	-2.85	.019

<sup>a</sup>All effects degrees of freedom = 9

# Discussion

This study constitutes the first social network analysis of a mental health Internet support group in which the community structure was determined quantitatively through analysis of modularity. We investigated whether several user characteristics were associated with the resulting modularity outcome. The findings of this analysis provide a new perspective on how users engage in peer-support in MHISGs.

### **Principal Findings**

We found that the community structure of the Internet support group BlueBoard comprised five main modules. Although there were several statistically significant parameter estimates across the different factors for this outcome, registration date contributed the most to the predictive power of the model. Statistically and visually, this factor stood out in the results. The pattern of results suggests that BlueBoard has progressed through a series of generations or eras. There were some minor differences in these generations in the degree to which their users posted in different subforums, but these frequencies did not differ substantially from the overall frequencies for BlueBoard reported elsewhere [Personal communication by Kathleen M Griffiths, 2016].

These results shed light on the nature of peer-support in MHISGs. They suggest that people who join the MHISG may communicate most with those who register around the same time. While this is not surprising, an important finding is the fact that registration date takes precedence over other factors such as demographic characteristics and type of mental health issue in predicting group membership in the MHISG. It raises the possibility that the social interactions of MHISGs are not largely affected by these characteristics. However, it is too early to draw a definitive conclusion as other factors may underpin the observed results.

In order to interpret the findings of this study, we considered whether artificial factors may have impelled the observed progression through each of the five subgroups. We considered two salient factors—external advertising and internal structural changes. Advertising of BlueBoard has occurred mainly via links from online mental health information hubs such as MindHealthConnect.org.au and bluepages.anu.edu.au. Following BlueBoard's establishment, postcard flyers were soon mailed to general practitioners to be displayed in waiting rooms.

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Subsequently, there has been a gradual increase in the number of user registrations on BlueBoard. Therefore, recruitment did not appear to be a probable explanation. Further, with respect to internal sources, there were three subforums (obsessive compulsive, borderline personality, and eating disorders) that were introduced at different stages after BlueBoard's establishment. As there has been little uptake of these forums and they do not correlate with the progressions between the five subgroups, we did not consider this to be a probable explanation. We are not aware of any other developments or improvements that may have resulted in the observed findings. For this reason, we focused on the pattern of results involving the date of registration by highly engaged and central users in each module relative to the majority of other users. This pattern suggests that these users may have some role in the formation of this generation-like structure. However, further research is needed to test this hypothesis and to investigate if these findings generalize to other MHISGs.

#### **Related Research**

This study involved the first analysis of its kind for the MHISG. However, we are aware of a study involving an Internet support group for diabetes, which conducted a similar analysis [18]. This study sought to determine if a modularity analysis could be applied to an online health community and generate meaningful results by creating a formula, which was designed to measure the quality of the modularity outcome. This formula was based on the principle of homophily [7], such that greater similarity among the characteristics (eg, diagnosis) of users in each module resulted in a higher score. The study found that the modularity outcome was associated with the number of years since a user was diagnosed with the condition, indicating the time elapse since diagnosis was similar for users within each module. If as might be expected, the time a person takes to join an Internet support group after being diagnosed is relatively invariant; the findings of this study may have implications for our own. We did not measure time since diagnosis in our study. However, it is possible that the significant effect of registration date is confounded with and attributable to time since the diagnosis period. Alternatively, the diabetes study results can be explained by time of registration.

Our results suggested that type of health concern was not strongly linked to modularity outcome. By contrast, Chomutare et al.'s [18] formula produced a higher score for diagnosis of diabetes type rather than the time since diagnosis, indicating

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that the former is the stronger determinant of the modularity outcome. This apparent difference in results might imply that the nature of peer-support in a mental health group is less strongly determined by specific health concerns than in a diabetes Internet support group. Alternatively, it could indicate that time since diagnosis has a much smaller effect on the modularity outcome as compared with the registration date in a diabetes Internet support group, or both.

# The Role of Highly Active and Central Users in MHISGs

The observed pattern of highly active and central members registering early in each group in our study is consistent with research which suggests that these users play a vital role in the development of the community at an early stage [16]. The broader literature on online health communities report that "core users" engage in activities of building community by, for example, welcoming newcomers and communicating with many different people [16]. This finding was based on action research on the community #hcsmca and was followed by a quantitative study of the same community, which suggested that core users could be identified as those who have the highest frequency of posts and network centrality [15]. A prospective study of a depression Internet support group suggests that these core users are veterans of the community who increasingly become "active help providers" after an initial period in which they are supported by the others in the community [19]. Thus, the findings from the current study interpret that each module represents an era in which several highly active users communicated with many other new users who registered at the same time regardless of whether they had similar characteristics (as measured in this study) or not, and that these core users played a key role in sustaining the community over time.

# **Limitations and Future Research**

Although BlueBoard contains a range of subforums for different mental health topics, BlueBoard is predominantly used for discussion on depression. Thus, the generalizability of the current findings to other MHISGs is uncertain and in particular the modularity outcome may differ in MHISGs, which have an evenly spread distribution of posts across different mental health conditions. BlueBoard does not contain subforums for all types of mental health issues. Given the possibility that some forums are, therefore, not used for their intended purpose, the pattern of results may differ in MHISGs with a different variety of subforums. A more refined representation of the social network could also be achieved through collection of systematic data on directed communications between users.

The demographic characteristics of BlueBoard users [Personal communication by Kathleen M Griffiths, 2016] are similar to those of depression Internet support groups reported elsewhere [19]. However, the applicability of the current findings to MHISGs comprising members with markedly different demographic characteristics, such as those dedicated to young people, is unknown. MHISGs including medical professionals as moderators and or active participants might also be

characterized by markedly different social dynamics. Accordingly, further research focusing on a range of MHISG types is required to gain a greater understanding of the generalizability of the current findings. Future studies may benefit by modularity in MHISGs to collect and analyze a greater array of user characteristics including diagnosis, time since diagnosis, symptom severity, digital skills, and other characteristics that may reveal motivations of the "core users."

The role of highly active and influential members is an important area for future research. There are multiple ways of measuring participation in an online health community including some specifying peer-leader roles [20]. We used broad measures in this study (posting frequency and eigenvector centrality), which may not capture the specific nature of different individuals' contribution to the observed results. Future research with a more specific focus may consider other predefined peer-leadership roles such as "hubs" and "community builders," who being high frequency posters, are also known for connecting many users and maintaining conversation, respectively [20]. In MHISGs where the identity of users is not anonymous, the role of users who act as hubs or bridges across multiple social networks should also be considered [21,22]. Concurrently, it is also important to understand which characteristics are associated with users who take up these roles. We recently conducted a study of BlueBoard to investigate the user characteristics associated with higher engagement than a single post [Personal communication by Kathleen M Griffiths, 2016], with consumers being found to be more highly engaged than carers. Further research is required to investigate the factors predicting the very highest levels of user engagement and other measures of peer-leadership in online health communities [20]. One previous study has compared the characteristics of the top 1% of users ("superusers") ranked by posting frequency across two smoking cessation Internet support groups and found no differences between them [23]. A study with higher statistical power may be required to detect significant differences and common characteristics among such a small group of users. As super users are communicating with people who have a range of different mental health concerns, it is possible that super users have multiple or more complex diagnoses, which enable them to relate to and support the other bulk of users who have more specific issues or one-time needs for peer-support. Alternatively, they may have conditions such as bipolar disorder, which result in high activity levels with greater engagement in the community.

# Conclusion

The community structure of the Internet support group BlueBoard comprised five main subgroups that occurred in sequence resembling generations of the MHISG. These groups were largely invariant in their demographic characteristics and the extent to which they communicated about different mental health issues. The community structure formation may be related to the contributions of the most active and central users who registered early as compared with other users in each group.

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# Acknowledgments

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# **Conflicts of Interest**

Kathleen Griffiths established BlueBoard; and Kathleen, Julia, Kylie, and Anthony are responsible for the provision of the BlueBoard service.

# **Multimedia Appendix 1**

BlueBoard social network growth timelapse.

[SWF File, 7MB - mental\_v3i2e20\_app1.swf]

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# Original Paper

The Preference for Internet-Based Psychological Interventions by Individuals Without Past or Current Use of Mental Health Treatment Delivered Online: A Survey Study With Mixed-Methods Analysis

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# Abstract

**Background:** The use of the Internet has the potential to increase access to evidence-based mental health services for a far-reaching population at a low cost. However, low take-up rates in routine care indicate that barriers for implementing Internet-based interventions have not yet been fully identified.

**Objective:** The aim of this study was to evaluate the preference for Internet-based psychological interventions as compared to treatment delivered face to face among individuals without past or current use of mental health treatment delivered online. A further aim was to investigate predictors of treatment preference and to complement the quantitative analyses with qualitative data about the perceived advantages and disadvantages of Internet-based interventions.

**Methods:** Two convenience samples were used. Sample 1 was recruited in an occupational setting (n=231) and Sample 2 consisted of individuals previously treated for cancer (n=208). Data were collected using a paper-and-pencil survey and analyzed using mixed methods.

**Results:** The preference for Internet-based psychological interventions was low in both Sample 1 (6.5%) and Sample 2 (2.6%). Most participants preferred psychological interventions delivered face to face. Use of the Internet to search for and read health-related information was a significant predictor of treatment preference in both Sample 1 (odds ratio [OR] 2.82, 95% CI 1.18-6.75) and Sample 2 (OR 3.52, 95% CI 1.33-9.29). Being born outside of Sweden was a significant predictor of preference for Internet-based interventions, but only in Sample 2 (OR 6.24, 95% CI 1.29-30.16). Similar advantages and disadvantages were mentioned in both samples. Perceived advantages of Internet-based interventions included flexibility regarding time and location, low effort, accessibility, anonymity, credibility, user empowerment, and improved communication between therapist and client. Perceived disadvantages included anonymity, low credibility, impoverished communication between therapist and client, fear of negative side effects, requirements of computer literacy, and concerns about confidentiality.

**Conclusions:** Internet-based interventions were reported as the preferred choice by a minority of participants. The results suggest that Internet-based interventions have specific advantages that may facilitate help-seeking among some individuals and some disadvantages that may restrict its use. Initiatives to increase treatment acceptability may benefit from addressing the advantages and disadvantages reported in this study.

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#### **KEYWORDS**

patient acceptance of health care; patient preference; patient satisfaction; Internet-based cognitive behavioral therapy; chronic disease; mental health care; eHealth; implementation; qualitative research

# Introduction

Increasing the access to evidence-based mental health services is crucial for improving global health [1]. The use of information technology, such as computers, mobile phones, and tablets—referred to as eHealth—is a relatively new way to promote self-care and well-being in a health care setting [2]. The use of the Internet has the potential to increase access to proven mental health services for a far-reaching population at a low cost [3]. For example, Internet-based cognitive behavioral therapy (iCBT) shows promising results for the treatment of common mental health problems, such as depression and anxiety disorders [4,5], and for improving psychosocial outcomes among individuals coping with somatic conditions such as chronic pain [4]. Internet-based interventions may be especially beneficial for individuals with somatic health conditions, due to its flexibility with regard to service use [6].

Although promising, implementation of Internet-based interventions in routine care has proven to be challenging [7]. This study builds on previous studies that investigate acceptability as a key determinant for successful implementation of Internet-based interventions. Research into treatment acceptability originates from the idea that a given intervention needs to be both effective and acceptable for intended users. A treatment is acceptable when it is perceived as appropriate, fair, reasonable, and nonintrusive for a given problem [8]. Treatment acceptability is important to consider since it may improve both adherence [9] and overall outcome [10]. For example, according to a meta-analytic review across different treatment formats and target populations, individuals that had been matched to a preferred treatment had a 58% chance of showing improvements and were nearly half as likely to drop out of treatment compared to those that did not receive their preferred choice of treatment [10].

Internet-based interventions have several advantages over traditional face-to-face delivery, some of which may improve treatment acceptability. Internet-based interventions typically consist of text-based material, which may enhance treatment fidelity and save therapist time [5]. Interventions may be used either as a sole treatment component or as a complement to other forms of treatment [11]. Some interventions include support from a therapist, for example, through mail or telephone. In a qualitative review, reasons for providing care via the Internet included reduction of health service costs, increased convenience for users, overcoming isolation of users, increased user and health provider control of the intervention, and stigma reduction [12]. Among primary care patients participating in an iCBT intervention for depression, major advantages include flexibility with regard to time and location of service use, and making it easier to fit therapy into daily life [13]. Internet-based interventions may also provide a sense of anonymity that encourages shy and embarrassed users to be more open about themselves [14].

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Treatment acceptability among patients in Internet-based interventions is generally high. In a meta-analysis of iCBT for mood disorders, the results indicated adequate adherence, with a median of 80% of the included participants completing all steps. Patient satisfaction was also high, with a median of 86% of the participants reporting that they were satisfied or very satisfied [5]. Similarly, in a review about iCBT for individuals with clinical levels of depression in routine care, positive expectancies and high satisfaction were reported [15]. While dropout rates were comparable to other formats of treatment, take-up rates were lower, ranging from 3% to 25%. However, in many studies a more detailed evaluation of treatment acceptability or satisfaction was lacking. The authors also raised concerns about low take-up rates, and concluded that the low take-up rates may either indicate a reluctance to take part in research or a reluctance to enter Internet-based interventions [15].

Treatment acceptability has been framed as a key factor for successful implementation in routine care. A given treatment may be clinically effective, yet unacceptable for patients [15]. A number of factors have been identified among individuals with past or current experience of Internet-based interventions related to treatment acceptability. In a qualitative study, some patients reported feeling more comfortable writing about their thoughts and feelings at their own pace, while others expressed a concern about how to develop a relationship with a virtual therapist and to communicate emotional content via a computer [13]. Moreover, patients commonly report concerns about privacy, confidentiality, and the trustworthiness of the system [16]. It has also been suggested that inadequate Internet provision and low levels of education are associated with a decreased likelihood of using Internet-based interventions [17].

Efforts to investigate treatment acceptability among individuals without past or current use of mental health treatment delivered online have been made. In a study recruiting primary care patients with an interest in some sort of behavioral treatment, approximately half (48%) considered the Internet as a valid treatment format, while the majority (92%) preferred face-to-face care [18]. When investigating predictors, time constraints were related to a higher interest in Internet-based interventions while symptom severity was not. In another study, individuals from the general population were recruited to fill out an online survey about the perceived acceptability of Internet-based interventions [19]. The sample consisted mainly of female university students that used the Internet daily. The results indicated a lower likelihood to use Internet-based interventions compared to face-to-face interventions. No significant differences were observed with regard to factors such as gender, previous or current mental health status, or computer literacy. Furthermore, Internet-based interventions only met participants' expectations in terms of convenience of access. Dissatisfaction was expressed regarding important factors for engaging in treatment, such as perceived helpfulness, the ability to motivate users, credibility, appeal, and feedback.

In sum, Internet-based interventions will have limited impact if potential users do not perceive them as acceptable. Previous studies have investigated the acceptability of Internet-based interventions among both individuals with and without past or current experience of them. However, these studies often employ online samples or patients already taking part in treatment programs. The representativeness of the participants included can therefore be questioned [20,21]. For example, patients with ongoing interventions may already have overcome some practical and stigma-related barriers for seeking psychological help. Therefore, the aim of this study was to investigate the acceptability of Internet-based interventions among individuals without past or current experience of mental health treatment delivered online. More specifically, we wanted to investigate the preference for Internet-based psychological interventions as compared to treatment delivered face to face. Furthermore, predictors of treatment preference were investigated. As a complement to the quantitative analysis, qualitative data about the perceived advantages and disadvantages were analyzed.

This study included two samples: one sample consisted of individuals recruited from a general occupational setting; another sample consisted of individuals previously treated for cancer. The latter sample was selected to represent a potential target group, since Internet-based interventions may have several positive effects for people coping with chronic diseases such as cancer [22,23]. Furthermore, the use of a paper-and-pencil survey was chosen to reach individuals less familiar with the use of computers and the Internet. This study may provide knowledge about the generalizability of previous studies, as well as new insights into potential barriers and facilitators for implementation of Internet-based interventions in routine care.

