How Lived Experience Expertise Shapes Research and Development in Digital Mental Health

A Review of Literature and Insights

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This report was primarily prepared on the unceded lands of the Wurundjeri people of the Kulin Nation, in Melbourne, Australia. We acknowledge their elders past and present.

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Table of Contents

At a Glance:

Report Insights and Implications

Context

This review addresses key questions about the perspectives, involvement, and practices for engaging people with lived experience in the development, implementation, and evaluation of digital mental health technologies.

This report presents findings from a review of scholarly and 'grey' literature and also expert interviews.

The findings and insights may support funding strategies and research practices, so that they better align with the needs and preferences of people with lived experience.

The study focuses on current and emerging forms of digitally-mediated support for people with lived experience of anxiety, depression, and psychosis, and how lived experience is and is not being embedded in research and development to develop these.

Current State

The report examines current practices for lived-experience engagement, partnership, and leadership in digital mental health research and development.

Key findings include a strong consensus among those with lived experience on the potential of digital technologies to support mental health support, emphasising the importance of supplementing rather than replacing in-person support.

Further findings address privacy and data protection concerns, peer support and social connection, and how digital support may best fit for people in their individual and social contexts.

This review finds that the involvement of people with lived experience has often been limited to assessing user experience and acceptance of digital approaches.

Few studies were identified that employed participatory, co-designed, and lived experience led approaches which were applied throughout the research and development journey.

The review did though highlight a small, but significant, body of literature and leading practices demonstrating engagement, partnership, and leadership of people with lived experience.

Moving Forward

The report outlines several best practices for lived experience engagement, including involving people in multiple research stages, ensuring projects are reflective and responsive to lived experience insights, supporting and compensating them appropriately, and striving for diversity and inclusivity.

Review recommendations centre around the need for projects to directly address the priorities and concerns of people with lived experience and to authentically integrate their expertise. The need to develop resources and supports to enhance capacity for meaningful lived experience and leadership is also explored.

The report particularly highlights the importance of digital technologies supporting holistic approaches to care, and the potential for digital tools to increase individuals' agency and social connection in their broader communities.

Authentic and meaningful involvement of people with lived experience is essential for the further development of effective and ethical digital mental health technologies. Integrating their perspectives and expertise throughout the research process is crucial for addressing the diverse mental health needs of populations worldwide.

Executive Summary

About this Report

Wellcome commissioned this review to better understand the involvement of people with lived experience in the development and evaluation of digital mental health technologies, ahead of launching a funding call on scalable digital mental health.

This review draws on document analysis and expert interviews to answer three core research questions:

1. What are the perspectives and priorities for research of people with lived experience on digital mental health technologies?
2. What has been the involvement of people with lived experience in the design and development of digital mental health technologies?
3. What are good practices regarding lived experience involvement in digital mental health technologies?

Supplementary questions included:

- What should researchers and others do to effectively engage and conduct research with people who have lived experience in the digital mental health context?
- From lived experience perspectives, what criteria and requirements should funders expect from researchers wishing to research and develop digital mental health technologies?

This review is specifically focused on the involvement of people with experience of **anxiety, depression, and psychosis**.

This review is based on:

- a literature review of scholarly literature, encompassing nine prominent databases, which returned 5,434 studies that we narrowed to 50 studies that met our selection criteria;
- a grey literature review, including a search of three grey literature databases and advanced Google searches, resulting in 19 texts that met our selection criteria;
- Interviews with 11 key lived experience experts, across commercial, academic, policy, and advocacy settings.

This review examines the views of people with lived experience on digital mental health technologies, including studies concerned with how those individuals are contributing – and in some cases, leading – research and development of digital mental health technologies.

For the scholarly literature review, we sought to undertake a comprehensive review of studies drawn from a range of different disciplinary backgrounds and experiences. However, the review cannot claim to be exhaustive. For example, time and language limitations prevented a more expansive inquiry to material published in languages other than English.

This review offers valuable research and engagement insights which may ensure digital mental health technologies can improve the lives of those they are meant to assist.

Defining 'Lived Experience' and 'Digital Mental Health Technologies'

'**People with lived experience**' is a term used throughout this report in line with recent work by the Wellcome Trust, in which 'lived experience' is defined as follows:

> We understand lived experience as a unique form of knowledge, insight and expertise, that comes from having experience of mental health challenges. When we refer to 'people with lived experience' or 'lived experience experts', we are referring to people who identify as having experienced anxiety, depression and/or psychosis (broadly defined), either in the past or currently. They do not need to have received a diagnosis (Wellcome Trust, 2023, 2).

We acknowledge that terminology can be contentious in the mental health context, and that different terminology is used globally.

The term '**digital mental health technologies**' is defined in this report as:

digital technologies used to assist with diagnosis, prognosis, targeted prevention, treatment, relapse prevention, maintenance of treatment effects, or monitoring of: depression, anxiety and psychosis. The intervention may be standalone or an adjunct to other treatments. The intended location of the tool can be in healthcare, home, school, workplace. The end user of the tool may be the individual or a mental health practitioner.

Lived Experience Perspectives and Priorities

People with lived experience mostly agree that there is a role for digital technologies in providing support and care in the mental health context. Many people are already using digital technologies to support their personal and social needs in ways that improve their mental health.

Although not all studies explicitly asked people with lived experience what they would prioritise in research and development agendas, the following issues were raised repeatedly.

People with lived experience want digital mental health that:

- *add* to existing face-to-face contact in care and support, rather than replacing it (even as standalone technologies may help);
- are worthy of trust regarding their privacy, data protection, safety, and security;
- can facilitate access to peer support;
- can potentially facilitate social connection;
- promote agency and choice, and humanise those who use them; and
- can be personalised and customised, offering choice in the support options available.

Other notable points:

- Some people prefer technologies that are not presented as mental health specific. This includes supports and solutions which use the language of 'wellbeing' and also where cultural framings of distress are integrated;
- Some people are attracted to monitoring technologies that allow themselves and mental health practitioners to monitor aspects of their lives and improve understanding.
- Others disagree and are averse to monitoring technologies. They are concerned monitoring is intrusive and an affront to dignity and privacy.

This diversity of viewpoints underscores the earlier point about people needing choice about which, if any, technological options are used.

People with lived experience call for an approach to research and design in which engagement is at the heart of planning, design, delivery, evaluation and oversight of the technology.

Involvement of People with Lived Experience

The involvement of people with lived experience in the design and development of digital mental health technologies appears overwhelmingly to have focused on user experience and acceptance of specific technologies. Often this is assessed quantitatively, such as through usage statistics and survey responses.

Only **a very small minority of studies in the original search results appear to have involved qualitative research and participatory methods to engage lived experience perspectives**.

One of our selection criteria was to exclude research that did not provide ‘rich qualitative insights’ into lived experience viewpoints on digital mental health. For example, user experience and acceptance studies that tested mental health-related apps were generally excluded. This latter material appears to constitute the bulk of literature in digital mental health technology research that involves – in any way – people with lived experience.

This material overwhelmingly offered little or no qualitative insight into the views of people with lived experience on the topic.

Taking a highly conservative estimate, we estimate **that only 7% of studies that involve people with lived experience in *any way*, involved qualitative research to capture lived experience viewpoints.** This is a highly conservative estimate, based on the 50 selected papers as a percentage of the 707 papers that we included in the early screening steps because their title or abstract suggested *some* lived experience input.

These 707 papers in turn, would be a small subset of research on digital mental health technology more broadly. The percentage of studies involving these qualitative insights within the *broader literature* on digital mental health technology is likely to be much lower. Studies that used methods of ‘co-design’, ‘co-production’, and ‘co-generation’ methods, are likely to be an even smaller percentage still.

Within the studies that *were* **focused on the qualitative views of people with lived experience, the authors used methodologies described as ‘participatory’, ‘community-engaged’, ‘inclusive’, and ‘co-designed’**. **These papers were often led or co-led by persons with lived experience.** Good practices arising from these studies are defined in the next subsection.

Terminology and definitions used to describe different and similar engagement approaches can differ. As we shall discuss, norms of ‘co-design’ and other approaches that promote high levels of engagement or leadership by people with lived experience do not appear to be well established, nor are they always uniformly reported upon with depth, reflection and transparency.

This can mean that two studies that purport to be ‘co-designed’ might have highly variable amounts of lived experience involvement. This lack of clarity can make it hard to identify the level of lived experience involvement in a given study, and it may make it difficult for researchers, new and experienced, to determine what good practice actually looks like.

Studies saw persons with lived experience engaged using varied practices. This included as research participants, as interviewees, as survey respondents, as members on advisory groups, as participants in design workshops, as peer researchers and as lived experience researchers and leaders. Some were included as co-authors in publications and outputs.

Based on the literature and insight analysis, we observe:

- Imprecise and inconsistent use of language to describe levels of lived experience involvement, and the methods used (for example, the term ‘co-design’ was used in multiple, and sometimes conflicting, ways). *This suggests confusion in the field about how lived experience perspectives can guide research, and makes it hard to raise standards in the sector and judge when co-design methods are ‘better’ than others. Community-views and end-user involvement is, as one study proposed, ‘pivotal in shaping the acceptability and safety of interventions’* (Fowler et al., 2023, 2705)

- Researchers in some cases, do not appear to address power imbalances between researchers and people with lived experience, including imbalances in relation to clinicians and other mental health professionals, but also computer programmers, designers, and similar professionals. *Acknowledging power imbalances can help ensure research is ethical and respectful, protecting participants from harm, and allows researchers to implement strategies that minimise the impact of imbalances, thereby enhancing the validity and reliability of the data collected or the commentary offered.*

- Limited efforts to seek a broad or representative sample of people with lived experience. For example, demographic diversity data was not always reported, and research participants were often recruited from those already using the digital platform (which can overlook the hidden denominator of people who do not seek or cannot access digital modes of care). *Seeking a broad or representative sample of people with lived experience ensures that the findings of the research can be generalised to the wider population, reduces bias, and improves relevance and appropriateness.*

- Lived experience of research team members or authors was not explicitly designated. *Some scholars argue that promoting lived experience leadership in the authorship team is a practice that enhances the research's relevance, integrity, and impact, though the standards and norms for doing so remain somewhat unsettled* (Hawke et al., 2022).

Good Practices in Lived Experience

The review reveals several good practices where digital mental health can be developed and evaluated in a way that is inclusive and respectful of lived experience perspectives and expertise.

Examples included people with lived experience as equal partners in helping define the problem, creating digital mental health content, identifying outcomes of interest, modifying research questions, identifying research sites, assisting researchers in hiring, training, and managing people with lived experience, and assisting with dissemination of findings.

Good practices identified included:

- **Research and development is relevant to lived experience needs and preferences**: The research agenda or questions were developed with people with lived experience. The research themes were important to people with lived experience, such as getting the right balance in 'blended' support models, ensuring person-centred approaches, and respecting privacy and confidentiality (Hollis et al., 2018; Veldmeijer et al., 2023).

- **Engagement with people with lived experience occurs throughout the research and development journey:** Lived experience engagement is embedded throughout the research process from shaping early ideas to knowledge translation (eg, Fortuna et al., 2019).
- **Reflective practices support adapting and learning in lived experience engagement activity**: Projects should include reflective practices to evaluate the role and impact of lived experience throughout the research process, with a focus on continual learning and adaptation (eg, Bennett-Levy et al., 2021; Bond et al., 2023; Buus et al., 2019).
- **Lived experience engagement where decision making is clarified and power is transparent:** Projects should clarify decision-making power when adopting methods of co-design, co-production, co-generation, and so on. Doing so can clarify to all involved who is responsible and accountable for which decisions and actions, identifying opportunities for lived experience leadership and cocreation, identifying limits or restrictions the project might have, and undertaking efforts to mitigation of challenges surrounding power balance (e.g. Schouten et al., 2022).
- **People with lived experience are appropriately supported and remunerated.** People with lived experience were appropriately supported and fairly compensated for their involvement in research projects (eg, Gan et al., 2023; Peck et al., 2020).
- **Diversity and inclusivity drives lived experience engagement activities**: Research sought to acknowledge and incorporate diverse lived experience perspectives to capture a broad spectrum of insights (Bergin et al., 2020; Oguamanam et al., 2023; Ospina-Pinillos et al., 2019; Povey et al., 2016).
- **Lived experience activity is reported and acknowledged in knowledge translation**: lived experience activities and contributions are shared in outputs and publications, with appropriate acknowledgements and authorships. People with lived experience contribute to broader knowledge translation and greater transparency of lived experience activity in research and development (Fortuna et al., 2019; Fowler et al., 2023).
- **Lived experience engagement is systematic, building on appropriate frameworks and models.** Arranging research activity within frameworks, standards, and lived experience models such as action research, peer research and co-design (Fortuna et al., 2019; Ospina-Pinillos et al., 2019; Patrickson et al., 2023; Schouten et al., 2022). Regardless, research and design approaches should involve participants as partners and decision makers and report on collaboration in a systematic and clear manner (Veldmeijer et al., 2023). Reporting frameworks such as GRIPP2, a standardised reporting framework to improve reporting of patient and public involvement in research, may be helpful (Staniszewska et al., 2017).
- **Engagement activity builds and empowers leadership and builds capabilities and capacities**: Good practices involved encouraging and facilitating leadership roles for people with lived experience within research projects which can empower these individuals and enrich the research with their unique insights (Carr, 2020; Chiauzzi & Newell, 2019; Patrickson et al., 2023; Strauss et al., 2019).

Is the Digital Context Unique?

Is engaging lived experience in the digital mental health context different from general mental health research?

Similarities with General Mental Health

Some of the main priorities for research do not substantially differ between digital-specific versus mental health research more generally.

The literature we examined generally promotes partnership with and leadership by people with lived experience—a call that is similar to the broader mental health research field.

This call generally involves a push for researchers to pursue phenomenological or priority-setting research in the development of research questions and digital interventions.

Other similarities include calls for services that are safe and effective; tailored to their cultural, economic, and social circumstances; and accommodated for a diversity of lived experiences.

Unique Aspects of the Digital Context

There are several unique features in the ecosystem of digital mental health technologies.

Compared to wider mental health research there are many **new** researchers and players in digital mental health research and development. This especially includes innovators in the not-for-profit and commercial sectors. Their approaches can feel very different to mental health research in more academic contexts.

Three other differences standout:

1. **Integration of technology-specific features**

In digital mental health, there's a particular interest in exploring and ‘optimising’ technology-specific features like gamification, real-time monitoring, and personalisation. These aspects don't have direct counterparts in non-digital mental health research, requiring new technical expertise and raising different conceptual issues.

For example, how is data given value? Is there an optimal balance between technology that can be adapted by individuals and communities, yet also remains standardised and scalable?

There are also questions about how such technologies are to be governed and who decides where digital approaches should, and should not, be used.

Finally, the question remains open about the appropriate and acceptable role and place of technological solutions compared to face-to-face human connection and support.

2. Concerns over privacy and data protection

While confidentiality is a concern across all mental health research, it takes on new dimensions in the digital realm.

People with lived experience express specific concerns about the privacy and security of their data in the digital context, especially given increasingly complex information ecosystems.

3. Accessibility and digital literacy:

The ‘digital divide’ becomes a significant issue in the context of digital mental health technologies.

People with lived experience point out that research needs to address barriers related to accessibility and digital literacy to ensure that these technologies can benefit everyone, especially underserved populations.

Recommendations

Lived experience engagement can, and should, be a core part of building the evidence base across digital mental health research and development. Yet, despite some good practices, presently there is a lack of established norms for ensuring high quality lived experience engagement, partnership, and leadership in research on digital mental health technologies.

Based on both the literature review and the interview analysis, we make the following recommendations to advance lived experience engagement in digital mental health research and development.

We have divided Recommendations into three categories: **Priorities**, **Principles**, and **Practices**.

We have also included alongside these Recommendations several **Reflective Prompts** which may assist researchers and developers working on digital mental health technologies to centre the perspectives and priorities of people with lived experience:

PRIORITIES in digital mental health research and development

These recommendations address strategic research and development priorities in digital mental that this review has identified as important and that deserve greater attention.

Recommendation 1: Priorities of People with Lived Experience

We recommend that researchers and developers in digital mental health should focus on issues which are prioritised by people with lived experience.

This review identified several such priorities. People with lived experience seek digital mental health technologies that:

- are worthy of trust regarding their privacy, data protection, safety, and security;
- can, in some cases, facilitate access to peer support;
- facilitate social connection.
- promote agency and choice, and humanise the people who use them;
- are designed with attention to equity across the diversity of lived experience perspectives.
- add to existing face-to-face contact in care and support, rather than replacing it;
- aligns with broader lived experience practice and principles in non-digital spaces; and
- can be personalised and customised, offering choice in the support options available.

This list is non-exhaustive and other priorities may emerge through agenda setting research with people with lived experience.

For further detail on these priorities from people with lived experience, see the Executive Summary.

Reflective Prompts
How have you considered the role in this digital mental health activity of people with lived experience, communities, users, and potential users?

Have you familiarised yourself with broader efforts in mental health research to ensure that the perspectives of people with lived experience are guiding or leading research priorities?

Recommendation 2: Prioritise Gaps in Research and Development

We recommend that researchers and developers should address several thematic gaps in research and development including:

- best practices for involving people with lived experience in foundational and priority setting research and development.
- greater engagement of people from low and middle-income countries.
- embedding lived experience perspectives and engagement in the activities of those outside academic settings such as not-for-profit and commercial actors developing tools and solutions.

Reflective Prompt
Have you sought assurance that your research on digital mental health is of demonstrated relevance to people with lived experience? These priorities may be articulated in existing research on what people say they want, or more currently in the work of representative organisations and advocacy organisations.

Recommendation 3: Prioritise Privacy and other Ethical Concerns

We recommend that researchers and developers engage individuals with lived experience in discussions about privacy, data security, and other ethical considerations specific to digital technologies. This includes exploring not just consent processes for data collection, but also establishing norms of data use, working out what types of data are valuable and why, and promoting accountable use of automation more generally.

Lived experience input is also needed in the ethical development and deployment of artificial intelligence (AI) and automation within digital mental health tools. Research and development should address community concerns related to empathy, human connection, and the potential risks associated with automated decision-making in mental health care.

Reflective Prompt
How will you establish lived experience engagement which explores and supports the ethical and acceptable research and development of digital mental health support? Especially consider what inclusive approaches are required to respond to existing and emerging concerns around privacy, automation, and artificial intelligence which may be barriers to adoption and use.

PRINCIPLES in shaping lived experience engagement in digital mental health research and development

These recommendations address the need for researchers, developers and organisations to consider more deeply lived experience principles which underlie their activities and ways of working.

Recommendation 4: Authentic Lived Experience

We recommend that digital mental health research needs to go beyond user acceptance and experience of tools. Researchers and developers should consider what authentic and embedded lived experience engagement looks like in their contexts and what efforts are needed to go beyond tokenistic engagement.

Authentic engagement requires researchers and developers to clearly consider the purposes of engagement and especially the impacts on shared power and decision making. Authentically embedding lived experience expertise may especially include supporting and resourcing designated lived experience researchers and leadership, who then become part of a research team.

Principles of authentic engagement will need to be clear and transparent to communities, to other research teams and other stakeholders.

Reflective Prompt
Have you considered ways to reflect on decision making and power dynamics between people with lived experience and researchers during the proposed research? What plans might be made to acknowledge and address these opportunities and challenges?

Recommendation 5: Engagement all through the Research and Development Journey

We recommend that opportunities for lived experience engagement are considered, assessed, justified, and resourced throughout the research and development journey of digital health approaches. Effective engagement especially means clearly considering the purposes of engagement and appropriate methods at different stages.

In the digital mental health context, this means a shift towards defining the problem and more foundational planning with lived experience expertise. More engagement activity which includes assessing lived experience needs and gaps would be valuable. These activities may draw on formal and informal methods and processes such as advisory panels, deliberative and priority setting methods, on deeper and ongoing engagement with communities and lived experience leadership and also by undertaking and sharing relevant qualitative research.

Broader engagement opportunities throughout the journey also include feasibility studies, pilot testing and validation, design specification and prototyping, user and community centred design. There are opportunities for greater lived experience engagement in implementation and deployment, in co-evaluation, in lived experience input into regulatory compliance and ethical considerations and for lived experience expertise to be part of in sharing insights and knowledge translation.

Reflective Prompt
Have you considered the role of lived experience in different stages of this research, such as research question formation, study design, data collection, analysis, and reporting?

Recommendation 6: Diverse and Inclusive Design

We recommend greater emphasis on the need for digital mental health research and development to actively include diverse perspectives across foundational research and agenda setting, design, development, implementation and evaluation processes.

In particular for digital health, this means considering, from the outset, what principles are required to ensure the needs and views of underrepresented and marginalised groups are included.

