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Consumer and Carer Views on Digital Mental Health Monitoring Technologies and Related Care Processes: Results from a Co-Design Consultation

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CONSUMER AND CARER VIEWS ON DIGITAL MENTAL HEALTH MONITORING TECHNOLOGIES AND RELATED CARE PROCESSES: RESULTS FROM A CO-DESIGN CONSULTATION

Full research paper

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Abstract

Objective: Advancements in digital monitoring solutions promise to enhance mental health care but can inadvertently also contribute to further stigmatisation and fear of disempowerment. This paper aims to identify problems and solutions from people with lived experiences of mental illnesses.

Methods: Data was gathered during a co-design study with 9 participants (consumers and carers) involving 10 focus group facilitated sessions (2 hours) where participants discussed two technology-enabled mental health monitoring solutions, contextualised to their broader lived experience.

Results: Participants outlined problems and solutions in access, agency, interactions with medical practitioners, medication management and self-monitoring. Design insights include recommendations for strengthened consent procedures, flexible service access options, humanised consumer interaction and mutual responsibility in the digital therapeutic relationship.

Conclusions: Whilst consumers and carers saw value in digital monitoring technologies, they had questions about their level of access to such services, and how they might change their interactions with health professionals.

Keywords Co-design, Mental Health Lived Experience, Digital Mental Health, Electronic Medical Records

1 Introduction

The potential advantages of mobile, connected, enhanced, and augmented digital technologies for mental health care are well recognised (Clarke and Yarborough 2013; Luxton et al. 2011; Price et al. 2014). A core aspect of their appeal in mental health care is the granularity of the data, as well as the ready linkage and streamlined processing of previously disparate information (Ben-Zeev and Badiyani 2017; Free et al. 2013; Torous et al. 2016). Whilst technology is no replacement for interpersonal therapeutic care, these digital capacity advancements can extend mental health care well beyond clinical consultation rooms.

Many digital health technologies can be "broadly classified as monitoring to gain a better understanding of illness, clinical assessment, and intervention" (Batra et al. 2017: 237). Monitoring of consumer mental health and wellbeing is already a feature of contemporary clinical mental health care, indeed in many cases it is a legal clinical care responsibility. Digital mental health interventions that streamline monitoring processes can reduce organizational labour and can also potentially scale easily at low cost (Roland et al. 2020).

Mobile applications that enable consumers to regularly self-monitor and report treatment outcomes have created opportunities to potentially improve those outcomes in a variety of ways (Lupton 2013; Thompson 2021). Real-time longitudinal patient data can guide diagnosis and treatment decisions or facilitate timely interventions before a crisis develops (Hermes et al. 2020; Schneeweiss and Patorno 2021; Thompson 2021; Watson et al. 2020), whilst remote on-demand provision of wellbeing monitoring and recovery support allows for more consistent and accessible treatment (Brewster et al. 2021; Eisenstadt et al. 2021). Objective measures of medication adherence can also allow for better-informed treatment decisions.

Whilst the value of digital mental health services, and mobile health applications in particular is well established, nevertheless such services are still not widely used in community care settings (Lattie et al. 2020). Despite their potential value for consumers, public engagement is lacking (Chan et al. 2017; Owen et al. 2015). Many technology-enabled mental health programs have failed (Bertagnoli 2018; Gilbody et al. 2015; So et al. 2013). Problem areas include low usability, fit, engagement, knowledge and the need for more implementation support (Borghouts et al. 2021).

These results may in part be driven by the lack of consultation with mental health consumers during the design and development of digital mental health interventions, as a result of which they are not well-designed for their target consumer (Borghouts et al. 2021; Lavallee et al. 2019; Simblett et al. 2018).