# Methods

# **Participants**

Two convenience samples were recruited. One sample was recruited in an occupational setting (Sample 1). The second

sample was recruited in cancer clinics and consisted of individuals previously treated for cancer (Sample 2). To be included, participants had to be over 18 years old, and able to read and write Swedish. Individuals with prior or current experience of mental health treatment delivered online, and individuals that had not used the Internet during the past two years, were excluded.

In Sample 1, 243 individuals working in a university setting (67/243, 27.6%) and a rural factory (176/243, 72.4%) were recruited. Of these 243 participants, 12 (4.9%) were excluded because they had not used the Internet during the past two years (5/243, 2.1%), had prior experience of psychological treatment via the Internet (3/243, 1.2%), or failed to answer questions on prior Internet usage (4/243, 1.6%). Of the remaining 231 out of the initial 243 participants (95.1%), 74 (32.0%) identified themselves as women and 157 (68.0%) as men. The mean age of Sample 1 was 44.1 years (SD 12.2).

In Sample 2, 285 individuals were recruited from outpatient, postcancer follow-up clinics. Only participants that had completed cancer treatment were included. Some participants were excluded because they had not used the Internet or computers during the past two years (70/285, 24.6%), or had prior experience of psychological treatment via the Internet (7/285, 2.5%). Of the remaining 208 out of the initial 285 participants (73.0%), 91 (43.8%) identified themselves as women and 117 (56.3%) as men. The mean age of Sample 2 was 60.5 years (SD 13.9). Among women, most had been treated for breast cancer (34/165, 20.6%), followed by lymphoma (18/165, 10.9%). Time since first diagnosis among women ranged from 1 to 33 years (mean 6.5 years). Among men, the most common diagnosis for previous treatment was prostate cancer (61/274, 22.3%), followed by lymphoma (10/274, 3.6%). Time since first diagnosis among men ranged from 2 to 33 years (mean 6.8 years). Further demographic description and analysis of differences between the two samples are presented in Table 1.



Table 1. Demographic description and analysis of differences between samples.

	Sample 1,	Sample 2,		
Variable	n (%) or mean (SD)	n (%) or mean (SD)	$\chi^2$ or $t$	Р
Total, n (%)	231 (100)	208 (100)		
Gender, n (%)				
Women	74 (32.0)	91 (43.8)	$\chi^2_1 = 6.40$	.01
Men	157 (68.0)	117 (56.3)		
Age in years, mean (SD)	44.1 (12.2)	60.5 (13.9)	t <sub>429</sub> =13.10	<.001
Civil status, n (%)				
In a relationship	169 (73.2)	176 (84.6)	$\chi^2_1 = 9.88$	.002
Single	62 (26.8)	30 (14.4)		
Education, n (%)				
High school	127 (55.0)	103 (49.5)	$\chi^2_1 = 1.41$	.24
College/university	100 (43.3)	102 (49.0)		
Country of birth, n (%)				
Born in Sweden	211 (91.3)	185 (88.9)	$\chi^2_1=0.49$	.49
Born outside of Sweden	20 (8.7)	22 (10.6)		
HOSQ <sup>a</sup> reading factor, mean (SD)	8.96 (6.43)	9.96 (9.17)	$t_{332.34}$ =-1.27	.21
HOSQ interacting factor, mean (SD)	2.73 (3.75)	4.92 (6.91)	$t_{278.24}$ =-3.89	<.001

<sup>a</sup>HOSQ: Health Online Support Questionnaire.

As shown in Table 1, participants in Sample 1 were older, more often female, and more often in a relationship as compared to those in Sample 2. There were no significant differences between the two samples in terms of level of education, country of birth, or the use of interacting online support. Participants in Sample 2 used the Internet for interactional support significantly more than the participants in Sample 1.

#### Procedure

Data were collected using a paper-and-pencil survey. Sample 1 was recruited using an advertisement posted at the workplace for 2 months. The survey contained written information about the study. Approximately 500 surveys were handed out. In total, 243 surveys out of 500 (48.6%) were completed and returned to the researcher by post.

Sample 2 was recruited from a university hospital. Recruitment lasted for 4 months. Eligible participants received verbal and written information about the study in the waiting room of the clinics—oncology and urology. Included participants filled out the survey in conjunction with their visit or at home, and returned the survey to the researchers by post. In total, 350 surveys were handed out and 285 (81.4%) were completed. The participants received no financial compensation.

#### Materials

#### **Demographics**

Data including age, gender, civil status (single/in a relationship), level of education (high school/university), country of birth (born in Sweden/born outside of Sweden), diagnosis, and year

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since diagnosis (only participants previously treated for cancer) were collected using a customized questionnaire.

#### **Health-Related Online Support**

The Health Online Support Questionnaire (HOSQ) is a self-report that measures the use of online support for health problems [24]. The HOSQ consists of 18 items rated on a 6-point Likert scale, ranging from 0 (not relevant/never) to 5 (on a daily basis). The scale is divided into two subscalesreading and interacting— with an equal number of items. Reading refers to searching for and reading health-related information online to improve health or to make informed decisions about treatments. Interacting refers to sharing health-related information, seeking encouragement, or communicating with others regarding health-related issues online. The two HOSQ subscales have shown adequate internal consistency (Cronbach alpha=.88 and .77, respectively) and content and construct validity [24]. In this study, the two HOSQ subscales showed adequate internal consistency in both Sample 1 (reading Cronbach alpha=.88; interacting Cronbach alpha=.76) and Sample 2 (reading Cronbach alpha=.92; interacting Cronbach alpha=.86).

#### **Treatment Preference**

Participants were asked to indicate which treatment modality they would prefer if in need of psychological help now or in the future: face to face, Internet, or both modalities to an equal extent. Internet-based psychological treatment was described as a program delivered via the Internet with or without support

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from an online therapist. Participants could also indicate that they would never seek any psychological treatment.

# Perceived Advantages and Disadvantages of Internet-Based Interventions

By means of open-ended questions, participants were invited to list perceived advantages and disadvantages of psychological treatment via the Internet separately on three blank lines each.

# **Statistical Analysis**

A total of 96 out of 439 (21.9%) participants-77 in the nonclinical and 19 in the clinical sample-did not respond to the question regarding treatment preference, and were therefore not included in further analyses. The variables HOSQ reading and HOSQ interacting showed a positively skewed distribution. A median split was conducted prior to analysis on both variables to create binary variables (high and low). Although a median split reduces the variability of continuous variables, it is a way to enhance clarity when group differences are in focus [25]. Multivariate logistic regressions were conducted to investigate predictors of treatment preference. A forced-entry approach was used since no hypothetical relationship was assumed between the predictors. Due to a low preference for Internet-based interventions in both samples, the criterion variable was collapsed into two levels: (1) preference for face-to-face intervention (used as reference category) and (2) preference for Internet or equal preference for both modalities. SPSS version 20 (IBM Corp) was used for the statistical analyses.

# **Qualitative Analysis**

Qualitative content analysis was used to analyze the open-ended questions regarding perceived advantages and disadvantages of Internet-based interventions. Qualitative content analysis is a method to systematically condense and organize data into categories describing a phenomenon of interest [26]. In this study, the open-ended answers were considered the unit of analysis. Advantages and disadvantages were treated as different content areas and analyzed separately. As a first step, the answers were divided into meaning units by one of the authors (EEKW). A meaning unit was considered as a part of data that conveyed enough information to provide a sense of meaning. Next, the same author (EEKW) condensed the meaning units by taking away redundant wording without changing the meaning or core content.

An inductive approach was applied to Sample 1, as is recommended when knowledge is missing or fragmented [26]. In an inductive approach, meaning units are arranged into categories with different levels of abstraction according to similarities and differences to create mutually exclusive categories [26,27]. To improve the credibility, two independent coders (the authors EMGO and SM) used a deductive approach to verify the initial categorization. Codes placed in different or more than one category were discussed and revised by the coders (EEKW, EMGO, and SM) to create mutually exclusive categories.

In Sample 2, a deductive approach was used to test the replicability of the categorization generated from Sample 1.

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Three coders (EEKW, EMGO, and SM) conducted this process independently. Only minor changes were made to the categorization obtained from Sample 1. As a final step, categories with similar content were grouped and labeled with an overarching theme (ie, categorizing the categories).

# **Ethical Approval**

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden (2013-11-20; Diary number 2013/436).

# Results

# **Preference for Internet-Based Interventions**

The preference for Internet-based psychological interventions was low in both samples. In Sample 1, the results showed that out of the 154 participants that responded to the question regarding treatment preference, 103~(66.9%) preferred face-to-face treatment, 10~(6.5%) preferred treatment provided via the Internet, and 32~(20.8%) preferred both formats of delivery to an equal extent. A total of 9 (5.8%) participants indicated that they would not prefer any treatment modality if needed now or in the future.

Similar results were obtained with Sample 2. There was no significant difference when comparing treatment preference between the two samples ( $\chi^2_2$ =2.7, *P*=.26). The results showed that in Sample 2, out of the 189 participants that responded to the question regarding treatment preference, 123 (65.1%) preferred face-to-face treatment, 5 (2.6%) preferred treatment provided via the Internet, and 41 (21.7%) preferred both modalities to an equal extent. A total of 20 (10.6%) participants indicated that they would not prefer any treatment modality if needed now or in the future.

Only participants that indicated a preference for face-to-face, Internet, or both modalities equally were included in further analyses. The results showed a significant difference between treatment preferences in both Sample 1 ( $\chi^2_2$ =97.8, *P*<.001) and in Sample 2 ( $\chi^2_2$ =129.9, *P*<.001). Post hoc analyses in Sample 1 showed that a significantly higher number of participants preferred psychological treatment provided face to face compared to via the Internet ( $\chi^2_1$ =76.5, *P*<.001) and both equally ( $\chi^2_1$ =37.3, *P*<.001). A significantly higher number of participants also preferred both modalities equally compared to the Internet as first choice ( $\chi^2_1$ =11.5, *P*=.001).

In Sample 2, post hoc analyses showed that a significantly higher number of participants preferred psychological treatment delivered face to face compared to via the Internet ( $\chi^2_1$ =108.8, *P*<.001) and both equally ( $\chi^2_1$ =41, *P*<.001). A significantly higher number of participants also preferred both modalities equally compared to the Internet as first choice ( $\chi^2_1$ =28.2, *P*<.001). These results suggest that most people preferred face-to-face psychological treatment, followed by both modalities equally. Internet-based interventions were the least preferred format of treatment.

#### **Predictors of Treatment Preference**

Multivariate logistic regressions were used to analyze predictors of treatment preference. The variables age, sex, civil status, education, country of birth, HOSQ *reading*, and HOSQ *interacting* were included in the analyses using a forced-entry approach. The results showed that a test of the full model had a low but acceptable goodness of fit in Sample 1 (Cox and Snell  $R^2$ =.08; Nagelkerke  $R^2$ =.11). Overall prediction success was 71.6%. Only HOSQ *reading* made a significant unique contribution in the prediction of treatment preference (*P*=.02). The odds ratio (OR) indicates that participants who already use online health-related information are 2.82 times more likely than those who do not to report a preference for Internet or both Internet and face-to-face treatment equally if in need of psychological help now or in the future (see Table 2).

**Table 2.** Summary of logistic regression for variables predicting treatment preference in Sample 1.

Variables	OR <sup>a</sup>	95% CI	Р
Age	1.00	0.97-1.04	.93
Sex (reference: woman)	1.05	0.45-2.47	.91
Civil status (reference: in a relation- ship)	1.42	0.60-3.35	.43
Education (reference: low)	1.36	0.60-3.11	.46
Country of birth (reference: born in Sweden)	0.70	0.16-3.10	.64
HOSQ <sup>b</sup> reading (reference: low)	2.82	1.18-6.75	.02
HOSQ interacting (reference: low)	1.33	0.56-3.17	.52

<sup>a</sup>OR: odds ratio.

<sup>b</sup>HOSQ: Health Online Support Questionnaire.

In Sample 2, the result from the multivariate logistic regression showed that a test of the full model had a low but acceptable goodness of fit (Cox and Snell R<sup>2</sup>=.13; Nagelkerke R<sup>2</sup>=.19). Overall prediction success was 73.3%. HOSQ *reading* made a significant unique contribution in the prediction of treatment preference (P=.01). The odds ratio indicates that participants that already use online health-related information were 3.5 times more likely to report a preference for Internet or both Internet and face-to-face treatment equally if in need of psychological help now or in the future. Furthermore, country of birth made a significant contribution in the prediction of treatment preference (P=.02). The odds ratio indicates that participants born outside Sweden were 6.2 times more likely to report a preference for Internet or both Internet and face-to-face treatment equally (see Table 3).

Taken together, results from the multivariate logistic regressions suggest that past online behavior, such as searching for and reading health-related information to improve health or make informed decisions about treatments, was positively related to a preference for Internet-based interventions in both samples. Country of birth was a significant predictor only in the sample consisting of individuals previously treated for cancer, suggesting that individuals born outside Sweden are more likely to prefer Internet-based interventions compared to individuals born in Sweden.

### **Perceived Advantages and Disadvantages**

A total of 116 out of 148 (78.4%) participants in Sample 1 and 113 out of 173 (65.3%) in Sample 2 reported at least one perceived advantage and/or disadvantage related to Internet-based interventions. Sample 1 generated 117 codes related to advantages and 72 codes related to disadvantages. Sample 2 generated 146 codes related to advantages and 134 codes related to disadvantages.

The result of the qualitative content analysis of advantages included the following themes: flexibility regarding time and location, accessibility, low effort, anonymity, credibility, user empowerment, and improved communication. A number of participants reported that Internet-based interventions have no advantages or that they did not know. Perceived advantages are presented as themes, categories, and example codes in Table 4.

With regard to disadvantages, the following themes were obtained from the categorization of codes: anonymity, low credibility, impoverished communication, negative side effects, and computer literacy/safety concerns. Some participants reported that Internet interventions had no disadvantages, or that they did not know. Perceived disadvantages are presented as themes, categories, and example codes in Table 5.



 Table 3. Summary of logistic regression for variables predicting treatment preference in Sample 2.

Variables	OR <sup>a</sup>	95% CI	Р
Age	1.01	0.98-1.04	.55
Sex (reference: woman)	1.10	0.45-2.65	.84
Civil status (reference: in a relation- ship)	0.60	0.17-2.11	.42
Education (reference: low)	1.80	0.77-4.19	.18
Country of birth (reference: born in Sweden)	6.24	1.29-30.16	.02
HOSQ <sup>b</sup> reading (reference: low)	3.52	1.33-9.29	.01
HOSQ interacting (reference: low)	1.15	0.44-3.02	.77

<sup>a</sup>OR: odds ratio.

<sup>b</sup>HOSQ: Health Online Support Questionnaire.



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 Table 4. Themes, categories, and example codes of perceived advantages of Internet-based interventions.