This requires strategic thinking and planning around what adaptation is required for ‘mainstream’ approaches so that they are accessible, relevant, and safe for more diverse communities and individuals. Separate engagement efforts may be also required to develop tools and supports for diverse communities who may not find mainstream approaches accessible or culturally appropriate.

We recommend that lived experience practices specifically address accessibility challenges which may be unique to digital or part-digital approaches. This goes beyond considering key user interface design and navigability to include people with varying levels of digital literacy. This is crucial for making digital mental health technologies inclusive and accessible to all.

Reflective Prompts
Have you considered ways to integrate a diversity of lived experience perspectives, including reflecting diverse demographics (according to a range of social determinants), as well as diverse views on matters of mental health and the use of digital technologies?

Have you considered the needs, possibilities, and importance of such inclusion in different aspects of research, including as research participants, advisers, members of the research team, and decision makers?

Have you identified what digital specific challenges exist which are impacted by varying levels of digital literacy and accessibility and how will engagement with people who have lived experience address these?

Recommendation 7: Principles and Frameworks for Digital Mental Health

We recommend that researchers, developers, and organisations deeply consider how their engagement activity can and should be informed by frameworks, standards, and lived experience models.

There is a diversity of principles and frameworks already available to practitioners such as participatory action research, peer research, and co-design. There are multiple lived experience engagement frameworks already available and also opportunities to adapt and shape such material to organisational needs and specific contexts in digital mental health.

Those lived experience principles and frameworks which are developed and adopted also need to be convincingly demonstrated in engagement practices.

Reflective Prompt
Have you explored and considered specific models of engagement, partnership, and collaboration and have you explained and justified how your engagement approach is appropriate in a proposal for research and development in digital mental health?

PRACTICES in lived experience engagement in digital mental health research and development

These recommendations address specific practices in lived experience engagement relevant to research and development of digital mental health technologies.

Recommendation 8: Reflective Practice in Digital Mental Health

We recommend that researchers and developers adopt and develop good practice models which promote reflection and learning in lived experience engagement.

This may include reflective practices assessing how engagement influences the design, implementation, and adoption of digital technologies. Such practices and tools may promote reflection around the impact of lived experience engagement and how decision making occurs when lived experience is embedded (e.g., Fortuna et al., 2019).

In the digital mental health context, this especially means building in and resourcing such reflective practices and learning opportunities. This means supporting teams who may be experts in digital, design, and clinical areas, to work together and grow their practice in how lived experience is effectively embedded in research activity.

Reflective Prompt
How will you support reflective practices and learning in research and development of digital mental health supports so that lived experience inputs are acknowledged and utilised and that they impact ways of working?

Recommendation 9: Support Collaboration, Partnerships and Lived Experience Leadership

We recommend researchers and developers take steps to support and promote lived experience leadership in the digital context.

In the broader field of mental health research, the number of people with lived experience who have specific interests and expertise in digital contexts may be limited. There are significant opportunities to build and support lived experience leadership with a specific focus around contributing to digital mental health initiatives.

Lived experience contributions and leaders need to be fairly compensated and payment systems and processes should be reviewed so they are transparent and effective.

Researchers, developers, and funders may also need to develop resources and training which supports successful collaboration with people with lived experience in the digital context.

In digital contexts there are opportunities for researchers and developers to build and support more collaborative partnerships with people with lived experience and their networks and representative organisations.

Reflective Prompt
Have you considered how such lived experience engagement will need to be supported including education and training, financial reimbursement, employment opportunities, and lived experience leadership and mentorship? Is this reflected in your proposed budget?

Recommendation 10: Knowledge Translation and Insight Sharing

We recommend a greater focus on sharing and reporting what lived experience engagement looks like in digital mental health. Much of the current reporting in the literature is limited or cursory in how lived experience is discussed.

Opportunities and plans could be included to communicate such learnings and share, both internally and externally, what has worked well, and what can be improved in lived experience engagement (e.g., Bennett-Levy et al., 2021; Bond et al., 2023; Buus et al., 2019, Veldmeijer et al., 2023).

Reporting frameworks such as GRIPP2, a standardised reporting framework to improve reporting of patient and public involvement in research, may be helpful (Staniszewska et al., 2017)

It is important that specific contributions of people with lived experience to digital mental health research and development are consistently acknowledged and that appropriate authorship is also considered and included.

Reflective Prompt
What specific strategies and actions will you take to involve people with lived experience to support knowledge translation, including the consistent and appropriate acknowledgment of contributions and especially the wider sharing and discussion of lived experience practice and impacts?

Background and Methodology

Background to Review

Digital mental health services have expanded rapidly throughout the world, particularly since the COVID-19 pandemic. Public demand is increasing, and the expanding range of digital mental health technologies has been driven by largescale public and private investment (World Economic Forum & Accenture, 2019). In 2021, digital startups focused on mental health reportedly attracted over US$5 billion in venture capital—more than double that for any other medical issue (CB insights, 2022).

To take just one type of technology – apps – there are reportedly around 30,000 mobile apps concerned with mental health available today (Chiauzzi & Newell, 2019). Yet, the growth of apps does not necessarily equal increased efficacy. Simon Leigh and Steve Flatt characterise the range of mental health apps as suffering from a 'frequent lack of an underlying evidence base, a lack of scientific credibility and subsequent limited clinical effectiveness' (Leigh & Flatt, 2015).

Another systematic search by Amit Baumel and colleagues, reported that only 4% of mental health users continue using mental health apps after two weeks, and 'continued use' is measured merely by opening the app (Baumel et al., 2019).

More recently, some promising evidence about the efficacy of a select number of apps is emerging (Linardon et al., 2024). Based on our review below, we would suggest that one key gap is that digital interventions are seldom rooted in lived experiences.

There are some exceptions to this trend, and some apps and other technologies most certainly have their genesis in the lived and living experiences of a portion of the founders. However, amid the increased interest in digital mental health technologies, the views of people with lived experience of mental health services appear to have been generally overlooked in foundational research (Gooding & Kariotis, 2021). This report brings those views to the fore.

Scope of the Review

Defining Digital Mental Health Technologies

To elaborate briefly on our use of the term **'digital mental health tools/technologies'** (defined on page 6), this term can be understood quite broadly.

Some practices may use contemporary computational technology to process large amounts of data and analyse it algorithmically—described variously as artificial intelligence (AI), machine learning, 'neural networks', predictive analytics, 'deep learning', natural language processing, robotics, speech processing and other forms of automation, that are used for the purposes of making decisions (Castelluccia et al., 2019).

Other technologies are simpler forms of computational technology, such as electronic records management software, and online-counselling platforms.

There are various uses for digital mental health technologies in the direct provision of mental health care. The following diagram provides one way to categorise the way technologies are changing mental health services.

Figure 1 Technologies transforming mental health (adapted from State of Victoria, 2018, Vol 5. fig 34.2, p.18).

In addition to these technology *types*, there are diverse *functions* enabled by digital technologies. Some technologies or tools will have multiple, overlapping functions depending on how they are configured.

Functions for digital mental health technologies within mental health services include:

- **Communication** – such as telehealth, which provide an online or phone-based interface through which clinical or social support communication can occur; and language and accessibility support (which could be valuable for people who benefit from a remote translator, or who require an assistive person to join them via videocall).

This category is largely outside the scope of this report. Using videoconferencing software to deliver services that would be otherwise face-to-face, for example, would not be included. There may be occasions where this type of technology remains in scope, such as where a chat service uses AI to analyse the written material of users and provide professional decision support to therapists.

- **Information Sharing –** this category typically refers to the sharing of electronic health records, but also service user records, collaboration platforms, and diagnostic support. This could include streamlining workflow where certain matters can be shared more quickly.

  This category is generally outside the scope of this project.

- **Professional Decision Support** – this category includes presenting data in a certain way to aid professionals with decision making, providing alerts and prompts for professionals, and making decisions without expert input, including during training.

- **'Digital Therapies'** – refers to the use of digital technologies as a treatment, such as mobile apps prescribed by doctors; chatbots in efforts to mimic a therapeutic encounter; virtual reality or 'VR'; and 'gamification'.

- **'Bio-informatics' and 'Personalised' Medicine –** these technologies involve the generation and analysis of 'Big Data' concerning a person's genes, environment and lifestyle for the purposes of medical treatment.

- **Patient and/or Population Monitoring and Surveillance** – this category involves the tracking of individual health or crisis information or population health information over time. Data analytics, for example, could be used in: efforts to identify people or communities at risk of suicide or psychosis (Corsico, 2019; Marks, 2019), behavioural sensing or digital phenotyping, 'digital pills' used to monitor medication compliance, or Global Positioning System (GPS) monitoring of forensic psychiatric patients.

- **Service User and Citizen Informatics –** this category of technology supports service user actions within social services, health systems and other services, including via personal health records or service user decision aids.

  There may be occasions where this type of technology remains in scope, but this category is generally outside the scope of this project.-

These categories are not necessarily discrete and may overlap, which makes it difficult to definitively rule out any particular category for analysis.

Further, there may be other ways of describing ways technologies are transforming mental health.

The categories we note are generally framed in relation to health care systems. Other ways of categorising may be helpful, particularly given such technologies are appearing *outside healthcare services*, including in social security (e.g., streamlining support claims, but also potentially imposing punitive conditions on people with lived experience), criminal justice agencies, online advertising firms, insurance companies, education settings, employer hiring practices, and employer assistance programs (Bossewitch et al., 2022; Gooding, 2019).

Elevating Lived Experience Perspectives

The terms of reference required this review to emphasise specific literature and insights where people with lived experience were involved and engaged in research and development of digital mental health. There are several rationales for focussing on current evidence of where lived experience perspectives are being elevated in such activity.

Briefly, these are:

- **Human Rights Support:** The Convention on the Rights of Persons with Disabilities advocates for active involvement of persons with disabilities, including in research (see preamble (o), Article 4(3)).

- **Pragmatic Reasons:**
    - Reducing biases in evidence-based medicine;
    - Enhancing patient and carer perspectives in research; and
    - Addressing power imbalances and focusing on those unable to access care (Greenhalgh et al., 2015).

Increasingly, lived experience expertise has been encouraged in health research by government funders such as the UK National Institute of Health Research (INVOLVE, 2012), the US National Institute of Mental Health (1998), and the Australian National Health and Medical Research Council (2016).

This trend in public research funding is also reflected in scholarly research, such as the Lancet Psychiatry facilitating transparent reporting of lived experience work (Davis et al., 2024). According to Brett Scholz (2024), this move 'answer[s] the calls of people with lived experience and their allies for recognition of the meaningful contributions made by lived experience leadership'.

Two authors of this report identify as lived experience researchers. They both bring academic and research skills into this analysis and review.

Panos Karanikolas is a consumer researcher and draws on their experience with mental health services and academic background in law.

Ian Muchamore is a public health researcher with a lived experience who has previously worked in lived experience roles in mental health support roles with a strong digital focus and he also currently co-chairs an Australian network of lived experience researchers across Australia (see https://alivenetwork.com.au/our-research/lived-experience-research-collective/).

Much of the grey literature listed in **Appendix B** includes lived experience led or engaged work. For example, the Australian government developed 'National Safety and Quality Digital Mental Health Standards' (Australian Commission on Safety and Quality in Health Care, 2020a). Of the three principles for accreditation of digital mental health technologies under the standards, one is partnering with mental health service users, requiring evidence of their input into design and development (Australian Commission on Safety and Quality in Health Care, 2020a, p. 20).

There were also lived experience-led initiatives such as the 'InnoWell National Community Consultation Program (NCCP)', which is described by Sue Muller as a 'lived experience led community consultation that uses both digital and face-to-face strategies to engage with individuals with a lived experience of mental ill health and their support networks' to help build and implement a digital mental health platform. Muller's report is not formally peer reviewed, but it seemed important to acknowledge this type of work and to include relevant grey literature throughout this Review.

Section One: Literature Review Analysis

Methods

A scholarly literature review was conducted using an adapted scoping review methodology. Full details of methods are presented in **Appendix C**.

Briefly, we drew on elements of the Joanna Briggs Institute scoping review methodology (Peters et al., 2020) and PRISMA extension for scoping reviews (Tricco et al., 2018) to identify studies and review articles that addressed our three core research questions (see p5).

Literature Search

English-language peer-reviewed literature published from Jan 1 2013 to 30 Jan 2024 was searched using search strings in keyword fields, or abstract and title fields across nine databases to identify studies of digital health technologies that included people with lived experience. Full search strings and database details are presented in **Appendix C**. Additional literature was identified from reference lists.

The search yielded **4,850 relevant peer-reviewed research studies and reviews** after duplicates and retracted studies were eliminated.

Study Selection

Literature was assessed using inclusion and exclusion criteria (detailed in **Appendix C**). Studies and review articles were included if they concerned digital mental health technologies and included the qualitative insights of people with lived experience. Studies were excluded if they focused on other health conditions, including eating disorders, or if there was unclear or insufficient lived experience input. The PRISMA diagram in Figure 1 sets out exclusion process. A total of 50 papers met the inclusion criteria for the qualitative synthesis and are listed in the references section, and in an annotated bibliography in **Appendix A**.

Diversity and Inclusion

One criterion for inclusion was research ‘particularly of lived experience perspectives that are often overlooked’ from both the global South and North.

We sought literature that reflected intersectional lived experiences across multiple domains and life experiences. Factors considered included gender, ethnicity, race, education level, socio-economic status, and sexuality.

We sought out any specific examples which directly address engaging communities and individuals in solutions and research concerning digital mental health services, practices, and so on.

Literature Analysis

An initial deductive analysis of the abstracts was conducted and several key themes identified. Full text of the papers was examined to determine how lived experience views were gathered, discussed, and presented.

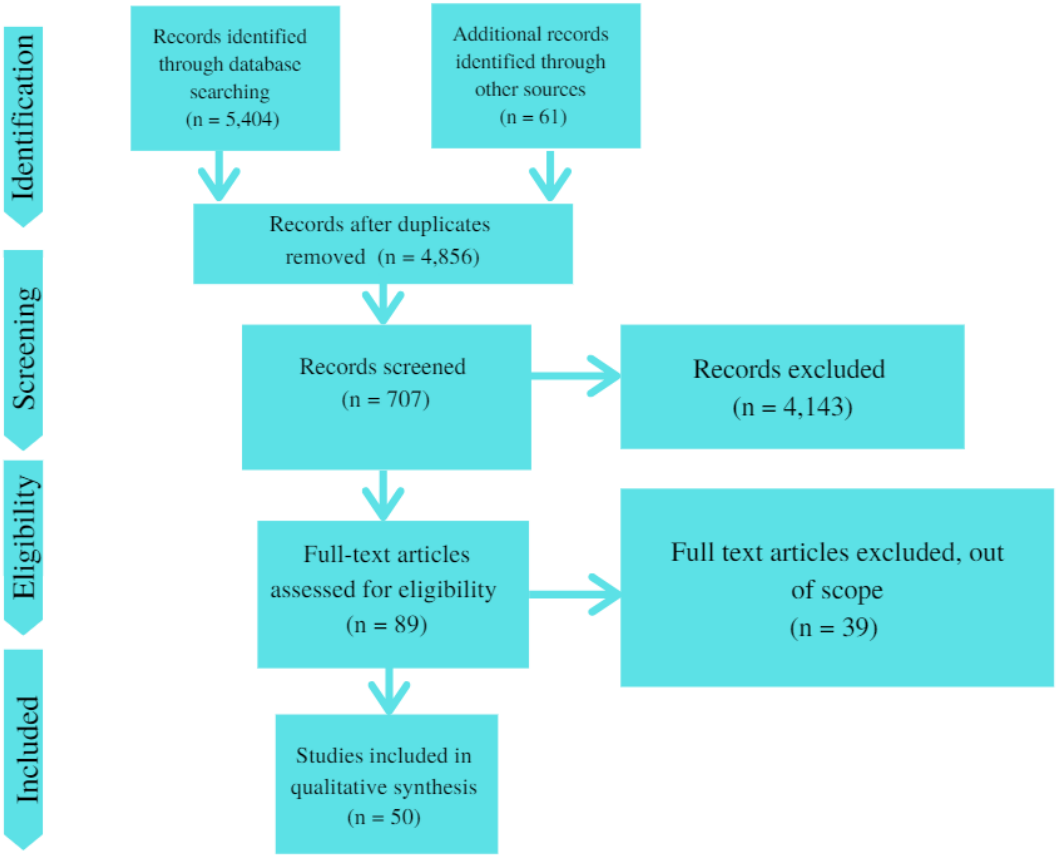
Supplementary Grey Literature Review

19 additional documents, including research papers by service user organisations and commercial entities, higher degree research dissertations, government policy documents, blogs, and activist reports relevant to this review were identified. This ‘grey literature’ spans theoretical work, guidelines, user experiences, and ethical considerations.

An annotated table of notable grey literature materials and a brief account of our streamlined review method can be found in **Appendix B.**

The grey literature was not included in the thematic analysis as it does not contain peer-reviewed primary data. However, we occasionally refer to relevant grey literature to supplement observations about themes emerging from the scholarly papers.

Figure 1. PRISMA diagram.



Findings

Study Characteristics

Of the 50 articles that met the inclusion criteria, the majority were conducted in high income countries. Authors were from Australia (17 studies), the UK (14), USA (13), Canada (3), Denmark (2), Netherlands (2), Bulgaria (1), Finland (1), Spain (1), Sweden (1), New Zealand (1). Four studies were from low- or middle-income countries: South Africa (2), India (1), Uganda (1). (Note: total is greater than 50 because some studies were conducted in and had authors from multiple countries).

Digital Technology Interventions

Studies covered a range of digital technologies, including mobile apps, online resources such as interactive websites and chatbots, and virtual reality or wearable technology. Studies on mobile apps comprised the majority of studies (46%), including in combination with websites or wearables.

Apps	19
Apps and website	4
Apps and wearables	1

The second largest category was a blend of technologies (14). A smaller number of studies reported on virtual reality (2), website only (4), a chatbot (1), social media content analysis (1), video games (1), automated messaging (1), and more abstract ideas like digital phenotyping (1) and gamification (1).

Many of the online or app-based tools delivered cognitive behavioural therapy (CBT) combined with elements like gamification to engage users in managing conditions such as depression, anxiety, sleep disorders, self-harm, and suicidal thoughts. Virtual reality, including ‘avatar therapy’, and automated text messaging tools offered more specialised immersive or straightforward, automated interactions to support mental health interventions.

While mobile apps and self-guided programs based on CBT principles were most common, the breadth of technology types—from VR and chatbots to web-based resources and wearables—illustrates a diversifying landscape of digital mental health interventions aimed at providing personalised, accessible, and engaging support across different communities and needs.

Study Methods Used

23 articles reported **qualitative interviews and focus groups** involving people with lived experience. A further 18 papers used **participatory approaches, including co-design workshops, peer research, and participatory design workshops—**with some combining these methods with standard qualitative interviews. These methods actively involved stakeholders such as service users, practitioners, and community members in the research process, fostering collaboration and ensuring the relevance and applicability of the findings to real-world contexts.

M**ixed methods approaches** were used in six cases and typically used surveys with open-ended questions, allowing researchers to gather quantitative and qualitative material.

We also drew insights from commentary and traditional review articles such as **scoping reviews, systematic reviews, and realist reviews** (totalling seven) that synthesised and evaluated existing literature.

What does the literature reveal?

Analysis of the literature reveals the breadth of people with lived experience and their diverse needs and preferences. It underscores the value of designing demographically inclusive, and ethically sound digital mental health practices with active lived experience involvement that examines digital technologies in context – not in isolation.

The following section describes the key take-aways from the literature analysis.

What do people with lived experience want in digital mental health technologies?

When people with lived experience are involved in the design and evaluation of digital mental health technologies, several key priorities emerge, as outlined below.

Peer support and social connection

People with lived experience want digital interventions to facilitate social connectedness and support, given the importance of these factors in mental health recovery. Indeed, many people with lived experience recognised the potential for digital technology to enhance connections with peers, as well as with professional healthcare providers, and supportive communities (eg, Bond et al., 2023; Brannelly, Trenoweth, and Tuck, 2022; Brown et al., 2020; Fortuna et al., 2022; Pozuelo et al., 2023; Venegas et al., 2022).

Kornfield and colleagues (2022) reported that the young people involved in the codesign of a mobile app, recommended 'leveraging digital platforms to enhance connectivity and support'.

Several studies found that young people use social media to connect with others and have a preference for peer connections or peer promotion of proposed digital resources (eg, Fowler et al., 2023; Strauss et al., 2019). Indeed, in a study of Australia LGBTIQ+ young people's mental health help-seeking experiences, many participants had not found mental health apps to be valuable in the past, and preferred peer-level engagement for mental health support, and the use of social media platforms, such as Tumblr and Facebook' (Byron, 2019).

