

## National Association of State Mental Health Program Directors 66 Canal Center Plaza, Suite 302 Alexandria, Virginia 22314

## Assessment #5

## Promoting Young Adult Mental Health through Electronic and Mobile Technologies

September 2016

Alexandria, Virginia

Fifth in a Series of Eight Briefs on the Use of Technology in Behavioral Health

This work was developed under Task 2.1.1 of NASMHPD's Technical Assistance Coalition contract/task order, HHSS28342001T and funded by the Center for Mental Health Services/Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services through the National Association of State Mental Health Program Directors.

# Promoting Young Adult Mental Health through Electronic and Mobile Technologies

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## September 2016

This working paper was supported by the Center for Mental Health Services/Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services.

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### **Executive Summary**

Many young adults, including those with mental health difficulties, use technology for information seeking and communications almost constantly. The internet, particularly social media, allows for these activities to take place in an anonymous environment, a major attraction for young adults concerned with the stigma associated with "mental illness". Apps are another platform young adults have begun to use frequently for data driven information displays and immediate feedback; apps supporting mental health include those for wellness planning, crisis line texting and support, and cognitive-behavioral feedback. Several technology-based mental health services and supports have been proven to be effective for young adults, but overall the field is in its early stages, with significant knowledge and practice gaps. In this paper, we explore the current role of technology in supporting the mental health of young adults, whether as a form of self-help, as a complement to formal treatment, or as a treatment itself. Also explored is the potential for technology to enhance young adult mental health through development and research.

#### Young Adults and the Use of Digital Technologies

Social media and the internet have transformed the ways in which youth communicate, learn, and interact. Most (92%) teens (ages 13 to 17) report going online *daily*, including 24% of teens who are online *almost constantly* (i.e., "24/7"). Three-quarters (76%) of teens use social media, and 45% use it every day<sup>ii</sup>; Facebook has been the most popular social media site, with 72% of teens using it. In addition, 52% of teens play video games interactively with friends and other players around the world, with 13% doing so every day. Young adults' regular use of communication and interactive technologies appears to be consistent across demographic categories, such as income level, race/ethnicity, and gender.

The primary mode of communication for young adults is mobile devices (i.e., smartphones), and thus 24/7 contact and communications is their norm. Nearly three-quarters of teens have access to a smartphone (which they use as frequently as other screen devices for videos and movies). According to a recent Pew report<sup>iv</sup>, teens regularly use technology-based devices for communicating with others, with text messaging being the most common method (see Table 1.)

Table 1. Young adult use of technology-based communications						
<u>Device</u>	Use for messaging friends	<b>Daily use with friends</b>				
Text messaging	95%	55%				
Instant messaging	79%	27%				
Email	64%	6%				
Video chat	59%	7%				
In person	95%	25%				

Technology is now a consistent part of young people's lives-- they do not exist in separate "off-line" and "digital" worlds, but rather in these combined mutually reinforcing worlds.

Communicating using online technologies creates a natural bridge between face-to-face and virtual interactions. Conversations that begin in person are often continued via texting or other social media platforms. This makes the transition from "traditional" interactions and "virtual" ones nearly non-existent; it is as seamless as resuming a conversation after a momentary interruption.

Young people frequently have the most recent health and wellness software products, such as activity trackers (e.g., Fitbit). Activity trackers are worn on the body, collect personal activity and physiological data, and provide the user with easy to digest personal health information, such as heart rate. This kind of app allows the user to assess the impact of physical or mental exercise on their health status, i.e., fitness.

In this paper "technology" refers to digital technologies and the uses and applications of those technologies. Thus, health technology is defined as information, feedback and communications technologies that promote personal wellness and improve health care. The relevant health technology platforms are described in Table 2:

Table 2. Types of Technology platforms used to improve personal health				
mHealth	Mobile Health is the use of mobile communication devices (i.e.,			
IIIIIcaitii	smartphones) to promote and support personal health			
	Social media llow groups of people and organizations to create, share, or			
Social Media	exchange information via the internet. Most prominent here are social-			
	networking web sites such as Facebook, Twitter, and Instagram			
App (software	An app is a type of software that serves as a platform for the performance			
application)	of specific tasks			
Computer-based	Computer based programs provide information in an interactive fashion			
	with the user and do require an internet connection.			
Web-based	Web based programs provide information through an internet interface.			

## Mental Health Information and Support Technologies for Young Adults

Youth transitioning to adulthood (ages 16-30) face many serious life challenges (social, self-identity, economic), and young adulthood is when serious mental health conditions are most likely to emerge. A majority of young adults with conditions that involve psychosis and depression have repeated episodes, which can disrupt critical aspects of development and functioning, from education and employment to social relationships. Many are at significant risk for suicide. Despite improvements in services for young adults, many continue to avoid treatment in large part due to stigma— their fear that what they say to providers will be shared with their parents and that seeking treatment carries the potential for a psychiatric label that will lead to social rejection. Technology creates the opportunity for them to explore and address mental health concerns with relative anonymity.

