Summary paper: Engaging experts by experience about the role of digital technology in the future of mental health care

Introduction

New technologies for mental health are advancing quickly. They have potential to improve the health and wellbeing of individuals and communities through new kinds of treatment and monitoring techniques. However, these technologies raise several ethical and social concerns, such as the reduction of human contact, the effectiveness and quality of care provided, potential health and social inequalities, and issues linked to the privacy and security of service users.

This collaborative project with the Nuffield Council on Bioethics engaged people with lived experience of mental health services through a series of scoped discussions, which aimed to explore key issues, questions, and challenges of using emerging digital technologies in mental health services.

This paper outlines some of the key themes that were raised in these discussions and suggests possible next steps.

Methodology

For the facilitated sessions, Rethink Mental Illness recruited 15 experts by experience using our existing co-production and involvement networks. This included our community links and our own services, alongside targeted social media communications. Before the sessions, we provided the group with background information and a detailed brief outlining their roles and expectations. This helped to ensure maximum participation for the co-design of the engagement session themselves.

The sessions were a combination of group discussions, supplemented by one-to-one discussions for those who could not attend group meetings. They were held virtually to avoid travel for people from different locations and maximise participation. All sessions were facilitated by Rethink Mental Illness colleagues experienced in group facilitation and working on co-production with people who have experience of severe mental illness. Each followed the Principles of Involvement and Co-production including equality and mutuality, accessibility.

At Rethink Mental Illness we are committed to ensuring that in all our involvement and co-production we serve and hear as wide a range of voices of lived experience as possible. We value inclusivity and the richness that diversity brings to any such piece of work. For this piece of work, we cast the net wide and the participants had a variety of backgrounds, experiences and demographic attributes, such as gender and age. Due to the small sample size, people from ethnic minority backgrounds were underrepresented. We will endeavour to ensure greater diversity and inclusion in future pieces of work.

A policy brief, written by the Nuffield Council of Bioethics, provided a foundation for the content of the sessions, which included a focus on the role of the pandemic on shifting attitudes towards digital technology in mental health care settings, the social and ethical issues of using this technology in mental healthcare, and specific conversations around different types of emerging technologies.

It was ensured that the approach to these sessions was appropriate and accessible to everyone who attended, meeting the needs of as wide a range of people as possible, with diverse characteristics and reflective of the demographics of people who have experience of services. The sessions contained a selection of questions (see appendix of full list) that were asked to experts by experience. Responses to each set of questions have been analysed and categorised into relevant themes within this report.

The role of the pandemic

We first asked the group to reflect on their experiences of accessing mental health services during the pandemic – a time when service users have been obliged to move to online and remote methods of mental health support. Four themes were generated from this discussion – easier access to support, access to new online materials, bringing together communities of experience, and inequality of access.

What have your experiences been in the last 2 years regarding accessing mental health services?

Easier access to support and continuity of care

The COVID-19 pandemic has seen the NHS come under more significant pressure than perhaps any other time since its inception. Significant time and resource have and continue to go into providing care and interventions directly designed to combat the virus. Measures taken early on in the pandemic, such as the temporary redeployment of staff, had a direct impact on capacity within mental health services. Increasing mental health need and changes to how services are delivered, demanded by COVID-19 restrictions or wider circumstances of the pandemic, have also impacted people's ability to receive the right support at the right time.

For some involved in our sessions, this impact had been negative. For example, one participant said that he found that mental health professionals had been far more likely to cancel his remote appointments last minute compared to when he used to attend in person, perhaps due to the practical ease of doing so when an individual has not already made a physical journey to attend.

However, others were positive that technology had ensured the continuity of care amid COVID-19 restrictions and had experienced greater availability of therapeutic services and support, as a move to online which allowed greater flexibility with finding appointments.

Several participants reported that this meant they had a shorter wait time for their appointment:

"As an outpatient, I have noticed that waiting lists have become shorter because of therapy being over zoom. The process has sped up and people can now get the support that they need. Prior to this, I have had CBT therapy in person which took months of waiting and caused me to become more stressed. Not everyone has digital access, but for me, it's been very helpful."

