

Co-production of Digital Mental Health Technologies to Support Individuals in Mental Health Crisis

Abstract

The purpose of this article is to present the findings of a discussion between people who use crisis services and academics about the development of a mental health digital technology app. The approach is underpinned by participatory methods that centralise the voice of lived experience in the development or delivery of mental health responses. The people who contributed to the conversation identified that the app may reflect a recovery approach to mental health whilst also supporting self-management. The app design was a central repository with links to other apps for self-monitoring or interventions. The app was designed with people with lived experience with an explicit aim to understand what people with lived experience would want from a mental health digital technology.

Keywords

Mental health digital technology, lived experience, consultation, app development, recovery, self-management

Introduction

International mental health policy calls for significant changes to the availability, accessibility and provision of services that better respond to the mental health needs of the population. In Aotearoa New Zealand and in England, the call includes development and evaluation of digital mental health interventions. Digital mental health includes the provision of services through telehealth or on video call platforms for assessment and interventions via professional services, as well as apps that can help people monitor their own mental health or provide simple interventions. In addition, there are formal and informal mental health support fora online where peers can share and gain information with each other about particular

conditions and possible support and interventions. It is already the case that these digitally based activities are the norm in the provision of mental health services but are not well understood or researched. It is also the case that coproduction is lagging behind other forms of service development and delivery in this area.

Destigmatisation of mental health challenges has seen an increase in the requests for help from all mental health and counselling services, with studies showing up to a sixth of adults in England having a probable diagnosable mental health condition (UK Parliament 2021). Evidence further suggests that individual responses to Covid has exacerbated mental health issues not only amongst people with existing conditions, but also amongst those with no previous experiences (The Health Foundation 2021) with some groups being more disproportionately affected than others such as younger people and those from minority ethnic groups.

This fundamentally challenges the abnormality model upon which psychiatry is based and calls for recovery-based interventions that have been called for over many years. When mental health needs are unmet, a crisis can occur where a person feels unsafe. In this situation, it is to crisis services that people turn, or to emergency responses by calling an emergency line such as 999 in the UK or presenting at an Emergency Department. These traditional services are currently complemented in many areas with recovery focused nonclinical services that promote respite and support self-management. This paper discusses an attempt to coproduce a mental health self-management app with people who use a recovery crisis service in the South of England.

Crisis mental health service provision is complex as there are few standardised crisis service models. Necessarily, it is an urgent service that aims to prevent risk escalation, such as people completing suicide, or assessing the suitability of the implementation of mental health law, to

detain a person for assessment, for example. The significant challenges of providing crisis mental health services are in the problem of the predictability of risk, and the narrow focus on the implementation of assessment under law. For many years, people who experience mental health crises have suggested that crisis services are unable to meet need because they do not allow people to identify their own crisis. Anecdotally, if you identify your own crisis then you are said not to be in crisis, a catch 22 situation for people trying to access help when feeling unsafe. One criticism of crisis services is that they do not engage a recovery approach and therefore are counterproductive to people who are in recovery as they tend to want to remove autonomy over decision making. Care improvements in mental health generally, and in crisis services are said to progress too slowly (Department of Health, 2017). Mental health crisis carries increased risk of serious self-injury or suicide, with devastating personal cost. Mental health had a social and economic cost of £105bn in 2009/10 (NIHR Signal 2016), with direct service costs of £10.5bn in 2008. Societal benefits include more timely and accessible services for individual and families affected by mental health crises, and the avoidance of unnecessary emergency service use. Commissioners are responding to increasing mental health need, decreased staff availability and largely stagnant funding, highlighting a need to change the way services are provided. Innovative service solutions are required that are resource efficient. There is a recognised need for information about digital mental health technology use in services, which has little evidence base.