A study on PeerTECH, 'a peer-delivered medical and psychiatric self-management intervention' by Fortuna and colleagues (2022) found that peer support, when integrated with digital tools, enhanced accountability, confidence, and hope, while also strengthening human bonds among participants. In Berry and colleagues' interviews with people with lived experience, most participants expressed a view that digital interventions should not be delivered without other support options available (Berry et al., 2019). Participants suggested that digital tools include telephone, video chat, or instant messaging options in case individuals need further support. In McClelland and Fitzgerald (2018), too, both clinicians and users recommended a 'help' option in their app, which could lead the user to internal and external support and advice.

Privacy and data protection

Fewer than half of the studies explicitly sought the views of people with lived experience on privacy, data protection, confidentiality, safety, and security (see Berry et al., 2019; Bucci et al., 2018; Pavarini et al., 2022; Reen & Orji, 2022; Torous J. & Friedman R., 2014; Venegas et al., 2022). Views on privacy and data protection are especially sparse for people with lived experience who are not already using online or digital mental health technologies.

Where views have been sought, people with lived experience expressed varying levels of concern, which often depended on the types of technology and data involved. Greater concerns were expressed about monitoring technologies, which gather self-reported or electronic health record data (e.g., Patrickson et al., 2023).

People with lived experience expressed concerns that user data could be used to justify involuntary admission into a mental health facility, or by third parties such as pharmaceutical companies (Berry et al., 2019). Others expressed strong concerns that biometric monitoring was invasive and degrading (Carr, 2020), a view shared in some of the grey literature (Bossewitch, 2019; Stop Oxevision Contributors, 2024).

But not everyone with lived experience shares these concerns. Pavarini and colleagues (2022), for example, found that young people in the UK did not view psychosocial and biological data as highly private data.

Other studies noted a privacy-technology trade-off. A participant in one study indicated they would be happy for everything they did to be monitored if it aided their treatment and helped them avoid their distressing mental health episodes ("If you could chip us all, and monitor everything, spending, the whole lot") (Majid et al., 2022). This trade-off was also described by Patrickson and colleagues (2023):

> Consumers who engage with monitoring technologies do not necessarily do so because they believe that they are harmless. Instead, they are more likely to have weighed up the perceived benefits of monitoring technologies versus the potential risks of monitoring technologies and have judged the former to outweigh the latter (Patrickson et al., 2023).

Amy Newell, who describes herself as 'a patient with bipolar disorder and… a software engineer', wrote that personal data put on digital devices is subject to privacy breaches, and that '[e]ach mental health patient needs to balance the risks and benefits of their technology use' (Chiauzzi & Newell, 2019).

The context in which technologies are deployed also matters. This is highlighted by the example of a phone app deployed in Uganda and South Africa, where multiple members of a household might be using the same phone or indeed, the same app (Pozuelo et al., 2023).

Other ethical considerations, including transparency, informed consent, and potential harm, were also identified as important principles in the development and deployment of digital health tools (Bossewitch et al., 2022; Carr, 2020; Mikal J. et al., 2016; Venegas et al., 2022; Walsh et al., 2024)).

People with lived experience value being able to address their distress or needs in a way that feels safe and supported (eg, Bond et al., 2023; Borghouts et al., 2021; Grove, 2021; Ludlow et al., 2023; Pozuelo et al., 2023; Storm et al., 2021).

Accessibility and flexibility

The studies collectively underline the importance of developing digital mental health technologies that are not only accessible but also flexible enough to cater to the varied preferences and needs of different population segments.

Limited internet access, low digital literacy, and lack of smartphone availability, can all reduce the accessibility of digital interventions (Berry et al., 2019; Borghouts et al., 2022; Brown et al., 2020; Carr, 2020; Ospina-Pinillos et al., 2019). This emphasises how crucial it is to design technologies that are accessible for individuals across diverse populations, and who engage with digital technology in equally diverse ways.

Technology usage can vary across age (eg, Bevan Jones et al., 2020; Gan et al., 2023; Torous J. & Friedman R., 2014; Walsh et al., 2024), ethnicity (eg, Bennett-Levy et al., 2021; Ospina-Pinillos et al., 2019; Povey et al., 2016; Sien et al., 2023), educational attainment (Oguamanam et al., 2023), and sexuality. Several studies raised concerns that the digital mental health field had paid insufficient attention to such diversity.

Oguamanam and colleagues (2023), for example, said that ‘digital maternal health intervention research has typically taken a "one-size-fts-all" approach to design and has rarely included women from racial and ethnic minority groups in studies’, despite this group itself being multifaceted. For instance, the level of educational attainment and income influenced the acceptance of technologies like self-tracking and mobile app usage for mental health support. Poor uptake of digital technologies could be because the tools were not designed ‘to meet the particular needs and values of women with lower income and education' (Oguamanam et al., 2023).

Most studies stressed a need for personalisation and tailoring to adapt for varying usage among and within different population groups (Storm et al., 2021; Borghouts et al., 2021; Kornfield et al., 2022; Ospina-Pinillos et al., 2019; Storm et al., 2021). Tailoring could, for example, assist people using an app to decide on their own privacy preferences by disabling certain functions. For example, a location tool, that could be used to located a user when lost could be disable by a user who does not want their location to be monitored (McClelland & Fitzgerald, 2018).

An optimal strategy would see digital mental health intervention design that recognises the complexity of human preferences and the necessity of providing individuals with the options that best support their mental health journey, respecting their autonomy, privacy preferences, and the diversity of their experiences. It may also require that services offer a spectrum of good practices from high digital technology usage to situations with minimal or *no* digital component.

Integration with face-to-face support services

There were mixed views on whether digital mental health technologies could be used as a stand-alone intervention or should only be used in conjunction with face-to-face support (eg, Berry et al., 2019; Bucci et al., 2018).

A large-scale participatory study conducted in the UK in 2018 found that the top research priority for mental health service users, their carers, and health-care practitioners was to determine the benefits and risks of technology-based mental health care, including the impact of removing face-to-face human interaction (Hollis et al, 2018, p. 7). Other papers also reported real concerns among people with lived experience that digital mental health technologies could ‘reduce access to other forms of therapy and support’ (Berry et al., 2019; see also Byron, 2019).

Overall, there was a view that digital mental health technologies, including apps, chatbots, gamification or other technologies, should not replace face-to-face services (eg, Bucci et al., 2018; Chiauzzi & Newell, 2019; Grove, 2021; Venegas et al., 2022; Hopia & Raitio, 2016).

Nevertheless, some people saw great potential for digital mental health tools. Some early psychosis service users in the UK, for instance, felt that digital health interventions offered additional benefits, such as the ability to track their symptoms and experiences in real-time, compared to face-to-face support alone (Bucci et al 2019). People who find the clinical environment threatening might also benefit from having a digital alternative, the authors note.

However, some interviewees described the absence of a human quality and lack of emotional reassurance and feedback as problematic. One participant stated:

> Talking to somebody is very personal. You can get their instant reaction, their emotions and everything. When you're opening up it’s crucial that you have somebody there to reassure you. If you are talking to a machine, you know you’re talking to a machine (Bucci et al., 2019).

Newell, who is a both a patient with bipolar disorder and a software engineer, writes that while apps have the potential to help patients manage their mental illness, such tools are ‘secondary to the core of good mental health care: personal attention from someone who cares’ (Chiauzzi and Newell, 2019).

Technologies that humanise and promote agency

Technology that promotes a person’s agency in their mental health care can help to promote trust and social connection, and thus enable therapeutic and healing relationships. Most papers suggested that digital interventions should give users control by providing choice of features, opportunities for reflection, pathways to services, and encourage a user’s engagement in their own support.

According to the literature, people with lived experience value personalisation, tailoring, and customisation, and in some cases, strategies like gamification, storytelling, and positive reinforcement were seen as ways to improve engagement and experience.

Tools designed with agency and choice in mind were seen as empowering for young adults with depression or anxiety (Kornfield et al., 2022). Kornfield and colleagues concluded that **personalisation** could include both **customisation** (‘where users explicitly choose between content offerings’) and **tailoring** (‘where preferences are inferred based on users’ characteristics, behaviours, and assessments’) (Kornfield et al., 2022).

In Walsh and colleagues’ (2024) review of remote measurement technologies for young people with depression, user choice was especially important in choosing whether a digital health intervention would be used in conjunction with, or as a replacement for, clinician care (see also Brannelly, Trenoweth, and Tuck, 2022).

Majid and colleagues (2022) recommended that tailoring be enabled in self-tracking technology so that users can keep track of information (e.g., tasks and feedback) using simple quantitative measures, or in more detailed reflections. For example, quantitative data could be annotated with personal experiences to provide context.

The ability to provide detailed reflections was seen humanising for the users. For example, Patrickson and colleagues (2023) write that there is a **'need to ensure that consumers are humanized by the design, rather than being objectified as data'**. Others also noted that digital approaches run the risk of objectifying users by reducing them to a mere agglomeration of data (e.g., Carr, 2020; Stop Oxevision Contributors, 2024).

Some people expressed a preference for tools that do not present as mental health-specific (Bennett-Levy et al., 2021; Bucci et al., 2018; Byron, 2019; Oguamanam et al., 2023). As one young person stated about an app in a study by Bucci and colleagues (2018), '[i]f the app is asking you to pull it out every time you're in a social situation, it gets embarrassing and that can add to the anxiety you feel.' But other participants felt the opposite: that an app was more discrete than a home visit from a mental health worker.

Several papers also raised concerns about how 'self-management' places responsibility on the individual. Byron (2019), for instance, noted that apps typically prioritise individualised self-care, and are not suited to addressing social stigma. Chiauzzi and Newell (2019) further write that 'phone use and screen time can also be addicting, individualising and isolating and cause feelings of inadequacy'. Parker and colleagues (2018) also concluded that the messaging in mental health apps over-emphasises 'individual responsibility for mental well-being' (Parker et al. 2018).

Equity, cultural appropriateness, and inclusivity

Many studies emphasised the need for digital mental health interventions to be culturally appropriate and inclusive (e.g. Bennett-Levy et al., 2021; Borghouts et al., 2022; Oguamanam et al., 2023). Specific populations included people who are d/Deaf and hard of hearing, people who are LGBTQ+ individuals, international students, and Indigenous people.

Specific groups differ in their levels of education attainment, access to and use of technology, and experience of poverty. Therefore, involving communities in defining their own 'problems' can improve equity. Useful queries investigated how technology is already being used in creative ways to support mental health, how these strategies can be bolstered, and what community members say could help.

Although several studies made explicit efforts to recruit participants from diverse socio-economic backgrounds (Oguamanam et al., 2023; Schouten et al., 2022; Venegas et al., 2022), most were smaller qualitative studies that did not include a broad or representative sample of people with lived experience.

Demographic diversity data was not always reported, making it difficult to ascertain which groups might be under-represented in those studies. This was also noted by Bergin and colleagues (2020), in their scoping review of 30 studies on digital mental health interventions for children and young people.

The issue of inequity is noted as a concern of those with lived experience. Sources of inequity identified include the digital divide, access to technology, bias and discrimination in design and the difficult economic and social conditions that many people with mental health conditions face.

Guta and colleagues (2018) argue that this could be overcome by ensuring that research on digital technologies places at the centre the experiences and knowledge of those who will be most affected.

Papers that catered to specific communities or demographic groups fell into two broad categories. **Technology-first** studies sought input from people with lived experience on a technology already developed by clinical innovators, technologists, or peer specialists. In contrast, **community-first** studies started by seeking the views of the community (e.g., perinatal Black women, people who are deaf and hard of hearing, LGBTQIA+ young people, Indigenous Australians) to guide what type of technology is developed. In a project by Bennet-Levy and colleagues (Bennett-Levy et al., 2021), for example, a community-based participatory research process successfully transformed a ‘top-down government funded digital mental health training project’ into a ‘community-guided, ground-up digital social and emotional wellbeing training project’.

Community-first studies were the minority and represent an untapped area of potential. According to Oguamnam and colleagues (2023), digital mental health technologies could remedy systemic inequities in US healthcare. They noted that that '[w]hile these devices are not a replacement for formal healthcare, they may be a useful resource amongst Black populations who often mistrust and receive lower quality perinatal care as compared to White populations in the U.S' (Oguamanam et al., 2023; see also, Williams, 2023).

Community-first studies can reveal specific preferences for what language is used. Some communities, for example, were averse to the mental health framing of digital technologies. According to Borghouts and colleagues’ (2022) people who are deaf and hard of hearing disliked ‘distress’ or ‘stress’ being framed as a matter of ‘mental health’. Similar conclusions were reached in Oguamanam and colleagues’ (2023) research on perinatal Black women in the US.

Likewise, numerous studies described mental health in biomedical terms, whereas few adopted practices that have emerged from the broader lived experience movement, such as Alternatives to Suicide or eCPR (Emotional Connecting, Empowering Revitalising; Myers et al., 2021; Rhodanthe et al., 2022).

Other observations from the literature

In addition to highlighting the priorities of people with lived experience, the literature also revealed trends in research and approaches to technology development that warrant attention. These are discussed in the following section.

Few studies include in-depth input from people with lived experience

A majority of the 4,850 studies identified through the initial search were about testing of digital mental health technologies. Where people with lived experience were involved, input mainly consisted of user testing and acceptability surveys.

Only 50 papers were within the remit of this report, and were chosen because they contained some form of rich qualitative research on the viewpoints of people with lived experience. The small number of qualitative studies in the broader field has been noted by others (A. Bergin et al., 2020; Berry et al., 2019; Bucci et al., 2018; Grove, 2021; Carr, 2020). Bucci and colleagues (2018) expressed surprise that their 2018 study ‘is the first qualitative study to examine early psychosis service users’ perspectives on digital technology use for health care needs’, given the growth of digital health services worldwide.

According to Berry and colleagues (2019) the collection of user views and ideas for future digital health technology developments is limited. They also note that survey-based research designs don’t capture in-depth information to yield such insights.

Byron (2019) writes that research on digital mental health technologies – as in public health more generally – often reflects social marketing approaches, which focus on a target population’s ‘passive reception of health information’ rather than as active users, contributors, and creators, who could helpfully participate in technology development.

Referring to app development, Pelletier and colleagues (2013) note that re-designing an app to match the expectations and values of psychiatric patients 'involved more than feedback on the app's colors and buttons', and required insights into how the app integrated with existing services.

More broadly, Veldemeijer and colleagues (2023), summarised the field well in their survey of studies that involved service users and people with lived experience in mental health care innovation. **'Service users and people with lived experience,' they stated, 'were involved in different roles but never as decision makers' and '[s]tudies that used co-design approaches exhibited the highest levels of involvement'.**

Similarly, Carr (2020) was critical of the digital health technology sector for its lack of meaningful partnership with people with firsthand experience of mental health services and their representative organisations.

Reporting of lived experience methods lacks consistency

Although the literature promote a co-production approach to research and design, there was a lack of precision, consistency, and consensus around terms like 'co-design' and other participatory methods (Bergin et al., 2020).

Terminology to describe the extent that people with lived experience were involved in research varies. Few studies reported whether lived experience contributors were remunerated for their time attending workshops, interviews, and completing surveys. The reporting of which methods were used also lacked consistency, making it difficult to assess the quality of lived experience input.

Fowler and colleagues' (2023) noted a similar trend in their review of 33 papers on LGBTQIA+ community engagement in the design of digital mental health interventions. Only about half reported how much the LGBTQIA+ community was involved in intervention design.

In other cases, terms used were not clearly defined. According to Fowler et al. (2023) terms like 'co-design', 'design-led' and 'participatory approach' are used interchangeably in the field. Some studies used the term 'co-design' to refer to practices that are more accurately described as consultation (Brannelly et al., 2022; Engdahl et al., 2023; McClelland & Fitzgerald, 2018). Buus and colleagues (2019) note that '[t]erms such as co-design, coproduction, and co-development often imply that users are only being consulted, that is, not involved as a resource in their own right, and continue to have very little actual power and control in health research and development.' Likewise, in studies referred to as 'collaborative', lived experience involvement was often limited to providing feedback or content tailoring of advertising materials and imagery.

In other papers, 'co-design' refers to detailed community-engaged research methods, including approaches specific to the mental health context (e.g., Fortuna et al., 2019; Patrickson et al., 2023; Pavarini et al., 2022; Venegas et al., 2022; Schouten et al., 2022). The broader health literature suggests that community engagement is important even on technical matters such as intervention functionality, which is a driver of digital intervention acceptability (Fernández-Álvarez et al., 2017; Storm et al., 2021).

In their review of digital mental health interventions for children and young people, Bergin and colleagues (2020) argued that '[c]o-design processes with children and young people should be recognised and reported as a necessary component of the research', especially given that how a tool is designed and developed underpins whether the tool is successfully adopted and implemented.

Inconsistencies in reporting of lived experience contributions could be because, as Engdahl and colleagues

(2023) write, 'researchers still struggle to implement coproduction activities in their research practice'. This includes participation in partnership, coproduction, and shared decision-making.

Inconsistent terminology is a problem because **researchers wishing to adopt good practices in participatory or community-engaged research may be misled about the extent to which something such as mere user consultation constitutes leading practice**. This creates the possibility of terms like 'co-design' being used superficially, whether inadvertently or otherwise. Veldmeijer and colleagues (2023) concluded that reporting on collaboration should be clear and systematic.

The concern with improving consistency, clarity and standards in collaborative research methods echoes those raised in general mental health research (Colder Carras et al., 2023; Rose, 2018; Scholz, 2024). According to Brett Scholz:

> The number of articles published each year claiming to have used a range of collaborative methods (such as co-design, service user involvement, or patient engagement) has increased by more than 600% over the past 10 years. Some of this research has been produced in legitimate partnership with people with lived experience, but often, vague terms are used to imply a greater amount of engagement than has actually occurred (Scholz, 2024).

Scholz calls for 'mindfully reporting lived experience work', including setting basic reporting standards. 'Mindful reporting' is the subject of growing scholarly examination (see Roper et al., 2018; Rose, 2023), but consistent reporting of collaborative methods in the digital mental health context requires attention.

Power imbalances can emerge

Some studies suggested that researchers could fail to address power imbalances between lived experience contributors and the broader research teams, including clinicians and other mental health professionals, but also computer programmers and designers (Buus et al., 2019; Carr, 2020; Schouten et al. 2022).

One study, by Buus and colleagues (2009), examined stakeholders' contributions to the design, function, and content of a mental health safety and planning app (MYPLAN app). The authors observed that 'it remained debatable to what extent the software developers and researchers were committed to collaborate and genuinely share control' with lived experience collaborators. For example, software developers were adamant about using a suicidal ideation measure despite users expressing dissent about its inclusion. Researchers also controlled the data-collection sessions and which information was recorded, prioritized, and fed back to the app developers (Buus et al. 2019).

Power imbalances were also reported in Bergin and colleagues' (2020) review of research on digital tools for children and young people. In one study, some participants did not realise they were engaged in a research study (noted in Bergin et al. 2020).

Schouten and colleagues (2022) advanced specific measures to mitigate challenges created by power imbalance to prevent 'vulnerable participants not being taken seriously'. This included steps before, during and after data collection, such as '[t]reat[ing] participants as equals and approach them as a 'designer of need' rather than a 'patient in need'', 'facilitating involvement of vulnerable participants', and 'closing knowledge and skills gaps' through training (Schouten et al. 2022, 332).

Best Practice in Collaborative Design

A small number of papers describe robust, systematic forms of co-design that could serve as 'best practice' examples for researchers in the field.

Patrickson and colleagues (2023) enlisted a Lived Experience Advisory Group, which met several times over an extended period to consider the development, design, and implementation of digital monitoring technologies in mental health services. There was a designated lived experience representative, and the researchers recognised the 'Consumer and Carer Advisory Group (CCAG)' as a listed author on the resulting research paper.

Another example of best practice is described in a paper by Fortuna and colleagues (2019). The authors developed a research framework for developing mobile health (mHealth) interventions delivered by certified peer specialists, who were involved in all phases of intervention development and research (Fortuna et al., 2019). The process required that additional time and resources be invested in the project to build trust and facilitate equal partnerships, but engagement is crucial to the success of the project.

Lessons can be drawn from the broader health literature. For example, reporting frameworks such as GRIPP2, a standardised reporting framework to improve reporting of patient and public involvement in research, may help guide efforts in the digital context (Staniszewska et al., 2017). Torous and Friedman (2014) combined principles of Patient and Public Involvement with methods of human and computer interaction.

Fowler and colleagues also point to Community-Based Participatory Research as set out by scholars like Nina Wallerstein and Bonnie Duran (2006). This approach would involve community involvement ‘from study conceptualization, design of interventions, through to dissemination of findings and informing translation’.