Others reported feeling more relaxed and comfortable in online therapy or support groups. This was because they were able to participate in their own home environment, as one participant said, "people can engage in their pyjamas." This meant avoiding the experience of waiting rooms and hospitals which some considered to be stress inducing. As a result, many participants said that their own support groups have changed permanently to a hybrid style, allowing attendees to join online or in person according to their own preference.

Access to new online materials

Several people also felt that the move to online therapy has also facilitated access to other digital resources that they would not otherwise have used:

"Early on in pandemic I was asked to access IAPT (Improving Access to Psychological Therapies) over telephone. As a result, I was given digital resources to help with an instance of bullying I was experiencing in the workplace. I found this very helpful, as I don't think I would have had access to those resources if the appointment had been in person."

Another participant, receiving online therapy for an eating disorder, was introduced to an app called Recovery Record – which allowed them to input their own updates on mood and what they had been eating. They said that this allowed them to feel more closely connected to their therapist, who could get a full insight into their day-to-day life via the app.

Enablement of access to specialist treatment and support

Many participants attended peer support groups with health professionals and others who experiencing mental illness. As a result of the pandemic, many of these support groups were taken online – for some, this switch to online, allowed access to more specialised, needs-focused support groups. These are attended by individuals who are perhaps geographically disparate, but whose needs and experiences are shared and specific. This is an advantage for those who may have complex diagnoses or history with services.

For example, one participant joined an online support group for 40-50 people around the world, which first started in New Zealand, and is designed for those with a very specific set of circumstances and experiences. The participant said that the group could relate to their experiences in a way they had not found anywhere else.

Difficulties in accessing NHS treatment led another to opt for private healthcare provision. While not an option for many, this participant had benefitted from the opportunity to choose a GP and psychiatrist outside of their local area who could provide treatment that was more tailored to needs or specialised, enabled by digital consultations.

Inequality of access

However, many emphasised that the COVID-19 pandemic has made it harder for others who do not have access to technology, do not understand how to use it, or may not have a private space to access support in their homes, to access treatment and support.

This adds to concerns and growing evidence that the pandemic has further widened the gap for those already left behind.

"*Many people local to me with mental health issues are rough sleepers or evicted, live in poverty, or share a phone or laptop with their family. These people will not be able to access mental health services online. As a result, I have seen the mental health of others deteriorate in my peer support work.*"

"*I run a support group which had to move online and many weren't able to engage.*"

One participant, who was a support worker, suggested meeting up with service users first to show them how to use the technology before meeting online - a method they had found to be effective:

"*In my support worker role, it has been easy to support other service users who aren't techy. Even if some have struggled to use the technology, most are very motivated to work out how to use it. I have now started to initially meet up with people face to face, to show them the tech skills which then allows them to participate online.*"

Ethical and social issues

Experts by experience asked to put forward their own social and ethical concerns about the use of new digital technology in mental healthcare. After this, they were presented with a list of key ethical or social issues of digital technology in mental health care selected by the Nuffield Council of Bioethics:

What do you think the potential ethical or social issues are of including digital tech in mental health care?

1. **Lack of human contact**
2. **Implications for the therapeutic relationship**
3. **Evidence of effectiveness**
4. **Inequalities**
5. **Accuracy**
6. **Individual responsibility and medicalisation in everyday life**
7. **Privacy and security**
8. **Reliance on technology**
9. **Trust and acceptability**

From this list, which issues are the most important to you?

Lack of human contact

Many emphasised that mental health treatment and support has an important human component which helps to reduce isolation and rebuilds trust, and cannot be entirely replaced.

This was raised with regards to both one-to-one and group interventions.

"Talking therapy cannot be addressed by digital technology alone. If I think back to the most recent counselling I had – I would have not been in a fit state to type on my keyboard whilst crying my eyes out. In moments of heightened distress, you need an individual, someone to support you and give you guidance."

It was felt in particular that the positive impact of in-person social interaction could not be entirely replaced by digital technology:

"As much as I like to do things online, human contact is so important. I tend to isolate myself and seeing someone has a very positive impact on me. Technology is fantastic, but we are humans, and it is nice to engage with others."

