

How people with severe mental illness use technology to manage

"I love monitoring myself. I feel good when I'm doing it. But I feel like I've got some control and I can feel like I can see where problems are starting to come up or what I've done in the past where I could actually do better."

Julia, service-user



The problem

With methods such as computerised therapy proving effective in the treatment of mental illness, it is conceivable that digital health interventions such as apps, websites and wearables may offer support to people with Serious Mental Illness (SMI) in managing health behaviours and long-term health conditions.

Prior to this project, a small evidence base suggested that digital interventions are acceptable for use in people with common mental illness. However, little research had been done to evaluate the use of such interventions in the context of SMI.

We wanted to find out which interventions people with SMI are currently using to help manage their physical health, and whether these interventions are effective in meeting the needs of the population as well as how this may be affected by contextual factors. We also wanted to assess the barriers and facilitators to use, and whether there is any tangible impact on people's physical health and health service use.

What we did

We invited people with a diagnosis of SMI who were using South London and Maudsley NHS FT Community Mental Health Services to take part in the research study. The study consisted of three stages:

Online survey: 33 South London and Maudsley NHS FT service users took part in a brief online survey, in which they were asked about their use of digital health interventions, including which devices they used, what behaviours they used them for and a number of questions regarding usefulness and ease of use.

Interviews: 15 participants who had completed the survey took part in a face-to-face interview with a member of the research team. The interview questions were based on the e-health literacy framework and explored participant's experiences of digital interventions in greater depth, covering attitudes and opinions towards acceptability, usefulness, accessibility, and safety.

Stakeholder workshops: Five service users, four staff, two commissioners, two voluntary sector staff members and one carer took part in two workshops, where the results from stages one and stage two were presented and discussed to develop recommendations for digital health interventions.

The study was co-designed with two experts by experience who assisted with research design, development of survey and interview guide, ethical approval and interview analysis

Main findings

Stage 1

- › Participants were generally satisfied with their preferred digital health intervention (DHIs)
- › Devices were most frequently used for diet, exercise and weight management.
- › Over 54 different DHIS were named, the most frequently used included Fitbit, MyFitnessPal, Apple Health, Sleepio and Noom.

Stage 2

- › Participants preferred DHIs apps which were simplistic, passive and incorporated data syncing and sharing. Negative qualities included intrusiveness and lack of consideration for diagnoses.
- › Participants reported several benefits to using DHIs, including

increased autonomy of care, encouragement, positive routine and tangible improvements to physical health. On the other hand, participants noted that DHIs could also have negative impacts, including encouragement of toxic behaviours and potential demotivating qualities.

- › Participants had a strong appreciation of the link between mental health and physical health: the level of device usage and motivation to engage in DHIs could be directly affected by fluctuating mental health.
- › DHIs aimed at physical health also had potential to impact mental health both positively and negatively which should be taken into consideration both prior to and during usage.
- › DHIs were seen as a positive aid but could not replace clinical care. Participants valued devices as an accessory to care which facilitated self-management of their own health, without having to rely on their care team for information.

Stage 3 (Workshop Recommendations)

- › Participants were interested in having clinical guidance on what DHIs they could be using to manage physical health. They noted that DHIs should be an addition but NOT essential to care to avoid contributing to digital exclusion.

- › Service users, carers and clinical staff agreed they could benefit from further training or information about DHIs- perhaps through a popular apps list, or peer support networks.
- › There is a need for more research on a much greater scale.

What does this mean?

- › We've successfully addressed a gap in research by gaining an understanding of use of DHIs for physical health, by people with SMI.
- › We've learned that there is a real appetite for information about DHIs from a range of stakeholders, ranging from service users, clinical staff and commissioners:
- › Participants felt that they could be a realistic and scalable addition to help people with SMI better manage their physical health and expand the impact of support from health services
- › Service users were interested in knowing more about what devices are available, and were interested in having more devices developed with consideration to their specific needs and preferences.

Key learning

- › The sample size for the study was smaller than expected but that did not compromise the quality of the findings.
- › Using a variety of methods to collect data was valuable to help explore individual experiences and how these influence personal wellbeing.
- › Learning from participants we spoke to, was that all valued different features as important when using technology to support their wellbeing, for example:
 - › Easy to use
 - › Convenient
 - › Real-time reminders and advice
 - › Accurate and person-specific
 - › Encouraging
 - › Practicalities – set-up, syncing, remembering device
 - › Addressing concerns about data safety
 - › Showing or evidencing tangible improvement to health
- › Advice/Guidance for NHS staff – be aware of and encourage service users look into devices, list of popular apps to suggest.