Parts of the grey literature also reveal efforts to integrate lived experience in policy-making. For example, the Australian National Digital Mental Health Standards includes a ‘Consumer Partnership Principle’ (Australian Commission on Safety and Quality in Health Care, 2020b). This principle requires that digital mental health service providers ‘develop, implement and maintain systems to partner with service users and their support people’, and that partnerships cover ‘the planning, design, delivery, measurement, review and evaluation’ of those services.

This call to elevate the role of people with lived experience in the research, development, and governance of digital mental health technologies was common across the literature. Jonah Bossewitch (2019), perhaps best exemplifies that call, writing:

> It is possible to redirect this wizardly technology to help support people better. Doing this well starts with inclusive design—people with lived experience need to be involved in planning and shaping the systems meant to support them. **Nothing about us without us**.

Gaps in the literature

There were several notable gaps in the literature.

Little foundational, priority setting research

There is little evidence of people with lived experience being involved in foundational, priority setting research, or examples of how to do this well. Notable exceptions are covered in previous sections (eg, Borghouts et al., 2022; Byron, 2019; Fortuna et al., 2019; Hollis et al., 2018).

This gap has been noted elsewhere. Gooding and Kariotis (2021), for example, report that only 4 out of 132 studies using algorithmic and data-driven technologies in ‘online mental health interventions’ involved people with lived experience in the design, evaluation or implementation of the proposals in any substantive way. There was a ‘near-complete exclusion of service users in the conceptualisation … of algorithmic and data-driven technologies’ and their application to mental health services (Gooding & Kariotis, 2021).

Low and middle-income countries overlooked

There is a notable gap in the scholarly literature on the views of people with lived experiences in low- and middle-income countries (LMICs) on digital mental health innovations. Most research on the development and implementation of digital mental health technologies is centred in high-income contexts, often overlooking the unique challenges, needs, and perspectives of individuals in LMICs. This oversight is critical because crucial insights that could inform the design of culturally relevant, accessible, and supportive digital mental health services tailored to the socioeconomic realities of these populations are absent.

Addressing this gap requires a concerted effort to conduct qualitative research that prioritises the voices and experiences of people with lived experiences in LMICs, ensuring that digital mental health innovations are both inclusive and equitable.

Many studies relate to specific groups, raising questions about scalability

There is limited rich qualitative research into the views of populations along diverse demographic lines. This raises questions about whether technologies could be scaled up without failing in some way to meet the diverse mental health needs in the population.

It is evident that researchers are trying to balance two competing priorities. The first is the need for individuals to personalise and control their digital mental health technologies. For example, the ability to tweak functions to cater to the unique cultural contexts, individual preferences, and specific mental health needs of diverse user groups.

On the other hand, technologies also need to be standardised and scalable for a large userbase. This ensures that the technology is widely accessible and can benefit a broad audience at a reduced cost. Scalability often relies on generalised designs that may not fully accommodate the nuances of individual and cultural differences.

Addressing this complex dynamic will require further technical and conceptual work.

Role of Industry

There was little substantive discussion about the role of the private sector in digital mental health technology development. Some commentators and research participants have raised concerns about the profit-drive of commercial operators, and the potential disconnect between market incentives and what is good for people with lived experience (Berry et al., 2019; Carr, 2020; Chiauzzi & Newell, 2019; Pelletier J.F. et al., 2013).

In one study Reen and Orji examined the potential development of a mental health app for working-class Indian women through 31 one-to-one interviews. Participants were asked about features and functionalities of two apps (Headspace and Happify), likes and dislikes. Some participants did not expect mental health apps to charge them for managing their stress/ anxiety. One participant stated:

> I installed headspace app a long back ago but I wasn’t able to cope with it. The reason was that again and again, it was asking for payment.

There is little to generalise from this single participant, but it does highlight a potentially unexamined area in the field: the emerging role of commercial operators in digital mental health technologies, and the impact of business imperatives on mental health support.

The role of commercial interests in the research was not always made clear. One study noted that conflicts of interest are not always reported (Bergin and colleagues 2020). In a review of 30 studies, they found that ‘[a]lthough the reports include statements that there were no conflicts of interest, the founders and developers of interventions were at times involved in the research' (see also Walsh et al., 2024).

Meanwhile, Pelletier and colleagues (Pelletier J.F. et al., 2013) wrote that commercial imperatives were common in app development. They note that actively involving users in the system design process has 'significant cost-benefit advantages … compared to when targeted users test a new product only when it is ready to be commercialized and that there is too little room for improvements'.

General research on the emerging field of 'commercial determinants of health' may help address research gaps concerning the role of industry in the digital mental health context.

Literature Review - Limitations

The principal strength of a scoping review is its *breadth.* Our broad and cross-disciplinary approach enabled us to identify cross-cutting trends in the literature as a whole, and the trends we identified are striking. Nevertheless, our review has limitations.

Firstly, we adopted a reasonably narrow definition of 'digital mental health technology', which excludes technology uses outside of formal mental health services. For example, one study that contained rich qualitative data about veterans' use of video games in their mental health recovery was excluded because, despite showing benefit, the games were not developed as mental health tools (Colder Carras et al., 2018).

Other technologies designed for use by the general population, such as messaging boards, were also excluded. However, these technologies could potentially be deployed in creative ways to help people deal with their distress and mental health conditions.

The review had an English-language bias. A larger scoping review covering languages other than English is needed to uncover scholarly literature and grey literature from non-English-speaking communities.

Section Two: Interviews with Lived Experience Experts

Methods

To better understand current practices of engaging people with lived experience in digital mental health research and development, we conducted semi-structured interviews with people involved in such programs.

We identified potential interviewees from the scholarly literature, grey literature, web searches and also through our existing networks. The people we approached were identified as being key facilitators and shapers of the lived experience approach their research team or organisation had adopted. Several global technology companies working in the digital mental health space were approached, but no willing participants were identified.

We conducted semi-structured interviews lasting between 45 and 80 minutes. Interviewees were provided with broad questions in advance of the interview about the value of lived experience engagement, the diverse approaches and processes being employed and relevant practical and structural considerations. Interviews also covered related topics that interviewees felt were important and relevant.

Interviews were conducted in conjunction with the literature review. About half the interviews were conducted prior to our initial thematic analysis of the literature. Insights from these interviews helped to shape our analysis framework for the literature. In turn, insights from our preliminary analysis of the literature were informed questions in the remaining interviews.

Findings

Interviewees

Ultimately, we conducted interviews with eleven participants. We spoke to leaders and experts in Australia (6), the United Kingdom (2), the United States (2) and India (1).

The majority of interviewees identified as having either personal or carer lived experience of mental health issues (8). In addition, several held dedicated roles and responsibilities for lived experience strategies and delivery of lived experience activities within organisations (6).

Five interviewees worked within academic institutions. Of those, one had a specific background in clinical care, one held a role in policy, and three had current or past experience as a peer worker in mental health support.

Three interviewees were involved in the development of digital mental health tools and apps in commercial and innovation settings outside of academia. One person led a not-for profit providing online mental health programs.

Insights from the interviews

The interviews allowed us to explore in greater detail and nuance how lived experience expertise is being used. They also provided an opportunity to explore assumptions, tensions, conflicts and gaps in how lived experience engagement in digital mental health is being formally reported in the literature.

Whilst there was much nuance across the eleven interviews, there were cross-cutting themes that connect strongly with our literature analysis. These are discussed in the sections below.

Lack of awareness of digital mental health technologies

There was strong enthusiasm among interviewees for digital mental health tools. Mostly, these interviewees saw digital support approaches as working alongside and integrated into non-digital care and support.

One interviewee, working in a commercial context, had a clear vision that digital tools had the potential to increase access to support, reduce stigma and help people face the world and their challenges.

> *"How can we make sure people get access to support that they need? How can we make sure that they get validated and supported? Not, you know, made to feel like they're wrong in some way. And how do we then turn that into something that supports people over time and helps them to start to practice self-care, compassion, kindness etcetera, etcetera? … That's what people who have lived experience hope that digital mental health opens up."*
>
> *Interview 4*

Nevertheless, interviewees expressed a need for greater awareness and discussions between patients and care providers, about the role, use and purpose of digital technologies.

Indeed, some participants said that a lack of awareness and understanding of digital mental health – amongst both people with lived experience and also health professionals – was the primary challenge impeding progress in the field.

> *"There's not much awareness here … so one of the things that is always on my focus is to try and talk about it to mental health experts and professionals, getting them to understand the various tools, cases and what digital mental health entails today and could entail tomorrow and how it could benefit. The end users, the patients, their perspective matters so much and they [have a] lack of awareness."*
>
> *Interviewee 5*

Digital tools should align with person-centred approaches

Most interviewees emphasised the role of human connection, including with peers, health professionals and community networks, in mental health management. As such, they wanted greater consideration of how digital approaches can augment and integrate with person-centred approaches.

> *"You can't expect that a digital app is going to be your only way of being able to maintain your mental health."*
>
> *Interviewee 1*

Several lived experience experts had past experience as peer support workers. Although enthusiastic about digital mental health tools, they expressed a desire to see peer support considered and embedded in these approaches.

People who had used a digital mental health tool – in particular, a mental health therapy and wellbeing tool – said that they wanted connection to additional support that could address the underlying causes of distress. This was especially noted for tools that focus on a specific therapeutic or clinical goal, without supporting people to address the broader challenges in their lives.

Some interviewees drew upon their experiences and knowledge of person-centred support models including patient engagement, peer support, survivor advocacy, and mental health consumer movements. This group expressed apprehension about how digital mental health approaches fitted into this person-centred support and recovery environment. In person-centred models of recovery individuals are supported in community with an emphasis on hope, empowerment and underpinned by the understanding that the journey of recovery is personal.

> *"I am cautious around new technology and any kind of process that takes away from the relationship component of support. [Discussion should be] drawing on the mental health consumer movement, family carer perspectives to ensure principles and approach of lived experience contribution are really grounded".*
>
> *Interview 2*

Concerns were also expressed about how digital and technology-based support approaches could add to the over medicalisation of mental distress, by taking a narrow clinical point of view and side-lining the importance of connection and relationships.

> *"For me, the biggest task in the lived experience movement, the lived experience work, is to push against the medicalisation of human experience and systematically to provide alternative pathways … If you're seeking to replace human connection and the relational component of the work that we push so hard for in the lived experience space, then it won't be well received."*
>
> *Interview 2*

Participating in lived experience engagement

In academic and research settings people with lived experience were mostly recruited through existing networks including those who have had past contact with the institution and those who have already trialled and used digital supports.

In commercial and innovation contexts lived experience engagement was often driven by those within teams who also identified as having their own personal experience of mental distress. Recruitment could be through existing professional networks or through clinical connections with clients at private practice or support services.

Some interviewees expressed concern that that more diverse voices and contributions of people with lived experience of mental illness might not be heard or respected. It was therefore important to understand what drives people with lived experience to participate in digital tool development and research.

For those with lived experience whose contribution is also part of their regular employment, the commitment to making a positive difference often felt passionate and personal.

There were fewer examples of people who contribute on an occasional basis. In most cases, a modest financial reimbursement might be driving engagement. Personal benefits other than cash incentives likely also play a role. In one case, involving a commercial partner, participation in digital mental health development was suggested as a way that people in distress may seek support for unmet needs.

Lived experience engagement in digital mental health was not fundamentally different from engagement in other mental health projects. However, concepts and modes of working in digital development and design environments, such as human centred design thinking and rapidly building a Minimum Viable Products (MVP), were sometimes unfamiliar. The work cadence in developing digital tools, with multiple iterative steps, might be more rapid than when developing non-digital support.

Engagement to support iterative development of digital support could also feel different to an academic research approach which seeks to test user responses and effectiveness of a more complete tool.

How do people with lived experience participate?

Lived experience engagement across the lifespan of a project

Most interviewees said that in order for lived-experience engagement to be authentic, it needed to be included throughout the research and development phases of digital mental health tools and solutions.

Early engagement with people with lived experience was considered critical for shaping ideas and guiding methodology. Equally, lived experience expertise should be included in the design stages for the solution, in shaping how the technology is analysed, and then in the delivery, evaluation and ongoing feedback phases of a project.

Further, lived experience engagement could be more deeply supported and sustainably embedded through organisational leadership and culture, in external and internal strategies and through addressing lived experience in advisory and governance structures.

Early and foundational engagement

Whether working in research or commercial settings, interviewees agreed that early engagement with people with lived experience is important and can be encouraged through institutional policies and leadership. These interviews also highlighted how a lack of funding and publication opportunities for such foundational engagement can be considered significant challenges.

Amongst those start-ups and commercial entities we spoke to, the value of early and foundational insights was recognised. Here, such engagement with people with lived experience is seen as necessary to assess the acceptability and commercial viability of a digital approach. A key driver described was whether a proposed approach would be safe and cause no harm to users. This was a crucial question to address early, before any commercial idea could progress.

> *“Digital products, whether mobile, AI, web-based, whatever, best practise will tell you do not build anything until you understand the user's need…don't design anything until you understand the users need, people quite often ignore that … lots of people build products without talking to their users.”*
>
> *Interview 4*

Government innovation projects were described that often stipulate that potential users be involved[1]. However, some interviewees felt that lived experience engagement in foundational work could be better coordinated and more collaborative.

In both academic and commercial settings, one challenge for early engagement is that lived experience and community engagement can be costly and is unlikely to be resourced through project specific funding.

> *“Engaging users or people with experience is difficult…It takes time, it takes effort. It takes way more effort than you think it does. If you're running a small start-up, then you can't really afford to spend that time or the money etcetera, etcetera, etcetera. But actually it's the most important thing, because otherwise what are you building? …How could you possibly build digital health products without understanding how you're going to engage people?”*
>
> *Interview 4*

In some cases, alternative sources of funding can be found to establish and run community engagement activities. For example, public events and community workshops, where institutions publicly highlight and promote ideas and activities in digital mental health, can be used to garner foundational insights for a project.

One research institution investigated the views of young people on the ethical use of artificial intelligence (chatbots) to support their mental health. But it wasn’t clear how the outputs and findings of that activity – not designed as a research project – should be analysed, shared and communicated.

We heard several examples of how early and foundational lived experience engagement was positively driven by organisational policies and senior leadership.

Some interviewees sought out engagement opportunities such as through informal community connections with external service users, lived experience and community organisations and networks. Maintaining and building such informal relationships and engagement outside of established research projects can be seen as challenging.

For several interviewees, activities like those above, that explore foundational perspectives from people with lived experience, are not suited to publication in an academic journal. Career academics may only prioritise disseminating community engagement activity if this is to be published in an academic journal or there are other clear benefits. Some also suggest that articles citing such formative engagement activity will not be of interest or acceptable to journals unless they can demonstrate approval though human ethics review structures.

Instead, it seems informal findings from some more formative community engagement may either be only shared internally and sometimes possibly more widely in institutional communications or reports.

Adaptative and reflective engagement

Interviewees emphasised the need for engagement plans to be reflective and flexible. Engagement approaches might need to be modified or even recast once a project commences. It did seem that in some respects the people in commercial and innovation environments (those we spoke to anyway) had greater opportunities than academic researchers to adapt and tailor their engagement approaches.

Achieving flexibility requires project leaders to relinquish central control in favour of a partnership approach where roles and responsibilities are shared among more local, targeted levels.

> *"I think the important thing there is to make sure that the output of your work gets shared and your people start to think seriously about how they engage with people about experience and so on …You know, going as far as sharing the power or involving people in decision making."*
>
> *Interview 4*

The time and capacity to reflect and adapt engagement strategies was seen as key to ensuring that engagement was authentic and effective.

Some interviewees felt that flexibility goes hand-in-hand with transparency about what lived experience engagement entails and its possible challenges and impacts in research and development.

> *"the key element is this idea around transparency…so we will be transparent in the way that we deal with people with lived experience. We will listen to them and we'll equip them with the necessary tools and information that they need in order for us to engage with them meaningfully. We will also support and promote flexibility, so we recognise that each person with lived experience comes with different requirements and different needs, so we'll recognise those and we'll do our best within the means that we have to accommodate those differences and needs in order to engage with them effectively."*
>
> *Interview 3*

Types of lived experience engagement

Lived experience engagement can take many forms, from gathering user surveys and feedback, to co-design models with advisory panels and peer researchers. In most cases, the form that lived experience engagement takes is guided by opportunities that arise and what was deemed possible and appropriate for each organisational or research setting.

Surveys and user feedback

Some interviewees discussed the value of anonymous surveys and user feedback in designing and delivering digital mental health tools.

Whilst these approaches are limited in their capacity to forge more collaborative engagement some form of data, often from a large number of respondents is available and those interviewees that had such feedback did consider this a valued dataset. These feedback insights are considered simple to collect and monitor.

According to these interviewees, user reviews and feedback provide valuable information for improving usability. Interviews in both commercial and non-commercial settings highlighted to us that these channels (and the mostly very positive reviews posted) were valued.

In one case, an interviewee reported that based on anonymous feedback several hundred changes and updates had been made to the original support tool, launched several years ago.

Insights can be gathered via feedback channels such as mobile phone app store. Popular digital mental health tools may have thousands of reviews on app stores posted every year and user feedback from in-app tools, surveys and feedback channels established within digital tools appears to be attractive to tool developers.

Some feedback channels, like reviews, allow anonymity but other feedback, such as within app channels and email feedback can be responded to personally. We heard examples of dedicated teams reaching out to users who had provided feedback and ideas. This can potentially lead to impactful conversations about changes that could be made to the digital tool.

Research groups might also use feedback and quantitative surveys to assess community views and attitudes towards key issues such as privacy and confidentiality.

Concerns about which voices and views are represented or missing in surveys and app feedback seems to be outweighed by the large number of responses and the accessibility of this data.

Co-design

‘Co-design’ and related terms are commonly cited in literature addressing lived experience and digital mental health. A commitment to ‘co-design’ was mentioned in at least four interviews. However, as was the case in the literature review, there was a lack of consistency in how different organisations define ‘co-design’ in their practices.

Several interviewees viewed as problematic the lack of consistency in how co-design is often described and defined. They expressed concern that engagement processes described in the literature as ‘co-design’ were not always authentic to co-design principles such as shared decision making. Some even saw claims of ‘codesign’ as a red flag that closer assessment was required to determine whether authentic co-design principles and practices were indeed in place.

Interviewees were concerned that in many situations when codesign was cited, participants are actually not engaged and consulted as ‘real’ partners in research and project decisions. Those in lived experience roles questioned whether researchers citing codesign were truly recognising and addressing power differentials and alternative ways of making decisions.

Advisory panels

Lived experience advisory panels, either organisational or project specific, were commonly mentioned as playing a central role in lived experience engagement in digital mental health research and development.

Such groups typically meet on an occasional basis and receive research updates where lived experience input is sought on current research and development and also new proposals.

In most cases, panels serve an advisory function, rather than having specific approval, decision-making or governance powers. Panel advice is most commonly sought around participant recruitment. In these interviews the role of panels in broader issues of relevance to people with lived experience, such as research dissemination or in considering ethical challenges and perspectives was not brought up.

In many cases it seems panel members and advisers are recruited through existing networks, typically as users or clients connected with the research team. Additionally, an Expression of Interest might be shared with known networks.

Some interviewees expressed concerns that the composition and diversity of panels could be limited and biased towards the more formally educated and mainstream points of view.

In most cases it was not transparent as to whether and how members of lived experience panels and advisers were being trained, remunerated and supported.

We also heard that, over time, maintaining engagement and momentum with established lived experience advisory groups could be challenging to sustain.

Peer researchers

Across our interviews there were two examples where a Peer Researcher model was developed and implemented.

In one case, the peer researcher approach had been refined over several years and was documented in academic publications. The key features of this approach were:

- At least 50% of the team were peer researchers
- Peer researchers received training
- Accountability tools were developed to monitor the quality of engagement and promote ongoing improvements
- An engagement model incorporating community participatory research and Human Centred Design was adopted
- Adherence to the engagement of principles of Fairness, Empowerment, Inclusion and Self-Determination
- Peer research model development was documented and published.

Designated researchers and leaders

One novel and potentially transformative development in digital mental health was the creation of specific lived experience researcher roles or lived experience coordination and leadership roles within organisations. These new designated lived experience roles can reflect new organisational commitments, such as developing or adopting organisation wide lived experience principles or frameworks.

Alongside the creation of new and specific roles there is a growing trend for academic researchers to be more open about their own experience of mental distress. So some experienced and career academics may also identify as a ‘researcher with lived experience’.

However, designated lived experience researchers and other specific lived experience roles within digital mental health activities appear to be distinct and different from this more academically focussed researcher group. It was also clear in these interviews that in project teams these different roles are working together and alongside.