When people experience a mental health crisis 'out of hours', the services that are available are accessed through emergency services, or at Accident and Emergency (A&E) departments. Otherwise, they contact a local crisis team. In the event that the crisis team do not meet the needs of the person, other services are enacted. People may phone an emergency line, 999 or 111, to elicit a response. Police and ambulance workers have noted the increase in mental

health calls, and have received training to respond to people in crisis. In A&E departments, mental health trained professionals work alongside practitioners focused on physical health, such as through consult liaison services. Conventionally, non-mental health services are often not well prepared to work with people in mental health crises.

In the UK, 2015 a Care Quality Commission (Care Quality Commission 2015) survey identified that only 14% of people thought that mental health crisis services were helpful. Following this, *The Five Year Forward View* (Department of Health 2016) called for significant improvements, new standards and innovation. In 2014, the Crisis Care Concordat (Department of Health, 2014) called for improvements to crisis care by introducing self-referral, improving the quality of treatment and care, and called for the promotion of recovery within crisis services. Areas for improvement include introducing innovative service provision, extending access to digital mental health technologies such as apps and online therapies, extending out of hours access, making sure that people can access services locally, that services are co-produced and codesigned with people with experience of services, and that quality improvement cycles are built into provision. These aims reflect the *NHS Long Term Plan* (Department of Health, 2019) priorities for community-based services, aims to reduce pressure on emergency services, individualised care with more control, digital mental health technology use and integrated care systems that partner NHS and non-governmental organisations. As a result, Clinical Commissioning Groups (CCGs) have reviewed mental health crisis provision. New services have been developed that respond to these policy calls by prioritising quality services, locality, recovery orientation, peer support, self-referral/drop-in, clinical and peer partnership, and coproduced recovery plans. The services aim to re-establish control and coping and promote self-management in alignment with recovery principles.

Digital mental health technologies, such as apps, use for self-management in crisis recovery services is an emerging field of enquiry. While there has been a boom in the development of digital health technologies, there are few that were co-created and co-produced with people with mental health experience, or that have been evaluated (Bucci *et al*, 2019). Bucci *et al* (2019) identify that digital interventions for a group of people with mental health problems were helpful in gathering and sharing information with family, friends and health professionals, and reaching out to build connective communities through online fora and social media for peer support. Concerns however, included recognition of risk and digital literacy skills to evaluate the validity of the information offered. Digital health technologies therefore are potentially helpful for the person to create a synthesised and integrated personal approach to their mental health care consistent with a recovery approach. One problem is that this may be at odds with approaches on offer from services.

More generally, there have been recent developments in crisis mental health care, such as the *crisis recovery* services, which are an amalgam of community crisis services and recovery services. Systematic reviews of community-based crisis services identified that they are viable approaches, but that more evaluative studies are required (Joy *et al*, 2006; Murphy *et al*, 2012). Compared to inpatient provision, crisis services were preferred by service users to stay out of institutions (Morant *et al* 2017). Recovery orientated practice that value the person as an expert in their care have also been found to be effective with evidence that joint crisis plans reduce compulsory admission (Henderson *et al* 2004) and offer cost savings to services (Flood *et al* 2006). A longitudinal study in Norway found that there was a disjuncture between short term crisis services and recovery services that prioritised self-management and longer-term crisis resolution (Biong *et al* 2012) whereas a continuum of recovery principles would benefit service users. Similarly, the CORE study implemented peer support to bridge

crisis and continuing care services to improve the quality of evidence available about peer supported services (Lloyd-Evans *et al* 2014). Many people who use crisis services do so repeatedly but using recovery-focused planning helped prevent further crises (Ashman *et al* 2017).