Monitoring technologies necessarily implicate issues of power and agency, raising concerns that when health systems involve forms of data surveillance, or 'Dataveillance' (Simon 2005: 2) they objectify consumers by framing them as a form a data, and transforming treatment into a form of data analysis. Inevitably, consumer engagement with monitoring technologies involves a trade-off between the perceived benefits and risks of monitoring technologies (Fox et al. 2021). Consumer agency is key to optimising benefits, as well as mitigating risks, supported by co-design efforts. Agency is a key aspect of this debate, supported by co-design efforts. Agency is dependent upon the ability to make choices that have meaningful consequences, or impact, whereas co-design can support that capacity by also ensuring that consumer "desire(s) are among those they can take"(Wardrip-Fruin et al. 2009: 1).

Without a grounded understanding of the consumer lived experience, as well as the barriers and enablers of consumer engagement that emerge from this experience there is a risk that consumer needs will either not be served, or worse, the consumer experience will be further challenged as a result of such implementations (Aref-Adib et al. 2019; Granja et al. 2018). A systematic review of studies that explored consumer engagement with digital mental health interventions found that severe mental health issues, compounded by technical issues, coupled by a lack of personalisation, or low credibility hampered engagement, whilst enablers included interventions that facilitated social connectedness, as well as access to increased health insights and the enabling of a greater sense of control of one's own health (Borghouts et al. 2021). As a result, this study emphasised the importance of co-design of digital mental health interventions

Whilst the number of studies of consumer acceptance of health monitoring technologies is growing, nevertheless these attitudinal surveys and interviews do not encompass the full range of consumer experience of digital health processes, and few studies consider the specific considerations of mental health lived experience. Digital mental health care processes may feature digital tools, but also encompass broader contextual concerns and service delivery considerations which can profoundly influence the consumer's lived experience of care (Borghouts et al. 2021).

To help address these concerns, co-design with consumers is gaining prominence. A co-design approach is intended to increase the usefulness of and satisfaction with technology and, hence, improve engagement with technology (Slattery et al. 2020). Co-design, in its most optimal form, leads to results that capture the best aspects of consumer input – like acceptability, utility, and novelty – also tempered by professional insights (Trischler et al. 2018). Co-design needs to validate consumers' experiences, while also being careful to achieve design constraints (Shah et al. 2009).

Amidst a growing demand to redesign digital mental health services to be more usable, compelling and implementable (Lyon and Bruns 2019), this paper reports findings from a co-design study carried out with people with lived experiences, with the aim of collaboratively identifying potential problems and solutions in regards to use of digital monitoring processes within mental health care.

2 Research Methods

2.1 Design Context

This process was undertaken in parallel to development and implementation activities undertaken by members of the Flinders University Digital Health Research Lab. First, the pilot implementation of the Actionable Intime Insights (AI^2) project, a digital health tool designed to enable clinicians to proactively intervene in medication and appointment non-adherence with psychosocial support (Bidargaddi et al. 2021; Bidargaddi et al. 2018). Second, Mindtick — an app designed to help track outcomes and actualise therapeutic tasks in-between sessions with a therapist (Standardization 2018).

Since numerous digital mental health implementation efforts have previously failed (Lattie et al. 2020), often due to the lack of consumer input into the design of these interventions, in this study we conducted an in-depth, research and development co-design consultation, on the understanding that mental health consumers have unique insights into their lived experience which will provide invaluable guidance into their design. We went further to also invite informal carers to join that consultation on the understanding that they also have unique insights into their loved ones' day-to-day lives that are just as valuable, and even more likely to be ignored within the design process. Informal carers are people who provide care for people living with mental ill health outside of a formal employment relationship, such as family members (Van Exel et al. 2008). Informal carers not only provide invaluable support for consumer engagement but may also have their own lived experiences of mental health challenges and social isolation that are unaddressed, despite being intertwined with their care providing work.

The consumer and carer consultation offered deep contextual grounding to researchers working on the parallel implementation and development work, ideated interaction designs and use cases for the consumer and carer facing versions of these tools, and uncovered new areas for further investigation, design and research.