Those in specific lived experience roles often come to their role via a non-academic pathway, as someone who has expertise and insights as a user or provider of support services. They also often bring with them strong connections with their communities.

Interviewees in these specific roles were clearly shaping and influencing how lived experience is incorporated into digital mental health research and development. They were knowledgeable about the opportunities and challenges of developing and embedding lived experience in their organisations.

We heard that that lived experienced roles could support a more progressive and advanced approach to lived experience in some projects and teams in an organisation. However such localised advances and changes in ways of working did not always translate to changes and adoption of practice across the organisation.

Equity, Inclusion and Diversity in Digital Mental Health

Several experienced interviewees expressed concern that lived experience engagement in digital mental health technology development was often not inclusive enough, and that further support is needed to ensure that diverse voices are better represented.

Interviewees were adamant that teams developing digital mental health should thoughtfully consider who is being heard and who is not being heard through lived experience engagement. However there were few examples of how diversity is being specifically fostered or how under-represented voices are sought out.

Young adults were the most common specified audience for digital mental health approaches. Lived experience engagement for young adults included lived experience panels, individual interviews and co-design groups guided by younger peer researchers.

Especially, but not only, in commercial and innovation environments there may be a priority and development focus on building digital mental health tool with the widest possible user audience. So it seems some digital projects may be initially designed with lived experience engagement which does not specifically seek out more diverse cultural and mental health experiences

We also heard that these more diverse needs around a digital tool might be considered at a later development stage. We heard some examples of how adaptations were then made to tools months or years after launch to address feedback from diverse communities. . Examples of such adaption of existing tools varied from the minimal (eg, language translation) to the more ambitious (establishing a new consumer lived experience panel).

Challenges and barriers to inclusive practice

When researchers and service developers reach out very broadly to capture lived experience input, the way in which engagement activities are designed can create barriers to participation for some groups and individuals.

For example we heard concerns that broader lived experience engagement in digital mental health often did not represent and hear voices from those at the more severe end of the mental health continuum.

The lived experience insights of those most in need can contribute deep insights into what support is effective and valued. Some lived experience experts reported seeing unhelpful assumptions about how to engage people currently struggling and most impacted by mental distress. Some interviews were concerned that digital projects too often consider such engagement with those most in need of support as challenging and even ‘problematic’.

Social and personal differences within communities also impacted the uptake and delivery of digital mental health technologies. Interviewees identified several key parameters that should be considered for inclusive engagement. These include education levels, urban versus rural location, social class and socio-economic situation, ethnicity, identification with a particular community, and social isolation.

Interviewees noted that particular care should be taken to include communities previously excluded or ostracised, such as people from specific ethnic and cultural backgrounds, as well as people with neurodiversity, people with physical disabilities and those who are socially and financially disadvantaged.

The physical location of engagement activities can create an accessibility barrier that is often overlooked. However, these can be overcome with adaptations such as working with smaller local community groups and networks, and undertaking engagement activities in familiar and trusted locations.

Interviewees expressed concern that without greater support to proactively prioritise diversity and inclusion, some perspectives would continue to be excluded and the digital tools and supports developed would be unsuitable and have very limited uptake.

Ethics Management in Digital Mental Health

Ethical considerations in research and development underpin lived experience engagement and are shared across settings. However, the specific requirements and practices do differ considerably between academic and commercial environments.

In academic settings, managing ethics approval processes for engaging with people with lived experience can be viewed as challenging and limiting. Interviewees reported that approval processes can be viewed as a barrier to authentic engagement approach where people with lived experience are partners rather than research subjects. Once a project receives ethics approval, it can become burdensome and impractical to adapt the engagement processes, as that would require additional ethics approval that delay progress.

Ethics approvals often require researchers to determine, in advance and in specific detail, how engagement will be undertaken. For example requirements might include detailing the number and format of interviews or discussion groups, and how recruitment would take place. This ‘set and forget’ system creates a distinction between researchers and research participants and can stymy more authentic and collaborative approaches to lived experience engagement such as authentic co-design, where research and project decision making is shared. Such a predetermined way of working also prevents iterative ways of working to design and develop digital ideas and solutions, as such processes do not fit well with rigid ethics requirements in academic environments.

Embedding lived experience engagement into an organisation via lived experience leadership, lived experience researchers and peer researcher roles is one way of better navigating and negotiating these ethics approval quandaries. Lived experience expertise in established and paid positions can become an internal human resources and asset for a digital mental health project.

Commercial and innovation settings can seem to offer greater flexibility in adapting engagement. Those we spoke to working in commercial settings were especially sensitive to external criticisms suggesting they were not considering or addressing the social and ethical challenges that digital technologies posed for mental health.

Several of those developing digital mental health products and solutions in commercial and innovation settings described a strong and positive corporate culture that encouraged authentic lived experience engagement and was underpinned by a commitment to making positive and valued change in mental health.

A positive organisational culture can promote ethical engagement with people with lived experience in developing digital mental health tools which. In such an organisational culture project teams are able to engage as required, and tailor their approaches to different communities and user groups.

One way of describing the thoughtful, transparent and authentic collaboration they sought with communities and people who have lived experience of mental distress could be summarised as "**working at the speed of trust**", a concept popularised in business and innovation writing and thinking.

Interviews - Limitations

We did not identify and speak to those with lived experience who were involved in research and development in ad hoc ways or who contributed primarily as participants. That would include people with lived experience who contributed through surveys, qualitative interviews and focus groups, as members of lived experience panels and those who took part in co-design activities.

Hopefully there are further opportunities to explore some of the opportunities and challenges we raise in this review directly with those who are and have contributed lived experience voices to research and development of digital mental health.

Review Conclusions

This report is premised on the view that active involvement of people with lived experience should not be seen as merely one of ‘stakeholder engagement’, but rather as an ethical orientation and a standard of research excellence.

This standard requires a stronger social and ethical commitment by digital mental health researchers to avoid the pitfalls of past research that was ‘done to’ and not *with* or *by* the people affected.

Even from a pragmatic perspective alone, thoughtful lived experience-oriented design is likely to result in higher quality technological innovation that better meets the needs and preferences of the imagined beneficiaries.

Without it, there is a greater likelihood of costly technologies being introduced in a misguided manner, created to address one issue without sufficient thought to genuine needs, or worse, the potential for harmful flow-on consequences.

Embracing lived experience engagement in research and development not only elevates the integrity and relevance of mental health technologies but also paves the way for solutions that transform the lives of those they are meant to assist.

Current algorithmic and data-driven initiatives in the mental health context are dominated by actors that have the most power, such as large private companies and public institutions, service providers, universities, and professional associations.

Where these entities lack attention to real-life usage and the social dimensions of the technologies they develop, their efforts are likely to be greatly limited. Sarah Carr (2020) captures this need for foundational work to identify research priorities, when she writes:

> It is not too late to involve patients, service users and carers as domain experts in AI research and discussions about the ethical use of AI [and other digital tools]. It is therefore time to assess the situation, to question those who are driving this transformative agenda forward and to listen to excluded experts – those whose lives these technologies will ultimately affect.

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Appendix A – Annotated Bibliography of Literature Selected for Full Review

Author	Year	Country	Aim	Type of Study	Main Findings
Bennett-Levy, et al.	2021	Australia	The aim of this study is to describe the transformation of a government-initiated digital mental health (d-MH) training project for Indigenous health professionals into a community-guided process through the use of community-based participatory research (CBPR) methods, and to illustrate how local Indigenous community involvement has reshaped the national government's digital mental health agenda towards a culturally relevant approach.	Descriptive and evaluative report on a community-based participatory research project.	Authors argue that using community-based participatory research (CBPR) methods helped create a shift in the project's focus to a culturally relevant Indigenous framework, the development and expansion of digital resources tailored to Indigenous social and emotional wellbeing, and successful advocacy for specific online therapy programs and resources, highlighting the power of community involvement in shaping health initiatives.
Bergin, et al.	2020	UK, USA, New Zealand, Australia	Aim: to examine existing evidence-based dgital health interventions and review how well the research literature described factors that researchers need to include in their study designs and reports to support real-world implementation. This paper is a scoping review of 30 studies concerning digital mental health interventions for children and young people (0-25 years), with a focus of prevention and early intervention.	Scoping review.	This review found that while there are continued attempts to design and evaluate DHIs for children and young people, there are several points of concern. More research is needed with younger children and those from poorer and underserved backgrounds. Co-design processes with children and young people should be recognised and reported as a necessary component within DHI research as they are an important factor in the design and development of interventions, and underpin successful adoption and implementation. Reporting the type and level of human support provided as part of the intervention is also important in enabling the sustained use and implementation of DHIs.
Berry, N; Lobban, F; Bucci, S	2019	UK (England)	This study had two aims: 1. explore service user views towards Digital Health Interventions [DHIs] for severe mental health problems; and 2. make recommendations for specific content within DHIs based on service user needs and suggestions. Methods: Qualitative interviews with eighteen people with severe mental health problems	Qualitative interviews.	Participants found DHIs acceptable due to the empowering nature of self-management and ability to take ownership of their own healthcare needs. However, concerns included the potential for digital exclusion, privacy and confidentiality and fears about DHIs being used to replace other mental health services. Service users want tools to help them self-manage their mental health, but also provide positive and recovery-

			focussed on two domains: 1) views about DHIs for severe mental health problems; and 2) ideas for future DHI content and design features. Data were analysed thematically. Paper provides rich, qualitative insight into lived experience views on digital mental health interventions.		focussed content that can be used in conjunction with other support options.
Bevan Jones, et al.	2020	UK (Wales, England, Scotland), USA, Australia, New Zealand	The aim of the study is to review the literature and practices surrounding the co-design of digital mental health technologies for children and young people. The goal is to inform practitioners and researchers about the principles, methods, and challenges of co-design in order to develop digital health technologies that are engaging, feasible, acceptable, and effective for this demographic. Additionally, the study aims to understand how co-design can involve stakeholders throughout the life and research cycle of a program and to assess its impact on the technology developed. Paper identifies 25 original articles and 30 digital mental health technologies that were designed/developed with children and young people.	Scoping and practice review.	Paper identifies 25 original articles and 30 digital mental health technologies that were designed/developed with children and young people. Notes the need for the age-appropriate approach to development of DHIs with considerations relevant to youth, and should not merely be adaptations from 'adult programmes'. Review focuses mainly on co-design during the initial development of the technology, as most studies reported only on this. The review itself contains a robust conceptual account of co-design, even as a lot of the studies reviewed have more of a user-testing and evaluation focus.
Bond, et al.	2023	UK (England)	The aim of this project was to set out to use a peer research approach to explore participants' experiences with gameChange VR therapy. This in-depth experiential exploration of user experience may inform the implementation in clinical services and future VR therapy development.	Peer Research with Interpretative phenomenological analysis (IPA) analysis.	Authors conclude that 'Automated VR can provide a therapeutic simulation that allows people diagnosed with psychosis to learn and embed new ways of responding to the situations that challenge them. An important process in anxiety reduction is enabling the presentation of stimuli that induce the original anxious fears yet allow for learning of safety. In gameChange, the interaction of anxiety and safety could be calibrated to provide a safe place to learn about fears and build confidence.'
Borghouts, et al.	2022	USA	The aim of this study was to investigate the mental health needs of the deaf and hard of hearing community and how mental health apps may be able to support these needs.	Focus group (n=10) and survey.	Findings identified a spectrum of needs for mental health apps, including offering American Sign Language and English support, increased education of mental health to reduce stigma around mental health, direct communication with a Deaf worker, and apps that are accessible to a range of community members in terms of culture, resources required, and location. Conclusions: These findings can inform

					the development of digital mental health resources and outreach strategies that are appropriate for the D/HH community.
Borghouts, et al.	2021	USA	The aim of this study is to identify common barriers and facilitators that influence user engagement with digital mental health interventions (DMHIs), by conducting a systematic review of empirical studies. This includes understanding the various factors related to the end user, the program or content offered by the intervention, and the technology and implementation environment that either impede or promote sustained interaction with DMHIs. The goal is to inform the design and development of future digital interventions to improve their effectiveness and user engagement by addressing identified barriers and leveraging facilitators.	Systematic review - 208 papers.	208 articles were included in the review, which used a variety of methodologies, including interviews, surveys, focus groups, workshops, field studies, and analysis of user reviews. Common barriers included severe mental health issues that hampered engagement, technical issues, and a lack of personalization. Common facilitators were social connectedness facilitated by the intervention, increased insight into health, and a feeling of being in control of one's own health. Authors conclude that '[a]lthough previous research suggests that DMHIs can be useful in supporting mental health, contextual factors are important determinants of whether users actually engage with these interventions. The factors identified in this review can provide guidance when evaluating DMHIs to help explain and understand user engagement and can inform the design and development of new digital interventions.'
Brannelly, T; Trenoweth, S; Tuck, J	2022	UK	The purpose of this paper 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.	Case study.	Preferences of users of a crisis recovery service-focused app included: that the app resemble a personalised journal; that the app support helping the person to remembering people to contact in crisis and support social connectedness; that the app offer/has functionality to assist with monitoring sleep, diet, medication or symptoms.
Brown, et al.	2020	Australia	The aim of this study is to enhance understanding of how a mobile application could support suicide prevention efforts by gatekeepers in Indigenous communities in Australia. Specifically, it seeks to identify the knowledge, skills, and support needs of these gatekeepers and explore how technology, particularly mobile apps, can be tailored to meet these requirements. Through participatory design workshops with Indigenous health workers and community members, the study aims to gather	Participatory design workshops.	Multiple support resources were recommended, including multi-platform options in the technology (eg, mobile applications, social media, physical tools, and a telephone hotline) and physical aspects (eg, wallet cards, regular meetings). Desired app features included culturally appropriate content on suicide intervention, training recall, integrated care, how to access gatekeeper peer support, and debriefing, Indigenous artwork, and potentially Indigenous language. Workshop participants raised barriers to technology, including lack of internet access; and the need for gatekeepers to be trained in how to use any technology that was developed. Digital technology was seen by

			insights into the roles and needs of suicide prevention gatekeepers, the technological and supporting resources that could assist them, and broader community issues impacting suicide prevention.		workshop participants as needing to be supplemented or in combination with other types of support.
Bucci et al.	2018	UK (England)	The aim of the study was to explore early psychosis service users' subjective views on digital health interventions. Young people who were experiencing early psychosis, viewed digital interventions as an acceptable resource that could aid in destigmatising access to mental health services.	Framework analysis' using 21 semi-structured interviews An expert user group helped prioritise the lines of enquiry with interviewees.	The authors note: 'In the first study of its kind, early psychosis service users' were largely positive about the potential use of DHIs supporting and managing mental health. Overall, service users felt that DHIs were a progressive, modern, and relevant platform for health care delivery. Concerns were expressed around privacy and data security and practical barriers inherent within DHIs, all of which require further attention. Future research should explore whether findings transfer to other service user groups, other technology delivery formats, and across a range of treatment modalities.'
Buus, et al.	2020	Denmark	The objective of this study was to explore different stakeholder perspectives on the MYPLAN app for suicide prevention safety planning.	Focus groups.	Not all users agreed on the benefits of involving their network in their safety planning through the app; most participants regarded assistance from clinicians as very useful when first working with a safety plan; user's personal motivation was described as a key factor as to how much the app was used; it is difficult to use the app when users are in crisis - "the red zone"; user focus groups had reservations about the app's ability to automatically share information, for instance GPS coordinates or pre-written text messages; and concerns about the sharing of personal data without context; users sometimes struggled to recognize the positive effects of seemingly banal strategies; should not be a stand-alone intervention.
Buus, et al.	2019	Denmark and Australia	Aim: to examine the negotiation of stakeholders' suggestions and contributions to the design, function, and content of the MYPLAN app and to characterize significant developments in the emerging user-involving processes. This paper builds off the previous one - participants were asked to participate in adapting the MYPLAN safety	Focus groups and user-involving workshops.	Results: The analyses identified 3 consecutive phases in the extensive development of the app: from phase 1, Suggesting core functions, through phase 2, Refining functions, to phase 3, Negotiating the finish. The user-involving processes continued to prevent closure and challenged researchers and software developers to repeatedly reconsider the app's basic user interface and functionality. It was a limitation that the analysis did not include potentially determinative

			planning app for Australian version of the app in workshops after being given access to an English language prototype of the MYPLAN app.		backstage dimensions of the decision-making process. Conclusions: The extended user involvement prolonged the development process, but it also allowed for an extensive exploration of different user perspectives and needs.
Byron, P.	2019	Australia	Aim: to consider the potential development of mental health apps for LGBTIQ+ young people and report on data from an Australian study of LGBTIQ+ young people's mental health help-seeking experiences.	Online survey, focus groups and focus testing.	Participants (aged 16–25 years) highlighted the potential value of mental health apps, yet also questioned the need for another digital intervention. Addressing stigma around mental health was seen as a greater priority for many, as was addressing the inadequate mental health information and support available to LGBTIQ+ young people through schools and mainstream health services. Participants noted that a mental health app must not only be useful, reliable and accessible but also actively sought, which was sometimes unlikely.
Carr, S.	2020	UK	This paper explores critical questions for research in and use of AI in mental health, including that which uses personal digital monitoring data for AI.	Commentary.	This is critique focuses on the use of power and power dynamics in mental health systems and the impacts on service users, patients, carers and families. The commentary considers the rise of AI in mental health research and calls for ethics frameworks that focus on public trust and address broader public concerns with the use of AI.
Chiauzzi, E.; Newell, A.	2019	USA	The aim of this review is to question the 'killer app' and condition-specific mentality of current mental health app development. The authors review the current mobile mental health app literature, identifying ways in which psychiatric patients use apps in their lives, and then exploring how these issues are experienced by a software engineer who has struggled with her bipolar disorder for many years.	Review of literature and lived experience commentary/reflection.	The authors argue that mobile apps have the potential to be harmful (inadequate, unsafe, security/privacy issues, poor quality content, led to stigma), as such, privacy issues are important for all users to be informed about. For patients with paranoia, this may be intensified, but fears about security/risk are very real. Phone use and screen time can also be addicting, individualising and isolating and cause feelings of inadequacy. More digital interventions may not always be 'the answer'. However, they argue that 'the key to effective deployment of apps in psychiatric treatment rests on the flexible use of apps rather than sole reliance on condition-specific (mental health) apps... [T]echnology should address the broad range of lifestyle challenges presented by bipolar and other mental disorders.'

Engdahl, et al.	2023	Sweden	This study aimed to describe stakeholder perceptions and the involvement of a design process during the prototype development of mWorks. mWorks is a co-design initiative to create a digital return-to-work solution for persons with common mental disorders that is acceptable and engaging for those receiving and delivering the intervention.	Co-design groups in development of prototype.	Authors conclude that 'Stakeholders' experience-based knowledge asserted that mWorks needs to empower service users by providing them with a personal support tool. To enhance return-to-work prospects, users must be engaged in a meaningful manner while focusing on their strengths and resources.'
Fortuna, et al.	2018	USA	This study examined certified peer specialists' perceptions of the barriers and facilitators to mobile health (mHealth) engagement. A total of 267 certified peer specialists from 38 states completed an online survey. Of this sample, 74 certified peer specialists completed open-ended questions.	Mixed methods study, using an online survey developed to assess certified peer specialists' perception of the barriers and facilitators of mHealth engagement among adults with SMI.	Certified peer specialists identified previously unidentified facilitators including the augmented use of certified peer specialists in combination with mHealth to improve engagement. One emerging theme identified was the belief that mHealth interventions may promote social isolation if not designed appropriately. Certified peer specialists appear to prefer using tablets instead of smartphones. Integrating certified peer specialists' perspectives of barriers and facilitators to mHealth engagement may promote initial and sustained mHealth engagement among consumers with serious mental illness. Future research using implementation science frameworks should examine these previously identified barriers and facilitators to mHealth engagement as correlates and/or predictors of engagement among service users.
Fortuna, et al.	2019	USA	The aim of this study was to present a framework that can be used as a guide for researchers and certified peer specialists to develop and implement peer-delivered mHealth interventions in community settings.	Development of a peer-led research method for developing digital mental health practices - Academic Researchers-Certified Peer Specialists mHealth Research Continuum.	Results: Overall, 4 certified peer specialists participated in all phases of intervention development and research. Individuals who participated in the Academic Researchers-Certified Peer Specialists' mHealth Research Continuum collaborated on 5 studies advancing peers' roles in services delivery using mHealth and secured grant funding from a foundation to sustain their study. The Academic Researchers-Certified Peer Specialists' mHealth Research Continuum has created a rare environment of inclusion by combining scientific expertise and certified peer specialists' expertise to achieve a shared vision. Conclusions: This study delineates a process by which academic researchers and certified peer specialists participated in community-engaged research to develop and implement peer-delivered mHealth interventions in community settings.