Themes	Frequency,	n (%)	Categories	Example codes
	Sample 1 (n=117)	Sample 2 (n=146)		
Flexibility regarding time and location				
	13 (11.1)	17 (11.6)	No transportation	No need to leave home when feeling sick No transportation More comfortable at home No need to go out and meet people No need to visit hospital/treatment facility
	8 (6.8)	10 (6.8)	Independent of time and place	I can work with the program when and where it best suits me Easier to fit into my daily schedule More flexible
	4 (3.4)	11 (7.5)	No need to schedule appoint- ments	No need to schedule/keep appointments Independent of visiting hours
Low effort	13 (11.1)	9 (6.2)	Time-saving	Quick Less time-consuming Time-effective
	16 (13.7)	5 (3.4)	Cheap	Cost-effective Cheaper for the individual and society Affordable
	11 (9.4)	4 (2.7)	Convenient	Easy Low effort
Accessibility	8 (6.8)	16 (11.0)	Reach	Accessible for more people Increased access for people working odd hours Increased access for people in rural areas/living abroad Easy to access
	3 (2.6)	12 (8.2)	Always available	Internet available 24/7 Always available
	5 (4.3)	4 (2.7)	No delay	No waiting list/queue Decreased delay of treatment onset Quick treatment onset
Anonymity				
	4 (3.4)	7 (4.8)	Integrity	More integrity More anonymous/private
	5 (4.3)	1 (0.7)	Lack of face-to-face contact with a therapist	No need to see a therapist Less embarrassing than seeing a therapist No eye contact—no shame
Credibility	5 (4.3)	0 (0)	Nobody needs to know	My family does not need to know More people would dare to seek treatment if anonymous
Стешошку	6 (5.1)	5 (3.4)	Treatment expectancy	Good If I had problems I would use it Interesting

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Themes	Frequency,	n (%)	Categories	Example codes
	Sample 1	Sample 2		
	(n=117)	(n=146)		
	2 (1.7)	5 (3.4)	Useful information	When you need concrete advice such as checklists
				Information is saved
	0 (0)	4 (2.7)	Standardized	Treatment less influenced by the individual therapist
				Independent of the therapist
User empowerment				
	2 (1.7)	8 (5.5)	Decide duration	I can initiate/terminate treatment when I want/need
				Sense of self-help
	1 (0.9)	4 (2.7)	Own pace	Time to reflect
				Work at your own pace
	0 (0)	2 (1.4)	Choose content	You can choose treatment
				More alternatives
Improved communication				
	7 (6.0)	4 (2.7)	Self-disclosure	Easier to express oneself
				Easier to be open and honest
				Easier to write than to tell face to face
				Dare to ask
None	1 (0.9)	15 (10.3)	None	N/A <sup>a</sup>
Do not know	3 (2.6)	3 (2.1)	Do not know	N/A
Total	117 (100)	146 (100)	N/A	N/A

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



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 Table 5. Themes, categories, and example codes of perceived disadvantages of Internet-based interventions.

Themes	Frequency,	n (%)	Categories	Example codes
	Sample 1 (n=72)	Sample 2 (n=134)		
Anonymity				
	6 (8)	64 (47.8)	Lack of face-to-face contact with a therapist	Human contact irreplaceable/helpful in itself Impersonal Dehumanizing
	8 (11)	10 (7.5)	Lack of empathy and trust	Lack of compassion/trust/affirmation Less closeness in the conversation Less empathic
Low credibility				
	12 (17)	9 (6.7)	Unable to motivate	Would not take it seriously Risk of not going through with the treatment Demands self-discipline
	9 (13)	6 (4.5)	Less effective	Impossible to involve the family Less effective Unprofessional
	3 (4)	2 (1.5)	Standardized	Less personal Less individualized
	1 (1)	0 (0)	Incorrect information	Incorrect/excessive information
Impoverished comm	unication			
	5 (7)	3 (2.2)	Absence of body language	Lack of eye contact Not being able to read facial expressions and reac- tions of the therapist
	3 (4)	5 (3.7)	Lack of instant feedback	Inadequate feedback Noninteractive Lack of follow-up questions
	2 (3)	3 (2.2)	Misunderstandings	Risk of misunderstandings Difficult to understand the treatment
	1 (1)	2 (1.5)	Difficulties expressing oneself	Difficult to express myself in writing Not being able to make myself understood
Negative side effects				
	3 (4)	9 (6.7)	Self-isolation	I will be alone and isolated at home Nobody to talk to
	5 (7)	6 (4.5)	Risk of incorrect decisions	Risk of wrong diagnosis Difficult to identify symptoms and people in need o more help
Computer literacy/ s	afety concerns			
	4 (6)	2 (1.5)	Confidentiality concerns	Integrity problems Do not trust computers
	4 (6)	1 (0.7)	Require technique and technical skills	Demands computer skills and willingness to use a computer Demands access to Internet
None	4 (6)	5 (3.7)	None	N/A <sup>a</sup>
Do not know	2 (3)	7 (5.2)	Do not know	Do not know how it works
Total	72 (100)	134 (100)	N/A	N/A

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

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The relative percentage of codes in each theme differed between the samples in some aspects. Low effort was reported more often as an advantage in Sample 1 (34%) compared to Sample 2 (12%). Anonymity was reported more frequently as a disadvantage in Sample 2 (55%) compared to Sample 1 (19%). Moreover, treatment credibility was reported more often as a disadvantage in Sample 1 (35%) compared to Sample 2 (13%). In sum, the result of the qualitative content analysis indicates similar themes in both samples. Some of the themes were presented both as an advantage and as a disadvantage, for example, anonymity and aspects related to credibility and the quality of communication.

# Discussion

# **Principal Findings**

The aim of this study was to investigate the preference for Internet-based psychological interventions in individuals without past or current experience of them. In line with previous studies, we found that the preference for Internet-based interventions was low [18,28]. Most participants preferred psychological treatment delivered face to face. Only 6.5% and 2.6% in Samples 1 and 2, respectively, reported a clear preference for Internet-based interventions. Although a higher percentage of participants reported that they thought the Internet would be an equally preferable alternative to face-to face treatment, the results of this study suggest an overall low acceptability of Internet-based interventions in both samples.

Participants that often use the Internet to find information in order to improve health or make informed decisions about treatments were approximately three times more likely to prefer an Internet-based psychological intervention across samples. This result suggests that those who already use online health-related support hold more positive attitudes toward Internet-based psychological treatment. It is also possible that HOSQ *reading* represents general computer literacy, Internet familiarity, and everyday Internet use not only restricted to health issues. On the other hand, sharing health-related information, seeking encouragement, or communicating with others regarding health-related issues online was not related to a preference for Internet-based interventions. However, the mean use of interacting support was low in both samples, which makes these findings less reliable.

In contrast to previous findings, level of education was unrelated to treatment preference [17]. Instead, country of birth was an unexpected significant predictor among participants previously treated for cancer. Individuals born outside of Sweden were about six times more likely to prefer an Internet-based intervention compared to those born in Sweden. In a systematic review, it was found that ethnic minorities are disproportionately deterred by stigma when seeking mental health services [29]. As reflected in the qualitative content analysis, the anonymity of Internet interventions may provide a less stigmatizing alternative to formal mental health services that may explain a higher preference for treatment delivered via the Internet.

The qualitative part of this study generated similar advantages and disadvantages as have previously been reported [12-14,16].

It appears that individuals without past experience of Internet-based interventions have a relatively clear idea about factors that they perceive as potential facilitators and barriers. Moreover, although similar themes were present in both samples, the relative frequency of perceived advantages and disadvantages varied. For example, low effort was reported more frequently as an advantage among the participants in the working population. This might be explained by the fact that individuals previously treated for cancer were older and therefore more likely to be retired and to have fewer time constraints. Moreover, anonymity appeared to be of greater concern among individuals previously treated for cancer. This may reflect more experience with health care as a result of past medical treatment for cancer. It might also be explained by the fact that the participants in this sample were older, on average. In a study about cognitive behavioral therapy (CBT) for depression provided face to face, older patients reported nonverbal communication and talking to a therapist as beneficial more often than younger patients [30].

#### Limitations

This study has several limitations. First, the response rate in Sample 1 was relatively low (49%). Furthermore, a large number of the participants did not respond to the questions regarding treatment preference. It is possible that this reflects a systematic bias, in which individuals with negative attitudes toward psychological treatment failed to respond to the survey.

Secondly, narrow or incomplete answers to the open-ended questions sometimes gave rise to uncertainty of the intended meaning in the qualitative content analysis, which may influence both the credibility and transferability of the categorization of advantages and disadvantages. The use of in-depth interviews may have generated a more thorough understanding of the specific categories. Furthermore, the nature of the qualitative content analysis does not permit analysis of the relative importance of different categories in the actual decision to seek care when needed.

Finally, the preference related to treatment modality was measured by the use of a single item. Using more items would likely have generated a more reliable overall score. It is also important to note that the question about treatment preference should be considered hypothetical since it is likely that many of the included participants do not perceive a current need for psychological treatment.

# Implications

The results of this study may prove useful to understand more about the acceptability of Internet-based interventions in a number of ways. A relatively high number of individuals previously treated for cancer were excluded because they had not used the Internet during the past two years. Although the Internet may no longer be considered a new technology, low computer literacy and poor access to the Internet have previously been reported as barriers for engagement in Internet-based interventions [17]. In our study, perceived disadvantages related to the treatment format, such as a fear of negative side effects, computer literacy and safety concerns, low credibility, and fear of impoverished communication indicates a general distrust and

reluctance to engage in an Internet-based intervention. Concerns about negative side effects and safety have also been reported among individuals that have completed Internet-based interventions [31]. Although Internet-based interventions are commonly secured by encrypting and double authentication, concerns about confidentiality and safety may limit its attractiveness [16]. Hence, in order to improve the uptake of Internet-based interventions, researchers and care providers may want to consider ways to address these barriers.

Internet-based interventions were perceived as empowering for the user in a number of ways. Participants reported that they believe the Internet format gives the user more control over the content, duration, initiation, and termination of treatment. Some individuals wrote that they would feel more comfortable writing about their thoughts and feelings. In addition to this, individuals also reported that Internet-based interventions may provide a sense of anonymity, which may help them overcome fear or discomfort associated with going or talking to a health care professional. A recent study suggested that mixing online and face-to-face treatment provides an opportunity to obtain optimal benefits from the advantages of both treatments [32]. The authors conclude that in order to enable added benefits, individual abilities, needs, and preferences should be considered in a structured way. Engagement of potential stakeholders in the process of developing interventions may improve both uptake rates and the outcome of eHealth interventions [2].

### Conclusions

This study suggests that the preference for Internet-based interventions is low. The past use of online health-related informational support emerged as a significant predictor across samples. Although Internet-based interventions may have specific perceived advantages compared to treatment delivered face to face, low acceptability appears to be an important barrier for large-scale dissemination. To promote large-scale service utilization, it might be beneficial to address the perceived disadvantages reported in this study. When doing so, practitioners and researchers may consider ways to address issues related to communication, fear of negative side effects, and concerns related to computer literacy and safety.

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#### **Conflicts of Interest**

None declared.

#### **Authors' Contributions**

EEKW was the corresponding author and was responsible for participant recruitment, formal analysis, and writing of the original draft and revision of the manuscript. SM was responsible for participant recruitment and revision of the manuscript. EMGO was responsible for formal analysis, and for preparation and revision of the manuscript.

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# Abbreviations

CBT: cognitive behavioral therapy HOSQ: Health Online Support Questionnaire **iCBT:** Internet-based cognitive behavioral therapy N/A: not applicable OR: odds ratio U-CARE: Uppsala University Psychosocial Care

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# Computer-Assisted In Sensu Exposure for Posttraumatic Stress Disorder: Development and Evaluation

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# Abstract

**Background:** Dissociative states during psychotherapy sessions reduce the benefit of exposure-based therapy for posttraumatic stress disorder (PTSD). Thus, in evidence-based therapeutic programs such as dialectical behavior therapy for PTSD (DBT-PTSD), therapists apply specific antidissociative skills to reduce dissociative features during *in sensu* exposure. In addition to therapist-guided sessions, exposure protocols often require that the patients listen to audio recordings of exposure sessions in self-management. The problem of how to prevent dissociative features during such self-administered exposure exercises has not been resolved yet. Hence, we developed the computer program MORPHEUS that supports the application of self-administered exposure exercises. MORPHEUS continuously monitors the level of dissociative states and offers state-related antidissociative skills.

**Objective:** This study sought to examine the acceptance and feasibility of the MORPHEUS program.

**Methods:** Patients who underwent 12 weeks of residential DBT-PTSD treatment used MORPHEUS during exposure exercises in self-management. After the treatment, they filled out evaluation questionnaires.

**Results:** In sum, 26 patients receiving a 12-week standard DBT-PTSD program participated in this study; 2 participants could not be analyzed because of missing data. All the patients used MORPHEUS as often as it was required according to the DBT-PTSD treatment (2 to 5 times a week). The overall acceptance and feasibility as rated by the patients was high: for example, patients found the skills useful to block dissociation (mean 4.24 on a scale from 0 to 5, SD 0.24) and stated that they would use the program again (mean 4.72 on a scale from 0 to 5, SD 0.11). Furthermore, patients indicated that they would recommend MORPHEUS to a friend (mean 4.44 on a scale from 0 to 5, SD 0.12). In 82% (32/39) of the cases, the use of antidissociative skills was related to a decrease in dissociation. In 18% (5/39), dissociation remained unchanged or increased.

**Conclusions:** The evaluative data suggest high acceptability and feasibility of MORPHEUS. Further studies should evaluate the effectiveness of the skills applied during the program.

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**Trial Registration:** World Health Organization International Clinical Trials Registry Platform: DRKS00006226; http://apps.who.int/trialsearch/Trial2.aspx?TrialID= DRKS00006226 (Archived by WebCite at http://www.webcitation.org/ 6hxuFbIUr)

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#### **KEYWORDS**

dissociative disorders; behavior therapy; posttraumatic stress disorder; technology

# Introduction

*In sensu* exposure is a widely used and effective intervention in the treatment of posttraumatic stress disorder (PTSD) [1]. *In sensu* exposure protocols require patients to repeatedly imagine the traumatic incident with high emotional engagement [2-4]. Usually this is a bimodal process: therapist-guided sessions are followed by self-management sessions, during which the patients repeatedly listen to audio recordings of the therapist-guided exposure sessions. Such exposure exercises can be considered an emotionally demanding task in the absence of therapist support.

One problem that might arise during such exposure exercises is the occurrence of dissociative states. In their literature review, Craske and colleagues [5] conclude that the effects of exposure therapy are the result of learning new associations with traumatic memories. There is evidence that dissociative states during exposure impede emotional learning processes. Dissociation is described as an intermittent "disruption and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control, and behavior" ([6] p291). High levels of dissociation in PTSD have been found in 15% to 33% of patients [7], which led to the inclusion of a dissociative subtype in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [6]. Patients show different levels of trait dissociation, but dissociation can also change on a state level as shown in an ambulatory assessment study in patients with a diagnosis of borderline personality disorder (BPD) or depression [8].

Dissociation positively correlates with the level of acute emotional distress and this association is highest in patients with BPD [9]. Dissociation can be provoked by imagining situations that previously led to dissociative states (interpersonal conflicts, trauma-related situations, and so on) [10,11]. This has strong implications for exposure-based interventions: retrieval of traumatic memories often induces high levels of emotional distress, which—mainly in individuals with high dissociation proneness—activates dissociative symptoms.

There is recent evidence showing that dissociation is associated with attenuated improvement after treatment of BPD [12] and other conditions such as obsessive-compulsive disorder [13,14]. In PTSD, the empirical evidence regarding the impact of trait dissociation on treatment outcome is relatively mixed [15-21]. However, a most recent analysis could show that state dissociation plays a powerful role in predicting negative treatment outcome [22].

Thus, therapists are faced with the challenge to apply exposure therapy in patients with high dissociation proneness. A range

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of strategies to cope with dissociation in PTSD can be found in the literature. In their Prolonged Exposure (PE) manual, Foa et al [23] provide treatment strategies for both emotional overengagement and state dissociation (eg, discriminating between the trauma itself and the traumatic memory, tactile stimuli such as holding the therapist's hand). Several trauma-focused treatment approaches that are specifically tailored for PTSD patients with emotional dysregulation have included emotion regulation skills used in dialectical behavior therapy (DBT): DBT-PTSD [24,25], DBT+PE [26,27], and Skills Training in Affective Interpersonal and Regulation-Prolonged Exposure (STAIR-PE [15,28]. In skills-assisted exposure, which is an integral part of DBT-PTSD, emotion regulation and stress tolerance skills are used to find a balance between emotional re-activation of traumatic memories and the awareness of being in the present moment during exposure. In patients who tend to dissociate, stress tolerance skills such as cognitive or sensory distraction are applied to tackle state dissociation during exposure sessions [24,25].

To the best of our knowledge, no studies to date have tested the effectiveness of distraction to address state dissociation in patients with PTSD. However, the role of distraction tasks and the effect on working memory performance have been discussed as a potential treatment mechanism of Eye Movement Desensitization and Reprocessing (EMDR) therapy [29], for example, by Andrade et al [30]. In experimental studies, both the standard EMDR intervention of rapid eye movements and auditory distraction reduced the vividness and emotionality of negative autobiographical memories to a comparable extent [31]. Although a recent meta-analysis on dismantling studies suggests the use of eye movements in EMDR to be most effective [32], its specific benefit above other forms of distraction remains controversial [33]. In conclusion, distraction might downregulate distress during the processing of traumatic memories, which, in turn, might reduce the likelihood of dissociation.

