Over promised, over-sold and underperforming? – e-health in mental health

Til Wykes & Mark Brown

Published online: 06 Jan 2016.

Submit your article to this journal ⌐

Article views: 4868

View related articles ⌐

View Crossmark data ⌐

Citing articles: 10 View citing articles ⌐

EDITORIAL

Over promised, over-sold and underperforming? – e-health in mental health

Til Wykes[1] and Mark Brown[2]

[1]King's College London, Institute of Psychiatry, Psychology and Neuroscience, London, UK and [2]Social Spider, The Mill, London, UK

Introduction

The Journal of Mental Health has had an interest in how the internet and digital technology can support (or not) mental health treatments and services over many years (Andersson et al., 2013; Bauer & Moessner, 2012; Bell, 2007; De Wattignar & Read, 2009). Now the neologisms e-health and m-health have entered the vocabulary of health service providers, clinical professionals and research funders. In the USA, the "stimulus package", known as the American Recovery and Reinvestment Act, incentivised providers to adopt electronic health records and use them in a meaningful way. In the UK, general practitioners are mandated to adopt interactive electronic health records by April 2018. These moves have been mirrored across the world with similar governmental pressures to adopt e-health systems. These systems and interventions supposedly herald a new era in health care by providing more options for treatment provision, plugging gaps in current services, reducing waiting lists, reducing medical errors, standardising information exchange and improving care links between different parts of the health care services (Rodrigues, 2008). These are all important areas for improvement but we feel the main reason for the recent stimulus to action has been the promise that the implementation of e-health services will reduce escalating healthcare costs. This is an issue highlighted in this journal three years ago (Schmidt & Wykes, 2012). We want to voice our concerns about these promises as increasingly the over-selling of the potential economic benefits, particularly in mental health services, may divert attention from the potential of e-mental health to improve the lives of people with mental health problems. Mental health involvement in the e-health

revolution has come later than in other conditions and as Ennis et al. (2011) pointed out mental health was generally used as an exclusion criterion in most e-health research studies. We think that overcoming implementation problems will be costly, and not just initially, and that there are other potential problems to overcome that affect mental health service users disproportionately which need more attention if e-health benefits are to be realised. We describe just a few briefly in this editorial. Although, we mention electronic patient records, most of our examples relate to e-therapy.

Attitudes to electronic medical data

When asked for attitudes to electronic data in the general sense there are more negative responses. But this is hardly an informed question. When asked a more concrete question then there are more positive responses. So for instance when mental health service users were asked whether their anonymised case records could be used for research they wanted to know a number of things – could they be exempted, what research would be carried out and was there any control. The research team responded by engaging with the community both in beta testing the search programme and also in setting up an Oversight Committee chaired by a service user which decided on what research will be carried out (Callard et al., 2014). Interestingly, in this exercise the main comment by service users was that the records were not good enough so they would like to put information into them. This was achieved soon after (Ennis et al., 2014; Robotham et al., 2015). Mental health conditions do have associated stigma (Ben-Zeev et al., 2010; Michaels & Corrigan, 2013; Schreiber & McEnany, 2015) and therefore the process of engagement needs to be clear and their informed consent needs to be one which is a nuanced agreement. In addition to all this we know that information sheets for mental health studies are poorly written and so service users do have problems in understanding the research that we do (Ennis & Wykes, 2015)

Skills and access to the internet

Individuals need to be able to access information electronically in a safe and private manner which means having access to the hardware as well as the internet in a private space. Equipment has become cheaper and Ennis et al. (2012) found