A systematic review on recovery (Langer Ellison *et al* 2018) identified that greatest concept concordance was for individualised/person-centred care, empowerment, purpose, and hope. In a review of crisis models, a large evidence base supported the NICE recommendations for peer support, for example through crisis houses (Paton *et al* 2016). People in crisis who received peer self-management support were less likely to be readmitted to hospital within one year (29% versus 39% in the control group) (Johnson *et al* 2018). People in crisis found access to a ‘Living Room’ community peer supported alternative to crisis presentation at A&E helpful (Shattell *et al*, 2013). A cross-sectional study found that service users experienced better therapeutic relationships and satisfaction levels in crisis houses than acute units (Sweeney *et al* 2014). A randomised control trial that examined fidelity and outcomes of peer-led service provision in comparison to case management found that peer-led service provision resulted in improved outcomes such as increased confidence, decreased symptoms and less hospitalisation for people with serious mental illness (Boevink *et al* 2016). There is scarce research about digital mental health technologies. NIHR signal (2018) identified the value of peer support at times of crisis (NIHR signal, 2018), also highlighting the need for an investigation into digital mental health technologies.

In the UK, a new service was established that was coproduced and codesigned. The service was similar to the 2017 evaluation of a self-referral peer collaborated crisis centre *Aldershot*

Safe Haven Service (Griffiths and Gale 2017) found that there was a positive response by users of the service:

- 56% service users did so to prevent crisis,
- A downward trend in use of A&E and inpatient admissions,
- Police ‘mental health related’ calls dropped 42%,
- 12-month costs avoided = £511K - A&E (£72K) and inpatient unit (£439K).

It was a self-referral drop in service, open from 4pm to midnight. The emphasis was on re-establishing control through self-management. Peer workers provided most of the support and one nurse was present on each shift. The service was non-clinical in that it did not assess people in the conventional sense of a mental state exam, and did not keep medication on site. Family members or other supporters were welcome to attend, although children were not allowed. Most therapeutic involvement was through one-to-one sessions with a worker where strategies were worked through for self-management. People who used the service used multiple other services including community mental health services, the crisis team, police and A&E access, Samaritans and general practice. Self-management was also about coaching to use services more comprehensively rather than repeatedly without needs being met, thereby rationalising service use. The police and ambulance staff were able to drop off non-injured people to the service, rather than formal processing through justice or health systems and this resulted in less use of mental health law. Of 360 unique presentations over seven weeks, there was one referral for inpatient stay. The lead author undertook interviews with seven staff at week seven of the implementation of the service. The main discussion was that more people than were planned were accessing the service, often for a number of weeks while in crisis. The service was strategically positioned in an area where people who were discharged from hospital with no home address were housed in temporary accommodation

and many of these services users cited isolation as detrimental to mental health so sought social engagement at the service. Groups moved themselves on to support each other outside of the service too. The police and ambulance service had stated their satisfaction with the accessibility of the service and not having to take people into hospital or to the police station. One observation was that the people using the service were engaged on mobile phones, often using apps. Digital mental health technologies were used for mindfulness, wellbeing promotion, meditation and peer support information. One area for development within the service was to understand more about the use of digital technologies, and it was noted that few apps were coproduced, so an app was coproduced with users of that service.

Methods

This project members co-created and co-produced an app to support self-management and was co-designed by people who use the crisis recovery service. The app helps people navigate their personal mental health crisis by bringing together all of the known strategies for supporting mental health and what to do in a crisis, thereby promoting self-management. The approach is founded on the value of experience in design of services, and in research practices (Brannelly 2018). Consultation with a local Mental Health Forum and Trust clinicians and Bournemouth University's Public Involvement in Education and Research (PIER) partnership (<https://bit.ly/2Vi4CTP>) identified the need for a coproduced app in crisis recovery services.

Recruitment

Four people who were users of the local crisis recovery service volunteered to be involved in developing the app. Time was taken for people to describe and explore what aspects they would like to see incorporated into the app. Subsequent meetings reviewed the development

of the app and finessed the concepts and language used in the app elements. The core group of four people attended four more meetings until the proof of concept had been established ready. The consultation did not require formal ethics committee consideration. Ethics were considered in terms of recognition of contribution, some compensation for time, and hospitality when we met face to face.