A second consequence of *in sensu* exposure exercises in self-management is strong emotional activation. Patients with PTSD experience a range of trauma-related emotions such as shame, guilt, and anger, which correlate with treatment outcome and dropout rates in therapy [34-38]. DBT-PTSD aims at monitoring such specific trauma-related emotions to guide treatment decisions.

As stated above, most exposure-based treatments include exposure exercises in self-management. Typically, during these exposure exercises patients are requested to listen to audio recordings of the exposure sessions [23]. No therapist guidance is available during these emotionally demanding exercises.

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Computer programs and apps might have the potential to provide additional support during this challenging task.

So far, a few apps have been developed to support PTSD treatment. To our knowledge, only two of them have been published in clinical journals: PE Coach [39] and PTSD Coach [40]. Both have been developed by the US Department of Veterans Affairs and offer a feedback tool that tracks symptoms via the PTSD symptom checklist (PCL) [41].

PTSD Coach can be used as either a stand-alone tool or an adjunct tool to face-to-face-therapy [42]. Coping strategies (eg, behavioral activation) are offered according to the patient's subjective units of distress (SUDs). Furthermore, the app offers a range of sensory grounding techniques (eg, "Focus all of your attention on the feel of a pebble or coin in your hand.") in case patients report dissociative symptoms. Users reported high levels of satisfaction and perceived helpfulness of the app [40,43]. However, a pilot randomized controlled trial on the effectiveness of PTSD Coach did not find a statistically significant reduction of PTSD symptoms in comparison with a waitlist control group [44]. PE Coach on the other hand is an adjunct to PE therapy, which enables patients to record and listen to their exposure sessions. The app monitors adherence to the exposure exercises and SUDs before and after each exercise. High satisfaction with the app was reported in a longitudinal case study with two soldiers [45].

Although these apps appear to be promising, they do not allow monitoring dissociation while listening to the recording. Furthermore, PE Coach does not provide strategies to cope with state dissociation. Moreover, apart from recording SUDs, none of the apps provides tools for monitoring other trauma-associated emotions. Therefore, we developed a computer program (MORPHEUS) that is designed to support self-administered *in sensu* exposure. It monitors state dissociation and offers skills to tackle dissociation if necessary. Furthermore, MORPHEUS is used for the feedback and monitoring of specific trauma-related emotional experiences. The study outlined here aimed at examining the acceptance and feasibility of the MORPHEUS program.

# Methods

# The MORPHEUS Program

MORPHEUS is a computer program that allows computer-assisted *in sensu* exposure exercises in self-management during the treatment of PTSD (see Treatment section). It can be used to listen to recordings of *in sensu* exposure sessions. A video showing the main functions of the program can be found in Multimedia Appendix 1.

Usability was a key requirement for MORPHEUS. The program was developed based on requirements expressed in interviews with patients and therapists at the PTSD unit of the Central Institute of Mental Health (CIMH), Mannheim (Germany). MORPHEUS was iteratively improved based on users' feedback.

# Audio Recording

Patients record their exposure sessions on a digital voice recorder where MORPHEUS is preinstalled. When the voice recorder is connected to a computer, the program imports and plays the recordings automatically (Figures 1 and 2).

Figure 1. Main screen: selection of audio recording and time interval for the iterative question for state dissociation.



Figure 2. Session recording with MORPHEUS.



### Monitoring of State Dissociation and Skills

While playing the recorded session, patients can monitor the level of state dissociation on a scale from 0 (not at all) to 100 (very much) in self-adjusted time intervals between 1 and 15 minutes. The question for state dissociation can be deactivated as well. During therapy, patients are trained to evaluate and monitor their individual levels of state dissociation on this scale. This intervention aims at increasing the patient's awareness of dissociation and thus fostering their ability to address these symptoms.

A dissociation level of 70 is defined as an anchor point: at that point, cognitive functioning is severely impaired, and sensory awareness of the here and now is perceived as increasingly "unreal." This concept corresponds to the idea of high aversive distress as defined by DBT [46]. According to DBT, high aversive distress requires stress tolerance skills that aim at the immediate downregulation of distress, for example, via distraction. Such distraction skills are used in MORPHEUS to block dissociative states. The program does not offer any other skills from DBT. If the patient endorses a dissociation rating of higher than 70, MORPHEUS randomly offers one of 15 available skills. These skills can be either used immediately or skipped. Patients can also predefine a subset of favorite skills from which the program chooses to offer one. On-demand use of skills is possible at any time during the exposure exercises and skills are available at any time after the exposure exercise as well. Patients can access and practice skills within the "skills box" of the program. Skills require a time frame of approximately 1 minute each or can be stopped earlier. Once it ends, MORPHEUS again asks for the level of dissociation. Skills in MORPHEUS are quick digital tasks. These tasks require full attention and serve as distractors that interfere with dissociation. MORPHEUS applies skills that address 4 sensory domains: spatial, cognitive, visual, and auditory (see Figures 3 and 4 and Table 1).

If a user is inactive for more than 10 seconds despite being asked for input (eg, during a skill or the monitoring question), white noise and an unpleasant tone (1-kHz sinus wave) are presented and the screen background alternates from white to black. This strong sensory signal serves as a distractor that helps the patient to interrupt a pronounced dissociative state and to reorient to the present.



Table 1. Overview of the skills in MORPHEUS.

Skill name	Task	Sensory domains
Treasure hunt	Find an audio signal with a noise detector.	Auditory Spatial
Square pattern	Click if you see a square pattern or if you hear a sound.	Visual Cognitive Auditory
Color logic	Click on the announced color.	Visual Auditory Cognitive
Color mapping	Click on the square that matches the background color.	Visual Auditory Cognitive
Go round	Don't let the moving squares touch the cursor.	Spatial Visual
Maze	Remember the luminescent squares on a maze and then click on them with the cursor.	Visual Cognitive Spatial
One-way pong	Catch a moving ball.	Visual Spatial
Rolling ball	Navigate a ball down the screen.	Visual Spatial
Reaction	Move the cursor to the objects that appear as soon as possible.	Visual Spatial
Finding new objects	Click on each new symbol.	Visual Cognitive
Mismatch	Find the symbol that differs from the rest.	Visual Cognitive
Brain Flic-Flac	Solve an arithmetic task.	Cognitive
Multitasking	Solve an arithmetic task and choose a symbol that differs from the others.	Cognitive Visual
2 in 1	Click on the symbol if it matches one of two symbols displayed above or if you hear a sound.	
Mother went shopping	Play the sounds that you've just heard.	Cognitive Auditory



Figure 3. Distribution of the 15 MORPHEUS skills along the 4 sensory domains.

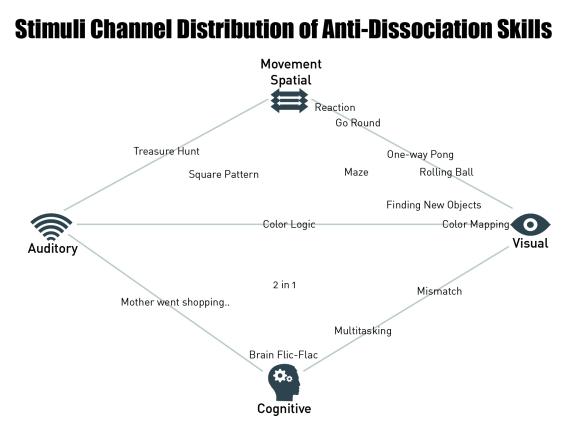


Figure 4. Finding new objects: in this skill patients need to click on the new object appearing on the screen.



# Monitoring and Feedback of Emotions

Several items are rated on a scale from 0 to 100 before and after each exposure session: the intensity of trauma-related emotions (guilt, shame, fear, anger, and helplessness), distress, dissociation, and acceptance of the traumatic event as part of the personal history (see Figure 5). State dissociation is measured with the Dissociation Tension Scale-4 (DSS-4) [8] with 4 questions on distorted hearing, derealization, depersonalization, and analgesia. The course of these trauma-related emotions and experiences is visualized within the statistics section of the program (see Figure 6). Data on trauma-related emotions in MORPHEUS and during exposure sessions will be published elsewhere.



**Figure 5.** Pre- and postsession assessments of dissociation (Dissociation Tension Scale-4) [8] and different trauma-related emotions. The questions on emotions adopt the following pattern: "If I think of the traumatic experience now, I feel [emotion, e.g. distress]."

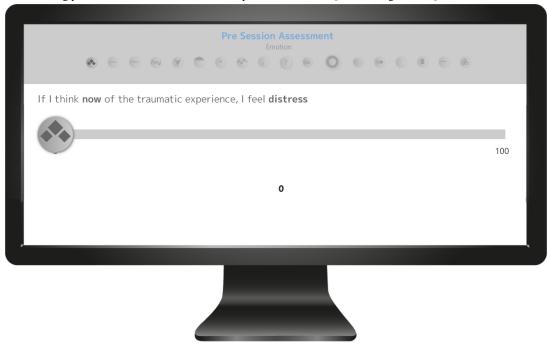


Figure 6. Statistics overview of trauma-related emotions and experiences. In this case, the patient chose to monitor fear (red). The time-dependent change of trauma-related emotions can be exported to a CSV file for research and feedback purposes.



#### **Study Design**

The participants received 12 weeks of residential DBT-PTSD at the CIMH in Mannheim, Germany, where MORPHEUS is a part of the standard treatment protocol. After 3 weeks in treatment, the participants were informed about the study and given a short introduction to the program by a doctoral level student (NG). Technical support was provided if any problems arose with MORPHEUS or with the devices needed to run the program (laptop, audio-recording device). If informed consent was given, the patients were directly asked to fill out a questionnaire on demographic details. The evaluation questionnaire was filled out after the exposure phase. The study

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has been approved by the Ethics Committee of the Medical Faculty Mannheim, Heidelberg University, and conducted according to the Declaration of Helsinki. The trial was registered in the World Health Organization International Clinical Trials Registry Platform (DRKS00006226).

#### Treatment

In this study, MORPHEUS was used as part of a DBT-PTSD residential treatment [24,25]. The patients received a 12-week multicomponent residential treatment. DBT-PTSD is based on principles of DBT and comprises trauma-specific cognitive interventions, exposure, as well as compassion-focused interventions. Exposure sessions usually take place between the

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fifth and the tenth week of treatment. If more than one trauma had been experienced, patients select the currently most distressing event as index trauma. During *in sensu* exposure, patients are asked to imagine and report the index trauma. In order to tackle state dissociation, stress tolerance skills (eg, distraction) are applied during exposure when necessary. In addition to the therapy sessions, patients were requested to listen to audio recordings of the exposure sessions, applying MORPHEUS on weekdays with no therapy session, that is, 2 to 5 times a week.

# **Participants**

The intake criteria for this study were as follows: (1) PTSD according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR* [47]); and (2) residential DBT-PTSD treatment within the PTSD unit of the CIMH. Exclusion criteria included (1) acute drug intake

and (2) medical contraindications to exposure-based treatment (eg, body mass index less than 16, cardiovascular disease). During the study period from July 2014 to July 2015, a total of 38 patients received regular treatment at the PTSD unit of the CIMH. Ten patients declined participation and 2 evaluation questionnaires were not returned. Thus, a final sample consists of 26 patients (25 females, 1 male; see Figure 7). Participants had a mean age of 42.15 years (SD 9.37). On average, they had received 10 years of education (SD 1.02). The average intake score of state dissociation during the session as measured with the DSS-4 was 3.05 out of 9 (SD 2.32).

As shown in Table 2, most of the patients had experienced childhood physical or sexual abuse. Other trauma categories included physical or sexual violence during adulthood, accidents, imprisonment, and suicide or violent death of a family member. Treatment focused on exposure to sexual or physical abuse experiences for all the patients.

Table 2. Co-occurring Axis I disorder and trauma categories (N=26).

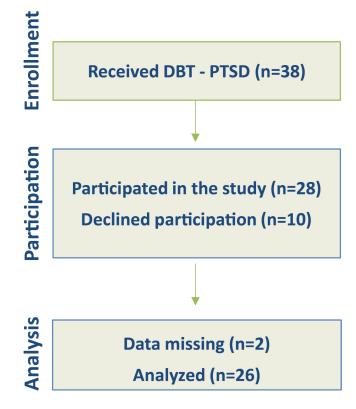
Sample Characteristics	n	
Current comorbidity:		
Major depression	20	
Dysthymia	1	
Eating disorders	5	
Panic disorder	3	
Specific phobia	3	
OCD <sup>a</sup>	2	
GAD <sup>b</sup>	1	
Substance abuse	1	
Somatization disorder	1	
Trauma category:		
Sexual abuse after age of 18 years	9	
Sexual abuse before age of 18 years	23	
Physical abuse after age of 18 years	8	
Physical abuse before age of 18 years	13	
Accident	2	
Imprisonment	1	
Suicide or violent death of family member	2	

<sup>a</sup>OCD: obsessive-compulsive disorder.

<sup>b</sup>GAD: generalized anxiety disorder.



Figure 7. Patient flowchart. DBT-PTSD: dialectical behavior therapy for posttraumatic stress disorder.



#### Assessments

Before admission, patients were interviewed with the German version of the Structured Clinical Interview for *DSM-IV-TR* (SCID-I) [48] to check for the inclusion criterion (PTSD) and co-occurring disorders. Additionally, patients were interviewed based on the BPD section of the International Personality Disorder Examination [49], which is part of the standard diagnostic procedure for the CIMH PTSD unit. The interviewers were graduate-level psychologists with ongoing training in cognitive behavioral therapy and supervised by senior-level clinicians.

Diagnoses were double-checked by experienced clinicians at admission to the PTSD unit. The acceptance of MORPHEUS was assessed with a 17-item questionnaire (see Figures 8,9, and 10 and Table 3). The questionnaire measures overall satisfaction with the program and with the digital skills, usability, as well as perceived helpfulness on a 6-point Likert scale ranging from 0 to 5 (Table 3). Frequency of skills use within MORPHEUS was rated on a 4-point scale (Figure 9). In addition, patients were asked in an open-format question what was helpful, whether they had suggestions for improvement, and what kind of additional support during MORPHEUS use they would have liked to see.



Figure 8. Frequency of MORPHEUS use per week on a 4-point Likert scale (N=25).

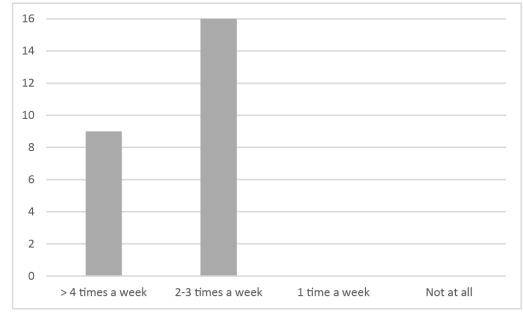
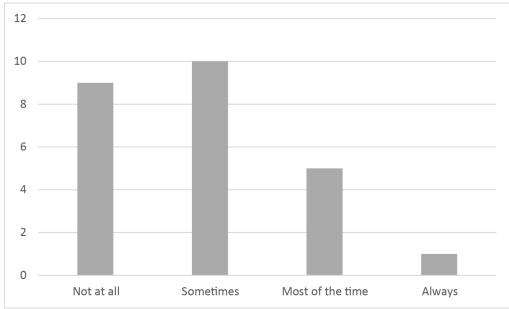


Figure 9. Frequency of digital skill use (N=25).



# **Data Analysis**

All data were analyzed on a descriptive level. Subjective ratings of dissociation on a scale from 0 to 100 were compared before and after skills use. As to the qualitative data, patients' comments were analyzed using procedures adapted from content analysis according to Mayring [50].

# Results

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All patients received *in sensu* exposure and were supposed to use the MORPHEUS program during exposure exercises. Mean duration of the exposure phase was 4.3 weeks (SD 1.9).

