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Guest Editorial

The digital divide in people with severe mental illness: lessons learned and challenges lying ahead

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Summary

In the post-COVID-19 pandemic era, a 'digital-first' agenda is being adopted in health/social care services, while digital exclusion has not been fully addressed. People with severe mental illness face profound inequalities at many levels (i.e. social, financial and health). Digital exclusion may further exacerbate some of these inequalities.

Keywords

Digital divide; severe mental illness; psychosis; bipolar disorder; digital exclusion.

The 'digital divide' is a form of social inequality referring to unequal levels of access to the internet, data and digital devices among groups of people in a given community. Those affected by the digital divide experience 'digital exclusion', a term describing missing out on the benefits provided by greater digital engagement, such as access to information and services. Traditionally, those more heavily affected by digital exclusion are the very same people requiring enhanced support from governments and societies. Vulnerable populations (e.g. ethnic/racial minorities, refugees, older adults, people with physical and/or mental health conditions, people on low incomes and those with caring responsibilities) are often disproportionally affected by digital exclusion.

People with severe mental illness (SMI; schizophrenia, psychotic disorders, bipolar disorder and depression with psychotic features) are a group of people facing profound inequalities at many levels, socially, financially and health-related. Apart from the complex and often debilitating symptoms of their mental health conditions, it is quite common to suffer from long-term physical illnesses and present high rates of obesity and health-risk behaviours (e.g. smoking, lack of physical activity) or experience loneliness. Complex interrelation between these health-hazardous factors leads to the point that people with SMI may experience a life expectancy 20–25 years shorter than that of people without SMI.[1] This suggests that people with SMI are in greater need of specialised health services and social support. Many of these services are currently undergoing significant digital transformation, exposing people with SMI to greater risk of digital exclusion, which may further exacerbate some of these inequalities.

Digital exclusion and its associated adverse effects is not a novel issue. However, during the peak of the COVID-19 pandemic in 2020–2021, digital exclusion of vulnerable populations resurfaced in the public discourse as a pressing and urgent matter. At that time, face-to-face service delivery restrictions were in place to reduce the spread of the virus, and health and social services widely adopted digital solutions to keep providing their vital services to those in need. Many aspects of daily life were digitalised at an unprecedented pace and scale. In a previous editorial we highlighted the risk of digital exclusion in people with SMI during the COVID-19 restrictions and urged all involved stakeholders (researchers, practitioners and policy makers) to join efforts in documenting, understanding and tackling this new (but also not so new) form of inequality. We predicted that many of the digital solutions that were implemented as contingency measures would become mainstream options after the pandemic. We also predicted that two contradictory scenarios were lying ahead: the pressing necessity for digital engagement during the pandemic would become a catalyst for increased digital access and skills, narrowing the digital divide. On the other hand, the pace of digitalisation would be so rapid that some people with SMI might not be able to catch up and would be left even further behind. As we gradually move into the 'post-pandemic era', we summarise below the developments that have happened in the meantime, the lesson learned and the new challenges that lie ahead.

Recent developments at the policy level reveal an emerging trend towards digital-first services as a strategic goal across the health and social sector. For example, the policy paper 'A plan for digital health and social care', released in June 2022 by the UK Government, discusses how the National Health Service (NHS) app is 'poised to become a "front door" to health and care services' and clarifies the government's support of the 'rapid uptake across the health and social sectors of [. . .] safe and effective digital products'. This trend seems to apply to mental health care as well, with £1.8 m awarded to the Medicines and Healthcare products Regulatory Agency (MHRA) and National Institute for Health and Care Excellence (NICE) to produce guidance on regulating digital mental health apps. The NHS Transformation Directorate issued a 'Mental Health Digital Playbook' outlining 18 case studies of NHS trusts across the country implementing digital tools and processes in their mental health services. It is encouraging that the 2022 policy paper recognises that an actions framework is needed to mitigate the risk for digital exclusion for those who might be unwilling or unable to access digital options.

In March 2024, the NHS released a framework outlining actions on five key domains: (a) increase access to devices and connectivity (e.g. through collaborations with other agencies and organisations); (b) offer technology that is accessible and easy to use (e.g. by considering the needs of people with physical, cognitive or communication impairments); (c) enhance skills and capabilities (e.g. by commissioning and providing training to NHS staff and the public); (d) build trust and positive beliefs (e.g. by conducting mixed-methods research to explore beliefs and trust and their impact on digital engagement); and (e) establish leadership and partnerships (e.g. working in partnerships with local communities in developing digital pathways).