"It is so important to be able to meet likeminded people, sitting with other others and doing activities together such as making something, or crafting, can be incredibly helpful. Digital technology could be an enabler, but I am not sure it is the solution."

Trust and acceptability

Trust was a key theme for most participants in mental healthcare - in the relationship with health professionals, in the sharing of data, in the transparency of the processes, and in the processes of sharing experiences with others.

For some, imbalance of power is a defining characteristic of their experience of mental health care, particularly for those who, in the past, have received treatments without their consent, due to lacking capacity or having been detained under particular sections of the Mental Health Act.

"Service users may have gone through unimaginable trauma and can feel little trust. Therefore, building a sense of trust is a big indicator of effective outcomes."

Use of technologies, in some instances, may serve as a barrier to building trust.

One participant noted that many are insufficiently educated around new technologies, and therefore don't understand or trust them. Moreover, the nature of certain mental health conditions may make it particularly difficult to respond positively to technological innovation. For example, for those experiencing psychosis or living with feelings of paranoia, technologies involving any kind of monitoring aspect may be received as being under surveillance.

These individuals and others may also be concerned that the information generated may be used 'against' them – for example, that conclusions will be drawn about their mental state from data generated via certain technologies, and/or that this information could be used as part of an assessment under the Mental Health Act.

Effects on the therapeutic relationship and implications for the accuracy of assessments and safeguarding

The therapeutic relationship is the client's positive emotional connection to the mental health professionals, and a shared conceptualisation between the individuals and mental health professionals of the tasks and goals of their treatment. This is a well-researched key component to the success of psychological therapies.

Participants were concerned that online interaction can weaken and jeopardise this therapeutic relationship between mental health professionals and the service user. In addition to issues around trust detailed above, it was pointed out that is easier to 'deceive' healthcare professionals that you are doing fine when speaking online, as long as you turn your camera off and 'say the right things'.

It was noted that this has clear implications for safeguarding and risk management. The example of trying to manage suicide risk via a remote consultation was raised as one such concerns.

Participants felt that workforce training be vital, but some expressed scepticism, noting that they felt NHS training was sometimes too piecemeal or not progressive enough for staff to learn comprehensively and buy into the appropriate and effective use of new technologies.

Privacy and security

Participants were particularly concerned by the ownership and security of confidential information about their or their loved one's mental state. With the introduction of third-party technology, there was a lack of certainty with regards to would legally be considered the data controller:

"Who is the data controller in all of this. That is really important to know – as a carer, it is hard to know who owns what…"

Over and above a general lack of trust in services, participants broadly perceived the NHS with having a poor reputation with regards to information management and confidentiality and emphasised the importance of secure, high quality tech:

"In mental health services your personal information can include your mental health status and current state of mind - there are greater consequences to this becoming compromised than other personal information. Therefore, it is important that tech is secure, and that there is no third-party risk of someone being able to access it. Unfortunately, the NHS does not have a good history in terms of management of information and confidentiality."

Participants also raised questions with regards to the ability of individuals to provide informed consent for the use of their data in this way – either because they may not fully understand what they are consenting to, or have sufficient mental capacity.

Inequalities

Inequality of access emerged again as a significant theme here and throughout the sessions. Participants expressed concerns about the financial, language, and educational barriers to treatment and support that can be created by use of technology:

"It is a challenge to convince deprived people that investment in hardware or software will pay off for them. Perhaps there needs to be a pot of money in local trusts that can be used to equip people with digital resources. In London the trusts are huge with big budgets, but in other parts of the country this is not the case."

"Software is also often only in English, and interpreters may not be available."

"It is wrongly assumed that everyone is digitally literate and understands English. Medications can also harm people's ability to think and understand the instructions of how to log on to Teams or Zoom."

Emerging digital technologies

Finally, participants were presented with five emerging technologies for discussion: smartphone apps and chatbots, digital phenotyping, immersive technologies, machine learning and natural language processing, and consumer neurotechnology.