# **Quantitative Data**

All patients used the program as often as it was required in the standard DBT-PTSD protocol, that is, at least 2 to 5 times a

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week (see Figure 8). As can be seen in Figure 9, most patients used the skills in MORPHEUS at least sometimes (16/25, 64%), whereas 9/25 patients (36%) never used them and 1 patient did not answer that question.

According to our session logs, a total of 10 patients used antidissociative skills. Because of technical difficulties, data were not available for 5 patients. On average, these patients started the skills 3.9 times. In 82% of the cases (32/39), the use of antidissociative skills was related to a decrease in dissociation. In 5%, (2/39) dissociation remained unchanged, and in 13%, (5/39) the scores of dissociation increased. In these outlier cases, the skills might have elicited great distress for the patients, maybe because they were not able to concentrate or because they felt enormous pressure to perform well in the skills. Mean change of pre- to post-skill dissociation was 17.82 with a standard deviation of 29.65.

Altogether, 96% (24/25) of the patients reported that they used other DBT skills, apart from the digital skills in MORPHEUS, during exposure (see Table 3), and 1 patient did not answer that question. Some participants (n=9) named reasons for not using the program (multiple choices were possible), such as technical difficulties (n=4), the wish to avoid exposure sessions (n=2), and the cancellation of treatment sessions (n=3; see Figure 10).

The results of the evaluation questionnaire revealed an overall high acceptance of the program as perceived by the patients (see Table 3). In the following, percentages are reported for patients who indicated at least a moderate agreement with the statements in the questionnaire, that is, who rated at least a 3

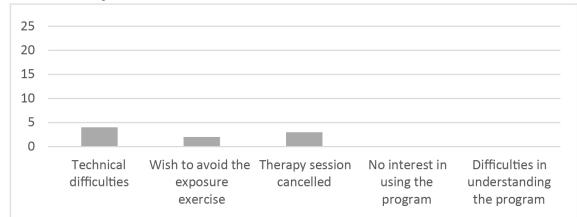
on this scale from 0 to 5. Skills were rated as highly useful to block dissociation: 95% (20/21) of the patients rated the skills at least moderately useful to block dissociation (mean 4.24, SD 0.24; n=21). In all, 100% (25/25) of the patients who answered the item indicated at least moderate agreement to the statement that they would recommend the program to a friend (mean 4.44, SD 0.12; n=25). Furthermore, 96% (25/26) of the patients rated the program at least moderately helpful (mean 4.62, SD 0.15; n=26). Altogether, 100% (25/25) of the patients who answered that question expressed at least a moderate level of perceived control during the use of MORPHEUS (mean 4.2, SD 0.15; n=25).

Question	0	1	2	3	4	5	Mean (SEM)	Missing, n
Program in general	•	-	-		•		•	
During the use of the program I had 0: no control at all - 5: complete control	0% (0/25)	0% (0/25)	0% (0/25)	20% (5/25)	40% (10/25)	40% (10/25)	4.20 (0.15)	1
The program meets my expectations 0: not at all - 5: very much	0% (0/24)	0% (0/24)	0% (0/24)	8% (2/24)	50% (12/24)	42% (10/24)	4.33 (0.13)	2
I did get along with the program 0: not at all - 5: very well	0% (0/26)	0% (0/26)	0% (0/26)	12% (3/26)	12% (3/26)	77% (20/26)	4.65 (0.14)	0
I found the program 0: not at all helpful - 5: very helpful	0% (0/26)	0% (0/26)	4% (1/26)	4% (1/26)	19% (5/26)	73% (19/26)	4.62 (0.15)	0
I would recommend the program to a friend 0: not at all - 5: very much	0% (0/25)	0% (0/25)	0% (0/25)	4% (1/25)	48% (12/25)	48% (12/25)	4.44 (0.12)	1
I would 0: not like to use the program - 5: like to use the program during therapy	0% (0/25)	0% (0/25)	0% (0/25)	4% (1/25)	20% (5/25)	76% (19/25)	4.72 (0.11)	1
The support I got for using MORPHEUS was 0: not suffi- cient at all - 5: absolutely sufficient	0% (0/26)	0% (0/26)	0% (0/26)	4% (1/26)	12% (3/26)	85% (22/26)	4.81 (0.10)	0
Skills								
The skills were 0: very unuseful - 5: very useful in order to avoid dissociation	0% (0/21)	5% (1/21)	0% (0/21)	19% (4/21)	19% (4/21)	57% (12/21)	4.24 (0.24)	5
I was 0: very unsatisfied - 5: very satisfied with the digital skills in MORPHEUS	0% (0/19)	5% (1/19)	0% (0/19)	21% (4/19)	47% (9/19)	26% (5/19)	3.89 (0.23)	7
The digital skills in MORPHEUS 0: didn't work as I would like to - 5: worked exactly the way I liked to	0% (0/19)	5% (1/19)	11% (2/19)	11% (2/19)	53% (10/19)	21% (4/19)	3.74 (0.25)	7
During my exercises with MORPHEUS I used my own skills beyond the skills in the program 0: never - 5: very often	4% (1/25)	0% (0/25)	8% (2/25)	16% (4/25)	28% (7/25)	44% (11/25)	3.96 (0.26)	1

<sup>a</sup>SEM: standard error of the mean.



Figure 10. Reasons for not using MORPHEUS (N=9).



# **Qualitative Results**

Altogether, 23 patients reported what they found helpful within the program in an open question format: the answers were related to the skills (eg, "no dissociation possible, skills directly available"), easy handling (eg, "suitable for people who haven't worked with computers before"), dissociation monitoring question, the possibility to pause recordings, and the graphs about the longitudinal course of trauma-related experiences and emotions (eg, "You were able to see any time what you have reached in your therapy"). One patient referred to the intervention as such ("hearing how my voice got stronger and how I acted opposite").

In all, 12 patients suggested ways to improve the program, again relating to the skills ("the program should offer skills to differentiate between present and past, for example: "Where am?" "How old am I?"), the pre- and postsession assessments ("the screen with the question disappeared too quickly after logging in the answer"), and the upload of the recording ("ability to upload two recordings with only one pre- and post-exercise assessment").

Only 3 patients answered the question whether they had wished additional information. One patient indicated confusion about the pre- and post-session ratings of trauma-related emotions ("How do I rate the questions if two trauma networks overlap? If there are no feelings, what should the rating be?"). Another participant mentioned problems regarding asking for help while using the program ("I didn't have the heart to ask for additional support"). A third patient expressed the wish for more support during the first use ("When you do your first exposure exercise with the program, someone should be with you, because I couldn't cope with MORPHEUS the first two times").

# Discussion

# **Principal Findings**

Our preliminary data show high acceptance and satisfaction with the computer program MORPHEUS as a self-administered adjunct to therapist-guided exposure therapy. Patients used the program as often as it is recommended in DBT-PTSD. Overall, patients found the skills helpful to block dissociation, and they stated that they would use the program again in therapy and would recommend it to a friend. In an open question format,

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patients mentioned all the elements within the program as being helpful. However, patients often used their own skills rather than the digital skills. Suggestions for improvement related to the skills, upload of session recordings, and assessment questions. Use of antidissociative skills by the participants was usually related to a decrease in dissociation (82%). Because of the lack of a control group and the small sample size, this result should be considered as preliminary and requires replication from a study designed to establish efficacy of MORPHEUS.

# **Comparison With Prior Work**

To our knowledge, this is the first study testing the longitudinal use of technology to reduce dissociative states and track trauma-related emotions during exposure exercises in PTSD therapy. Other programs such as PE Coach and PTSD Coach emphasize other aspects of PTSD therapy such as breathing retraining, in vivo exercises, and psychoeducation. Acceptance rates of MORPHEUS were comparable to the ratings from the feasibility study of PTSD Coach, using veterans as participants [40]. Thus, the usability of our program seems comparable to existing technology in PTSD treatment.

#### Limitations

On the basis of the finding that patients more often used the skills already learned in DBT skills groups as compared with the MORPHEUS program, it can be assumed that patients rely heavily on already established antidissociative skills that are available without electronic devices. However, we did not test whether monitoring of dissociation in MORPHEUS might have increased patient's awareness of state dissociation. Increased awareness of dissociation might have prompted the use of skills outside of MORPHEUS. Future versions of this program should prompt skills use outside of MORPHEUS in addition to the digital skills, comparable to the grounding techniques suggested in PTSD Coach.

At this point in our research project, we cannot provide data about the efficacy of the digital skills in MORPHEUS to block dissociation. To the best of our knowledge, studies that empirically test the efficacy of distraction skills or grounding techniques to block dissociation during trauma exposure do not exist. Thus, future studies will test whether the skills in MORPHEUS are effective in blocking dissociation during exposure as compared with a control condition without skills.

The program was explained to the patients by one of the authors (NG) during a 30-minute information session. This procedure might have resulted in a bias within the evaluation questionnaires toward more positive ratings. All patients learned about digital antidissociative skills within this session and also had the chance to test some of the skills. This might explain why patients gave overall positive ratings for the skills while at the same time indicating infrequent use of the MORPHEUS skills during the actual exposure exercises. During the trial period, one patient spontaneously reported that she used the MORPHEUS skills after the exposure exercises in order to reduce dissociative states. Thus, she might have rated the skills as highly useful to block dissociation yet at the same time she did not use them during the exposure. However, only skills use during the exposure exercise was monitored for the purpose of this study.

Some technical problems arose because of the need to use different electronic devices to run the MORPHEUS program (computer, digital voice recorder). Therefore, a mobile app version of MORPHEUS was developed and a prototype with the MORPHEUS skills is freely available for Android devices [51].

A major limitation of this study is that all except one participant were female. The PTSD unit of the CIMH is specializing in the treatment of consequences of early interpersonal violence. However, the majority of patients seeking this treatment are female (around 11 out of 13). Studies on the prevalence of childhood sexual abuse point to the direction of a higher prevalence of severe forms of victimization in girls than in boys (eg, higher rate of penetration; see [52-54]). As a consequence, the population of treatment seekers is represented sufficiently by our sample. However, future studies should be more adept to recruit male patients and patients with different types of traumatic experiences. In addition, the program should be tested within outpatient samples.

### Conclusions

With MORPHEUS, patients can record and listen to the therapy session and check the feedback of pre- and postexercise assessments. Our data suggest high acceptability and feasibility of the program. Further studies will evaluate the effectiveness of using MORPHEUS through mobile apps.

### Acknowledgments

We would like to thank all participants in this study. We would also like to thank Andrea Schropp and Daniel Graf for testing and optimizing the pilot version of MORPHEUS and Annika Deufel for her help with the literature section of this paper. Finally, we would like to thank the team of the CIMH PTSD unit for their help in recruiting participants and with data collection: Silke Huffziger, Janina Tervoort, Christine Jung, Corinna Groß, Nadine Defiebre, Julia Herzog, Franziska Rother, Barbara Beckmann-Schumacher, and Teresa Knorz.

# **Conflicts of Interest**

The authors TD and MS have developed both the MORPHEUS app and the MORPHEUS software. They are planning to sell the full version of the MORPHEUS app in the future. MS and TD were not involved in collecting or analyzing the evaluation data of this study.

# **Multimedia Appendix 1**

Presentation and video material showing the main functions of the MORPHEUS program.

[MP4 File (MP4 Video), 16MB - mental\_v3i2e27\_app1.mp4]

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## Abbreviations

BPD: borderline personality disorder
CIMH: Central Institute of Mental Health
DBT: dialectical behavior therapy
DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision
DSS-4: Dissociation Tension Scale-4
EMDR: eye movement desensitization and reprocessing
GAD: generalized anxiety disorder
OCD: obsessive-compulsive disorder
PE: Prolonged Exposure
PTSD: posttraumatic stress disorder
SEM: standard error of the mean
STAIR: Skills Training in Affective and Interpersonal Regulation
SUD: subjective units of distress

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**Original Paper** 

# Process and Effects Evaluation of a Digital Mental Health Intervention Targeted at Improving Occupational Well-Being: Lessons From an Intervention Study With Failed Adoption

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# Abstract

**Background:** Digital interventions have the potential to serve as cost-effective ways to manage occupational stress and well-being. However, little is known about the adoption of individual-level digital interventions at organizations.

**Objectives:** The aim of this paper is to study the effects of an unguided digital mental health intervention in occupational well-being and the factors that influence the adoption of the intervention.

**Methods:** The intervention was based on acceptance and commitment therapy (ACT) and its aim was to teach skills for stress management and mental well-being. It was delivered via a mobile and a Web-based app that were offered to employees of two information and communication technology (ICT) companies. The primary outcome measures were perceived stress and work engagement, measured by a 1-item stress questionnaire (Stress) and the Utrecht Work Engagement Scale (UWES-9). The intervention process was evaluated regarding the change mechanisms and intervention stages using mixed methods. The initial interviews were conducted face-to-face with human resource managers (n=2) of both companies in August 2013. The participants were recruited via information sessions and email invitations. The intervention period took place between November 2013 and March 2014. The participants were asked to complete online questionnaires at baseline, two months, and four months after the baseline measurement. The final phone interviews for the volunteer participants (n=17) and the human resource managers (n=2) were conducted in April to May 2014, five months after the baseline.

**Results:** Of all the employees, only 27 (8.1%, 27/332) took the app into use, with a mean use of 4.8 (SD 4.7) different days. In the beginning, well-being was on good level in both companies and no significant changes in well-being were observed. The activities of the intervention process failed to integrate the intervention into everyday activities at the workplace. Those who took the app into use experienced many benefits such as relief in stressful situations. The app was perceived as a toolkit for personal well-being that gives concrete instructions on how mindfulness can be practiced. However, many barriers to participate in the intervention were identified at the individual level, such as lack of time, lack of perceived need, and lack of perceived benefits.

**Conclusions:** The findings suggest that neither the setting nor the approach used in this study were successful in adopting new digital interventions at the target organizations. Barriers were faced at both the organizational as well as the individual level. At the organizational level, top management needs to be involved in the intervention planning for fitting into the organization policies, the existing technology infrastructure, and also targeting the organizational goals. At the individual level, concretizing the benefits of the preventive intervention and arranging time for app use at the workplace are likely to increase adoption.

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## **KEYWORDS**

acceptance and commitment therapy; intervention studies; mHealth; cccupational health; process assessment; stress; mindfulness; attrition; adoption

# Introduction

Prevention of mental health problems is a topical issue. Psychosocial stress is a risk factor for mental health problems [1], and many serious medical conditions such as coronary heart disease [2,3]. Mental ill-health also causes an enormous economic burden and is becoming a key issue for the functioning of the Organization for Economic Cooperation and Development (OECD) labor markets and social policies [4].

Wider adoption of workplace wellness programs could prove beneficial for financial and productivity outcomes as well as health outcomes [5]. Occupational interventions usually aim to improve employees' working conditions and/or health, reduce absences and employee turnover, and increase motivation and job satisfaction. Other objectives may include increased product quality, productivity, or customer satisfaction. Occupational interventions are evaluated by assessing the effects of planned activities at the worksites [6].

Work stress interventions utilizing acceptance and commitment therapy (ACT) have been shown to reduce stress and increase well-being and job performance [7,8]. ACT belongs to the third wave of cognitive behavioral therapies and emphasizes mindfulness and acceptance skills. The core concept of ACT is psychological flexibility, which refers to the ability to focus on the present moment and take actions that are aligned with personal goals and values even in uncomfortable or distressing situations [9-11].

Recently, digital interventions have been presented as more cost-effective and scalable means to promote health and well-being compared to face-to-face interventions [12]. Employers have started to incorporate Web-based approaches into their wellness programs, because the Internet provides an efficient avenue to reach and engage a large number of people [13]. Mobile apps could be especially suitable in well-being management in everyday life because they are easily accessible [14]. Digital interventions also have the potential to influence health and well-being at workplaces. However, the evidence of their effects on stress is still scarce. Until now, studies of preventive digital interventions have largely focused on physical health [15]. Although physical activity interventions can have a positive impact on both physical and mental health [16], apps focused on preventing mental health problems could be more effective in terms of stress management. Luckily, the importance of mental and social well-being has been acknowledged recently, and various systems have been developed specifically for the treatment of mental disorders [17].