Fowler, et al.	2023	Australia	The aim of this narrative review is to explore how the LGBTQIA+ community has been engaged inthe design of digital mental health interventions, how content has been tailored to the LGBTQIA+ community, and features identified as important by LGBTQIA+ participants.	Narrative review.	Content tailored to LGBTQIA+ experiences, providing connection to community, and links toother relevant LGBTQIA+ resources was identified as important; the facilitation of social connectedness is important; a range of digital interventions can be useful; privacy concerns raised, privacy concerns re: having to disclose LGBTQIA+ identity as distressing, and these concerns limiting how much people engaged with an app; preference for LGBTQIA+ relevant content;
Gan, et al.	2023	Australia	This study aimed to detail the processes and activities involved in developing an adjunctive strategy for promoting engagement with LifeBuoy—a smartphone app that helps young people manage suicidal thoughts.	Design workshops and interviews.	According to the authors, this is the first study to describe the development of a technology-supported adjunctive strategy for promoting engagement with a digital intervention. It was developed by integrating perspectives from end users with lived experience of suicide with evidence from the existing literature. The development process documented in this study may be useful for guiding similar projects aimed at supporting the use of digital interventions for suicide prevention or mental health.
García, et al.	2023	Spain	The two contributions of this paper are (1) the description of an avatar creation system and the main technical details of the configuration of auditory hallucination avatars, and (2) its evaluation from both the therapists' and the patients' viewpoints. Users from several hospitals in Spain were engaged in AVATAR therapy as part of a study, and asked to design an avatar based on their auditory hallucinations, and provide feedback on an avatar creation system, with assistance from psychiatrists.	Usability/acceptability study, interview questionnaires.	Participants expressed the desire for the avatar creation system to allow for further customisability (more hair styles, clothes etc to choose from, some wanted the avatar to have a voice). 38% of the patients were afraid of the avatar, and some reported feeling threatened by it. The authors note that the avatar creation process was challenging and that most of the participants found the task difficult. In a questionnaire, while a high number of participants rated the avatar system as 'wonderful', when provided with the statement 'I feel I need to use the avatar creation system', the percentage reduced to 35%, suggesting some ambivalence about the digital intervention.
Grove, C.	2021	Australia	To discuss how the Chatbot has been developed, highlighting its participatory, co-design process with youth who are the key stakeholders to benefit from this digital tool.	Questionnaire, interviews.	The development of a mental health and wellbeing Chatbot, co-designed with youth, technology partners, and expert stakeholders, uses artificial intelligence and natural language processing to offer evidence-based resources, support, and adaptive coping strategies. Research, including interviews and surveys, informed its 'personality' and design, with the study concluding that such digital tools could potentially support the mental health of young people in secondary schools or healthcare settings.

Hopia, H; Raitio, K	2016	Finland	Aim: to explore the perceptions and experiences that mental health service users (n = 10) and healthcare professionals (n = 32) have regarding the use of gamification in mental health care.	Qualitative interviews.	Game playing could bring ambition and regularity to daily routines. Participants emphasised playing as a social activity that could connect them with peers or for social interactions in groups. Games were seen as able to provide momentary escape from stress or overwhelm. Participants felt that games should be fun and sufficient level of quality, and not too difficult or expensive. The participants also felt that the game users should be included in the development of games from the very beginning of the process. Games should not replace face to face contact, as participants wanted to receive encouragement and support from professionals.
Hollis, C., et al.	2018	UK (England)	The James Lind Alliance Priority Setting Partnership for digital technology in mental health care was established to identify research priorities that reflect the perspectives and unmet needs of people with lived experience of mental health problems and use of mental health services, their carers, and health-care practitioners. 644 participants contributed 1369 separate questions, which were reduced by qualitative thematic analysis into six overarching themes.	Qualitative thematic analysis of research question proposals, followed by online questionnaires and workshops involving 628 participants.	134 questions were verified as uncertainties suitable for research. These questions were then ranked online and in workshops by 628 participants to produce a shortlist of 26. The top ten research priorities, which were identified by consensus at a stakeholder workshop, should inform research policy and funding in this field. Identified priorities primarily relate to the safety and efficacy of digital technology interventions in comparison with face-to-face interventions, evidence of population reach, mechanisms of therapeutic change, and the ways in which the effectiveness of digital interventions in combination with human support might be optimised.
Kornfield, et al.	2022	USA	Aim: to recruit young adults with depression or anxiety symptoms to codesign a digital tool for self-managing their mental health concerns. In particular, the authors were interested in the following three questions: 1) How would young adults make decisions about adopting an automated digital mental health tool?, 2) What sorts of content do they envision that such a tool could deliver and how would they wish to navigate that content?, and 3) How should the tool deliver support and motivation to users?	Qualitative - three focus groups and phenomenological analysis.	The study indicated a preference for easy-to-use digital self-management tools that offer independence, support through personalised automated messaging, and the flexibility to engage at varying levels depending on users' mood and availability. Participants valued the potential for personalisation and experimentation within the tool but expressed a desire for the motivational tone to avoid mimicking human interaction too closely.

Ludlow, et al.	2023	Australia	Aim: to co-design a digital mental health platform that provides self-directed, tailored, and modularised treatment for young people aged 7–17 years experiencing anxiety, depression and other related problems. The authors seek to enhance the potential acceptability, usability and integration of digital platforms into youth mental health services.	Online discussion group and workshops (conducted online)	According to the authors: 'This research showcased co-design as a powerful tool to facilitate collaboration with young people in designing DMHIs. Two sets of recommendations were produced: 1) recommendations for the design, functionality, and content of youth DMHIs, supported by child- and adolescent-designed strategies; and 2) recommendations for clinicians and researchers planning to conduct co-design and intervention development research with children and adolescents.'
Majid, Shazmin; Morriss, Richard; Figueredo, Grazziela; Reeves, Stuart	2022	UK (England)	Aim: Using principles of Patient and Public Involvement (PPI) and design and HCI-oriented research approaches, the authors conducted interviews and workshops with people with lived experience of BD to explore reasons and methods for self-tracking, and challenges and opportunities for technology.	20 Co-designed workshops with 68 participants, thematically analysed using Gale et al.'s Framework Method.	Six overarching themes were identified in terms of what young people want: 1) Interactive, 2) Relatable, 3) Customisable, 4) Intuitive, 5) Inclusive, and 6) Personalised, transparent and trustworthy content. (Recommendations accompany each theme). Three recommendations made for researchers for conducting co-design and intervention development research with children and adolescents. Collaborate with end-users as partners in codesign. Utilise diverse data collection methods when working with children and adolescents. Structure co-design workshops based on participants' age.
Matanov, A; McNamee, P; Akther, S; Barber, N; Bird, V	2021	UK (England)	The aim of this study was to explore the acceptability and relevance of DIALOG+, which is a 'technology-assisted and resource-oriented intervention found effective for people with psychosis', for the treatment of chronic depression in community-based settings.	Human computer interaction design and evaluation methods.	Analysis of the combined dataset identified five overarching themes: DIALOG+ Structure; Therapeutic Communication; Reflecting and Monitoring; Empowerment and Powerlessness; and The Impact of Technology. Overall, service users and clinicians were interested in the continued use of DIALOG+ as part of routine care. Conclusions DIALOG+ was viewed as acceptable by both service users with chronic depression and their clinicians who work in community care settings, albeit with some caveats. Clinician training required significant improvements to address the issues that were referenced, most notably around support with using technology.

McClelland, GT; Fitzgerald, M	2018	UK (England)	The aim of this study was to establish the utility of a bespoke mobile app for mental health service users and clinicians.	Exploratory, qualitative design focused on eliciting views from service users who have chronic depression and community-based professionals.	Five themes about the experience of using the DIALOG+ intervention: DIALOG+ Structure; Therapeutic Communication; Reflecting and Monitoring; Empowerment and Powerlessness; and The Impact of Technology. Authors conclude that digital health technology is an extremely important asset with scope to improve people's lives when combined with behaviour change techniques. Co-design with service users, clinicians and digital technologists is critical to product design and adoption. The use of quality standard criteria and evidence-based content in app development and evaluation is essential.
Mikal J.; Hurst S.; Conway M.	2016	USA	Aim: to investigate public attitudes towards utilizing public domain Twitter data for population-level mental health monitoring using a qualitative methodology.	Social media analysis. Five, 2-h focus group interviews. Following a semi-structured protocol, 26 Twitter users with and without a diagnosed history of depression.	Focus group participants expressed a wide range of attitudes towards the use of public-domain social media “big data” in population health research, from enthusiasm, through acceptance, to opposition. Yet, there was an overall trend towards a relatively positive view of using public domain Twitter data as a resource for population level mental health monitoring, provided that results are appropriately aggregated. Key themes were: (1) a profile of respondents’ Twitter use patterns and use variability; (2) users’ privacy expectations; (3) attitudes towards social media based population-level health monitoring in general, and attitudes towards mental health monitoring in particular; (4) attitudes towards individual versus population-level health monitoring; and (5) users’ own recommendations for the appropriate regulation of population-level mental health monitoring.
Oguamanam, et al.	2023	USA	Aim: to understand the extent to which mental health apps are being adopted and satisfying the mental health needs amongst perinatal Black women through a survey of 101 pregnant and postpartum Black women in the U.S. According to the authors, the findings offer a 'detailed picture of digital mental health platform use and satisfaction amongst Black pregnant and postpartum women.	Mixed methods. Survey of 101 pregnant and postpartum Black women, which included an open-ended question to capture qualitative data.	Digital approaches to self-care are being adopted by the majority of respondents, though not necessarily formal 'mental health' technologies, even as they may be used in coping strategies. Authors promote an in-depth phenomonelogical approach to lived experience of perinatal black women in the design of digital technologies designed to assist their mental health.

Ospina-Pinillos, et al.	2019	Australia	Aim: the research used participatory design methodologies with users (young people aged 16-30 years, supportive others, and health professionals) to (1) conduct workshops to co-design and culturally adapt a 'Mental Health eClinic' into a Spanish-language version (MHeC-S); (2) inform the development of the MHeC-S alpha prototype; (3) test the usability of the MHeC-S alpha prototype; (4) translate, culturally adapt, and face-validate the MHeC-S self-report assessment; and (5) collect information to inform its beta prototype.	Workshops and app development. Participatory design methodologies with users (young people aged 16-30 years, supportive others, and health professionals.	According to the authors: 'Through a research and development process, we co-designed and culturally adapted, developed and user tested, and evaluated the MHeC-S. By translating and culturally adapting the MHeC to Spanish, we aimed to increase accessibility and availability of e-mental health care in the developing world, and assist vulnerable populations that have migrated to English-speaking countries.'
Patrickson, et al.	2023	Australia	The aim of this study is to explore the perspectives of mental health care consumers and informal carers on the integration of digital monitoring technologies with electronic medical records, focusing on their potential benefits and risks within the Australian mental health care context. Through facilitated focus group sessions, the study seeks to identify problems and solutions in areas such as access, agency, and interactions with medical practitioners, ultimately providing design insights for developing and implementing these technologies in a way that addresses concerns about stigmatisation, decision-making, and disempowerment.	The method included 'several participatory design phases: co-design workshops; knowledge translation; language translation and cultural adaptation; and rapid prototyping and user testing'.	The study identified that mental health care consumers and informal carers see potential benefits in digital monitoring technologies for proactive wellness management but express concerns about access, agency, and altered interactions with health professionals. Key findings highlight the need for improved consent procedures, flexible access, and humanised care to address fears of stigmatisation, prejudicial decision-making, and disempowerment.

Pavarini, et al.	2022	UK (England), Slovenia, Bulgaria	This study aimed to investigate young people's interest in predictive testing for mental health challenges and their attitudes towards sharing biological, psychosocial and digital data for such purpose.	Over ten facilitated focus group format sessions the participants shared their lived experience of mental health challenges, care, and recovery within the Australian context, with a focus on monitoring technologies.	Problems and solutions were outlined in the following areas—access, agency, interactions with medical practitioners, medication management, and self-monitoring. Emergent design insights include recommendations for strengthened consent procedures, flexible service access options, and humanized consumer interactions. While consumers and carers saw value in digital monitoring technologies that could enable them to take on a more proactive involvement in their personal wellness, they had questions about their level of access to such services and expressed concerns about the changes to interactions with health professionals that might emerge from these digitally enabled processes. Of key concern to the lived experience group, was "the importance of the consumer and carer co-design of DMHI, the need for flexible applications that can adapt to consumer needs, the importance of a focus upon wellness maintenance and thriving, as opposed to illness, and the need to ensure that consumers are humanized by the design, rather than being objectified as data."
Peck, et al.	2020	Australia	This paper describes the creation of a web-based digital resource designed for tablet computer use during peer work sessions to structure discussion about recovery in early psychosis.	80 UK adolescents aged 16–18 years took part in a digital role-play.	According to the authors: 'Participants saw multiple benefits in predictive testing services, but were highly selective with regard to the type of data they were willing to share. Largely due to privacy concerns, digital data sources such as social media or Google search history were less likely to be shared than psychosocial and biological data, including school grades and one's DNA. Participants were particularly reluctant to share social media data with schools (but less so with health systems)… Two core themes were identified from participants' justifications of data sharing choices: considerations around the relevance of the data source for predicting mental health issues and privacy concerns.'

Pelletier J.F.; Rowe M.; Francois N.; Bordeleau J.; Lupien S.	2013	Canada	Aim: to reports on a pilot-study that involved 120 psychiatric patients in the development of a mobile application (app) that is being used for data entry into the Signature Project data bank at the Institut universitaire en santé mentale de Montréal (IUSMM), Canada. The pilot project aimed to answer two questions regarding the participants' experience using an app: (1) Are psychiatric patients able to use the mobile application technology? and (2) How can the mobile application be improved to better meet patients' needs?	A participatory research method.	This study (n = 120) indicated that psychiatric patients are clearly capable of using a tablet computer to fill out questionnaires for quantitative data entry, and that they enjoyed this experience. Results from the focus groups (n = 27) highlight that the app could also be used by patients to communicate some personal and contextual qualitative information. This would support a holistic and person-centered approach, especially at the ER where people acutely need to describe their recent history and receive emotional support. This pilot-study has confirmed the necessity of involving patients not only in the testing of a new mobile application, but also as active contributors in the entire research and development process of a person-centered information and communication technology infrastructure. The input of participants was essential in designing the Signature Project computational procedure and making use of the app a positive and empowering experience. Participants also gave critical feedback remarks that went beyond the initial scope of the pilot-study, for example they suggested the addition of a client-clinician component.
Povey, et al.	2016	Australia	This study aimed to explore Aboriginal and Torres Strait Islander community members' experiences of using two culturally responsive e-mental health apps and identify factors that influence the acceptability of these approaches.	Questionnaire, focus groups	Findings suggest strong support for the concept of e-mental health apps and optimism for their potential. Factors that influenced acceptability related to three key themes: personal factors (eg, motivation, severity and awareness of illness, technological competence, and literacy and language differences), environmental factors (eg, community awareness, stigma, and availability of support), and app characteristics (eg, ease of use, content, graphics, access, and security and information sharing). Specific adaptations, such as local production, culturally relevant content and graphics, a purposeful journey, clear navigation, meaningful language, options to assist people with language differences, offline use, and password protection may aid uptake.

Povey, et al.	2022	Australia	This paper aims to present an in-depth account of the second phase of participatory design in the development of the Aboriginal and Islander Mental Health Initiative for Youth (AIMhi-Y) app.	Participatory design workshops	The participatory design process identified the app features preferred by young people and service providers and assessed their alignment with current recommendations from the scientific literature. Findings from the co-design process are presented across 9 app characteristic domains. Integration of findings into app design proved complex. Although most preferred features identified by young people were included to some degree, other inclusions were restricted by budget, time, and the need to integrate best practice recommendations. A process of prioritization was required. The authors concluded that, '[p]articipatory design is often cited in the development of digital mental health resources; however, methods are diverse and often lack detailed descriptions. This study reports the outcomes and strategies used to determine priorities in the second phase of the development of the AIMhi-Y app. We provide an example and the key learnings to inform others seeking to use participatory design with a similar cohort.'
Pozuelo, et al.	2023	Uganda and South Africa	Objective: to describe the user-centered development of a smartphone app that delivers behavioral activation (BA) to treat depression among adolescents in rural South Africa and Uganda and to summarize the findings from multicycle usability testing.	Usability testing, interviews, workshops	Adolescents' views revolved around four main themes: app features, cultural validity, confidentiality, and technological aspects. Limited access to mental health treatment in both study settings was a recurring theme. User participants expressed desire for the use of stories, gamification, confidentiality and for the app to be culturally relevant and appropriateness. The authors concluded that 'The Kuamsha app uniquely delivered BA for adolescent depression via an interactive narrative game format tailored to the South African and Ugandan contexts. Further studies are currently underway to examine the intervention's feasibility, acceptability, and efficacy in reducing depressive symptoms.'
Reen, Jaisheen Kour; Orji, Rita	2022	India, Canada	Aim: to create a stress and anxiety management application for working-class Indian women (people who are a part of the workforce), seeking their qualitative input.	Interviews	Participants – working class Indian women - highlighted household work, workload, and childcare responsibilities, with less time to devote to themselves, as major sources of stress/anxiety for them. Support from family, partners, salary, and the view of Indian society about mental health play a major role in people's mental health. Participants were disappointed that the important features in the app require premium subscriptions for a fee, as they did not expect mental health apps to charge them for managing their stress/anxiety.

Schouten, et al.	2022	Netherlands	The aim of this study is to identify best practices for involving people with severe mental illness (SMI) in the co-design of eMental Health technologies, to ensure that these technologies better meet their needs and preferences. Through a qualitative multi-method approach, including a systematic scoping review, expert surveys, and participant interviews, the study seeks to improve the fit between technology design and the skills, context, and preferences of people with SMI, thereby enhancing the adoption and effectiveness of eMental Health solutions.	A qualitative, multi-method approach was used, consisting of a systematic scoping review of 21 included studies, 25 co-design expert surveys and six participant interviews.	The results delivered 23 best-practices divided into four overarching aspects of co-design, namely: (1) activities to carry out before the start of a co-design study; (2) fruitful collaboration of the co-design team; (3) bespoke approach within co-design to accommodate the skills and abilities of SMI participants; and (4) mitigation of challenges surrounding power balance. The best-practices may help researchers and designers offer the SMI population a more specialized approach for co-design, which can cause the innovative output of eMH projects to be more effective and better adopted. Throughout the co-design process, more attention should be paid to the personal and clinical benefits of participation for the participants themselves.
Sien, Sang-Wha; Ahn, Jessica Y.; McGrenere, Joanna	2023	Canada	Aim: to understand concretely what types of designs for interactive technologies suit international students' mental health needs and challenges. We address the following two research questions: 1) How do international students and campus student-wellness professionals envision how technology can help the students' mental health? 2) Which designs could be helpful for international students to access the services and support they need for their mental health concerns?	Codesign workshops	The study indicated that international students negotiate a complex interplay of helpfulness, comfort, and trust in considering the design of technologies to support their mental health needs, with a need for designs that accommodate individual differences and cultural backgrounds. The development of four medium-fidelity mockups, informed by co-design sessions with international students and mental health professionals, served as a foundational step towards creating interactive technologies that improve accessibility and inclusivity for international students' mental well-being.
Slade, et al.	2024	UK (England)	The aim of this study was to evaluate the effectiveness and cost-effectiveness of the Narrative Experiences Online (NEON) Intervention, a web application providing access to a collection of mental health recovery narratives, for adults experiencing non-psychotic mental health problems, through a pragmatic parallel-group randomized trial against usual care. The primary focus was on assessing quality of life, with secondary outcomes including psychological distress, hope, self-efficacy, and meaning in life, to determine if the intervention could offer a	pragmatic parallel-group randomized controlled trial (RCT).	The study found that access to the Narrative Experiences Online (NEON) Intervention significantly improved the quality of life and presence of meaning in life for adults experiencing non-psychotic mental health problems, with a mean increase in quality of life and meaning in life scores. Additionally, the intervention was deemed cost-effective, with an incremental cost-effectiveness ratio well below the National Health Service in England's threshold, indicating that it could be a cost-effective use of health service resources.

			beneficial and economically viable addition to existing mental health services.		
Storm, M.; Venegas, M.; Gocinski, A.; Myers, A.; Brooks, J.; Fortuna, K. L.	2021	USA	The purpose of this study was to identify stakeholders' perspectives on partnering to inform the software development lifecycle of a smartphone health app intervention for people with SMI.	Qualitative - 35 semi-structured qualitative interviews with 20 mental health patients and 15 peer support specialists.	The authors identified six themes: (1) co-produce health app intervention content; (2) selection of app technology features; (3) integration of human factors in digital health apps; (4) consideration of personalized patient preferences in digital health apps; (5) identify unrecognized concerns early in the software development lifecycle; and (6) inclusion of real-world social, cognitive, and environmental contexts. They conclude that '[i]ntegration of these considerations may elucidate the partnering process to facilitate engagement among vulnerable populations that commonly disengage from mental health smartphone apps use such as people with SMI.'
Strauss, P; Morgan, H; Toussaint, DW; Lin, A; Winter, S; Perry, Y	2019	Australia	Report on attitudes towards digital games and game-based digital mental health interventions. Specific research questions included: what do trans and gender diverse (TGD) young people find appealing about digital game-based mental health interventions? What are necessary aspects of these interventions to improve uptake amongst TGD young people? Study is one component of a multistage study that aims to adapt an existing game-based intervention, SPARX, to prevent depression in TGD young people.	Focus groups	Findings include that transphobia, and anticipating it digital environment, is a big factor for trans and gender diverse young people. Many participants reported engaging in online diversionary activities when feeling distressed including social media, games and watching online media – very much showing that use of digital technology for the purpose of 'mental health'. Many participants said that they prefer chat and/or email services because it is easier to talk about their mental health issues using indirect forms of contact and easier to remain anonymous. Social media was also seen as difficult to navigate because of negative interactions with other people online, while other participants felt that expressing themselves online was safer than in face-to-face contexts. Participants were open to having a digital mental health intervention delivered as a game, especially if it was a game with good-quality playability and was not solely focused on mental health.