Correspondence: Prof. Til Wykes, Vice Dean Psychology and System Sciences, Professor of Clinical Psychology and Rehabilitation, Co-Director Service User Research Enterprise, Institute of Psychiatry, King's College London, De Crespigny Park, London SE5 8AF, UK. Telephone: +44(0) 20 7848 0596/5040; Fax : +44 (0) 20 7848 5006. E-mail: til.wykes@kcl.ac.uk

similar levels of access to the general population in a sample of people with severe mental illness. However, there were problems for individuals from Black, Minority and Ethnic groups in accessing hardware except *via* libraries. In addition, although, many individuals in their study possessed a mobile phone, it was often a pay-as-you-go phone and with little or no credit. For this group poverty, as well as skill, seemed likely to prevent access. More recently OffCom produced a market report suggesting that 60% of individuals over 55 years had a poorer than average Digital Quotient, meaning they had poorer confidence and knowledge of digital communication (OFFCOM, 2014). Migo et al. (2015) investigated these issues further in a study of individuals attending a memory clinic. They tracked smartphone ownership over 2012 and 2013 and found a significant increase but again with older people being less likely to have a smartphone. The level of ownership (40%) was less than in the general population but not that much less. So in terms of implementation we need to invest in accessibility with the provision of smartphones, notebooks, computers and access to the internet for a proportion of people with mental health problems. This would be the first of several steps towards reducing the digital divide and support parity and fairness. It would provide the means to access health information privately but is only a first step. As we have discovered training is vital to improve skill and/or confidence in working with an electronic health portal as well as to support individuals in developing and managing their personal self-monitoring goals (Ennis et al., 2014). This is for the same reasons that are found in the general population – older people have fewer skills – but also because the early onset of mental health conditions interferes with digital learning.

Digital empowerment and choice

The word empower means to make (someone) stronger and more confident or to give (someone) the authority or power to do something. In the digital health world, this may mean having access to our own data either in an electronic patient record or that we gather data ourselves *via* self-monitoring of our blood pressure, activity, diet, etc. Having access to data is important but it also has its downside. It just begs the question of what are we supposed to do with it? Is it supposed to help us change our behaviour and if so is it the most cost-effective or acceptable mechanism for doing so. For example, we know that some people might prefer to access therapy online as they do not want to attend a clinic and therefore the anonymity offered through the internet is beneficial. But some individuals may want contact with a health professional person. Will moves towards digital health reduce these choices?

Self-monitoring where is it taking us

We self monitor all the time. Our bodies provide information from proprioceptors that track our body's position and sensory receptors that provide us with all sorts of data on the world around us. Biometric devices, like Fitbit or aps, on a smartphone make our monitoring transparent and so we cannot fool ourselves, for instance into thinking we have met our target of being active most of the day. This focus on internal mechanisms or on self-awareness may be beneficial

to some especially for short-term goals but it might make us too self-absorbed. Psychological interventions often help individuals to focus attention away from the self to interactions with the world. The change of focus may be more difficult with digital self-monitoring and may produce negative consequences for the individual. This is very different from the monitoring in physical health where monitoring of exercise and diet may impact obesity or monitoring blood glucose may impact diabetes outcomes. Monitoring mood is assumed to be valuable but only if it leads to some understanding of the causation of fluctuations or allows the effectiveness of behaviour change to be evaluated. Otherwise it is just a whole load of data.

Adherence

Failure to realise the potential benefits of e-health for mental health also depends on whether people actually use them. Adherence to e-health systems is generally poor both in the general population (Greenhalgh et al., 2010) and in those seeking health advice and treatment. Many people may begin to sign up to an electronic health record or click a web address for an internet therapy. Fewer people sign in and even fewer actually complete the task they set themselves. At every stage there is a dropout and these rates are enormous in many internet therapy studies. There are reports of only 1% of individuals actually completing therapy (Christensen et al., 2009; Van Gemert-Pijnen et al., 2014). There is little structured understanding of what helps people to ''stick with the programme''. Support in the form of more user friendly feedback can be provided (Musiat et al., 2012) and simply having the person's name as part of the feedback can humanise the information to encourage engagement. Involvement of individuals with mental health problems in the development, design and implementation of the digital interface must surely be beneficial but we can find few instances where this has happened.

