Mental health and wellbeing plan: Department of Health and Social Care call for evidence

Nuffield Council on Bioethics response
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Introduction

The Nuffield Council on Bioethics welcomes the opportunity to respond to the Department of Health and Social Care (DHSC) mental health and wellbeing plan: discussion paper and call for evidence.

Our response focuses on digital forms of mental health support and treatment, and on the values and principles that should underpin the new long-term mental health plan in relation to digital technology. Our response is informed by our recently published bioethics briefing note on the role of technology in mental healthcare and a series of engagement activities with experts by experience conducted in partnership with Rethink Mental Illness.

From this work, we think the digital aspects of the mental health plan should be underpinned by:

1. Equality and fairness in access
2. Autonomy and choice
3. Effectiveness and safety

1. Equality and fairness in access

As pointed out in the DHSC’s discussion paper, despite recent progress, a significant number of people do not have access to mental health support. Others are only able to access mental health services once they have reached a point of crisis. This is particularly true of children and young people. In December 2021, the Health and Social Care Committee reported that, in England, approximately 60% of children and young people in need of mental health support are currently unable to access mental health services.

Technology for mental health support has the potential to increase access to care, for example by helping to reach underserved population groups, those who find it difficult to leave their homes and those who do not feel comfortable in accessing in-person services because of the perceived stigma associated with mental health problems. Indeed, some people might prefer virtual support for several reasons. For example, some might feel less judged or embarrassed when disclosing their symptoms to virtual agents. Others find the experience of attending therapy sessions and group support meetings in hospital stress-inducing and tend to appreciate the possibility to access virtual support in the comfort of their homes.

In leveraging the power of digital technology, it is important to make sure that steps are taken in order not to exacerbate existing inequalities in mental healthcare. An increased reliance on technology for mental health support could lead to the exclusion of a number of population groups, such as those who cannot afford technology or find it difficult to use it, and those who do not have access to private or safe space, such as rough sleepers and victims of domestic violence. As highlighted by many of those who participated to our engagement sessions involving people with lived experience of mental health conditions, an increased use of digital
technology for mental health support could further widen the gap for those already left behind. For example, carers and those attending peer support groups reported seeing a deterioration in the mental health of others during the Covid-19 pandemic, as people struggled to access online support.

In this context, it might be helpful to organise sessions involving mental health professionals, carers, and potential users to show them how to use different technologies ahead of digital therapy sessions. For example, a participant to our engagement sessions, who runs support groups, found this method to be very effective in increasing access and building trust.

In addition, any focus on technology solutions should not divert resources from other important interventions, such as increasing social interactions or tackling the social determinants of poor mental health. This may impact the quality of support, as mental wellbeing depends on a number of intertwined factors, including social connectedness, housing, employment, and education.

2. Autonomy and choice

Access to technology, a safe and private space, and digital literacy are not the only barriers to digital mental health support. Many people are not comfortable with or not willing to access digital mental health services because virtual support simply does not work for them. It is important to recognise that technology does not always represent a good or a better solution for everybody, and that different people have different needs.

For some, virtual support may exacerbate feelings of loneliness, social isolation and a sense of disconnection from their community. As highlighted in our engagement sessions, patients who tend to isolate themselves often benefit from forms of intervention designed to encourage in-person human interaction such as community activities, peer, and group support. For those patients, virtual support could encourage further isolation and lead to steps backwards in the recovery process.

Other service users might find it very difficult to build a relationship of trust with health professionals without face-to-face contact. This could negatively impact patients’ clinical outcomes, given the importance of the therapeutic relationship for the recovery process.

Some service users are concerned that technological forms of support such as digital therapy might be imposed on them in the future. Throughout our engagement sessions, participants emphasised the importance of ensuring that patients have options about different forms of care, and are sufficiently informed to make decisions about the different options available to them. The benefits of emerging technologies will be limited if potential users are not provided with sufficient choice and control around their use.

3. Effectiveness and safety of digital interventions

Chapter 4 of DHSC’s discussion paper asks how the quality and effectiveness of mental health treatments can be improved. Digital technology could have a role to play in improving the effectiveness of some interventions. For example, smartphones, wearables, and other devices with sensors can be a source of a large amount of information about users' everyday life, including their habits, moods, and feelings. In the future, access to this information by mental health professionals could inform clinical decision-making and help tailor interventions to a patient’s specific needs, ultimately improving effectiveness. By linking patients and clinicians, apps and monitoring tools could also play an important role in certain settings, for example when transitioning from impatient to outpatient services.
While some technological forms of mental health support are proven to be effective in improving symptoms of mental health conditions, concerns have been raised about the lack of evidence supporting the use of some technologies. In our conversations with different stakeholders we heard that, despite having millions of users, many commercially developed apps have not undergone rigorous scientific testing. In addition, we found that when they have, they are often not accompanied by any follow-up studies to help determine their effects over time. As a result, it is often unclear to service users and mental health professionals whether an app is effective or not, whether it can deliver high-quality care and, importantly, whether it can cause harm.

Using digital forms of interventions that are not evidence-based could put users at risk. Interventions that are not proven to be safe could lead to a further deterioration in users’ mental health. Furthermore, interventions that are not adequately regulated may also not have adequate systems in place to respond to situations where users’ immediate safety might be at risk, with implications for safeguarding and risk-management.

Mental health technology involves the collection and use of extremely sensitive information. In this context, it is important to ensure that transparent data and privacy policies are in place. Trust in the sharing of data was a key theme during our engagement sessions. Many participants were concerned about the security and confidentiality of information about their or their loved one’s mental health states. Some expressed concerns with regard to the ability of individuals to provide informed consent for the use of their data, especially those who may not have sufficient mental capacity to make that decision. It is also important to ensure that these tools meet high security standards in order to protect users from the risk of cyberattacks targeting mental health service providers, given the devastating consequences that data breaches involving mental health information could have on service users.

Some mental health technologies, such as wearables and apps, are considered to be medical devices and are regulated by the Medicines and Healthcare products Regulatory Agency (MHRA). To qualify as a medical device, software, instruments and other tools must have a ‘medical purpose’. The same tool might not be considered a medical device in a different context. We welcome the recent clarification of the meaning and scope of the term ‘software’ in UK medical device regulations by the Government.

However, many mental healthcare technologies do not fall under the category of a medical device nor are in scope to be assessed for use in the NHS. The regulatory landscape for these technologies has been called ‘fragmented and not fully developed’ and there are calls for more work to help developers navigate the market. It will be important to involve service users, their family, and care professionals in the development of future regulation and research priorities to gain public trust and acceptability.