Smartphone apps and chatbots

Smartphone apps and chatbots are mobile phone apps that are used to support meditation, self-care, mood tracking, and to deliver therapy (for example cognitive behavioural therapy). These also include automatic 'non-human' chatbots who reply to your questions via an algorithm with the aim, for example, to provide wellbeing tips or to assess mental health status.

There was a mixed response regarding smartphone apps and chatbots. Some highlighted the usefulness of being able to seek help independently and instantly:

"I am excited that these things are coming out. I have used chatbots for immediate help before, rather than having to go to hospital. I don't always want to go to a hospital in a moment of crisis, or to inform those around me; chatbots allows me to seek help independently."

However, others argued that chatbots can be limiting if you have a complicated problem that might require human interaction, such as social anxiety or agoraphobia, suggesting that apps and chatbots may be more appropriate for some groups than others:

"As someone who has dealt with agoraphobia and social anxiety, they needed to force themselves to go out and anything that encouraged the opposite would have been damaging for treatment."

Digital phenotyping

Digital phenotyping is the gathering of personal data from other aspects of people's lives through wearables, smartphones, social media to get insights into people's mental health status. Data can be of different types (e.g., changes in heart rate, interactions with the phone, things posted on social media).

There was a significant level of scepticism towards digital phenotyping, which participants identified as a threat to people's rights to their own data and privacy:

"Digital phenotyping really goes against everything I believe in. Why would you not just ask a person? I don't think it is ethical to gather data without asking the person about each type of data. The person really needs to understand every aspect of data and give permission."

The idea of digital phenotyping, for some was reminiscent of a historic power imbalance in mental health care, where patients have had limited power over their own treatment and support:

"Mental health treatment historically has been something where the patient has not had permission or control – and this feels like a movement back to that. For example, when people are experiencing mental health difficulties, they post certain things on social media that they wouldn't normally – I feel uneasy about digital phenotyping tracking this sort of thing."

Participants also argued that digital phenotyping could produce inaccurate results because people may choose to give selective data about themselves, leading to an unrepresentative picture.

Immersive technologies

Virtual Reality (VR) technologies include wearable headsets that simulate certain situations. For example, VR can be used to simulate situations that people may find particularly challenging. This might help them to learn psychological techniques to overcome their difficulties that they can then apply to real-world situation. VR can be used with a therapist, but automatic VR therapies are also being studied.

While some were sceptical with regards to what value can be added by VR as an alternative to the 'real-life' versions of the experiences it attempts to replicate, many were intrigued about the potential benefits of immersive technologies allowing one to be exposed to their fears, anxieties and phobias in a virtual setting. They felt this could be a useful step that is currently not available in face-to-face therapies:

"I think that immersive technologies are one of the most useful and practical applications that you can see really working."

"Immersive technologies sound quite interesting – especially for certain types of anxieties. For example, I have anxiety about driving; it would be amazing to address my fear using Virtual Reality."

"This could help people work through phobias in a controlled environment… I hope this becomes more widespread."

Some who were otherwise optimistic about VR more generally, expressed concerns around the use of automatic VR. One participant felt that facilitation of use of this kind of technology was an important element in building trust:

The only thing I feel strongly about is that it should be done alongside a therapist or health professional. Anyone who experiences a phobia needs to learn trust. Having a health professional there helps to develop that trust, and I think that is really important. I have a phobia of waters and dogs; I can imagine being very keen to try something like that, but I would be scared doing that on my own."

Machine learning and natural language processing

Machine learning and natural language processing analyses large amounts of data to make predictions about people's mental health and wellbeing in the future. For example, they can help predict how well a treatment is going to work for a specific person or whether a person is likely to experience a relapse soon and might need extra help.

The advantage of this technology is its ability to make predictions around mental health care, which can enable for preventative treatments and early intervention. There was a degree of interest in this idea in discussions, and the opportunity it presents for patients to further understand themselves and their own condition and potential use in understanding trends at population level:

"Machine learning and natural language processing could be good for people who are struggling to understand themselves."