Adoption processes of digital interventions at organizations have received little attention. In the context of this paper, the term adoption refers to a process that ends in the appropriate and effective use of a technology or digital service. In other studies the term operationalization has been used instead, referring to the actual introduction, adoption, and employment of the technology in practice, including also training and education [18]. Most Web-based or mobile interventions are primarily self-guided programs that are used by individuals who seek health or mental health-related support [19]. When such programs are introduced into a workplace, their adoption is influenced by organizational goals and stakeholders on higher organizational levels [20]. Due to mixed success of interventions in organizations, process evaluations explaining why the intervention succeeded or failed are advocated [21,22]. They can help to understand the entire process for creating successful organizational interventions. Even if an intervention program has been shown to be efficacious in controlled trials, the benefits will not be realized in the real world context unless implementation, adoption, and maintenance in an organization are successful.

Adoption of digital interventions should not be considered only from the organization's point of view, but also from the individual's point of view. Employees' adherence, including the extent to which individuals experience the content of the intervention [23], has to be high enough to create successful outcomes. Users' motivations and experiences play a central role in adoption because they affect people's mental models and behaviors, and therefore the intervention outcome. The more people are intrinsically motivated, the higher the probability is to engage a person in long-term changes in behavior [24]. Documenting the experiences of the participants receiving the intervention helps to explain how and why changes were or were not achieved [25].

The aim of this paper is to evaluate the adoption process and effects of an individual-level unguided digital mental health intervention at organizations. In addition, it explores users' motivations and experiences related to the mobile and Web app used to deliver the intervention. An earlier pilot study showed that the app can be acceptable, useful, and engaging among stressed working-age adults [14]. Thus, the two hypotheses of this study are (1) employees take the technology into active use supported by the organization; and (2) the intervention has a positive impact on employees' well-being.

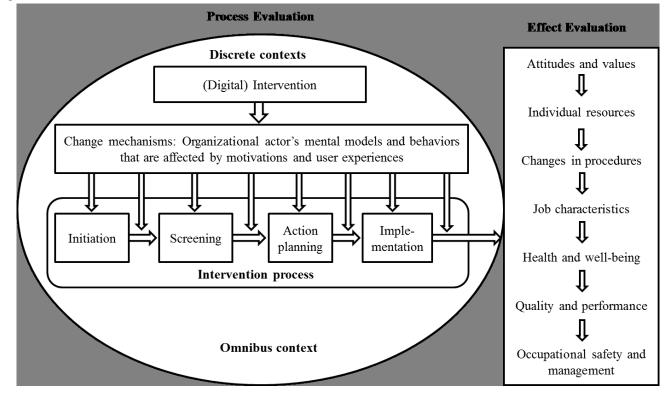
# Methods

## **Intervention Evaluation**

Nielsen and Abildgaard's intervention evaluation framework was used for intervention process and effects evaluation [22]. The framework, where we also highlight the central components including digital intervention, motivations and user experiences as part of the change mechanisms are illustrated in Figure 1. The results are structured first with process evaluation including change mechanisms and intervention process. Then the effects evaluation is done on the effects on well-being.



Figure 1. Intervention evaluation framework [22].



## **Intervention Context**

#### **Organizations**

The intervention took place in two companies (Company A and Company B) working in the information and communication technology (ICT) industry (Table 1). At the time of the planning

of the intervention, Company A was growing and had a higher employee turnover than Company B, which had reduced the number of personnel during the recent years. The companies did not have any previous experience on adoption of individual-level digital interventions. The purpose of the study was to evaluate the intervention process and effects within a company, not between companies.

Table 1. Description of the companies.

	Company A	Company B
Number of employees	230 in Finland	102 in Finland, over 4000 worldwide
Offices	2 locations	2 locations
Age of employees	35 years on average	30-40 years on average
Gender	83% men	28% men
Most common job titles	Software designer, consultant, project manager	Technical writer, consultant, project manager
Amount of remote work	Occasional remote work and travel	Technical writers often work at customers' premises and consultants travel often
Amount of sick leaves	3-4% of working days, length of a sick leave usually 1-3 days	5-6% of working days, also some long sick leaves
Top 3 reasons for sick leaves	Common cold, stomach flu, musculoskeletal problems	Common cold, musculoskeletal problems, mental problems
Occupational health care	All employees are within the occupational health care	All employees are within the occupational health care
Work well-being assessments	Annual survey	Annual survey

## **Digital Intervention**

The intervention content was delivered through a digital training app which was available in a mobile (iOS and Android) and a Web-based version (Figures 2 and 3) [14]. Participants received a link [26] for the app in the info sessions, emails, company intranet and flyers. Both apps were available only in Finnish.

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The app was based on ACT and targeted at stress management and mental well-being, teaching ACT skills in bite-sized sessions that could be listened to or read. The app was originally designed in cooperation between experts in user-centered design, psychology and computer science [14]. Its effects on stress have been studied in a randomized controlled trial [27], the results of which are not yet published.

Figure 2. Screenshot of the mobile app (texts translated from Finnish).



Figure 3. Screenshot of the web app (texts translated from Finnish).



## Participant Recruitment

The participants of the study were the human resource (HR) managers and employees of the two ICT companies. The

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employees of both companies with sufficient computer literacy and fluency in Finnish were eligible to participate in the study. The HR managers of the companies invited the employees via email messages to an initial info session, which was held by

researchers. The session consisted of a 20-minute presentation about the ACT approach, the app, and the aims and procedures of the study. In Company A, two info sessions were held at the two company offices. In Company B, the info session was arranged as an online meeting. In addition, the HR managers put information about the study in the company intranet and distributed paper flyers at the company offices. In all invitations and recruitment materials, the study was framed as a positive opportunity to improve one's well-being and learn new skills to manage stress. The participants were instructed to use the digital app regularly, in brief sessions several times per week, but the intervention was otherwise unguided.

#### **Intervention Design**

The intervention was designed to follow the stages outlined in Table 2 according to Nielsen and Abildgaard [22]. The delivery of the intervention was planned to be similar in both companies, with only small adaptations resulting from the information gathered during the initiation and screening stages.

Table 2. Intervention process design based on Nielsen and Abildgaard's framework [22].

Stage	Tasks	Program design
Initiation	Clarify roles of different actors; create a communi- cation strategy	First contact with companies through their HR managers
Screening	Assess organizations' needs; select measures on individual and organizational level	Interviews with HR managers at the companies to recognize organi- zation-specific needs and context; selection of suitable measures that complement existing assessment methods in the companies, with emphasis on measures focused on strengths and skills rather than problems and weaknesses
Action plans	Clarify intervention activities, their purpose and timeline; select methods for evaluating success of actions	App available on Web and mobile platforms; baseline survey con- ducted online; approximate intervention duration 3 months; kick- off events for employees held by researchers on-site and/or through online meetings; email and calendar invitations, intranet announce- ments and flyers at worksite; if possible, events aligned with other events/trainings in the company
Implementation	Document intervention activities; assign person who makes intervention happen in the organization	Regular contact with HR managers to keep track of the progress and activities inside the companies; mid-survey (online) to assess initial engagement and experiences among employees
Evaluation of effects	Measure changes in health and well-being; measure changes in working conditions and organizational procedures	Follow-up survey (online); analysis of changes in different well- being measures from baseline to follow-up; interviews with volunteer employees, superiors and HR managers

## **Ethical Considerations**

The study and all the related questionnaires were reviewed by the Ethics Committee of the Pirkanmaa Hospital District. Participants' informed consent was obtained in the beginning of the baseline questionnaire online. The data was stored on a secure server. All the data was anonymized for reporting and publication.

## **Data Collection**

Data was collected between August 2013 and May 2014. The study began in August 2013 with HR managers' interviews, and the intervention took place between November 2013 and March 2014. The study ended with the final interviews with the participants in April to May 2014.

Electronic questionnaires were sent via LimeSurvey (version 2.00) in the beginning of the study for all employees, and at two and four months for those employees who completed the baseline questionnaire. Occupational health and well-being was assessed in the beginning and in the end using a 1-item Stress questionnaire (Stress) [28], and a 9-item Utrecht Work Engagement Scale (UWES-9) [29,30] as primary outcome

measures. The scores in the Stress questionnaire range from 1-5 with higher scores signifying a worse stress situation, whereas scores range from 0-6 for the UWES-9 test, where a higher score signifies a better work engagement. The Stress scale has shown satisfactory content, criterion, and construct validity for group level analysis [28]. The internal consistency of UWES-9 is good, with Cronbach's alpha varying between .85 and .92 across samples in 10 different countries [31,32].

Secondary outcome measures were an 84-item work-related well-being questionnaire which assessed both personal and work community well-being (P-TyHy, TyHy) [33], a 5-item Satisfaction With Life Scale (SWLS) [34], a 14-item Mindfulness questionnaire (FMI) [35], and a 7-item Work-Related Acceptance and Action Questionnaire (WAAQ) [10]. Motivations related to participation in the study and using the app were studied in the beginning, in the middle of the study, and in the end using ad hoc 16- and 14-item Self-Regulation Questionnaire (SRQ) [36]. Because an existing SRQ questionnaire for this specific context did not exist, questions were adaptations of the existing SRQ questionnaires. Motivations were inquired with additional open-ended questions. Details of the questionnaires and scales are shown in Table 3.



Name Score range		Significance of higher scores	Internal consistency	Cronbach's alpha range	
Work-related well-being questionnaire (P-TyHy, Ty- Hy)	0-70	Better occupational health and well-being	N/A	N/A	
Satisfaction With Life Scale (SWLS)	5-35	Higher satisfaction with life	Good	.7989	
Mindfulness questionnaire (FMI)	14-56	Higher mindfulness skills	Good	.8693	
Work-Related Acceptance and Action Questionnaire (WAAQ)	0-42	Higher psychological flexibility	Good	.8184	
Self-Regulation Question- naires (SRQ)	1-7	Higher motivation	N/A	N/A	

Qualitative data consisted of several semi-structured interviews. Before the intervention, HR managers (n=2) were interviewed separately, face-to-face for the companies' characteristics, needs, and well-being challenges. In addition, the schedule for the intervention activities was outlined together with them. After the intervention, the HR managers were interviewed for their views on the success of the intervention, attitudes toward occupational health and mobile coaching in an organizational context, as well as intervention adoption in organizations. It should be noted that the HR manager of Company A changed during the course of the study.

After the intervention, a voluntary subset of employees (n=17) were interviewed, including 13 employees who had participated in the intervention study and 4 who had not participated. The interviewees were enquired about their experiences with the intervention process, motivations to learn stress management skills and participate in the study, attitudes toward occupational well-being, and mobile coaching in an organizational context. The intervention participants were also enquired about the motivations and user-experiences related to the app use. If an interviewee was working as a manager, such as team manager, additional questions were presented concerning the possibility of app use in team meetings and benefits of the app for managers. Interviews, after which notes were written and significant parts transcribed.

Data about the app usage was collected via app logs. When signing the informed consent, participants received a study identification code which was used to link the intervention usage logs to the participant. The participants were asked to input their code into the app settings so that their usage data could be identified. The usage log of the app, including time stamped user actions, was transmitted to a database on a secure server.

## **Data Analysis**

## Quantitative Data Analysis

Baseline and final questionnaires were considered in the data analysis. The scales were analyzed, and their median values and inter-quartile ranges calculated. Statistical tests were conducted with IBM SPSS Statistics (version 20) software. Change in participants' ratings of well-being was analyzed with a

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## Qualitative Data Analysis

For the qualitative data, the overall evaluation was made by combining both populations due to the small sample size. The questionnaires' open-ended questions and data from the final interviews were processed by putting the information from written documents into tables (MS Excel 2010, version 14) according to the original themes of the questionnaires and interviews. After this phase, common themes related to adoption as well as participants' motivation and experiences were identified. In identifying motivations, themes arising from Self-Determination Theory (SDT) were used [24]. New categories and themes were created based on the data using principles of inductive content analysis.

## Log Data Analysis

Usage logs were processed to calculate the usage duration in days and unique uses of the app. The duration was calculated as the time between the first and last timestamps. Actual use days, meaning the number of days when the app was used, were calculated.

## Results

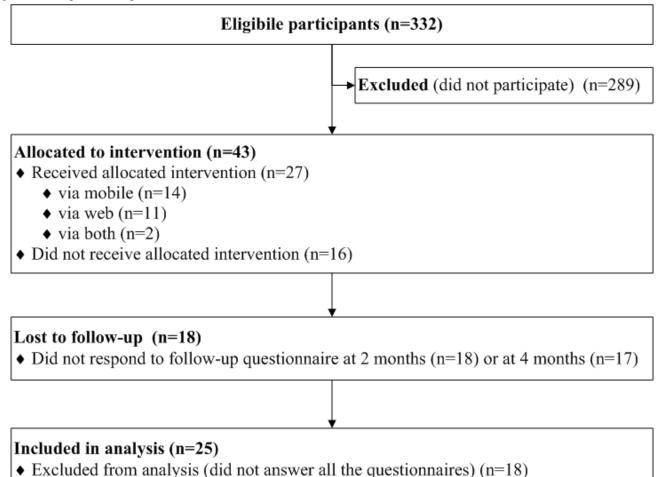
## **Participant Flow and Intervention Adoption**

In total, 13.0% (43/332) of the employees participated in the study (Figure 4). The mean age of the participants was 37 years (range 25-54) and 67% (29/43) were female. It was found that 63% (27/43) of the participants, that is 8.1% (27/332) of all the employees started using the app, and 43 (13.0%, 43/332) answered the baseline questionnaire, 25 (58%, 25/43) the mid-term questionnaire, and 26 (60%, 26/43) the final questionnaire. Of those, 25 (58%, 25/43) participants answered all the questionnaires and were included to the longitudinal statistical analyses.

From the identified 25 logs, the mean use of the app was used 4.8 (SD 4.7) different days (range 0-19) and the mean app use period was 65.7 (SD 60.3) days (range 0-154). The app use

period means the time between the first use session and last use session. For 64% (16/25), the use period was over week.

Figure 4. Participant flow diagram.



## **Process Evaluation**

## **Intervention Process**

Since the face-to-face interviews in the beginning of the study provided largely similar information from both companies with respect to the companies' characteristics, needs, and well-being, the intervention was implemented in a similar manner in both companies. However, there were minor deviations in the informing of the intervention. In Company B, the employees were more thoroughly informed of the upcoming study by the monthly letters and the participation of a researcher in one of the company's remote meetings. Furthermore, the company culture, motivational factors, and challenges were somewhat different, and therefore, the information sessions emphasized different benefits, namely personal well-being and new skills in Company A and occupational well-being and helping others in Company B.

The findings show the intervention process applied in this study did not lead to successful adoption of a digital intervention in occupational well-being: only 13.0% (43/332) filled in the baseline questionnaire and only 8.1% (27/332) of all employees started using the app. In the following sections, the assumptions

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which the intervention design was based on, the correct assumptions (italics), and a clarification of where the assumptions failed are described.

#### Initiation

The assumptions in the beginning were that the HR managers (1) *are responsible for employees' training, development, and actions that influence their overall performance and occupational health and well-being*; and (2) are authored to make relevant decisions or actions. The second assumption was incorrect; the top management made the final decisions about participating in this study and that employees could participate in kick-off meetings during working hours, but the app use had to take place on their own time. Although the HR managers were a rich source of information and a suitable first point of contact in the companies, more effort should have been taken to involve the top management because they made the strategic decisions.

#### Screening

The assumptions in the beginning were that (1) the HR managers know the well-being situation in the company best; (2) they can provide contacts to other organizational actors as well as occupational health care; (3) they can benefit from the

intervention personally; (4) combining study measures with assessment tools already in place (current context) makes participation easier for the employees; and (5) positive tone in the questionnaires attracts more participants and can work as an intervention already by itself. The second assumption was only partially correct; contact between the occupational health care and the researchers was never established. The third assumption was correct but it was found that the app could also be extended to provide support for the HR managers in their work, such as leading for health and well-being. The fourth assumption could not be tested because it was not possible to combine the study measures with the existing ones in the organization due to conflicting schedules. The fifth assumption was incorrect; questionnaires with a positive tone and an instant feedback after submitting the questionnaire did not encourage people to stay in the study which can be seen in the high dropout rate (approximately 40%).