#### Use of technology

Young adults with serious mental health conditions are very active on the internet, and often use video games and virtual reality programs. A recent study showed that young people diagnosed with psychosis or depression are using social media an average of 2 to 3.5 hours per day. Young people with mental health difficulties use online spaces to strengthen off-line relationships, make new friends/connections, share photos of their experiences, and for general identity exploration.

Young adults with mental health conditions already use technology with the aim of improving their mental health (e.g., reducing anxiety and depression), and numerous technologies have been developed over the last decade with this aim in mind. Most young people have positive attitudes toward internet-based help-seeking and services. The online environment offers youth a sense of privacy and provides a rapid response, something millennials have come to expect and depend on. These services increase feelings of comfort and control in self-expression, reduce feelings of embarrassment, and decrease the sense of emotional exposure.

Ownership of smartphones appears to be high among young people with first-episode psychosis, with around 69% of clients in a recent study owning one. Vi Young people with serious mental health conditions are willing and able to use smartphones for a variety of health purposes, including peer support and self-management. When provided with a smartphone and instructions for use of self-help and physician communication, most people with mental health conditions used it correctly and fairly easily even when in crisis, and few are lost, stolen, or broken. Vii

#### Apps as a mental health technology platform

Though young adults have reported improved mental health due to the use of apps, to date there is no experimental evidence supporting the effectiveness of any specific app and there are concerns about how they are designed. These Mental Health (MH) apps have typically not been framed using evidence-based self-help guidelines. For example, the content of currently available apps for bipolar disorder is not in line with practice guidelines or established self-management principles; these apps do not provide the information necessary for users assess their quality, with most lacking source citations and a privacy policies viii Additionally, the number of MH apps used by young adults has proliferated greatly, and there are insufficient resources to study the effectiveness of each one. They are also difficult to study because their continued creation outpaces the timeline of conventional randomized controlled trials, resulting in apps that are obsolete by the time trial results become available.

Observers have also raised concerns that any available MH apps target specific disorders, and thus provide users with a diagnosis, which stigmatizes and can lead to misguided help seeking. Apps would be much improved if they were developed using participatory design methods, with end-users actively involved in the inception, design, and delivery of the app. There is a need for the collaborative input of clinicians, creative writers, experts in human computer interaction, and others.

## The Development and Assessment of Internet-based Tools for People with Mental Health Conditions

A major goal of the US national initiative Healthy People 2020 is to develop "health communication strategies and health information technology (IT) to improve population health outcomes and health care quality, and to achieve health equity" by increasing access to electronic personal health management tools and to the Internet.

SAMHSA<sup>xi</sup> has a focus on supporting the development of internet-based tools for use by mental health clients (with or without clinicians) through eTherapy, smartphone technologies, text messaging, apps, web-based virtual recovery services, and through client linkages to Electronic Health Records (EHR). SAMHSA reports that these technologies should be evaluated according to their Integrity (information accuracy), Confidentiality, and Availability to those who are authorized and have a need to use it.

SAMHSA is particularly interested in bringing technology use into **rural** communities, where access to care is a serious problem (e.g., <u>Expanding Care and Training the Workforce in Rural New Mexico</u>). SAMHSA also prioritizes the development of apps that provide resources and linkages that support the individual's mental health.

#### **Examples of SAMHSA supporting apps:**

- Emory University's <u>ReliefLink</u> app, which provides continuity and follow-up services for someone at risk for suicide who was discharged from an inpatient psychiatric unit or emergency department
- SAMHSA's Garret Lee Smith State and Tribal Suicide Prevention Grant supports the Texas Department of State Health Services and community partners to offer a free suicide prevention app, featuring warning signs and helpline information.

In addition, SAMHSA's new Project to Achieve Wellness supports the development of apps that improve peoples' "Eight Dimensions of Wellness": emotional, physical, environmental, financial, intellectual, occupational, social, and spiritual. These apps will allow people to set/track goals and activities, and access timely tips and resources to support their wellness on-the-go.

## **Aims and Purposes of Mental Health Technology**

In the following sections we discuss mental health technologies according to thirteen identified aims and purposes, subcategorized into four categories according to its connection to the provider's role, as displayed in Table 3.