Mohr et al. (2011) provide a structure for understanding how we might blend human and internet therapy to improve engagement with e-health interventions. They suggest that we consider three factors: human support, motivation and communication ''bandwith''. The human support or coach effect is fragile and depends on a whether the supporter is seen as trustworthy and benevolent, has the right expertise, includes the service user in defining the therapy goals and helps to tie these to wider goals. The type of support depends on the amount of motivation experienced and whether it is extrinsic or intrinsic and is likely to differ between individuals and over time. Intrinsic motivation is more effective and depends on the e-health intervention addressing the problem that the service user has identified and thinks is important. An exciting and engaging platform which crucially meets user expectations will enhance this type of motivation. This is something that earlier programmes certainly ignored. Extrinsic motivation arises from sources outside the individual through rewards, such as payment or ones that build self-esteem. Verbal rewards have consistently been shown to enhance intrinsic motivation by affirming competence, whereas tangible rewards have inconsistent effects with some being detrimental to learning, engagement and

adherence. The final part of the model is the communication ''bandwith'' which refers to the number of communication cues a medium can display. Face to face communication involves verbal (including prosody), nonverbal and visual cues. Telephone contact removes visual cues, and text and email remove the social presence and synchrony of communication and produce the ''leanest'' communication. Leaner media are fast, becoming a necessary method of communication but it is not clear if this is the most accepted method of communication support for internet therapies especially in mental health.

The role of the coach will need to change over the e-health intervention as the service user changes the balance of their intrinsic and extrinsic motivators and as therapy progresses and goals are achieved. The process of moving towards more independence is important as this is the process of empowerment, but should be at the service user's pace and not defined by the e-health intervention.

Reciprocity

If mental health services want service users to provide self-monitoring data then they need to make use of it and respond when there are clear signs to suggest clinical involvement is necessary. Remote systems for monitoring symptoms especially in high risk groups, such as those with schizophrenia (e.g. Ainsworth et al., 2013; Palmier-Claus et al., 2012, 2013), rely on the responses from clinical staff to gain benefits and prevent risks. This requires specific skills in the coach as well as close monitoring. One recent study reports on the effects of providing expert support through a trained telehealth nurse who viewed the output from an adapted version of Health Buddy (Pratt et al., 2015). The nurse examined the information collected from each participant several times each day during the working week and followed a communication protocol depending on the category of response from the participant (red, yellow and green) where red are responses that are of major concern. Benefits were noticeable with reductions in self-reported psychiatric symptoms and service use (emergency room visits). But like most e-health studies this is an early evaluation and the design is just pre- and post-treatment. However, this type of allocation of staff time shows potential for cost effectiveness and it reduces clinical team concerns that remote monitoring will increase their workload.

Practitioners are also wary about the benefits particularly to shared care and especially on the personal interactions between the practitioner and service user as well as between members of the treatment teams. Although, these were mainly studies of physical health, the findings are likely to be the same (MacLure et al., 2014).

User involvement

Most programmes go through an acceptability assessment but fewer develop with the close involvement of individuals who have mental health problems. There are some emerging general design rules, e.g. simple visual interfaces, avoiding complex reasoning, etc., especially when presenting such interventions to individuals who may have some cognitive impairment (e.g. Ben-Zeev et al., 2013). But the close involvement of service users can benefit the usability and potential engagement of those who are likely to benefit. This has been adopted in mood monitoring (Drake et al., 2013), the development of electronic health records (Ennis et al., 2014) and in developing specific therapies (e.g. Reeder et al., 2015) and for developing apps to support young people going to the GP for the first time with a mental health problem (DocReady, see O'Sullivan & Brown (2015)).

Benefits

There has been differential development of interventions of different diagnoses with those for anxiety, depression, eating disorders and addictions tending to be developed earlier. There have been reported benefits to these groups but it is unclear whether these last beyond the end of treatment and it is clear that there is a relationship of size of benefit and the amount of human support provided (Arnberg et al., 2014; Cuijpers et al., 2008). Remotely delivered interventions for those with serious mental illness (schizophrenia or bipolar disorder) have been slower to develop. In a recent review, Naslund et al. (2015) report on the effects of e-health and m-health intervention effects for those with serious mental illness. Although, there were many and various methods of measuring feasibility and acceptability (dropout, returning the device, etc.), the study designs were poor making it difficult to judge their validity. Many of the reviewed studies were at the pilot or feasibility stages so are likely to be less rigorous and this seems not to have changed much over time. The absence of rigorous studies has not however, affected the enthusiasm for this type of therapy provision. Naslund et al. (2015) also point out that most of the reviewed studies were carried out in high income countries and that despite mobile phone ownership increasing there remains the significant costs of continued access to data services which will continue to limit access in low income groups.