App preferences of people using crisis recovery services

All members of the group used mental health related apps for various interventions such as meditation, mindfulness and sleep monitoring. These apps were described as supporting self-management and coping when feeling unwell. One of the group, described how she had developed her own version of the app on paper which was a personalised journal with reminders of the people who help, the apps that help, and who to contact when feeling unsafe. When explaining the journal approach to the app, it was agreed within the group that this was a really helpful way of bringing together other useful apps in a journaling and toolbox approach. It was agreed that this was the style of app that would be most helpful. This was set out as a challenge for the app builder to see if it was possible to create a personalised journal with access to multiple apps to support self-management.

The key aspects of the app that were requested by people with experience:

- That the app resemble a personalised journal when it was opened, which the user would be able to load with photos and pictures.
- The app was a way of remembering people to contact and connect with in times of challenge – who can help right now – but also to maintain social connections that helped the person stay well and not isolated
- The language used in the app was welcoming and reassuring, and sympathetic to the challenges that people face.

- The elements of the app reflected the experiences of challenge and were focused on practical responses
- Space for favoured YouTube clips, or online peer support forums
- That the app might capture what a good day looked like to remind people in the midst of challenge that brighter times were ahead
- Monitoring sleep, diet, medication or symptoms could be offered if that helped people to identify potential factors that contributed to the development of mental health challenges
- It was preferred that links to social media remain outside of the app.

An app developer also attended meetings The app, at this stage, was described as working in a way that the user could swipe right to siphon the helpful aspects of the app, while relegating less useful elements by swiping left. One main challenge at this point was whether other apps could be incorporated into the journal app or not.

At the second meeting the app developer was pleased to report that other apps could be linked into the app, which was welcomed by the people with experience. Working out how to include apps while enabling them to be freestanding for appropriate upgrades and updates was overcome and the links could be built in. There was some sharing of the apps that people would include, which were viewed as useful and a moment of peer support.

In this second meeting, the discussion then focused on what was helpful in terms of monitoring and how to present this in a way that supported recovery. For example, some people valued the monitoring of symptoms and would like to be able to list their main symptoms and review how they were affecting them, and others thought this would make

them spend too much time focusing too much on what was wrong, rather than how they were well. Sleep monitoring was welcomed by all, as a self-completion diary. Diet monitoring was valued by some but not others as too much focus would be more stressful and not helpful. The same went for exercise. It was thought that apps already available, such as step counters could be incorporated if so wished. People with particular challenges may like to include specialist apps designed to support calorie counting if trying to gain weight, for example.

At the third meeting, attention was paid to the inclusion of medication. Within the group, the decision to include medication was viewed as controversial, as the focus was favoured in a non-clinical assessment and treatment approach. If medications were to be part of the app, there were multiple aspects to the inclusion of medication. These were the correct names and dosage of medication, when to take them, whether they were taken, what to do when the medication was reviewed, how to record side effects, how to record taking medications or not taking medications, and keeping a log of information about medications within the app. A key question here was about who had access to the information and how it may be used, especially if a person is subject to compulsory treatment, such as under a Mental Health Act Community Treatment Order. This prompted a broader and more in depth discussion about the right to access in the app and the right to privacy. It was agreed that the person had sole access and chose who to share the information with.

If medications were included, this raised another area of discussion about how to include medications. One person wanted an alert system set up so that they would be alerted every time medication was required, but others thought this intrusive and too much to deal with. One area of agreement here was the need to record possible side effects of medications and discuss them with their treating team. This was also valued because the medical terms of side

effects were unknown, and the side effects of medications seemed to be so expansive that any unusual sensation could realistically be included. The group thought that logging these consistently and being able to present that to the treating team would create a better discussion about the experience of side effects and the implications that the experience of side effects had on the acceptability of the medication. The discussion resulted in a better understanding of the complexity of medications in an app such as the journal, and the group decided that a record of current medications, and an opportunity to record the experience of taking medication rather than the recording of taking medication would be useful for self-reflection and to use the information for more in depth discussions with the treating team.