Table 3: Aims and purposes of mental health technologies							
Relationship to providers role:	1. Self-help	2. Self-Help or as Formal Complement to Treatment	3. Formal Complement to Treatment	4. E-Therapy			
	Mental health support and treatment Information seeking	Psycho-education	Engagement/coordination	Clinical delivered therapy (e.g., CBT)			
	Accessing services and early engagement	Web or Computer generated therapy (e.g., CBT)	Treatment/Servic e Decision aids				
	Crisis Lines and apps	Wellness and crisis planning	Accessible electronic health record systems- Open Notes				
		Virtual Reality and Video Games					
		Web-based forums and peer support groups					
		Monitoring and feedback					
Terms	Self-help technologies can be used to improve health independently of formal service provision. Many of these technologies have been developed outside of the health system commercially or by users themselves.  "Formal complements" to treatment are technologies that the client uses in conjunction services offered by a provider For example, a clinician engages in office based therapy with a client while providing him/her psycho-educational modules and access to virtual reality anxiety reduction computer programs.						
	<b>E-therapy</b> is a therapy or other service traditionally provided in person but now also delivered in an asynchronous fashion over the internet (e.g., texts, emails, chat space) while the parties are in separate or remote locations.						

Recent research shows that young adults are comfortable combining electronic technologies with mental health services, though some make clear that it should not take the place of face-to-face provider interactions Additionally, the use of health technologies "along with" in person service delivery (e.g., talk therapy) has proven to be effective (discussed below).

However, providers don't typically integrate technology use with in person service provision because of lack of interest and/or experience and inflexible organizational policies. In addition, there are financial challenges regarding the billing of clients' engagement in health technology and funding for health technology development. Additional research is needed on how best to support providers to embrace technology as value added toward clinical and recovery outcomes.

#### **Self Help**

### Mental Health Support and Treatment Information Seeking

Young adults with emerging symptoms of psychosis seek information related to mental health care primarily through websites and social media, often using mHealth devices. Because the internet provides a platform to safely explore topics without disclosing personal details, they are very appealing to young adults with mental health difficulties. Many health-based websites now summarize research results (and "Google Scholar" can at times provide access to health research papers).

Because of the Internet "Medical knowledge is no longer exclusive to the medical school and the medical text; it has 'escaped' into the networks of contemporary infoscapes where it can be accessed, assessed and re-appropriated." Nettleton S, Burrows R. E-scaped medicine? Information, reflexivity and health. Critical Social Policy, 2003; 23: 179.

Social media sites are valued by young people as a forum for asking questions, receiving feedback, sharing illness-related experiences, building camaraderie, and receiving information about provider services. Many utilize social media to inform self-management strategies, drawing on both prepared content and others' experiences. These types of platforms usually offer message boards, where users can post a question or statement and others can comment on it at their leisure. Young adults place the highest value on the illness and recovery stories of other young adults, either posted online or in "conversation." Examples of social media mental health sites with message boards include the <a href="Big White">Big White</a> Wall and the Mental Health Forum.

#### Finding the best information

Young adults frequently locate relevant content through search engines, particularly Google, though their searches are not always most effective. Many review only the first few websites provided by Google, which are often the most mainstream social media sites such as Wikipedia and YouTube. This approach limits their universe of site possibilities and is more likely to lead them to commercially influenced sites through which sponsors market *their* products in very subtle ways. In addition, poor web design and formatting can make it difficult to sort out content.

Like search engines, social media is not neutral, but impacted by a range of explicit and tacit influences, including advocacy groups and commercial interests. Sites may place a heavy emphasis on the importance of diagnoses and medications, but not on evidence based self-management and peer support approaches; these sites may represent the financial interests of industry (pharmaceutical), which often operate through often through organizations they fund. It is thus important that young adults have a clear avenue to websites that provide a variety of perspectives on the experience of mental distress. The good news is that many young adults do consciously assess online information's credibility and reliability by<sup>xiii</sup>:

• Comparing multiple sources, relying on signposts such as logos, recognizable URLs and 'about' sections

- Learning the purpose of the site; for example, they tend to value user-generated content more as a source of "opinion" rather than fact
- Assessing the website design-- Is it well organized? Does it have a nice look? Are the images, pictures, language relevant to the young adult experience?xiv

#### **Accessing Services and Early Engagement**

The internet, social media, and mobile technologies are increasingly being considered promising avenues to facilitate young people's engagement in mental health care. The primary ways young adults learn about providers on-line are through articles written by or about a provider, peer contacts, provider rating websites, and the provider's own website. On-line peer sharing and article reviews can be a good start towards the consideration of engaging specific providers. Provider rating websites can provide useful information when there are a sufficient number of ratings and detailed clients experience comments but they should be used with caution and not as the only source of information.<sup>xv</sup>

Many young adults find that the provider vetting process benefits greatly from online provider/clinician profiles that demonstrate their expertise, availability, and personal interests (profile), and videos are likely to have a greater impact on engagement than written information alone. While some young adults would prefer to make contact with providers by scheduling an appointment on line, others prefer to leave a cell phone number for a voice or text chat with the provider prior to scheduling.<sup>xvi</sup>

The major challenge here is that clinicians are not using social media as an engagement tool, and clinics are not necessarily encouraging it. Financial incentives may be required to generate clinicians' interest in using social media clear provider profiles. And to the degree that social media provider profiles promotes effective provider-client matches, it is fair to presume that therapeutic alliance will be stronger and continued engagement will be more likely. More research on the impact of provider use of social media on engagement, therapeutic alliance, and outcomes is needed.