The future for e-health

We have tried to raise some issues for e-health which we think will interfere with any potential benefits. None of these issues are hard to overcome. We are, however, concerned that these limitations are not being addressed as they appear over and over again in the limitations sections of research papers. Improvements in the design of studies, the development of systems that involve users from the beginning and considering models of therapeutic support would help. We know that benefit is associated with more sessions of internet treatment and so a science of engagement and adherence needs to be developed. What is absent is the investigation of the specific effects on service user-professional consultations and some consideration of the cost–benefit and therapeutic alliance benefits of providing human support. A race towards robotic provision of psychological therapy and support seems inappropriate when we can train the healthcare workforce to provide blended therapy. We have only carried out a straw poll but we believe that service users would prefer this option.

We should not paint the future as being too bleak. We know what the problems are and we know that involving people with mental health problems at each stage is crucial in defining the use and presentation of e-health interventions.

The new wave is to collect data remotely, try to identify events that influence mental health or provide monitoring more remotely without the need to interfere with the everyday life of the person with mental health problems. This has potential to identify personalised pinch points, such as early sleep problems, indicating a relapse even before these signals are noticeable to the individual. This could provide individuals with chronic relapsing mental health difficulties with more sophisticated control to avert crises. But again this is only likely to be important if service users are involved in the development of the monitored outcomes, the technology to measure them and the definition of the support they need to manage these potential crises. Finally of course we need to know how they are used in practice, something where there are few data outside the realms of a randomised controlled trial. Only by collecting these data too can we hope to maximise the potential of digital health.

Declaration of interest

References

Ainsworth J, Palmier-Claus JE, Machin M, et al. (2013). A comparison of two delivery modalities of a mobile phone-based assessment for serious mental illness: Native smartphone application vs text-messaging only implementations. J Med Internet Res, 15, e60.

Andersson G, Hesser H, Hummerdal D, et al. (2013). A 3.5-year follow-up of Internet-delivered cognitive behavior therapy for major depression. J Ment Health, 22, 155–64.

Arnberg FK, Linton SJ, Hultcrantz M, et al. (2014). Internet-delivered psychological treatments for mood and anxiety disorders: A systematic review of their efficacy, safety, and cost-effectiveness. Plos One, 9, e98118.

Bauer S, Moessner M. (2012). Technology-enhanced monitoring in psychotherapy and e-mental health. J Ment Health, 21, 355–63.

Bell V. (2007). Online information, extreme communities and internet therapy: Is the internet good for our mental health? J Ment Health, 16, 445–57.

Ben-Zeev D, Davis KE, Kaiser S, et al. (2013). Mobile technologies among people with serious mental illness: Opportunities for future services. Adm Policy Ment Health Ment Health Serv Res, 40, 340–3.

Ben-Zeev D, Young MA, Corrigan PW. (2010). DSM-V and the stigma of mental illness. J Ment Health, 19, 318–27.

Callard F, Broadbent M, Denis M et al. (2014). Developing a new model for patient recruitment in mental health services: A cohort study using Electronic Health Records. BMJ Open, 4, e005654.

Christensen H, Griffiths KM, Farrer L. (2009). Adherence in internet interventions for anxiety and depression: Systematic review. J Med Internet Res, 11, e13.

Cuijpers P, van Straten A, Andersson G. (2008). Internet-administered cognitive behavior therapy for health problems: A systematic review. J Behav Med, 31, 169–77.

De Wattignar S, Read J. (2009). The pharmaceutical industry and the internet: Are drug company funded depression websites biased? J Ment Health, 18, 476–85.

Drake G, Csipke E, Wykes T. (2013). Assessing your mood online: Acceptability and use of moodscope. Psychol Med, 43, 1455–64.