The fourth and final meeting saw a prototype of the app build which was reviewed. The journal part of the app included the ability to load photos of loved ones, pictures or recordings of art work and other accomplishments, and contact details for mental health teams and workers. The second part of the app was the toolbox where other apps could be loaded in so that rather than looking around for the apps that help, they were available in one space. The toolbox was viewed as essential to self-management, promoting a sense of safety and self-reliance, a place of stability when challenged. The third part of the app was the place where monitoring could take place. This was fronted by a description of the person on a good day – what the person is able to do on a good day and how they cope well. This was followed by a selection of self-monitoring apps, including but not limited to medication, sleep, exercise and diet. The emphasis was on personalisation and an enthusiastic and welcoming space that people would enjoy using.

Discussion

It is perhaps unsurprising that a group of people who use mental health crisis services which are recovery orientated take an intuitive recovery approach to the app. Taking Leamy *et al* (2013) summation of recovery principles, it is possible to see the CHIME elements applied in the app. These are Connectedness, Hope, Identity, Meaning making (and material resources) and Empowerment. Connectedness was the first aspect that was called for through an immediate reminder of who was available to contact and maintaining connections. Hope was present through the depiction of the good day and reference to how people had taken themselves through rough times previously which sig resat evidence for being able to achieve that again. Identity is constructed through our relationships with others as well as our characteristics and the emphasis here was again on accessing what was known to help, and the right people who were able to help too. Evidence suggests, for example, that where people run into racism in services, they are not likely or willing to engage in that service (Kidd *et al*, 2020). Services that are culturally safe and afford engagement are necessary to support identity. Opportunities to make meaning and reflect on experience was present in the journaling aspect of the app, and the daily engagement that the users of the app thought they would have. Although monitoring symptoms, sleep, diet, exercise and medication may be too much for some users, they may also be helpful for others to identify what helps and does not help, especially earlier in the process of self-management. Empowerment was a central question in the right to preserve or share information from the app. There was unequivocal agreement that the decision about whether to share information remained with the person whose app it was and their willingness to share that information at any time. Knowledge is also empowering, and some of the discussion about recording side effects of medication, for instance, was about being able to report in some detail recorded at the time, the intensity of the experience, for example by a short voice recording, rather than a written statement.

Limitations

Following the build of the app, the plan was to test the app with university students. The decision was made to postpone that research phase for two reasons. It was decided that the app could be built better with more investment. Secondly, with the advent of Covid19 restrictions in England, teaching was remote and students were not on campus. The research team wanted to be able to discuss the app with the students in for a that included the people with experience, and the preference for doing that was face-to-face, so it was postponed.

Another limitation is the level of consultation undertaken to develop the app. The group consisted of people with experience of mental health challenges and service use, but also of other aspects of their lives that were very helpful when considering the development of this app. These included being digital natives, previous education in digital technologies and digital arts. Nevertheless, a larger group may have been able to contribute other areas of development that our group overlooked.

Conclusion

This small consultation project orientated care and recovery in the digitisation of mental health and approaches that promote wellbeing. In addition to the aspects above, connections to nature and green spaces that enable wellbeing could feature. The people involved valued the interdependencies they had with others, and the opportunities to care for each other through those relationships. This included reaching out for care when it was needed, a strength that acknowledges a need for care and seeks to meet that need. Humans and the world/universe are viewed in an interconnected and interdependent state. The digitisation and use of a technology service as a reminder for contact with others, rather than a replacement for contact with others. It may help people to know who to contact so that multiple contacts

are avoided, as we are aware that happens for this service use group. Reaching out to multiple people in different services is an act to meet an unmet need. A journal approach provides an opportunity for the recording of experiences of people using digital technologies for more accurate explanations of accounts of health episodes, for example. Meetings with professionals are often after the event and explaining the episode is challenging to get across even for people who are articulate. Digital technologies need to be framed according to the principles that engage and support people to recover, which is frequently missing from the app development priorities that have resulted in multiple single use apps that largely cater for wellbeing upkeep. So, it is necessary that the starting point for the development is the voice of experience and the core knowledge that enables needs to be met.

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