## **Crisis Lines and Apps**

Texting and apps like Skype and Facebook Messenger are young adults' primary ways of connecting with family and friends, and are thus naturally used to reach out when in psychological distress, even when feeling suicidal. Thus, the text-based "crisis line" is a new and promising approach for young adults to reach counselors or peers to discuss immediate mental health problems through their primary mode of communication—mobile phones. mHealth crisis supports, often available 24/7, can also help young adults locate crisis service centers, medical facilities, or groups or supportive individuals (e.g., peers, family members). Some mHealth technologies contain an "emergency" button feature, with a one touch direct connection to a crisis line or other resource whenever and wherever a person may feel in crisis.

<u>Crisis text line</u> is an organization that provides direct assistance to teens struggling with a mental health crisis, often related to depression, suicidal ideation, and eating disorders. By sending the organization a text, the teen becomes connected to a pool of volunteer crisis counselors. From the website:

- 1. Text START to 741741 from anywhere in the USA, anytime, about any type of crisis.
- 2. A live, trained Crisis Counselor receives the text and responds quickly.
- 3. The volunteer Crisis Counselor will help you move from a hot moment to a cool moment.

In almost three years of existence, the organization has managed and addressed over 18.5 million messages from teens, with growth being exponential.

There is currently a paucity of evidence for online and mobile interventions for suicide prevention in youth. More high quality empirical evidence is required to determine the effectiveness of these novel approaches to improving mental health and reducing suicide in young people.

#### Self Help as a Formal Complement to Treatment

#### **Psycho Education**

Psycho-education is an evidenced-based practice for providing information about particular mental health conditions (e.g., symptoms, treatments, and early warning signs) and self-management tools. Information is typically delivered through modules (self-taught or through a facilitator) or on-line forums. Psycho-education for people with psychosis has been shown to increase satisfaction with mental health services, reduce relapse rates, promote social functioning, and increase medication adherence. Young adults with emerging psychosis tend to prefer technology supported psycho-education, often through websites and apps. Preliminary research suggests that computer or web-based psycho-education for young adults is as effective as written materials and face-to-face clinician delivered communication. The Additional research indicates that good psycho-education encourages young adults to seek help when needed. More research is needed to ascertain the most effective elements of technology-based psycho-education.

## **Internet and Computer-Based Cognitive Behavioral Therapy**

Internet and computer-based cognitive behavioral therapy or training for young adults with schizophrenia can generate significant improvements in cognition, including global cognition, verbal memory, problem solving<sup>xviii</sup>, as well as improved positive symptom<sup>xix</sup>.

#### Advantages of Internet or computer based CBT include:

- 1. Accessible to most young adults
- 2. Always available to use
- 3. User can self-direct and self-pace
- 4. Reduction in travel time and costs
- 5. Interactivity, and thus improved outcomes over static learning
- 6. Anonymity
- 7. Appears to produce significant reductions of anxiety and depression in youth and young adults<sup>xx</sup>

#### **Wellness and Crisis Planning**

In terms of crisis planning, apps and other online tools have the potential to be very useful. Mobile apps are easily accessible and often include interactive safety plans. Safety plans within mobile apps typically feature facts about suicide, personal narratives, and links to additional information and resources. In addition, users can upload advanced directives, specific instructions for mental health care if the person were to become unconscious or otherwise "incompetent." Traditionally these plans have been difficult to share with others who might act on the person's behalf (family, clinicians); on-line platforms and electronic medical records now make this very possible. The <a href="My3 app">My3 app</a>, for example, provides a template to create a safety plan that is adapted from content developed by the Veterans Administration (VA). The My3 website contains instructions on how to use the app to work with clinicians.

Mobile technologies also provide a platform for clinical contact interventions (e.g., SMS texting). Through these communications, the clinician can document his/her assessment of risk and facilitate access to crisis support and coping resources. Most of the available suicide prevention apps include education functions that provide information to patients, care providers, and other individuals (i.e., peers and family members).

While safety plans are crisis-oriented, wellness plans incorporate personal practice and actions to maintain and enhance wellness. Often included is a well thought out written action plan of what to do when a person is emotionally triggered; these plans are more reliable than acting on instinct or memory. If this plan is web-based or through an app, people will be able to make changes and share it with individual supporters. While there is research supporting the effectiveness of wellness plans in reducing symptoms and improving self-management, the evidence base for technology supported wellness plans has yet to be developed.