Ennis L, Robotham D, Denis M, et al. (2014). Collaborative development of an electronic Personal Health Record for people with severe and enduring mental health problems. BMC Psychiatry, 14, 305.

Ennis L, Rose D Callard F, et al. (2011). Rapid progress or lengthy process? Electronic personal health records in mental health. BMC Psychiatry, 11, 117.

Ennis L, Rose D Denis M, et al. (2012). Can't surf, won't surf: The digital divide in mental health. J Ment Health, 21, 395–403.

Ennis L, Wykes T. (2015). Sense and readability: Participant information sheets for research studies. Br J Psychiatry. [Epub ahead of print]. doi: 10.1192/bjp.bp.114.156687.

Greenhalgh T, Hinder S Stramer K, et al. (2010). Adoption, non-adoption, and abandonment of a personal electronic health record: Case study of HealthSpace. Br Med J, 341, c5814.

MacLure K, Stewart D, Strath A. (2014). A systematic review of medical and non-medical practitioners' views of the impact of ehealth on shared care. Eur J Hosp Pharm – Sci Pract, 21, 54–62.

Michaels PJ, Corrigan PW. (2013). Measuring mental illness stigma with diminished social desirability effects. J Ment Health, 22, 218–26.

Migo EM, Haynes BI, Harris L, et al. (2015). mHealth and memory aids: Levels of smartphone ownership in patients. J Ment Health, 24, 266–70.

Mohr DC, Cuijpers P, Lehman K. (2011). Supportive accountability: A model for providing human support to enhance adherence to ehealth interventions. J Med Internet Res, 13, e30.

Musiat P, Hoffmann L, Schmidt U. (2012). Personalised computerised feedback in E-mental health. J Ment Health, 21, 346–54.

Naslund JA, Marsch LA, McHugo GJ, et al. (2015). Emerging mHealth and eHealth interventions for serious mental illness: A review of the literature. J Ment Health, 24, 321–32.

O'Sullivan C, Brown M. (2015). Digital reality. In: Crepaz-Keay D, ed. Mental health today. and tomorrow: Exploring current and future trends in mental health. East Sussex: Pavilion Publishing and Media Ltd.

OFFCOM. (2014). The Communications Market Report. Available from: http://stakeholders.ofcom.org.uk/market-data-research/market-data/communications-market-reports/cmr14/uk/.

Palmier-Claus JE, Ainsworth J, Machin M, et al. (2012). The feasibility and validity of ambulatory self-report of psychotic symptoms using a smartphone software application. BMC Psychiatry, 12, 172.

Palmier-Claus JE, Rogers A, Ainsworth J, et al. (2013). Integrating mobile-phone based assessment for psychosis into people's everyday lives and clinical care: A qualitative study. BMC Psychiatry, 13, 34.

Pratt SI, Naslund JA, Wolfe RS, et al. (2015). Automated telehealth for managing psychiatric instability in people with serious mental illness. J Ment Health, 24, 261–5.

Reeder C, Pile V, Crawford P, et al. (2015). The feasibility and acceptability to service users of CIRCuiTS, a computerized cognitive remediation therapy programme for schizophrenia. Behav Cogn Psychother. [Epub ahead of print]. doi: 10.1017/S1352465815000168.

Robotham D, Riches S, Perdue I, et al. (2015). Consenting for contact? Linking electronic health records to a research register within psychosis services, a mixed method study. BMC Health Serv Res, 15, 199.

Rodrigues RJ. (2008). Compelling issues for adoption of e-health. www.ehealthstrategies.com: The Commonwealth Health Ministers Reference Book. Available from: www.ehealthstrategies.com.

Schmidt U, Wykes T. (2012). E-mental health – A land of unlimited possibilities. J Ment Health, 21, 327–31.

Schreiber M, McEnany GP. (2015). Stigma, American military personnel and mental health care: Challenges from Iraq and Afghanistan. J Ment Health, 24, 54–9.

Van Gemert-Pijnen JE, Kelders SM, Bohlmeijer ET. (2014). Understanding the usage of content in a mental health intervention for depression: An analysis of log data. J Med Internet Res, 16, e27.