"I think this could work on a widespread scale – statistics determining predictions throughout populations…"

However, participants also highlighted limitations within machine learning in terms of understanding the complexity of the human experience, particularly with regards to wider determinants of health:

"*Machine learning and natural language processing is problematic because people's mental health is so unique and individualised that it is very hard to predict outcomes. You cannot predict for all these variables – such as job, family, location, drugs and medication, social indicators, and not to mention the pandemic.*"

Consumer neurotechnology

Consumer neurotechnology is a wearable technology that can be used at home, for example to record brain activity or to stimulate brain areas that are thought to be linked to certain mental health conditions. This can be used to improve symptoms of mental health conditions, such as depression and anxiety (e.g., portable transcranial direct current stimulation can stimulate parts of the brain through electrical currents).

In discussions there was curiosity about consumer neurotechnology and the benefits that it can have of allowing people to understand themselves better:

"*I quite liked consumer neurotechnology, it would be good to see how behaviour influences my wellbeing. My mental health is quite up and down – so being able to understand myself and my triggers better would be very helpful, especially for my recovery.*"

How would you feel about these digital technologies being a part of your mental health support?

A risk to social isolation

Some reiterated concerns that widespread use of these technologies will ultimately increase social isolation, pointing to research linking technology and loneliness.

Technology must be an addition, not replacement

Participants felt that if these technologies should be used in mental healthcare as an addition to what is already available, rather than a replacement. Again, participants emphasised the importance of human contact and felt this could not be replicated.

There was a prominent concern that the health system's primary motivation behind introducing new technologies was for the sake of a cost saving exercise. Participants were

aware that investing in technology might be cheaper for the NHS than hiring new staff and did not want technological innovation to become a replacement for human support in the long term.

It was hoped that technology would, first and foremost, extend the options available to individuals around their treatment.

Must be down to the individual

While many were positive about the benefits that emerging technologies could bring, they felt this would be limited if not provided with sufficient choice and control around their use in treatment and support. Participants emphasised that the use of these technologies must ultimately be down to an informed decision made by the individual.

"Will people be given a choice to use this technology or will it be forced on them? There is an ethical question as to the extent people will feel confident in saying no."

"It should be explained to the individual first and then they can be asked if it were something they would like to try."

Culture change

In addition to concerns around sufficient knowledge and experience of digital technologies, participants also expressed scepticism that the dominant culture within the mental health workforce will lend itself to offering patients the choice and control necessary:

"There is a tendency amongst mental health staff to not give people control or options. A shift in attitude will be needed to allow patients the option over whether to use digital services or not. If we are going to integrate digital tech, it must come with a more consultative culture within the NHS of collaborating with the patient."

Need for a co-produced approach

It was felt that tech companies should embed a culture of co-production, as most felt the service user perspective had not been sufficiently explored in the development of new technologies.

With existing emerging technologies, was felt a co-produced approach is an important next step:

"It would be good to get the point of view of patients and health professionals. For example, occupational therapists could first trial technologies with patients and communities for their feedback."

Conclusions

This series of facilitated discussions brought to light new issues and considerations around the introduction of emerging technologies in mental health services.

From discussions, it was clear that new technology must add to existing face-to-face contact in mental health care, rather than replacing it. Many emphasised that face to face contact is essential for building trust with health professionals, as well as reducing isolation and

creating a sense of community – both factors are key to positive outcomes in services. Most were also concerned that technology will make access to support more unequal, meaning that those without money to invest in equipment, lacking digital literacy, or who do not speak English, could be left out.

However, there was curiosity about the potential of technology to enrich existing offers with new materials, resources, and types of support. This optimism was partly due to the benefits that some had felt whilst receiving treatments online during the pandemic. In the best cases, technology can add to existing support - allowing service users to seek support independently between their face-to-face sessions – which could result in a more continuous model of support. The potential for one to monitor and understand themselves better can be particularly useful for someone experiencing mental illness who is curious about their state of mind. However, it is essential that these benefits are balanced with the patients right to choose, and their right to privacy of their own information.

A co-produced approach will be vital for the introduction of emerging technologies moving forward. Many felt that service users and carers must become more involved in future development and pilot projects. This will be key to building a sense of confidence and ownership that can make emerging technologies a useful part of treatment and care in the future.