Apps have now been designed to provide coping tools that may be used to augment traditional treatments. The <u>Virtual Hope Box</u> (VHB) is a therapeutic tool used by clinicians to help depressed and/or suicidal patients redirect their negative thoughts or conduct reality checks. This tool contains a collection of personal items, such as favorite music, photos of family/friends, and pleasing art that help people cope with negative thoughts. Several studies show promising results for the use of technology-based coping tools for young adults with mental health difficulties. However, there is a need for more research on their

effectiveness, particularly with regard to crisis prevention and suicide prevention.

### Virtual Reality (VR) and Video Games

Virtual reality technologies create a virtual world in which users can interact with computer simulations of 3D images or environments in a seemingly physical way, using equipment like headsets or gloves. Because VR creates a psychological sensation of "being there," conditions can be adjusted precisely to affect perceptions and emotions for therapeutic purposes. VR has been used in clinical settings to treat a range of cognitive and emotional problems in various mental disorders. VR has been shown to be more effective than treatment as usual, with similar results as conventional CBT and/or in vivo exposure. VR has been used most effectively over multiple sessions to treat agoraphobia.

Video games include games played on a computer, such as *Solitaire* or massively multiplayer online games (MMOGs) such as *World of Warcraft*. For youth with early psychosis, almost half use technology devices for different types of gaming activities (action, adventure, role playing, brain teasers, simulation, and strategy). Commercial video games, often designed for action and suspense, have the greatest engagement potential. In studies of the cognitive effects of video gaming, there is evidence for increased working memory, processing speed, and attention across a variety of game types. <sup>xxii</sup> Video games are particularly good at facilitating group player interaction and enabling relationships. However, there are no published reports on the effects of commercial videogame use people patients with serious mental health difficulties. And while video games have been developed for educational purposes and to treat different mental health problems such as anxiety (e.g., fears and phobias) and depression, effectiveness research (though now emerging) is currently lacking. <sup>xxiii</sup>

## Web-based Forums and Peer Support Groups

Young adults with mental health challenges rely on electronic and mobile technology for social and informational networking to create new relationships, maintain existing social connections, and reconnect with old friends. Social support has been shown to be a protective factor against psychotic relapse in First Episode Psychosis (FEP) by lowering social isolation and suicidal ideation. Two thirds of young FEP clients agreed or strongly agreed with the use of technology to facilitate social contact with other young people receiving services for FEP. Young people have found support from peers on social media and blogging communities, and find peers to be a helpful source for both mental health information and education. Some young adults share their experience of their emerging psychotic and mood symptoms via social media, actively reaching out to others before considering professional care. Online forums or chat rooms could facilitate the establishment of new social relations for patients who have fewer offline contacts. In addition, helping others online and sharing information and experiences can improve personal self-esteem. Nevertheless, experimental evidence on these online social supports is lacking.

Support groups are planned meetings in which participants share their stories and offer

emotional and sometimes practical advice, sometimes as an adjunct to treatment programs. There is promising evidence that support groups with people with mental health disorders increase personal empowerment and quality of life and reduce isolation. With regard to online support groups, the research on the effects on young people with mental health challenges is sparse, though preliminary evidence suggests improvements in self-efficacy, problem solving, and social recovery. Given that peer support is frequently used as an adjunct to internet interventions for a variety of mental health conditions, research is needed to assess the effectiveness of peer support as an active intervention.

The downside of these on-line groups is that emotional despair and suicidal ideation can spread among members of a group, online or offline. Thus it is important to have highly skilled group moderators to intervene when a participant is at risk for suicide or otherwise in crisis and to contain the spread of negative emotions. An experienced moderator can foster more group cohesion and help participants feel comfortable interacting. The moderator can specify the conditions of participation and prohibited behaviors, and can address the potential problems of sharing personal information (e.g., phone numbers). Experienced peers are seen by many as the ideal moderators, though some have suggested mental health "professionals" may be better when the group is made up of people "at risk".

#### Monitoring and Feedback

Many technologies now allow people to track their physiological and self-reported states, and the information can be reported to themselves and/or their clinicians. Young adults with emerging psychosis tend to like these technologies, but only if they have a choice on whether to use them. Monitoring, such as mood tracking, has been shown to help people with regard to disorder-specific symptoms. Such technologies can assess when symptoms/moods are worse or better over the day, month, and so one. This information can give individuals a sense of independence and empowerment; if they are in treatment, this can also enhance their ability to take control of their own mental health and well-being between appointments. For clinicians, the advantages diagnostically and for treatment are well documented, and they become better positioned to provide personalized advice when an irregularity is noticed.