Torous J.; Friedman R.	2014	USA	The aim of this study was to assess the prevalence of smartphone ownership among patients with mental illness in the United States, including geriatric patients, and to evaluate their interest and willingness to use mobile applications to monitor their mental health conditions. Through surveys conducted at Beth Israel Deaconess Medical Center, the study sought to understand how mental health patients, particularly those over 60, utilize smartphones and their openness to employing technology for managing their conditions.	Survey	For mental health patients age greater than 60: -90 percent had daily access to the internet -35% owned smartphones -The mean number of smartphone application was 10 currently on their smartphones -The mean number of smartphone applications related to healthcare was 0.6 currently on their smartphones. -27% had accessed personal healthcare information on their smartphone in the last six months. -71% indicated interest in using a mobile application to track their mental health condition. -63% indicated that they would use such an application on a daily basis. Authors conclude that the results indicate that patients greater than 60 years of age have a strong interest in using smartphones and mobile applications to track their mental health conditions.
Valentine, et al.	2020	Australia	This study aimed to gain young people's perspectives on the design and implementation of a blended model of care in first-episode psychosis treatment.	Qualitative – semi structured interviews	According to the authors, 'We found that young people were very enthusiastic about the prospect of blended models of mental health care, in so far as it was used to enhance their experience of traditional face-to-face treatment but not to replace it overall. Aspects of blended treatment that could enhance clinical care were readily identified by young people as increasing accessibility, continuity, and consolidation; accessing posttherapy support; strengthening the relationship between young person and clinician; and tracking personal data that could be used to better inform clinical decision making. Future research is needed to investigate the efficacy of blended models of care by evaluating its impact on the therapeutic alliance, clinical and social outcomes, cost-effectiveness, and engagement.'
Veldmeijer, et al.	2023	Netherlands	This systematic review aims to present an overview of how service users and people with lived experience are involved in mental health care services through design approaches and to synthesize the benefits of these approaches in mental health care. It seeks to categorize the added value reported in existing studies, highlight the level of involvement of service users in the design and evaluation of digital interventions, and address the challenges faced during these processes, advocating for a more systematic and	Systematic Review - 33 papers	The authors report that: 'Most studies involved service users, primarily adults, and used various design approaches. Most of these studies aimed to design or evaluate digital interventions. Service users and people with lived experience were involved in different roles but never as decision makers. Studies that used co-design approaches exhibited the highest levels of involvement. Various added values were reported, including tailoring and testing interventions and digital interventions, improving engagement and collaboration, gathering the needs of stakeholders, and empowering participants as resourceful actors. The challenges reported were maintaining participants' continued participation throughout the study, managing the iterative nature of design, providing a safe space, balancing insights from design and

			clear reporting on collaboration and participant involvement as partners and decision makers.		medical science, and navigating design processes in medical environments.' The authors conclude that 'Future studies using design approaches in mental health care should involve participants as partners and decision makers and report on collaboration in a systematic and clear manner.'
Venegas, MD; Brooks, JM; Myers, AL; Storm, M; Fortuna, KL	2022	USA	This study aims to delve into the ethical considerations surrounding digital mental health technologies by exploring the perceptions and experiences of service users and peer support specialists on privacy, confidentiality, and security issues. Through semi-structured qualitative interviews, it seeks to uncover the barriers to engagement with digital mental health interventions and proposes the involvement of peer support specialists to enhance ethical engagement and literacy among users.	Semi-structured interviews	The authors conclude that service users face significant barriers to engaging with digital mental health interventions due to a lack of technology literacy, including a limited understanding of privacy, confidentiality, and security, while peer support specialists show higher levels of technology engagement and awareness of digital ethics. The study suggests that peer support specialists could play a crucial role in facilitating ethical engagement with digital mental health tools among service users, emphasising the need for including end-users in the development process and for stricter privacy regulations.
Walsh, et al.	2024	UK (England), South Africa	The aim of this study is to understand the mechanisms by which remote measurement technologies (RMT) for depression in young people operate, assessing their effectiveness, accessibility, and potential challenges. It seeks to offer insights into how RMT can be effectively integrated into mental health care for young people, highlighting the importance of addressing ethical, data protection, and methodological issues for their successful application.	Realist Review	The study found that remote measurement technologies (RMT) have the potential to improve depression management in young people by enabling real-time data collection, which can enhance emotional self-awareness, strengthen the therapeutic relationship, and monitor the effectiveness of interventions. However, it also identified significant challenges related to ethical considerations, data protection, and the need for standardization, suggesting that RMT's current best use is for self-monitoring and providing feedback to healthcare professionals.

Appendix B – Annotated Bibliography of Grey Literature Selected for Full Review

We undertook a rapid review method (streamlined literature review) that simply involved numerous search strings in multiple combinations. A detailed and structured search strategy is not possible regarding grey literature. Instead, we experimented with a variety of search strings, and ran a series of searches in each source. This included using modified versions of the search string in:

- Google and Google Scholar
- Open Access Theses and Dissertations,
- ProQuest Dissertations & Theses Global
- relevant reports or initiatives published by Wellcome Trust;
- SSRN

These searches return 91 studies. Following a truncated application of the Arksey and O'Malley framework for scoping reviews set out in **Appendix C**, we were left with 19 items, listed with annotation below.

As a side note, we were struck by the number of higher degree by research theses which offer a rich range of research projects in the field (eg, A. D. Bergin, 2017; Eagle, 2021; Molloy, 2021; Nicholas, 2017; O'Leary, 2023; Pine, 2022; Williams, 2023).

Author	Year	Title	Type	Summary
Australian Commission on Safety and Quality in Health Care.	2022	National Safety and Quality Digital Mental Health Standards – Guide for service providers	Report	The National Safety and Quality Digital Mental Health (NSQDMH) Standards are a set of guidelines established by the Australian Commission on Safety and Quality in Health Care. These standards aim to ensure the safety and quality of digital mental health service delivery, providing a framework for service providers to evaluate and improve their services. They are designed to support a wide range of digital mental health services, including websites, mobile apps, and other online resources that offer therapeutic interventions, information, peer support, and/or social networking to individuals seeking help for mental health conditions or for improving their mental well-being.
Bergin, Aislinn D.	2017	Digital Mental Health in the Wild: An Adapted Grounded Theory Study	Thesis	This study explores Digital Mental Health (DMH), referring to the use of digital technologies in mental health, from the perspective of users and system builders – individuals 'in the

				wild'. Using an adapted constructive Grounded Theory Methodology, it qualitatively explores DMH and how it is applied to everyday life. Interviews with users, developers and academics were supported by data collected from extant documents and observations.
Bossewitch, Jonah	2019	Brave New Apps: The Arrival of Surveillance Psychiatry	Webpage	This paper provides critical commentary about the use of Big Data to train algorithms to identify signs of mental illness. Argues that such technology rarely delivers as promised.
Bossewitch, Jonah; Brown, Lydia X. Z.; Gooding, Piers M.; Harris, Leah; Horton, James; Katterl, Simon; Myrick, Keris; Ubozoh, Kelechi; Vasquez Encalada, Alberto	2022	Digital Futures in Mind: Reflecting on Technological Experiments in Mental Health & Crisis Support	Report	Project report by a majority lived experience authorship group. They examine legal, policy, ethical, and social issues raised by digital mental health technologies. The report 'is written to promote basic standards of algorithmic and technological transparency and auditing, but also takes the opportunity to ask more fundamental questions, such as whether algorithmic and digital systems should be used at all in some circumstances—and if so, who gets to govern them. These issues are particularly important given the COVID-19 pandemic, which has accelerated the digitisation of physical and mental health services worldwide, and driven more of our lives online. ***Note: Piers Gooding was one of the co-authors of this report.***
Eagle, Tessa	2021	"Like Talking to a Person": User-Perceived Benefits of Mental Health and Wellness Mobile Apps	Thesis	This thesis examines the subjective user experience of mental health apps. This paper describes 'two thematic analyses conducted on user reviews of 39 health and wellness apps, with a deep dive into six chatbot apps, as these are increasingly developed and downloaded'. They discuss 'user-perceived benefits general to these types of apps – such as the 24/7 availability, social and motivational benefits – as well as benefits specific to apps implementing conversational agents, many pertaining to the development of some sort of advantageous relationship with a chatbot. We suggest implications for the future design and research of mental health apps.'
Gibson, Kerry	2019	What do young people want from digital support?	Presentation	Digital communication provides exciting new opportunities to engage with young people who might not otherwise make use of mental health support. To maximise this promising resource, we need a better understanding of what matters to young people in contemporary societies and how this shapes their engagement with digital resources. Based on interviews young people in New Zealand about their priorities for digital support, this webinar was aimed at professionals working with young people to understand what young people want from digital support.
Milton, Alyssa C; Am, Ingrid Ozols; Cassidy, Tayla; Jordan, Dana; Brown, Ellie; Arnautovska,	2023	Co-production of a flexibly delivered relapse prevention tool to support self-management for long-term mental health conditions	Report	This report outlines efforts to co-design a self-management intervention for mental health conditions and test the intervention with end users. The research highlights four key findings: (1) self-management tools should be flexible and well- integrated into mental health services; (2) language is important and preferences vary between individuals; (3) self-management should have the option of being supported when delivered in services; (4) digitising the intervention could allow for greater customisation and features based on

Urska; Cook, Jim; Phung, Darren; Lloyd-Evans, Brynmor; Johnson, Sonia; Am, Ian B Hickie; Glozier, Nick				the individual’s unique preferences and needs. When designing self-management mental health interventions, involving end-users from the beginning is vital to address their need for personalised and customised interventions, and choice in how interventions are delivered. A co-production approach to research and design is also recommended, where lived experience is central to informing the planning, design, delivery and evaluation of the intervention.
Molloy, Anthony	2021	Moving Toward Successful Implementation of Digital Mental Health Interventions: Improving User Attitudes and Evaluating User Behavior	Thesis	This thesis explores strategies to enhance the adoption and efficacy of digital mental health interventions by focusing on improving users' attitudes towards these technologies and rigorously evaluating their behaviours when interacting with digital interventions. This work aims to identify factors that promote engagement and adherence, ultimately contributing to the more effective implementation of digital mental health solutions.
Nalini Badloe	2021	A narrative review of community insights and experiences in the development and use of digital gateways, products and services which support population level mental health and wellbeing.	Report	This report contains a literature review into community knowledge, attitudes, experiences and needs in developing and using DMHIs for population level mental health and wellbeing. This study was designed in collaboration with Beyond Blue to specifically address a gap in their understanding on the topic of focus. Comprehensive and systematic searching of published and grey literature identified 28 papers for inclusion. After rigorous critical appraisal the literature was thematically analysed. The research aims drove this process. The literature unveiled common themes of DMHI features that were associated with positive user attitudes and knowledge. These were the DMHI accessibility, functionality, credibility and validity, and its position in the wider health system. User needs and positive experiences with DMHIs were associated with the ability to tailor the experience, to connect with others, to access practical resources, and DMHIs that had been created through a co- design process. Co-design processes were highlighted as particularly effective to ensure DMHIs meet user needs, particularly when target groups were meaningfully engaged with a representative sample.
National Institute for Health and Care Research	2022	Mental health research service user and carer involvement 2022 award winners announced	Document	National Institute for Health and Care Clinical Research Network, the McPin Foundation and MQ: Mental Health Research, award reporting. The award is for the achievements of study teams who actively seek to involve carers and service users at each stage of the research process. The award for personal experience as a recovery resource in psychosis were the ‘Narrative Experiences Online (NEON) Programme’. ‘The NEON programme evaluates whether having online access to people’s real-life stories of recovery from mental health problems can be helpful for people affected by mental health problems. The different NEON studies are aimed at: those with psychosis related mental health problems, those with non-psychosis related mental health problems and people who self-identify as informal carers for those affected by mental health problems.’

Nicholas, Jennifer	2017	Young adults’ perspectives on using smartphone apps for bipolar disorder self-management	Thesis	This thesis seeks to examine consumers’ perspectives on mHealth and self-management for bipolar disorder, particularly in young people. The thesis examined four objectives across three studies, resulting in four published papers. Study 1 used a mixed-methods online survey to examine what young people with bipolar disorder currently do to manage their mental health and their thoughts about the potential use of smartphone apps for this purpose. Study 2 adapted a systematic review methodology to assess the features, functions, and quality of available apps for bipolar disorder. Study 3 employed a qualitative methodology to examine data from app store reviews to understand what users of bipolar disorder apps thought of them.
O'Leary, Teresa Kenyon	2023	Co-design and evaluation of a smartphone-based mental health promotion and anti-stigma embodied conversational agent for church-affiliated Black adults	Thesis	‘This dissertation investigates using a smartphone-based Embodied Conversational Agent (ECA) counselor to reduce mental health stigma in the community to support mental health care-seeking intentions. Given the importance of religion in the lives of many African Americans and pre-existing close social relationships, this work was centered in predominately Black and African American faith communities. My dissertation research is the culmination of four years of community-engaged work in predominantly Black churches in Boston.’
Pine, Russell	2022	Developing, Co-Designing and Testing a New Approach in Digital Mental Health for Young Adolescents: Match Emoji, a Casual Video Game Adapted for Mental Health and Well-Being	Thesis	This study examined ‘the potential of casual video games to enhance mental health and well-being among young adolescents. I undertook a stepwise series of studies exploring existing literature, establishing interest from young adolescents and adult stakeholders, and developing and testing Match Emoji, a casual video game adapted to enhance mental health and well-being’.
Rethink Mental Illness	2022	Summary paper: Engaging experts by experience about the role of digital technology in the future of mental health care	Report	This paper highlights the insights and perspectives of individuals with lived experience of mental health issues regarding the integration of digital technology into mental health care. The report outlines key areas where digital technology could enhance access to services, personalisation of care, and self-management of conditions, while also addressing concerns related to privacy, accessibility, and the risk of exacerbating inequalities. Through consultations with experts by experience, the report advocates for a balanced approach that leverages the advantages of digital innovations without losing sight of the importance of human connection and tailored support in mental health care.
Stop Oxevision Contributors	2024	Stop Oxevision: Lived Experience	Webpage	The StopOxeVision campaign is promoted by a group of UK service user activists focused on raising concerns and advocating against the use of what it describes as intrusive surveillance technology in mental health settings, specifically targeting the deployment of Oxehealth's digital care assistant technology. Oxehealth's system, which includes cameras installed in psychiatric patients' rooms to monitor vital signs and behaviours without physical checks, has been criticized for potential privacy intrusions and ethical issues. This website provides first person accounts that criticise the technologies.

Sue Muller	2020	National Community Consultation Program Final Report. Lived Experience leading the exploration of how digital products and engagement change the way people experience mental health care and well-being.	Report	Presents the findings from a comprehensive consultation process involving individuals with lived experience of mental health issues in Australia. It highlights the potential of digital tools to enhance access to care, improve the quality of support, and empower individuals in managing their mental health, but also addresses concerns related to privacy, the digital divide, and the need for digital solutions to be inclusive, accessible, and respectful of users' rights and preferences. By centring the voices of people with lived experience, the report offers valuable insights into how digital mental health services can be designed and implemented to meet the diverse needs of users, ensuring that technology serves as a complement to traditional care models rather than a replacement.
Ting, Louise	2023	Research Cycle. Engaging Patients and the Public - Datamind	Webpage	Effective Patient and Public Involvement and Engagement (PPIE) in research requires planning and a considered approach. Members of the public (patients, carers, service users and communities) should be included wherever possible, as their input will help research to be more relevant, ethical, and accessible. The public can be involved at every stage of the research process. The earlier they are included, the greater the impact they can have. The webpage entails a diagram created by a Public Contributor with lived experience. She is a member of the DATAMIND Super Research Advisory Group and also provides PPIE advice to other research organisations around the UK. This diagram was produced with their support, including consultation with other Public Contributors. It is intended as a visual resource to help researchers consider how they can involve people, and illustrates how these activities align with the research cycle.
Williams, Lucretia A.	2023	Design and Evaluation of Culturally Responsive Digital Mental Health Technology for Racial-Ethnic Minorities	Thesis	‘This dissertation examines the presence of cultural responsiveness in digital mental health solutions for three different racial-ethnic minority groups. Through four research studies, I explore the ways in which social determinants of health impact how racial-ethnic minorities engage and seek digital mental health support, provide evidence of how community-based research is beneficial for ideating and designing for cultural responsiveness, and emphasize the ways researchers can design accessible, scalable, and inclusive digital mental health solutions… Overall, these studies show that designing culturally responsive mental health solutions should be implemented to help reduce mental health disparities for racial-ethnic minority populations and the possible ways it can be accomplished. The findings highlight the importance of designing solutions that consider the unique needs and challenges of diverse communities to ensure increased access and appropriate support.’
Woebot	2022	Woebot Health Research Publications and works in progress NOVEMBER 2022	Report	Outlines the latest findings and ongoing studies related to Woebot, a mental health chatbot designed to offer psychological support through conversational AI. It details the effectiveness of Woebot in reducing symptoms of depression and anxiety among users,

				highlights user engagement statistics, and discusses future research directions aimed at improving the chatbot's capabilities and understanding its impact on various populations.

Appendix C – Detailed Methods and Scholarly Literature

Search Strings

The scholarly literature review component of this report adapted a scoping review methodology to undertake a broad exploration of the literature. This section will provide a truncated account of the methods.

Scoping reviews are useful for surveying a potentially large and interdisciplinary field that has not yet been comprehensively reviewed, and for which clarification of concepts is required (Peters et al., 2015). This characterisation fits research on digital mental health technologies. The scoping review method is also appropriate due to its ability to capture literature from several sources and disciplines with varying terminology and conceptual boundaries.

We adapted the Arksey and O'Malley framework for scoping reviews (Arksey & O'Malley, 2005). The framework involves 5 steps, or 'framework stages':

1) identifying the research question,

2) identifying relevant studies,

3) study selection,

4) charting results, and

5) collating, summarising and reporting results.

A description of each step is outlined below.

We drew on elements of the Joanna Briggs Institute scoping review methodology (Peters et al., 2020) and PRISMA extension for scoping reviews (Tricco et al., 2018) to support the rigor of our methods. Study selection included all study types, and the overall aim was to chart data according to key issues, themes and gaps (Arksey & O'Malley, 2005). Materials were analysed using conventional content analysis.

Identifying the Research Question (Step 1)

We sought to identify all studies within a selective sampling frame (Cooper, 2010) that answered the following research questions:

1. What are the perspectives and priorities for research of people with lived experience on digital mental health technologies, products, interventions, and so on?
2. What has been the involvement of people with lived experience in the design and development of digital mental health technologies, products, interventions, and so on?
3. What are good practices regarding lived experience involvement in digital mental health technologies, products, interventions, and so on?

These questions, which were refined in consultation with staff at the Wellcome Trust, were chosen to maintain a wide approach in order to generate breadth of coverage (Arksey & O'Malley, 2005).

Identifying Relevant Studies (Step 2)

A rapid or streamlined literature search was used. We started with a search string that emerged from our initial review of the literature (noted in background section) and refined it in collaboration with staff at the Wellcome Trust. We also undertook handsearching of relevant reference lists of included papers to identify other papers for inclusion. The search was not exhaustive, due to the breadth of the topic area – but it did aim to be inclusive of diverse disciplines and varying conceptualisations of the topic.

The following search strings emerged through experimentation and refinement with input from the Wellcome Team. The strings were applied in keyword fields, or abstract and title fields (where available in each database).