2.2 Co-Design Process

This study reports on an extended co-design consultation with a consumer and carers advisory panel made up of mental health consumers and informal carers. Since clinicians are under-resourced, informal caregivers (CG) were also invited to discuss their use of and willingness to use digital technologies to support someone living with a chronic mental health condition.

In order to join the lived experience consumer and carer advisory panel, participants submitted an expression of interest outlining their motivations, relevant qualifications and expected contribution to the process of co-designing an automated wellbeing monitoring service with a view to maximising potential benefits for mental health consumers. Applicants ranged from people in mid recovery seeking to create a more purposeful frame for their past experiences, to those who had many years lived experience under their belt, including two applicants who had managed life as both mental health carer and patient for over twenty years. One applicant had undertaken advanced mental health related studies, whilst others were serving in public facing roles in the fields of mental health consumer and carer advocacy.

The study used an iterative workshop design with nine lived experience members. They ranged from people in mid recovery seeking to create a more purposeful frame for their past experience, to those who had many years lived experience under their belt, including two applicants who had managed life as both mental health carer and patient for over twenty years. One applicant had undertaken advanced mental health related studies, whilst others were public advocates.

The consultation unfolded across ten workshops. The co-design groups were co-ordinated and facilitated by researchers Mike Musker and Yasmin Van Kasteren. Meeting topics and areas for shared inquiry were determined by Yasmin van Kasteren, Mike Musker, and Niranjan Bidargaddi over the duration of the co-design phase (June 2019-March 2022), with each group session lasting roughly two hours. Agendas, minutes, and preparatory readings were sent in advance of the meeting, with participants encouraged to ask any questions or raise concerns between meetings via phone or email. Finally, given much of this process overlapped with COVID-19 and associated restrictions, participants could attend virtually or in-person dependent on personal preference and/or public health requirements at the time of the meeting.

Table 1. Agenda Topics, Homework, and Attendance at Meetings

Date	Agenda Topics	Homework	Number of Consumers and Carers in Attendance	Number of Researchers in Attendance
03/10/19	Welcome and Introductions Brief Presentation of AI^2 Consent to record voice, Terms of reference review.	NA	9	2
07/11/19	Review of Research Impact Statement for AI^2 Review of notice informing clinicians about the use of AI^2 Discussion of how consumers are likely to react to AI^2 Introduction to existing consumer-facing mental health monitoring app —Mindtick	Review of documents pre-session.	6	2
05/12/19	Mindtick presentation with Q&A. Mindtick Posters and feedback.	AI2 room notice review	8	4
06/02/20	Recruitment protocol and methods for AI2 call centre trial. Consumer concerns about AI2 – best practice protocol Mindtick review focussed on problem questions feedback	Participant diversity recruitment reviewed.	8	4
05/03/20	AI2 waiting room notice accepted. M3Q questionnaire discussed. Pharmacogenomics presentation with Q&A session		9	1

06/08/20	Data collection for the COVID-19 multi country project on changes in healthcare for COVID-19	NA	8	2
03/09/20	Medication management, background (Two perspectives – Consumers/Carers)		8	2
01/10/20	Discussion of Medication Management – Part 2 – Medication decision making. Carer groups – and Covid	Research on Medication Management – Part 1	7	2
04/02/21	Medication Management – Part 3: Concrete Solutions – IT based solutions for consumers/carers & medication management.		7	2
01/04/21	Further exploration of solutions with regards to personal goals, Frustrations/problems/barriers, Behaviour, Motivation and Device usage.		7	4

An experienced mental health practitioner was the lead facilitator of these focus groups to ensure consumers and carers were supported throughout the process. An appropriately qualified person in mental health was an ethical requirement with the purpose of monitoring wellness or minimising distress throughout the consultation process. The mental health facilitator was able to support the welfare of participants and to manage or guide the forum process to minimise distress.

As the group became more familiar with the design and functionality of the service, they offered deep contextual grounding to researchers working on the parallel implementation and development work to ideate interaction designs and use cases for the consumer and carer facing versions of these services.