Mobile devices provide a convenient platform for conducting assessments with standardized measures, clinical inventories, or interviews. The inclusion of electronic versions of measures and surveys on mobile devices allows the resulting data to be integrated with other functions of the app such as data displays through graphics and resource connections. For example, the ReliefLink app includes a mood tracker that provides an assessment of suicidal thought. These monitoring systems are often combined with using the internet for individuals who are considering the type of assistance they might need, and in the clinical context with electronic health records and self-improvement apps.

At this point, there is little published efficacy research on the effectiveness of electronic monitoring and feedback for young adults with mental health difficulties, and is thus sorely called for. Also helpful would be an assessment of how self-monitoring can interact with social media toward increasing the uptake and use of information collected.

## Formal Complement to Treatment Engagement, Support, Reminders

The major barrier to formal technology use is that many mental health professionals do not use integrated online social media technologies in treatment, even though they use it in their personal lives.

Young adult clients report that technology can help them maintain engagement with treatment services if individual preferences for mode of clinician contact are considered and respected.\*\* In general, a personal telephone phone call to young adults from the clinician is a useful means to start the therapeutic relationship, reducing anxiety prior to the first face-to-face session. Phone calls are cited as more comfortable and warm at that point. However, young adults generally prefer not to communicate by telephone with the clinician after the initial session, subject to personal preferences. Telephone calls are often seen as too intrusive, while text messages represent convenience and flexibility.

Additionally, texting can be done anywhere, whereas a confidential phone call needs a quiet, secluded space outside of earshot from anyone else. Feasibility studies show that young adults like text message communication within the clinical relationship, most frequently when used to schedule appointments and share treatment information. It has also been used to provide low levels of support to clients with psychotic symptoms between meetings. Young adult preferences regarding medication reminders varied. A recent systematic review indicates that text message reminders significantly improve appointment attendance in adults. The provided the intensity and frequency with which young people use mobile technologies, there has not been any research into the effect of SMS contact on richer forms of treatment engagement, such as shared decision making and medication effectiveness.

## **Decision Aids (DA)**

Electronic decision aids (DAs) guide people to identify their needs/values and clarify treatment/service options, and thus promote shared decision making with providers. This is important because young adults generally experience a lack of involvement in treatment decision making. They can be clinic based and/or available through internet. However, there are few such aids available in mental health and most focus only on medication decisions only.

Studies show that first episode and/or depressed patients are interested in and capable of using decision aids. \*xvii And many clinicians are open to the idea of receiving patient generated information. But outcome evidence at this point is mixed regarding its impact on clinical interactions, such as patient input. \*xviii Clinicians believe that patient generated written expressions of preferences and values would most likely be used when easily available during patient encounter, either on paper or electronically. Future research and development should focus on electronic DAs that: 1) generate greater patient input, and 2) impact clinical decision making.

### **Electronic Health Record Systems- Open Notes**

With the advent of secure internet portals, a growing number of healthcare organizations are providing patients with electronic access to information contained in their medical records. The goal of this "Open Notes" approach is to help patients become more actively involved in their care and take greater control of their health. With Open Notes patients can review clinical assessments and treatment plans, as well as check the accuracy of their clinician's notes on symptoms, medication doses, etc. Early evidence suggests that patients with such access feel more informed about their health, are more engaged and satisfied with care, and have improved health outcomes.

People of all ages who have been diagnosed with mental illness have benefited from an Open Notes approach. In one recent study, patients with mental disorders attending primary health clinics reported improved communication with their doctors, care coordination, and ability to self-manage and self-coordinate. Nearly all interviewed patients reported that reading notes led them to correct their therapeutic regimen in some way, with most changes focusing on medication intake, such as correcting dosages. According to Esch et al. xxix mental health patients reported that this access led to improved memory and understanding of one's own health information, and created a stronger sense of trust with their physician in part through using the notes as a reference.

However, some mental health providers are concerned that an Open Notes approach could harm patients and interfere with their work (if they have to respond to questions/comments about records). Many feel that "sensitive" information (e.g., psychotherapeutic notes) will exacerbate patients' illnesses and interfere with the therapeutic alliance. Although research here is minimal, there is little evidence for these concerns. Walker showed that most patients with serious mental health conditions who accessed records benefited and few became worried or concerned. XXX In addition, Open Notes has resulted in clinicians writing about the mental health of their clients in a more descriptive and nonjudgmental way, with less labeling. And studies show that as physicians use Open Notes they tend to like it better. The main barriers for patients are when there is onerous login process and/or slow processing speeds.

Education modules on writing more descriptively and less cryptically about patients' mental illness experience and easing the record access process for patients should be developed. Additional effectiveness research is needed with regard to young people with mental health conditions.