> ("mobile phone" OR “mobile application” OR "Online therapy" OR “online program*” OR Internet OR "web-based" OR "Wearable technology" OR smartphone OR “smartphone app” OR "cell phone" OR "mobile app*" OR "internet-based" OR "Internet-delivered” OR “digital media" OR "digital technology" OR "app-based" OR “Digital mental health interventions” OR “digital intervention*” OR “digital-based intervention*” OR “mHealth app*” OR virtual OR videogame OR gaming) AND (“mental health" OR “bipolar” OR “schizophrenia” OR “behavioral health” OR depression OR anxiety OR psychosis OR “psychosocial disabilit*” OR suicid* OR “mental illness” OR psychiatry OR “mental disorder”) AND (consumer* OR user* OR participant* OR patient* OR “lived experience” OR “lived-experience” OR client OR “experts by experience”) AND (barriers OR consult* OR experience OR feedback OR Ux OR engage* OR “user review*” OR viewpoint* OR perception OR perspective OR involvement OR engagement OR attitudes OR codesign)

This string was adapted for diverse databases, discussed shortly.

A date limit was applied to the search, encompassing literature from **1st January 2013 to the 30th of January 2024**. We justify this because initial search results indicated a tapering off of results from around 2014 and 2013. There is a risk that some important material concerning things like teletherapy that occurred before this time would be excluded. However, we felt reasonably confident that, for the purposes of our adapted scoping review, literature from 2013 onward would reflect most pre-existing literature concerning the views of people with lived experience the use of digital technologies in healthcare.

A language filter was applied to focus on English-language results, which was applied for pragmatic reasons to reduce the scope and complexity of the search. (For more on limitations, see the Discussion section below).

After an extensive search, **5,434 relevant peer-reviewed research studies** were identified for the study selection stage.

The following table (Table 1) provides the initial phases of the search strategy, listing the diverse indexed and non-indexed databases that were searched, and the results they generated.

Table 1: Database Search Results

Database	Results
Indexed Databases	
PubMed	1,404
ProQuest	280
APA PsycInfo	246
EMBASE	1,081

Web of Science	1,331
Non-indexed Databases	
Google Scholar	105
ACM	769
Scopus	86
Cochrane Library	73
Additional records identified through other sources	60
Total	**5,434**
Duplicates and retracted studies removed	**4,850**

A detailed table of search strings adapted for each database presented below (Table 2).

Table 2: Search Strings for Review of Scholarly Papers

Database	**Search String**
Indexed Databases	
Embase ovid	Step one: ("mobile phone" OR “mobile application” OR "Online therapy" OR “online program*” OR Internet OR "web-based" OR "Wearable technology" OR smartphone OR “smartphone app” OR "cell phone" OR "mobile app*" OR "internet-based" OR "Internet-delivered” OR “digital media" OR "digital technology" OR "app-based" OR “Digital mental health interventions” OR “digital intervention*” OR “digital-based intervention*” OR “mHealth app*” OR virtual OR videogame OR gaming).mp Step two: (consumer* OR user* OR participant* OR patient* OR “lived experience” OR “lived-experience” OR client OR “experts by experience”).mp Step three: (barriers OR consult* OR experience OR feedback OR Ux OR engage* OR “user review*” OR viewpoint* OR perception OR perspective OR involvement OR engagement OR attitudes OR codesign).mp Step four: *mental health/ Step five: *mental disease/ Step six: 4 or 5 step seven: 1 and 2 and 3 and 6 Step eight: limit 7 to (english language and yr="2013 - 2024")
Pubmed	("mobile phone"[mesh] OR “mobile application”[mesh] OR "Online therapy"[mesh] OR “online program*”[mesh] OR Internet[mesh] OR "web-based"[mesh] OR "Wearable technology"[mesh] OR smartphone[mesh] OR “smartphone app”[mesh] OR "cell phone"[mesh] OR "mobile app*"[mesh] OR "internet-based"[mesh] OR "Internet-delivered”[mesh] OR “digital media"[mesh] OR "digital technology"[mesh] OR "app-based"[mesh] OR “Digital mental health interventions”[mesh] OR “digital intervention*”[mesh] OR “digital-based intervention*”[mesh] OR “mHealth app*”[mesh] OR virtual[mesh] OR videogame[mesh] OR gaming[mesh]) AND (“mental health"[majr] OR depression[majr] OR anxiety[majr] OR psychosis[majr] OR “psychosocial disabilit*”[majr] OR suicid*[majr] OR “mental illness”[majr] OR psychiatry[majr] OR “mental disorder”[majr]) AND (consumer* OR user* OR participant* OR patient* OR “lived experience” OR “lived-experience” OR client OR “experts by experience”) AND (barriers OR consult* OR experience OR feedback OR Ux OR engage* OR “user review*” OR viewpoint* OR perception OR perspective OR involvement OR attitudes OR codesign)
Proquest central	summary((barriers OR consult* OR experience OR feedback OR Ux OR engage* OR “user review*” OR viewpoint* OR perception OR perspective OR involvement OR attitudes OR codesign)) AND summary((consumer* OR user* OR participant* OR patient* OR “lived experience” OR “lived-experience” OR client OR “experts by experience”)) AND subject(Usability OR "User experience") AND subject("mobile phone" OR “mobile application” OR "Online therapy" OR “online program*” OR Internet OR "web-based" OR "Wearable technology" OR smartphone OR “smartphone app” OR "cell phone" OR "mobile app*" OR "internet-based" OR "Internet-delivered” OR “digital media" OR "digital technology" OR "app-based" OR “Digital mental health interventions” OR “digital intervention*” OR “digital-based intervention*” OR “mHealth app*” OR virtual OR videogame OR gaming) AND subject(“mental health" OR “mental disorder” OR “bipolar” OR “schizophrenia” OR “behavioral health” OR depression OR anxiety OR psychosis OR “psychosocial disabilit*” OR suicid* OR “mental illness” OR psychiatry)
Web of Science	Step one: TS=(digital mental health interventions) Step two: (AB=(barriers OR consult* OR experience OR feedback OR Ux OR engage* OR “user review*” OR viewpoint* OR perception OR perspective OR involvement OR attitudes OR codesign)) AND (AB=((consumer* OR user*

	OR participant* OR patient* OR “lived experience” OR “lived-experience” OR client OR “experts by experience”)))) Step three: Combine 1 and 2 Step four: Limit to 2013 to date
APA PsycInfo	Step one: exp Mental Health/ and exp Digital Interventions/ (207) Step two: digital mental health resources/ (65) Step three: 1 or 2 (266) Step four: Limits: Date 2013-2023 and English Language (246) Note: there does not seem to be common keywords or subjects for the relevant hits within the 243 results: authors use ‘codesign’, ‘engagement of community members to inform design’, etc. Terms varied considerably.
Non-indexed Databases	
ACM	[[All: "mobile phone"] OR [All: "mobile application"] OR [All: "online therapy"] OR [All: "online program*"] OR [All: internet] OR [All: "web-based"] OR [All: "wearable technology"] OR [All: smartphone] OR [All: "smartphone app"] OR [All: "cell phone"] OR [All: "mobile app*"] OR [All: "internet-based"] OR [All: "internet-delivered"] OR [All: "digital media"] OR [All: "digital technology"] OR [All: "app-based"] OR [All: "digital mental health interventions"] OR [All: "digital intervention*"] OR [All: "digital-based intervention*"] OR [All: "mhealth app*"] OR [All: virtual] OR [All: videogame] OR [All: gaming]] AND [[Abstract: "mental health"] OR [Abstract: "bipolar"] OR [Abstract: "schizophrenia"] OR [Abstract: "behavioral health"] OR [Abstract: depression] OR [Abstract: anxiety] OR [Abstract: psychosis] OR [Abstract: "psychosocial disabilit*"] OR [Abstract: suicid*] OR [Abstract: "mental illness"] OR [Abstract: psychiatry] OR [Abstract: "mental disorder"]] AND [[Abstract: consumer*] OR [Abstract: user*] OR [Abstract: participant*] OR [Abstract: patient*] OR [Abstract: "lived experience"] OR [Abstract: "lived-experience"] OR [Abstract: client] OR [Abstract: "experts by experience"]] AND [[Abstract: barriers] OR [Abstract: consult*] OR [Abstract: experience] OR [Abstract: feedback] OR [Abstract: ux] OR [Abstract: engage*] OR [Abstract: "user review*"] OR [Abstract: viewpoint*] OR [Abstract: perception] OR [Abstract: perspective] OR [Abstract: involvement] OR [Abstract: engagement] OR [Abstract: attitudes] OR [Abstract: codesign]] AND [E-Publication Date: (01/01/2013 TO 31/12/2023)]
Google Scholar	allintitle: mental health user ("mobile" OR "Online" OR Internet OR web OR Wearable OR smartphone OR "cell phone" OR "mobile app *" OR digital OR "app based" OR “mhealth app*” OR digital OR virtual OR videogame OR gaming) 2013- allintitle: suicidal user ("mobile" OR "Online" OR Internet OR web OR Wearable OR smartphone OR "cell phone" OR "mobile app *" OR digital OR "app based" OR “mhealth app*” OR virtual OR videogame OR gaming) 2013- allintitle: suicide user ("mobile" OR "Online" OR Internet OR web OR Wearable OR smartphone OR "cell phone" OR "mobile app *" OR digital OR "app based" OR “mhealth app*” OR virtual OR videogame OR gaming) 2013-
Scopus	(ALL ((consumer* OR user* OR participant* OR patient* OR "lived experience" OR "lived-experience" OR client OR "experts by experience") .mp) AND PUBYEAR > 2012 AND PUBYEAR < 2024) AND (ALL ((barriers OR consult* OR experience OR feedback OR ux OR engage* OR "user review*" OR viewpoint* OR perception OR perspective OR involvement OR engagement OR attitudes OR codesign) .mp) AND PUBYEAR > 2012 AND PUBYEAR < 2024) AND ((ALL (("mobile phone" OR "mobile application" OR "Online therapy" OR "online program*" OR internet OR "web-based" OR "Wearable technology" OR smartphone OR "smartphone app" OR "cell phone" OR "mobile app*" OR "internet-based" OR "Internet-delivered" OR "digital media" OR "digital technology" OR "app-based" OR "Digital mental health interventions" OR "digital intervention*" OR "digital-based intervention*" OR "mHealth app*" OR virtual OR videogame OR gaming) .mp) AND PUBYEAR > 2012 AND PUBYEAR < 2024) AND (ALL ((consumer* OR user* OR participant* OR patient* OR "lived experience" OR "lived-experience" OR client OR "experts by experience") .mp) AND PUBYEAR > 2012 AND PUBYEAR < 2024) AND (ALL ((barriers OR consult* OR experience OR feedback OR ux OR engage* OR "user review*" OR viewpoint* OR perception OR perspective OR involvement OR engagement OR attitudes OR codesign) .mp) AND PUBYEAR > 2012 AND PUBYEAR < 2024)) AND ((KEY (*mental AND health/) AND PUBYEAR > 2012 AND PUBYEAR < 2024) OR (KEY (*mental AND disease/) AND PUBYEAR > 2012 AND PUBYEAR < 2024)) AND (LIMIT-TO (SUBJAREA , "COMP"))
Cochrane Library	("mobile phone" OR "mobile application" OR "Online therapy" OR (online NEXT program*) OR Internet OR "web-based" OR "Wearable technology" OR smartphone OR "smartphone app" OR "cell phone" OR (mobile NEXT app*) OR "internet-based" OR "Internet-delivered" OR "digital media" OR "digital technology" OR "app-based" OR "Digital mental health intervention" OR (digital NEXT intervention*) OR "digital-based intervention*" OR (mHealth NEXT app*) OR virtual OR videogame OR gaming) AND ("mental health" OR "bipolar" OR "schizophrenia" OR "behavioral health" OR depression OR anxiety OR psychosis OR (psychosocial NEXT disabilit*) OR suicid* OR "mental illness" OR psychiatry OR "mental disorder") AND (consumer* OR user* OR participant* OR patient* OR "lived experience" OR "lived-experience" OR client OR "experts by experience") AND (barriers OR consult* OR experience OR feedback OR Ux OR engage* OR (user NEXT review*) OR viewpoint* OR perception OR perspective OR involvement OR engagement OR attitudes OR codesign)

Study Selection (Step 3)

The process of identifying the inclusion/exclusion criteria below was settled over several discussions between the co-authors, as well as advisory meetings with Wellcome representatives (See Table 3) (Arksey & O'Malley, 2005).

Table 3. Inclusion/exclusion criteria

Inclusion Criteria	Exclusion Criteria
Study undertaken in a mental health context OR with application to a mental health context. Study that includes in some way, the perspective of people with lived experience whether as research participant, research lead or co-author, advisor, or in other ways in which views can be incorporated into the study, including commentary pieces, where written from a lived experience perspective. Text available in English. Study related broadly to the use of digital technologies in mental health interventions, products, services, treatments, and so on, including use of big data, internet technology, artificial intelligence, apps, sensors, smart technology, and other contemporary technologies of automation, digitisation, computation, and so on. Study provides rich qualitative insights into lived experience viewpoints on digital mental health (particularly of lived experience perspectives that are often overlooked), such as through the use of qualitative interviews, focus groups, consultation or co-design workshops.	Studies focused on other health conditions. Application of data science methods to clinical data collected via clinical technologies (for example, application of data science methods to MRI data). Data science methods paper with no specific real-world application or objective. Application of data science methods to psychiatric research in very general terms. Studies applied to animals or animal models. Studies focused on eating disorders. Studies where there is insufficient lived experience input or where such input is unclear, such as research methods that only involve people with lived experience as participants through clinical assessment tools, acceptance or experience surveys, or stakeholder group consultations in which only one of a large group of stakeholders has a designated lived experience position.

Systematic reviews, according to the PRISMA criteria described by David Moher and colleagues (2009), would include a full-text review after duplicates were removed, to assess all articles for eligibility. We did not take this step, as the initial screening and eligibility phases of the review could take place by reviewing the abstracts/titles. This adaptation enabled us to review a large body of work in a rapidly expanding field.

This process resulted in a total of 50 papers included in the review. Figure 1 provides a PRISMA diagram that sets out the process of exclusion for our adapted study.

The Prisma Diagram is Each box, from left to right, top to bottom, represents a step along the way of how we reached the papers included in our narrative summary. The Prisma Diagram is set out on page 25. Each box, from left to right, top to bottom, represents a step along the way of how we reached the papers included in our narrative summary. These ‘PRISMA Steps’ occurred as follows.

- **PRISMA STEP 1:** Records identified through database search (n = **5,434**)
- **PRISMA STEP 2**: Additional records identified through other sources, such as citations identified in the reference section of other papers or papers suggested by interviewees (n = **61**)
- **PRISMA STEP 3:** Removed Duplicates + Retracted Items (n = **4,856**)
- **PRISMA STEP 4:** Records screened (n = **707**)
- **PRISMA STEP 5:** Records excluded (n = **4,143**)

- **PRISMA STEP 6:** Full-text articles assessed for eligibility (n = **89**)
- **PRISMA STEP 7:** Full-text articles excluded, out of scope (n = **39**)
- **PRISMA STEP 8:** Studies included in qualitative synthesis (n = **50**)

Steps 4 and 5 were completed as follows. The authors took a random sample of 100 of the 4,850 papers emerging from Step 3. The three authors separately undertook screening and exclusion. We then compared answers and in the few instances of divergence of perspectives, discussed the application of exclusion/inclusion criteria, refining our application, and achieving consensus. The papers were then divided up between the three authors to expedite screening and seclusion. Regular consensus meetings were held throughout screening and exclusion to promote consistent application of inclusion/exclusion criteria.

At Step 6, PK and PG undertook full-text analysis of the remaining 89 articles, and again held regular consensus meetings to discuss any divergences in opinion in applying the criteria. Articles were then charted to assist with thematic analysis.

Charting Results (Step 4)

Through an initial deductive analysis of the abstracts, and discussions between the researchers, we identified several key issues and themes through which to consider the broad research field. We analysed the material to determine how lived experience views were being gathered, discussed, and presented. Conventional content analysis was undertaken. We sought a uniform approach to the 50 studies included in the review. However, in practice it was often impossible to extract all the information required where research reports used varying terminology, concepts, and disciplinary approaches, and potentially failed to include relevant material (for example, some of the papers used terms like ‘co-design’ in ways that were not defined or used very generally, as we discuss).

Appendix D – Additional insights and literature shared by interviewees

We are grateful to the interviewees who shared their valuable time:

- Emma Elder, Black Dog Institute, Australia
- Kylie Bennet, Ecouch and Mindspot, Australia
- Chris Boyd Skinner, Australian Digital Health Authority
- Karen Fortuna, Dartmouth College, USA
- Steve Gilbert, Thalamos, UK
- Smriti Josh, Digital mental health adviser, India
- Shona Lewi, Orygen, Australia
- Kate Larsen, Mind, Australia
- Michael McTerna, Voxio
- Dan Thorpe, Wellways, Australia
- Robert Walker, Dartmouth College, USA

Insights Highlighted by Interviewees

Through these interviews several published articles and other insights and tools were mentioned which are relevant context to considering what they shared and whilst some of these were captured through our scholarly and grey literature search there are additional resources to note.

Boyd-Skinner, Christopher. 2022. 'Driving Safety and Quality Improvements in Digital Mental Health Service Provision in Australia. International Perspectives on Digital Mental Health, Digital Therapeutics, and Prescribing and Reimbursement Models'. The Winston Churchill Memorial Trust.

Crowe-Cumella, Hannah, Joanne Nicholson, Adrian Aguilera, Terika McCall, and Karen L. Fortuna. 2023. 'Editorial: Digital Health Equity'. *Frontiers in Digital Health* 5: 1184847. https://doi.org/10.3389/fdgth.2023.1184847.

'Research Cycle: Engaging Patients and the Public'. 2023. Datamind Super Research Advisory Group. https://datamind.org.uk/patients-and-public/research-cycle-engaging-patients-and-the-public/.

Fortuna, Karen, Paul Barr, Carly Goldstein, Robert Walker, LaPrincess Brewer, Alexandra Zagaria, and Stephen Bartels. 2019. 'Application of Community-Engaged Research to Inform the Development and Implementation of a Peer-Delivered Mobile Health Intervention for Adults With Serious Mental Illness'. *Journal of Participatory Medicine* 11 (1): e12380. https://doi.org/10.2196/12380.

Fortuna, Karen L., Arya Kadakia, Theodore D. Cosco, Armando Rotondi, Joanne Nicholson, George Mois, Amanda L. Myers, et al. 2023. 'Guidelines to Establish an Equitable Mobile Health Ecosystem'. *Psychiatric Services* 74 (4): 393–400. https://doi.org/10.1176/appi.ps.202200011.

Fortuna, Karen L., Anjana Muralidharan, Carly M. Goldstein, Maria Venegas, Joseph E. Glass, and Jessica M. Brooks. 2020. 'Certified Peer Specialists' Perspective of the Barriers and Facilitators to Mobile Health Engagement'. *Journal of Technology in Behavioral Science* 5 (4): 318–23. https://doi.org/10.1007/s41347-020-00138-7.

Fortuna, Karen L., Amanda Myers, Jessica Brooks, Caroline Collins-Pisano, Skyla Marceau, Sarah Pratt, Kathy Lyons, et al. 2021. 'Co-Production of the Quality of Patient-Centered Outcomes Research Partnerships Instrument for People with Mental Health Conditions'. *Patient Experience Journal* 8 (1): 148–56. https://doi.org/10.35680/2372-0247.1533.

Fortuna, Karen L, John A Naslund, Jessica M LaCroix, Cynthia L Bianco, Jessica M Brooks, Yaara Zisman-Ilani, Anjana Muralidharan, and Patricia Deegan. 2020. 'Digital Peer Support Mental Health Interventions for People With a Lived Experience of a Serious Mental Illness: Systematic Review'. *JMIR Mental Health* 7 (4): e16460. https://doi.org/10.2196/16460.

Fortuna, Karen L., Maria Venegas, Emre Umucu, George Mois, Robert Walker, and Jessica M. Brooks. 2019. ‘The Future of Peer Support in Digital Psychiatry: Promise, Progress, and Opportunities’. *Current Treatment Options in Psychiatry* 6 (3): 221–31. https://doi.org/10.1007/s40501-019-00179-7

Kuhn, Eva, Maham Saleem, Thomas Klein, Charlotte Köhler, Daniela C. Fuhr, Sofiia Lahutina, Anna Minarik, et al. 2024. ‘Interdisciplinary Perspectives on Digital Technologies for Global Mental Health’. *PLOS Global Public Health* 4 (2): e0002867. https://doi.org/10.1371/journal.pgph.0002867.

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