#### **Action Plan**

The assumptions in the beginning were that (1) aligning the intervention activities with existing activities in the company makes the process simpler for the employee; and (2) *multiple channels for recruitment and intervention content delivery reach more people than a single one*. The first assumption was not possible to be followed in the intervention realization because no other relevant ongoing activities could be identified within the proposed timeline of the study. The second assumption was correct but it has to be noted that not all channels were equally efficient. The paper brochures did not reach many employees, and a message from the HR and the management was mentioned to have more impact on participation.

#### Implementation

The assumptions in the beginning were that (1) the HR managers pay attention to intervention penetration; and (2) *the midterm questionnaire also works as a reminder for participants*. The first assumption was incorrect; since the intervention was not visible in the everyday life at the workplace, the HR managers did not know who took the app in use and did the exercises. Moreover, the HR manager of Company A changed during the study, which meant that the HR manager who was interviewed in the end had not been involved from the beginning of the study. The second assumption was correct, but even though the questionnaires reminded about the use of the app, the effects unfortunately did not realise in higher use activity.

## **Evaluation of Effects**

The assumptions in the beginning were that (1) three months is a sufficient time to detect meaningful changes in well-being indicators; and (2) introduction of the intervention leads to changes in organizational procedures. The first assumption was not possible to test with such a small study population and low adherence. The second assumption was also incorrect. The intervention had no observable impact on organizational procedures.

## **Change Mechanisms**

This section describes findings regarding individuals' motivations related to study participation, digital intervention use, and user experience. The findings suggest that autonomous

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regulations were strongly present in both motivations to participate in the study and in the motivations to use the digital intervention. This is important since it is the most beneficial type of motivations in terms of long-term behavior change.

## Motivations and Barriers to Participate in the Intervention

Motivations to participate in the intervention were inquired in the beginning of the study with an ad hoc SRQ. The most common reasons to participate in the study among the respondents (n=42) were (1) desire to feel better at work (100%, 42/42); (2) desire to improve well-being (100%, 42/42), (3) desire to learn new skills (98%, 41/42); (4) enjoyment of trying something new (93%, 39/42), (5) desire to advance scientific research (86%, 36/42), (6) interest in participating in a research study (86%, 36/42), (7) interest in figuring out how the digital intervention works (76%, 32/42); and (7) feeling good about doing something for the good of the society (67%, 28/42). Interviews highlighted similar motivations.

Barriers for participating were inquired with a separate mini-questionnaire from the non-participants (n=62) and they reported not participating in the study mainly because they (1) did not see problems in their occupation well-being and thus, they had no need for the app (68%, 42/62); (2) did not have time (65%, 40/62); and (3) did not remember to participate, which implies that the study was not in high priority for them (48%, 30/62).

#### Motivations and Barriers to Use the App

Motivations to use the app were inquired in the midterm questionnaire during the study with an ad hoc SRQ. The most common reasons to use the app among the respondents (n=18) were (1) importance of the personal well-being (100%, 18/18); (2) interest in making life changes (100%, 18/18); (3) desire to learn new things (100%, 18/18); (4) appreciation towards the app contents (94%, 17/18); (5) it was fun to do exercises with the app (83%, 15/18); and (6) it brought enjoyment to process everyday issues with the app (72%, 13/18).

Barriers for use were inquired in the midterm questionnaire from the participants who did not use the app. The most common reasons among the respondents (n=7) not to use were (1) not finding the time (100%, 7/7); and (2) not having a suitable phone (71%, 5/7) (eg, Windows phones were popular in Company B). Interviews confirmed that lack of time, having no need, and not remembering (ie, low priority) hindered app use. As one project manager from company B commented: "As a mother of small children, my time is limited."

Participants suggested several ways to support app use, such as group meetings, common use sessions at a workplace, reminders, follow-ups and provision of information on study progress.

#### **User Experience Findings**

User experiences were collected in the end of the study from the 13 interviewees who had used the app relatively actively.

The participants experienced that using the app helped mindfulness to become part of their routines, because the exercises gave concrete instructions how mindfulness can be practiced. They learned ways to perform breathing and relaxation exercises and the app made them aware of the

importance of being present. As one team manager from Company B commented: "From that you remember those things and there are good phrases which are good to remember that 'oh yeah, this is exactly how it goes', kind of the awareness and reminding that these are good things."

However, participants, who were already familiar with mindfulness, experienced that the app did not bring anything new to them.

The app was seen as a toolkit for personal well-being. It helped in stress management, removed anxiety, brought relief in stressful situations, and helped to concentrate (eg, on themselves and their well-being) through improved mindfulness skills. As one project manager from Company A commented:

I got positive feelings (about this). It gave such an impression that if I would like to think about a small relaxation in the middle of the day, it would help and it could provide tools for this.

However, participants often stated they had used the app so little that it did have a noticeable influence on their well-being yet, despite feeling that intervention had a positive impact on the underlying factors of stress.

The app was mainly found to be easy to use. As a software designer from Company A commented:

I liked that the exercises were short and you were able to mark them as done. You didn't have to remember where you were going. When you logged in it took you where you were going. So in that respect it was good (app) in my opinion.

However, sometimes the structure caused some confusion. For example, it was difficult to find the same exercise again or to understand where they were in the app. The short exercises were seen positively but there were varying opinions about the introduction videos. For example, the credibility of the videos was questioned and it was difficult to find time to watch them. Performing the exercises at one's own pace was seen both as a possibility and as a risk. Because participants had to use the app on their own time, performing exercises occasionally at work gave them bad conscience.

## **Effects Evaluation**

Stress and work engagement (UWES-9) were the primary outcome measures in the effects evaluation. The changes between well-being measures were calculated for the participants who provided information for all the measures both in the beginning and in the end (Table 4). The table demonstrates that the baseline level of the participants was quite good. Stress was significantly lower in Company B in the beginning (Mann-Whitney U=40.5, P=.03) and TyHy (work community well-being) was significantly higher in Company A both in the beginning (Mann-Whitney U=35.0, P=.02) and in the end (Mann-Whitney U=38.5, P=.03). The reliabilities of the measures were calculated using Cronbach's alpha with the data from the preliminary and final questionnaires. For UWES-9 it was between .94 and .95, .95 for P-TyHy, .96 for TyHy, between .88 and .92 for SWLS, between .89 and .94 for FMI, and between .95 and .96 for WAAQ. For the single-item Stress scale, Cronbach's alpha could be calculated but showed satisfactory content, criterion, and construct validity for group level analysis [28].

Intervention had no significant effects on well-being in the two companies, neither separately nor when considered as one population calculated by the Wilcoxon test.



Table 4. Median effects on the well-being-related measures.

		Company A (n	=12)	Company B (n=1	3)	Both companie	s (n=25)
		Beginning	End	Beginning	End	Beginning	End
Stress						· · · · · ·	
	MED	3.0	3.0	2.0	3.0	3.0	3.0
	IQR	1.8	1.8	1.0	0.5	1.0	0.5
UWES-9							
	MED	4.4	4.3	4.2	4.3	4.2	4.3
	IQR	2.4	2.3	2.1	1.6	2.2	1.8
P-TyHy							
	MED	51.5	51.0	53.3	52.5	51.7	51.3
	IQR	17.9	17.5	12.9	9.4	14.0	10.0
ТуНу							
	MED	55.3	56.1	40.6	45.0	47.8	46.7
	IQR	16.8	16.5	12.5	8.6	18.9	19.2
SWLS							
	MED	24.0	24.0	21.0	21.0	24.0	23.0
	IQR	8.5	7.8	8.0	10.0	10.5	7.0
FMI							
	MED	34.0	30.0	35.0	39.0	35.0	36.0
	IQR	12.5	23.5	4.5	6.5	9.0	14.0
WAAQ							
	MED	26.5	23.0	31.0	31.0	29.0	29.0
	IQR	16.0	12.3	8.0	6.0	8.5	11.0

# Discussion

## **Principal Findings**

This study evaluated the adoption process and effects of a mental health app targeted to individual employees at organizations. Because the findings from a prior pilot study were positive [14], it was expected that the app would be well received and it would have a positive impact on employees' well-being. However, the adoption rate of the app was low as only a small number of employees (13.0%, 43/332) chose to take part in the intervention, and therefore, the effects of the intervention on the employees' well-being could not be verified. However, the multiple item questionnaires were tested with Cronbach's alpha and were proven reliable (alpha >.8).

The assessment of motivations and user experiences shows that employees participated in the intervention and used the app for the "right reasons" (eg, personally motivating reasons). However, the lack of time, the lack of perceived benefits, and the lack of perceived need prevented them from actively using the app and practicing its exercises to improve their stress management skills. Although the app was not targeted only for people under stress or with a diagnosed illness, it apparently failed to bring enough value for mostly healthy people. The app should be developed further in order to concretize its benefits

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as a preventive approach with immediate positive impact on well-being.

Based on our study, some specific factors that could have a positive influence on the adoption process were identified. Because time was not allocated for employees to use the app at work, its use did not become a part of organizations' everyday practices. Thus, it would be beneficial to allocate time for app use at work. The HR managers stated that management has to make a decision in principle to adopt the app and only then they can suggest that all employees use the app at work. This finding is in line with earlier studies that have shown that managers' attitudes influence the intervention success [37].

Management might have more positive attitudes toward the app if it would have proven benefits related to organization's functions and overall performance of the employees, such as a possibility to measure, monitor, and manage workload or employee welfare. However, the HR managers pointed out that an action plan is needed to describe what to do in risk situations, such as if the employee welfare suddenly decreases. It is also important that the app has proven benefits for the employees and they are communicated properly.

In this study the intervention was delivered through a mobile and a Web app, but the mobile app was not available for Windows phones, which hindered the adoption. It would be

important to provide the tools for using the app or develop an app for all the platforms that are used in the end-user organisation. Earlier studies have reported similar findings [38].

Overall, co-operation with HR managers was found to be useful in this study. They were a good source of information for the researchers. It would have been useful to co-operate with them in the concept design phase in order to get a more thorough understanding of the organization's needs. Moreover, it should be considered to include top management in the intervention planning since they make the strategic decisions. Then it might be possible to make necessary changes in the organisation for the intervention or design them as part of the intervention

Before and during the intervention the employees should have been motivated to participate in the study and use the app, and arranging concrete activities or events at the workplace could have increased the reach and engagement. Earlier research suggests that lack of support outside training sessions can be a barrier for individual or group training in the workplace [38]. Moreover, it is important to avoid burdening employees with data collection activities and rather aim to use the data that is already being collected. In this study, it proved difficult to integrate the data collection activities with the existing ones, especially as the researchers were working outside the organization. With an open setting used in this study, it was challenging to engage employees in research procedures, especially final interviews.

There are many possibilities for future research. For example, traditional training methods or well-being campaigns could be combined with digital interventions. Offering physical contact with other people as one intervention component could make also the digital component more engaging [13,39]. In addition, other solutions on how to raise the participation among employees should be studied. Building incentives into wellness programs has been suggested as one solution [5].

## Limitations

This study has some limitations. The small number of participants makes it difficult to assess the effects of the intervention on their well-being and on the organizational settings. Also, the appropriateness of the well-being measures can be questioned, because their sensitivity in the relatively short duration of the study may be suboptimal. Additionally, the open study setting and the uncontrolled participant selection increases the probability of biased results [39]. Even though ACT-based exercises are suitable for everyone for preventing mental health problems and stress, it is not known whether the results would have been different if the intervention would have been targeted for people under stress or with a diagnosed illness.

## Conclusions

This article presents findings from a 4-month study of an individual-level digital mental health intervention at two organizations. Process and effects evaluation from the organization's point of view was conducted together with the study of employees' motivations and user experiences. The low number of participants and low intervention adoption show that both the intervention process as well as the digital app should be developed further in order to be successful in this context. Importantly, the study suggests that the intervention planning process should aim to involve the top management of the organization. Although the intervention was not successful as such, the process evaluation provides important insights into how digital interventions should be planned and conducted in the context of occupational well-being. At the organizational level, top management needs to be involved in the intervention planning for fitting into the organization policies, the existing technology infrastructure, and targeting the organizational goals. At the individual level, it has to be tackled how to create time for use and concretise the benefits of the preventive intervention.

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## **Conflicts of Interest**

None Declared.

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## Abbreviations

ACT: Acceptance and Commitment Therapy FMI: mindfulness questionnaire HR: human resource ICT: information and communication technology P-TyHy: personal well-being questionnaire SRQ: Self-Regulation Questionnaire SWLS: Satisfaction with Life Scale TyHy: work community well-being questionnaire UWES: Utrecht Work Engagement Scale VTT: Technical Research Centre of Finland Ltd WAAQ: Work-Related Acceptance and Action Questionnaire

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**Original Paper** 

# Feasibility of an Immersive Virtual Reality Intervention for Hospitalized Patients: An Observational Cohort Study

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# Abstract

**Background:** Virtual reality (VR) offers immersive, realistic, three-dimensional experiences that "transport" users to novel environments. Because VR is effective for acute pain and anxiety, it may have benefits for hospitalized patients; however, there are few reports using VR in this setting.

Objective: The aim was to evaluate the acceptability and feasibility of VR in a diverse cohort of hospitalized patients.

**Methods:** We assessed the acceptability and feasibility of VR in a cohort of patients admitted to an inpatient hospitalist service over a 4-month period. We excluded patients with motion sickness, stroke, seizure, dementia, nausea, and in isolation. Eligible patients viewed VR experiences (eg, ocean exploration; Cirque du Soleil; tour of Iceland) with Samsung Gear VR goggles. We then conducted semistructured patient interview and performed statistical testing to compare patients willing versus unwilling to use VR.

**Results:** We evaluated 510 patients; 423 were excluded and 57 refused to participate, leaving 30 participants. Patients willing versus unwilling to use VR were younger (mean 49.1, SD 17.4 years vs mean 60.2, SD 17.7 years; P=.01); there were no differences by sex, race, or ethnicity. Among users, most reported a positive experience and indicated that VR could improve pain and anxiety, although many felt the goggles were uncomfortable.

**Conclusions:** Most inpatient users of VR described the experience as pleasant and capable of reducing pain and anxiety. However, few hospitalized patients in this "real-world" series were both eligible and willing to use VR. Consistent with the "digital divide" for emerging technologies, younger patients were more willing to participate. Future research should evaluate the impact of VR on clinical and resource outcomes.

**ClinicalTrial:** Clinicaltrials.gov NCT02456987; https://clinicaltrials.gov/ct2/show/NCT02456987 (Archived by WebCite at http://www.webcitation.org/6iFIMRNh3)

(JMIR Ment Health 2016;3(2):e28) doi:10.2196/mental.5801

## KEYWORDS

virtual reality therapy; hospitalization; feasibility studies

## Introduction

For decades, inpatient health care providers have recognized that patient management does not merely entail acute symptom

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management; hospitalized patients may also experience anxiety, uncertainty, and boredom exacerbated by a radical change in living environment and loss of customary rights and privileges [1]. In order to care for the whole patient, hospitalists must

consider not only the biological impact of illness, but also the psychosocial impact. However, the dynamic nature of hospital medicine, coupled with limited time to spend with individual patients, pose challenges to offering holistic inpatient care.

Recent advances in virtual reality (VR) technology offer a compelling opportunity to address inpatient biopsychosocial distress. VR devices provide immersive, realistic, three-dimensional experiences that "transport" users to novel environments. Thus, VR has potential to alleviate negative aspects of hospitalization by providing multisensory information and allowing patients to "escape" to pleasant locations and realities [2].