Once the first round of consultations was complete and the participant's responses were thematically coded, the group was reconvened to review those findings, add comments as appropriate and check the accuracy of the researcher's summary thematic analysis (codes and related discussion).

The cohort associated with this study was set up with support from a Medical Research Futures Fund (MRFF) Rapid Translation Grant to contribute to the development of the Actionable Intime Insights (AI^{2}) project [13–15]. Ethics oversight and approval was provided by the Southern Adelaide Clinical Human Research Ethics Committee (AK03478). The trial was registered with ANZCTR retrospectively (ACTRN12619000838112).

2.3 ANALYSIS APPROACH

Workshop discussions were recorded, transcribed and thematically analysed in two stages. First, using a grounded (Glaser et al. 1968) qualitative content analysis approach (Krippendorff 2018) researchers Yasmin van Kasteren and Mike Musker described problems and solutions identified by participants in the space of (particularly digital, but not exclusively) mental health care. These findings were then categorised into overlapping areas of enquiry common to participants and derived directly from the text — or, "Problem Areas". Once these problem areas were identified, potential solutions were further workshopped and discussed in two further feedback rounds. The following process was, therefore, implemented:

1. Comparative analysis of both the discussion group transcripts and developing system design identified an initial set of analytical themes. These themes were further discussed and refined amongst the research team with consensus met on an initial set of themes.
2. This initial list, together with suggestions for potential solutions was presented to the consumer and carer cohort for feedback and refinement.

3. Following a further redraft of the thematic summary, taking account of any initial feedback from the consultation panel, the consumer, carer and advocacy group (CCAG) were invited to a final post hoc discussion of these conclusions.

A final research analysis and write up was undertaken collaboratively by Bronwin Patrickson, Dan Thorpe, Mike Musker and Niranjan Bidargaddi.

3 Results: Problems and Solutions

The panel identified a range of problems encountered in the Australian mental health care landscape which the research team thematically classified as issues with access, agency, interactions with healthcare providers and medication management. In this section these challenges are reviewed, alongside the proposed solutions which were also discussed.

3.1 ACCESS

3.1.1. PROBLEMS

Access barriers almost all related to material (physical, financial, environmental) need**.** Limited access to smartphones and clinical care was seen to constrain the types of digital health tools that could have the most reach. For example, smartphone ownership is funded by the NDIS, but the data plans that enable those phones to be used are not. Participants also noted that differing levels of computer literacy and fear of technology were a barrier to access.

Consumer-participants also noted difficulties accessing trusted clinicians. Indeed, multiple consumers identified access to their current treating mental health specialist clinician as crucial to their care and being unable to see their clinician as having far-reaching consequences.

3.1.2 Solutions

Access to preferred doctors was seen as an area in which technology could have a significant impact. The concept of using digital means to enable more adequate briefing between clinicians and services was appealing. As it is electronic medical records are dense, and important historic information can be lost, whereas an easier to digest summary overview may help to avert this problem.

Participants also noted that digital interventions need to be tailored to different needs and levels of support. This included specific mental health conditions, medications, and management plans — but it also included access to a diverse variety of resources (i.e. for people without a smartphone), and different levels of technical and medical proficiency.

Adaptations such as editable account details, preferred names, alternative, preferred methods of contact, and so on were felt to go some way to solve access challenges. This includes options for paper print outs of wellness monitoring tools, alongside the option to upload scanned copies of these documents. Further opportunities for flexibility include notifications: for example, scheduling prompts and notifications for optimal times of day, or on nominated days. Technologies and algorithms that accommodate flexibility can also enrich the participatory experience, such as the facility for medication taken PRN (*pro re nata*: when needed) and the allowance for "pauses" of self- or system-monitoring when appropriate.