## eTherapy

With eTherapy the clinician uses technology as the primary mode of service delivery (rather than meeting in person) for forming relationships and treating patients. eTherapy can be the primary treatment or replace a portion of the client-clinician face to face therapy plan. eTherapy allows healthcare entities to treat more clients and some more intensively with the same number of clinicians. This is very relevant in an era in which access to mental health care is challenging and technology continues to develop rapidly. It is particularly relevant

for rural areas and for populations such as young adults who hesitate to engage in treatment. In a recent study focused on first episode clients, about one half were interested in receiving counseling or therapy through online technologies. \*\*xxi\* Most felt it was a matter of personal preference and that clients should be given the choice (of on-line or in person) as part of a collaborative discussion between clinician and client. As for providers, technology should have a clear, tailored rationale for any given client's treatment plan.

Barak et al. xxxii in their systemic review, have identified three main eTherapies that have been studied:

- CBT (changing thought patterns and contents)
- Psycho-education
- Behavioral activation (to modify and shape target behaviors)

The research showed that the mode of delivery did not produce significantly different outcomes and both were effective in promoting positive change for all ages. CBT was generally more effective than the other electronic therapies. Maintenance of longer-term engagement remains a key challenge.

Barriers to use are similar to the ones noted above about combining technology with treatment, but probably more intense for clinicians who define themselves by their in person therapeutic skills. Greater clinician buy-in would benefit from concerned clinicians being involved in the research and

### **Examples of Health Technologies Combination Use**

Many multi-modal technologies have been developed to support and treat people with mental illness. In Australia, as part of a substantial effort to provide effective services and supports for young people with FEP, a clinical leadership team obtained feedback from young adults and developed the HORYZONS system, a web-based platform offering a range of interactive supported psychosocial interventions and moderated on-line social networking environments. \*\*xxxiii\*\* HORYZONS provides:

#### Individually tailored interactive psychosocial interventions

When first episode clients enter the system they answer standardized questions designed to help them choose the most applicable modules, which are based on practices supported by evidence. The modules address key risk factors related to depression, social anxiety, and early warning signs of relapse (EWS), and provide resources such as stress management and psycho-education. Some modules are "mandatory," (e.g., 'how minds work') and others are optional and used according to client preferences (e.g., EWS).

#### Peer to-peer on-line social networking

The homepage shows notifications and activity, a "friending" function, and a "job zone" with information about vocational supports and on-line access to a vocational rehabilitation specialist. Also included are a number of moderated social networking features that are made available as clients make progress through the modules. Participants are invited to join moderated online groups focused on personal problem solving. Clients propose discussion

group topics and they are discussed through a structured format. Shared suggestions and resolutions are stored in a database in which participants can create and change content. In addition, participants are encouraged to use the database to share their personal coping strategies.

## Involvement of peer or mental health "professional" moderator to ensure safety

To date, research has demonstrated the feasibility and acceptance of the Horyzons approach by both clinicians and clients, with relatively low attrition rates. A small study found that over one month's use clients generally experienced a notable reduction in depressive symptoms and an increase in social connectedness. \*\*xxxiv\*\* Another study found that the platform was a safe and secure therapeutic environment for young people with FEP. Thus, this multi-modal platform shows some promising results, but larger experimental research is needed to demonstrate effectiveness.

#### **Discussion and Recommendations**

Young adults are very comfortable and capable of using technology to seek mental health guidance, support, and treatment. They usually prefer the internet when seeking information because of concerns about privacy and stigma. In addition, young adults who have difficulty getting to in person treatment (e.g., school or work during the day, parents with young children) are more likely to engage in treatment on-line. Thus, health-related technologies have an unlimited potential toward improving the lives of young people with serious mental health conditions.

Many young people with mental health difficulties have reported on how technology-assisted health has improved their well-being, but effectiveness research in this space is insubstantial for many interventions and supports. Although promising, monitoring and feedback devices, electronic decision aids, and texting for crisis support and treatment engagement do not have strong evidence for positive outcomes; more product development and research in these areas for young adults is necessary. There is an emerging evidence base supporting the effectiveness of well-designed video games, electronic crisis and wellness planning, and Open Notes, but more information is needed on implementing them with young adults and their providers.

Of note, several technology-based mental health services and supports do have a strong evidence base with young adults. eTherapy for CBT and psycho-education is as effective as in person therapy. In addition, studies demonstrate the effectiveness of certain self-help and complementary technologies that address young people's mental health concerns, including cognitive behavioral feedback, psycho-education modules, and well-designed virtual reality programs. Thus, clinicians who provide clients with the opportunities to use evidenced-based self-help technologies can see more clients. However, many providers will need to better integrate technology into their practices.