Previously, VR has been tested in a variety of disease states, including obesity [3-5], anxiety disorders [6-8], pain management [2,9-12], oncology [13], and neurorehabilitation [14,15]. Concurrent improvements in software and hardware design, as well as associated cost reductions, have made VR promising for more widespread use in health care. However, the practicality and qualitative experiences of using VR at scale in the general acute hospital setting has not been formally evaluated in peer-reviewed publications. Because the hospital environment poses unique challenges that outpatient clinics or rehabilitation units do not, it is important to understand the "real-world" practicality of using VR in hospitalized patients-this is a necessary first step before pursuing more extensive evaluation of VR on inpatient outcomes and resource utilization. Thus, we assessed the eligibility, usability, and acceptability of VR equipment and software in a diverse cohort of hospitalized patients in an urban, community-based, academic medical center.

# Methods

## **Participants**

We screened adults ( $\geq$ 18 years) admitted to the Inpatient Specialty Program at Cedars-Sinai Medical Center in Los Angeles, California, over a 4-month period (August to November 2015). We excluded patients who could not consent, were placed in contact isolation, or had head wounds or bandages that would interfere with the VR goggles. In addition, because VR may cause motion sickness in some users [16], we excluded patients with a history of motion sickness and vertigo, and anyone experiencing active nausea or vomiting. Because there is a theoretical risk of inducing seizures with VR (Samsung Gear user manual cites a 0.025% risk from pediatric data) [17], we also excluded patients with a history of seizures or epilepsy.

## Virtual Reality Hardware and Software

We used a Samsung Gear VR Innovator edition goggle set, fitted with a Samsung Galaxy Note 4 mobile phone to deliver VR images and sound (Figure 1). We selected this equipment because, at the time of our study, it was a commercially available headset in wide use. In addition, the equipment has minimal visual latency (ie, minimal lag time between head movement and visual tracking) compared to other available form factors, such as Google Cardboard. In consultation with experts in VR health care software (AppliedVR, Los Angeles, CA, USA), we selected four diverse VR software modules: (1) Paint Studio, where users "paint" a picture using head gestures to control the paintbrush; (2) TheBluVR, an underwater ocean exploration; (3) Cirque du Soleil, where users share the stage with performers performing a graceful and harmonious aerial acrobatics while suspended from long, silk bands of fabric; and (4) Tours of Iceland, an aerial tour of rich topographies. These modules were selected because they contain minimal triggers of emotional distress or motion sickness, present a wide range of visual and auditory stimuli, and are considered pleasant experiences by typical users. Each VR experience lasted between 3 and 5 minutes in length.

Prior to patient use, we cleaned fabric surfaces of the Samsung Gear set using Virex, the plastic housing using Sani-Wipes, and the glass lenses using alcohol-based lens cleaner. We placed sanitary disposable fabric covers on the VR goggles for each individual user, and fitted head caps on patients to minimize direct contact with the device—precautions recommended by our infection control department. We briefly instructed patients on the use of the VR goggles, and asked them to watch the four VR experiences in the order preferred by the patient. After each patient completed the study, we discarded the disposable head cap, fabric cover, and foam backing from the device.



Figure 1. Samsung Gear Goggles.



## **Quantitative Analyses**

We collected descriptive data from the health record for each patient, including age, sex, race, ethnicity, and the reason for admission. We recorded VR experience presentation order and any use of corrective lenses. We used chi-square and Fisher exact tests to compare characteristics of patients willing versus unwilling to use VR. All analyses were conducted using Stata version 13.0 (StataCorp LP, College Station, TX, USA)

## **Qualitative Analyses**

We conducted semistructured cognitive debriefing interviews [18,19] with patients after exposure to VR, asking questions about their overall experience, the VR device, and the software. Before initiating the study, we developed a guide with patient instructions, open-ended think-aloud exercises [18], and scripted probes (Multimedia Appendix 1). For example, the think-aloud exercise instructed patients as follows: "When you think about your experience participating in the VR study, what is the first thing that comes to your mind?" An example scripted probe was: "If a friend or family member asked you about the device, what would you tell them about it?"

A trained moderator led each interview, which lasted approximately 15 minutes. We initially asked patients to describe their experience in their own words and without

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prompting, followed by scripted probes regarding specific experiences with the VR hardware and software. A social scientist with training in qualitative text analysis (BM) coded responses to the debriefing interview based on themes described by patients (eg, software novelty; device comfort), and presented the results as qualitative findings.

This study was approved by the Cedars-Sinai Institutions Review Board (Protocol #00039751).

## Results

## **Patient Selection and Enrollment**

Figure 2 presents the flowchart of patient identification and enrollment. We evaluated a total of 510 hospitalized patients for eligibility, of whom 423 (82.9%) failed to meet inclusion criteria. The most common reason for exclusion was presence of one or more neurological diagnoses that either hindered ability to participate or increased risk of a VR adverse event (epilepsy: 6.4%, 27/423; recent stroke: 11.8%, 50/423; dementia: 10.6%, 45/423; other neurological disease: 23.8%, 101/423). Another 26.0% (110/423) of excluded patients were ineligible due to respiratory or contact isolation status. The remainder were excluded because of being too frail/debilitated (4.3%, 18/423), non-English speaking (2.4%, 10/423), unable to consent (0.7%, 3/423), prone to nausea/vomiting/dizziness (5.7%,

24/423), organ transplant (3.3%, 24/423), mechanical ventilation (2.4%, 10/423), and injury to face/neck (2.4%, 10/423).

Of the remaining 87 patients eligible for VR, 57 (66%) refused to participate in the study. Common explanations included not understanding the purpose of VR, feeling anxious about using the goggles, feeling too tired or too ill to participate, concerns about "losing control" of one's personal environment at a time when control is already limited, and harboring concerns that VR is a "psychological experiment." After excluding patients who were ineligible or unwilling to participate, there were 30 remaining participants, of which 28 completed the full VR protocol. Two patients did not complete the study because of VR-related nausea (n=1) or being too frail to support the weight of the goggles (n=1). Of those who completed the study, one patient reported minor and transient dizziness that subsided within minutes of completion. Table 1 provides descriptive statistics of the final 30 patients who used VR.

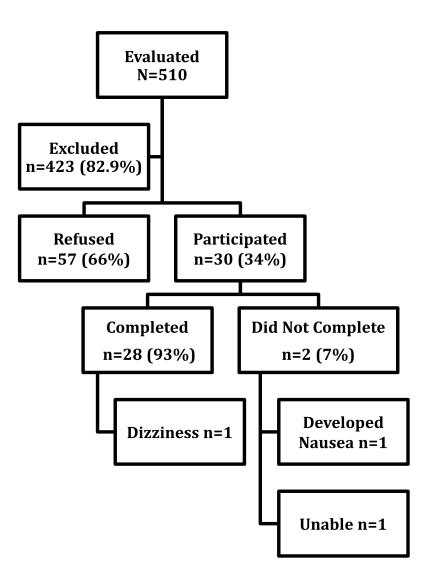
Table 1.	Patient	characteristics.
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Patient characteristic	Patients willing to use VR (n=30)	Patients unwilling to use VR (n=57)	Р
Age (years), mean (SD)	49.7 (17.4)	60.2 (17.7)	.01
Sex (male), n (%)	19 (63)	28 (49)	.21
Race/Ethnicity, n (%) <sup>a</sup>			.47
Non-Hispanic white	25 (83)	29 (66)	
Black	3 (10)	9 (20)	
Asian	1 (3)	1 (2)	
Hispanic white	1 (3)	4 (9)	
Other	0	1 (2)	
Reason for hospitalization, n (%)			.43
Gastrointestinal	9 (30)	22 (39)	
Cardiac	3 (10)	7 (12)	
Pain control	3 (10)	1 (2)	
Infectious disease	8 (27)	7 (12)	
Hematological/Oncological	2 (7)	7 (12)	
Neurological	1 (3)	1 (2)	
Pulmonary	1 (3)	2 (4)	
Rheumatologic	1 (3)	1 (2)	
Other	2 (7)	9 (16)	

<sup>a</sup> Race/ethnicity data only available from 44 of the 57 patients in the unwilling group.



Figure 2. Study flowchart.



## **Comparison of Participants and Nonparticipants**

Among eligible patients, those who agreed to use VR were significantly younger than patients who refused (mean 49.1, SD 17.4 vs mean 60.2, SD 17.7 years; P=.01). There was no statistical difference in sex, race, ethnicity, or reason for admission among patients who were willing versus unwilling to use VR (Table 1).

## **Patient Global Experiences With Virtual Reality**

Among the 28 patients who completed the full VR experience and responded to the "think-aloud" exercise, 24 responses were coded as positive (86%), two were neutral (7%), and two were negative (7%). Representative examples of positive responses included the following:

Good distraction... welcome distraction...fun detour. Because it's boring here in the hospital.

It provides a separation from what's going on. Difficult to verbalize how.

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Representative examples of negative responses includes the following:

The headset was uncomfortable and hard to focus with the dial. The nose part was causing me pain, and I could not fully enjoy it.

This was a new experience for me. But I know there are now holograms you can see in front of you, so this technology is already outdated.

When asked: "How did participating in this study make you feel?" 22 responses were positive (79%), three neutral (11%), and three negative (11%). Representative examples of positive responses included the following:

It made me feel good. Really amazing!

Excited to try something new.

Happy. Got away from being here in the hospital. Who wants to be here? It improved my mood.

Representative examples of negative responses includes the following:

It made me feel like I need classes to learn how to operate this thing.

Anxious about getting dizzy during the experience, even though I didn't feel that way.

I was disappointed.

When asked: "Would you like to participate in a study like this one again?" 22 responses were "yes" (79%). Representative examples of positive responses included the following:

Yes. Definitely. I can see how it would benefit people. I don't think it will replace drugs, but in mild pain it can work.

Yes, it is an incredible experience. Very alive. Especially for someone like me that can't walk. The possibilities are endless.

Representative examples of negative responses includes the following:

No, it didn't impress me. It didn't change anything. I would like to see it much better, with a better form of focus. It was hard to focus on the images.

No, the goggles were not comfortable. I would consider it again if there were more comfortable goggles.

# Patient Experiences With Virtual Reality Hardware and Software

Regarding the VR hardware, most participants had a positive view about the device (61%, 17/28). However, patients were split on the comfort level; 14 found the device comfortable and 13 found it uncomfortable (one abstained from answering). When asked regarding improvements on the device, most patients requested enhancements in fit, form, and weight, whereas others indicated it was hard to achieve focused images.

Of the four VR modules in the protocol, most patients (57%, 16/28) selected Tours of Iceland as their preferred VR experience; this module was considered by many to be the most "relaxing" and "real life" of the four selections. Conversely, the Paint Studio was selected as the least preferred VR experience; patients noted that this module did not allow adequate control of the paintbrush, leading some to feel more bothered than satisfied with the experience. The majority agreed that all the videos should be longer, but generally less than 10 minutes at a time. Some suggested longer videos, including full-length feature movies.

# Patient Perceptions About Clinical Benefits of Virtual Reality

We asked participants whether they thought VR could affect their level of anxiety or pain. In all, 43% (12/28) of patients believed VR could change anxiety level, although four individuals thought it might worsen anxiety. Most participants (75%, 21/28) believed that the experience could improve pain by means of distraction. Representative quotes included:

It can help with anxiety because it controls the mind.

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I'm easily distracted and this helped because I was focusing on the experience and the instructions. My pain medications were due around the time you came in, but the experience improved my pain, and now I don't feel like I need them right now.

I did have pain, but this was definitely helpful because it made me forget about the pain. It can improve pain by making you forget about it.

It has the ability to take you out of your pain. You still have the pain but you don't mind it as much.

This was most relaxing to me, especially since I had pain.

## Discussion

Although VR is widely studied in outpatient settings for a variety of pain, affective, neurological, and behavioral conditions [3-13], there is limited experience using VR in the general hospital setting. Given the significant expense of hospital medicine, coupled with the substantial impact of hospitalization on biopsychosocial well-being, it is possible that VR might be effective and cost-effective in managing hospitalized patients. However, before these claims can be made or tested, it is important to first evaluate the pragmatic aspects of using VR in the hospital.

There are two overarching and somewhat contradictory results of this study. First, we found that despite evaluating 510 inpatients for VR, only 30 (5.9%) were both eligible and willing to experience the technology. Strict application of exclusion criteria, including presence of motion sickness, stroke, seizure, dementia, nausea, and isolation status, rendered 82.9% of participants immediately ineligible. Of the remaining eligible patients, 66% refused to participate for a variety of reasons, including anxiety about the technology and high levels of illness severity. In short, despite seeking to apply VR to a cohort, only a small number of patients were ultimately able and willing to participate. Future research should evaluate patient knowledge, attitudes, and beliefs about VR in the hospital, and enumerate specific reasons why some patients are unwilling to use VR.

Second, among participants, most patients found VR to be a positive and pleasant experience. Patients described how VR could ease anxiety, reduce pain through distraction, and provide an "escape" from the confines and boredom of the hospital room. These qualitative results were further supported by endorsement of most participants that they would use VR again if given the opportunity. Common reasons for enjoying the experience were distraction, immersion, being away from the hospital, doing something beyond their means or ability, and the novelty of the experience. In this manner, VR may support the unmet need for patients to virtually "escape" the hospital environment and achieve some degree of normalcy. Of note, our study was not designed to compare VR to other patient engagement technologies, compare it to online forums or other social networks, place it in the larger context of behavior change interventions, or offer a systematic review of digital mental health interventions for inpatients. We solely tested how patients qualitatively experience VR in a hospital. Indeed, a wide variety

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of new interventions, including augmented reality and mixed reality will soon compete with VR.

Similar to other evolving digital technologies, we found that patients willing to try VR were significantly younger than those who refused. Older individuals can have more difficulty than younger individuals in adopting new technologies—a term described as the "digital divide" that results from variations in self-efficacy and confidence with technology [20-22]. However, although older patients were more hesitant to participate in this VR study, they tended to be less critical of the technology than younger patients were, and most participants enjoyed the experience, independent of age. Based on this observation, encouraging older patients to use VR may offer benefits to some individuals even if there is initial hesitancy to use the technology.

Although most patients described benefits of using VR, there were important limitations identified as well. The goggles were frequently described as too heavy, hard to fit, uncomfortable, and difficult to focus. In addition, because the VR goggles were considered a medical device by our institutional review board, they required meticulous cleaning between patients, application of fresh liners for each use, and provision of a head cap to minimize infection risk. These technical shortcomings may limit the scalability of VR in the hospital and provide opportunities to improve the form factor of current devices. Optimally, a disposable device, such as Google Cardboard goggles or Homido clip-on goggles, could be used to minimize infection risk and logistical concerns, although the current disposable goggles do not yet provide the same immersive experience as higher-end sets.

This study has several important limitations. First, we did not measure the impact of VR on objective outcome measures, including pain level, vital signs, or resource utilization. We believe it is first important to understand and address pragmatic limitations of VR before commissioning large intervention trials. Nonetheless, if the shortcomings identified in this study can be addressed, and if VR can be scaled to a large population, then future research should evaluate the impact of VR on patient outcomes. Second, we excluded a large majority of patients due to preexisting conditions, most commonly neurological disorders that theoretically increase the risk of VR adverse events. Our exclusion criteria were conservative and strict; future research may consider loosening these criteria to allow more patients to participate, particularly given the very low risk of seizures from VR. Third, because members of our research staff were not directly embedded in the immediate hospitalist care team, it is possible that some patients refused to participate merely due to unfamiliarity with the study personnel. If primary caretakers offered VR, then more patients might be willing to try the technology.

The notion of a "Virtualist Consult Service" that offers tailored VR experiences for hospitalized patient is appealing. However, to realize this vision, several intermediate steps will be necessary. Based on this study, we believe that next steps should be to test different goggle sets and form factors, evaluate longer video experiences, offer VR directly through primary providers, and evaluate the impact of VR on both patient reported outcomes (eg, pain, satisfaction scores) and objective outcomes (eg, vital signs). If VR is shown to be pragmatic, scalable, and effective, then we should evaluate its cost-effectiveness and budget impact by monitoring resource utilization (eg, pain medication), length of stay, and readmissions.

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## **Conflicts of Interest**

None declared.

## Multimedia Appendix 1

Patient debriefing script.

[PDF File (Adobe PDF File), 39KB - mental\_v3i2e28\_app1.pdf]

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## Abbreviations

VR: virtual reality

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