To understand digital engagement of people with SMI and the impact of the COVID-19 pandemic, we collected data via a longitudinal survey of people with SMI across three waves roughly coinciding with three phases of the pandemic restrictions: From

July to December 2020 (intermediate phases of partial restrictions and second national lockdown),[2] from January to March 2021 (third national lockdown and intermediate phases of partial restrictions)[3] and from October 2021 to February 2022 (after the UK's 'Step 4', when most legal limits on social contact were lifted, had been implemented).[4] The survey was conducted over the phone, on paper via post or online, with the majority of participants completing the survey over the phone.

Based on responses of people who took part in all three waves, the proportion of people using the internet for their daily activities increased from the first to the second wave (from 65.8% to 80.8%) but reached a plateau at the third (from 80.8% to 84.9%). Although one might have expected that as we moved further into the pandemic more and more people would transition from offline to online out of necessity, our finding suggests a rapid initial trend, probably driven by those who had the foundations to do so, that gradually ran out of steam, showcasing that a sizable proportion were and remained offline. At the third and final wave, 42.5% still reported experiencing some form of digital exclusion (defined as being unable to do online something they wanted/needed because of lack of skills or access).

Roughly eight in ten in our sample had access to digital devices and an internet connection, suggesting that lack of means did not seem to be a main barrier. Encouraging as this might be there are two points of consideration: first, we do not know the quality/functionality of people's devices and connections. Second, around 20% still had no access to devices and internet connection. According to Office of National Statistics (ONS) reports on 'Percentage of home and individuals with technological equipment' released in August 2022, 93% of households in the general population have access to a digital device. In contrast, lack of skills came up as a major deficit when assessed with the Essential Digital Skills framework: 46.2% of the sample did not have the necessary skills to complete 'everyday life' activities, such as communicating, handling information or completing financial transactions online.

People's specific SMI conditions seemed to play a role. Across all three waves, people with bipolar disorder were doing better in terms of digital engagement indices compared to those with psychosis. The exact reasons for this difference remain unknown and should become the focus of future research explorations. Across all participants, the most commonly reported mental health problems acting as barriers to using the internet were concentration problems and depression, while positive psychotic symptoms such as hearing voices and visual hallucinations were among the least frequently reported.

Moving forward we believe that digital upskilling of people with SMI is integral to address the ongoing digital divide in this population. Similar endeavours are already being implemented in the USA, like the DOORS programme, a 6–8 week programme aimed at increasing smartphone use competency in people with SMI.[5] In our studies we found that greater internet knowledge was associated with greater e-health literacy, which refers to people's ability to find and understand health-related information online and apply this knowledge to self-manage their conditions. This is an important skill for people living with complex long-term health needs, both physically and mentally. We also found that the most common activities missed out by those experiencing digital exclusion had to do with important life administrative activities such as dealing with official bodies, ordering repeat prescriptions, making appointments and bookings and changing/communicating with utility providers. Such barriers may have implications for people's finances as well as health and well-being. Encouragingly, our data showed that 59.3% of the participants who self-identified a deficit in their knowledge were interested in learning more about the internet, showcasing that people understand the importance of enhancing their digital literacy and have the motivation to do so.

To our view these findings also highlight that the issue should not be seen to lie with individuals only, but also the lack of investment in local, regional and national support systems around digital skills and access, and their embedding in wider policy areas and agendas. Social support should also become an area of consideration as people often rely on friends and family to resolve digital challenges. Therefore, improving and facilitating sources of support should also be part of the wider solution to digital exclusion.

We suggest that future research on this area should focus on the following topics. (a) Understanding the specific needs of people with SMI, compared to other vulnerable populations as well as the general population, in reducing the digital divide. For example, we need to understand more about what drives the difference between people with psychosis and bipolar disorders in overall digital engagement. (b) Produce a more finely grained understanding of how people with SMI use the internet and digital devices and to what end, as well as how this relates to important health outcomes. (c) Design appropriate resources for digital upskilling training programmes tailored to the needs and requirements of people with SMI.

It is often argued that lessons learned from the COVID-19 pandemic should inform our responses to future health-related or other public crises to react in a more timely and efficient manner. We argue that the same applies to the lessons learned about digital engagement and digital exclusion. In their review on digital mental health applications during the pandemic, Torus et al[6] propose a clear potential for increased access and quality of mental health services in the post-pandemic era. However, they also provide a useful warning suggesting that 'developing programs like this one (referring to digital upskilling programmes), which ensures everyone is able to connect and receive care, many not have the attention-grabbing status like artificial intelligence and virtual reality but such programs are likely of more importance now more than ever'.[6] Amidst the rightful enthusiasm for novel digital solutions that may provide answers to long-lasting problems, we should not overlook the fact that digital illiteracy will amount to continuously increasing levels of exclusion and inequality and therefore should be addressed imminently.

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