An interesting development here is the clinical use of on-line personal data (medical records, monitoring and feedback) to make assessments/predictions about risk for disengagement, relapse, self-harm or suicide attempts, and dangerousness. Many people with mental illness are concerned about this "big brother" approach to their treatment, particularly with regard to the use of data to obtain commitment orders or medication guardianships. Young adults in our studies did emphasize the importance of informed technology choice, and would expect an explanation of the benefits and risks of each using possible health technologies. Whether there is a concern about privacy and security among young adults is difficult to tell, but many studies have demonstrated good security features for these platforms.

Below we touch on keystone topics that require additional thought, development and research:

#### **Technology platforms**

The technology platforms most commonly used by young adults for self help are social media and apps. They are both user friendly and show great promise as vehicles for better mental health. However, there is much to be learned toward improving their effectiveness as platforms:

- Health oriented *social media* is most commonly used for information seeking and support, and at times for seeking provider services. We also know that social media is most valuable to young adults when user generated content and personal story sharing is encouraged and the emphasis is not on diagnostics. Rice et al. xxxv report on the major research questions for social media moving forward:
  - "How do the characteristics of online social networks mediate their effects on mental health and social outcomes?
  - o Can online peer-to-peer support result in improved real world social functioning?
  - What is the level of participation in a therapeutic social network that is required to gain benefits?
  - O How do clinicians or 'peer supporters' best intervene at the level of social networks as well as with individuals?
  - o How can we scale and disseminate effective social media-based interventions?"
- *Apps* are most commonly used for wellness and crisis planning, crisis lines, psychoeducation, and cognitive-behavioral feedback. Below we list the strengths and challenges for using mental health related apps at this time:
  - o Strengths
    - Easily available and accessible
    - User friendly
    - Many young people have reported that apps can offer helpful assistance with self-care, reduce anxiety, and make connections with others
  - o Challenges
    - There are so many apps available, and few of them are researched. There's no clear guidance on which apps to use, and many are competing on the commercial markets

- Some apps aim to diagnose people and sometimes use offensive language, potentially driving people away from care
- Evidence for effectiveness is weak. It's not a question of whether apps in generally are effective, but instead whether specific apps produce the desired outcomes

**Technology for mental health information seeking, engagement, and coordination** At this point the effectiveness research for such technologies is weak, in part because it is difficult to measure engagement and health outcomes, as they are not always immediate or apparent. Based on the research, we recommend the following as next steps:

#### • For Information/website developers

- o Integrate the perspectives of young people with serious mental health conditions in developing content and features they perceive as most helpful for mental health information. An example of a website developed in this manner is based in Oklahoma, <a href="http://oknowisthetime.org/">http://oknowisthetime.org/</a>.
- Make it easier for young adults to find well-developed websites through effective usage of search engines and key links
- o Make it difficult to link out of the website before reviewing the key material
- o Use mixed formats (e.g., video, visual graphics) in addition to text.

#### • Providers

- Become aware of the best online mental health information and support websites for young people with mental health conditions;
- o Share with young adults useful guides and trainings on searching the web critically for valid and useful health information;
- O Develop a web presence with the following "easy to find" features:
  - Specific services offered
  - Biographical information (expertise and personal) of the individual providers, their availability, and how they can be reached
  - A user option to have a provider make an initial engagement contact (by phone is best).

#### Moving forward with research

A multi-step approach is in order to develop an effective research agenda on young adult use of mental health technologies:

First, convene a group co-led by young adults with mental health that includes health providers, technology experts and other key stakeholders to develop an organized technology-assisted health research agenda. Developing an effective way of studying app utility and effectiveness is an important component here.

Second, identify a research framework for health technology needs and efficacy to be applied widely and to implement well-designed and consistent studies. For example, Torous et al. xxxvi have developed a framework to research and evaluate apps, which could be applied to other mental health technologies. It is called ASPECTS:

- Actionable Data produced informs personal health and clinical decisions;
- Secure Protected through passwords and encryption;
- Professional- Meeting professional, legal and ethical standards, for young adults technology is not stigmatizing;
- Evidence-Based Data at the very least offers promising results;
- Customizable Based on personal preferences and characteristics;
- Transparent Clarity for people on how the technology will be used, what data is being collected, and from whose consumption.

Third, research and development should follow a participatory design approach, including the involvement of service users in a lead position from beginning to the end of a project.

#### Conclusion

Technology-based mental health supports and treatments are here to stay, constantly growing and improving, and are usually preferred by young adults with emerging psychosis and other young adults with mental difficulties. Greater collaboration and consensus thinking must go into their development, perhaps organized around a registry on the effectiveness of specific technologies for young adults. It is also important for young adults to take the lead in this effort, not only because they are the ones ultimately impacted but also because their user-based knowledge is essential.

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