3.2 Agency

3.2.1 Problems

Where treatment was mandatory, consumers and carers alike often experienced a sense of disempowerment. Additionally, for carers the experience of seeing a loved-one undergoing crisis treatment could be (re)traumatising for carers.

When consumers felt that their treatment agency was low, such as situations where they might be subject to mandatory treatment orders, this could result in a variety of concealment behaviours: hiding medication administered by carers, picking up medication but not taking it, attending psychiatry appointments and successfully lying about adherence, for example.

Carers found agency particularly challenging to navigate when consumer capacity was low. Medication non-adherence was a familiar challenge. People are non-adherent for a variety of reasons, from losing insight due to illness, to struggling with memory, to concerns about side-effects. Carers reported helping to manage medication— although the "permission" to do so diminished as consumers became more unwell.

3.2.2 SOLUTIONS

Linked to this, advisory group members strongly requested that any medication adherence monitor be designed to avert heavy-handed interventions.

In the context of designing digital solutions agency, fundamentally, became a question of consent. The need for consumer consent for carer access to their record and/or treating clinicians was repeatedly emphasised. However, one carer noted that this was complex, particularly in the context of young adults, where the line between increasing independence, psychopathology, and capacity was more blurred. Since informal carer relationships are as unique as the people involved and are also likely to change over time, the advisory group also emphasised how important it is that any care, consent, or information sharing agreements enabled by digital mental health care services can accommodate variation.

Consumers noted the importance of being able to feel in control of their own account, or story. For some this was about privacy. For others this was simply about being able to make their own choices regarding how to best to care for themselves. Given the consumer group's repeated emphasis upon the strong link between consumer agency and successful health outcomes, the importance of full transparency was emphasised. The consumer advisory group also noted the importance of being able to set their own agenda — of what is monitored, when, what it means, and how this relates to life-plans.

This was linked strongly to the importance of being seen as a whole-person. Participants urged further investigation of the ways that digital health tools — and electronic health records in particular — could emphasise the human in the system and in turn, nudge treating clinicians towards providing more humanising care.

3.3 Interactions with Medical Professionals

3.3.1 Problems

Discontinuity of care was a common theme. Participants reported setbacks in their care, frustratingly slowed-down processes, or appointments, or — for some consumers in the public system — discontinuity being their *entire* lived-experience of seeking support for their mental health. Seeing someone who was not their usual clinician could result in differences of opinion in management that could change a consumer's medication, therapies, and life substantially. Carers meanwhile identified that they were not looped-in to discussions about treatment of their loved ones. This was a barrier to them taking part in their loved one's recovery.

3.3.2 SOLUTIONS

Lived experience led nudging interventions were identified as an effective route for investigation. In particular, the ways that lived-experience workers embody the possibility of recovery (in whatever sense this may resonate with the consumer) were identified as encouraging and affirming. Carers also noted the importance of their advocacy role for their loved ones, and how this could be integrated into digital solutions (including reminders) to potentially enable more positive experiences.

3.4 MEDICATION MANAGEMENT

3.4.1 Problems

Medication management (and the potentially devastating impact of medication effects) was widely discussed. The impact of forgetfulness was a particularly sensitive issue — for some consumers, this forgetfulness had been interpreted as treatment resistance which had flow-on effects impacting the rest of their life in drastic ways.

3.4.2 SOLUTIONS

In terms of insights for technical solutions, this was split into two categories — *tasks* to be mediated, and *processes* requiring additional support that could be alternately provided through digital means. Tasks identified as key targets for digital reminders, feedback, or intervention included blood test appointments, the booking and management of injectables, checks for drug interactions, medication reviews, medication information, and the management of complex and (often) numerous prescriptions.

Accessible, useful information about medication effects and potential drug interactions aimed at both clinicians and consumer-users was encouraged in digital medication management tools. Linked to this, building an understanding of what was "normal" was regarded as useful for establishing whether a physical health concern was worthy of further investigation. The group agreed that tools to track and identify signature patterns of thriving, as much as unwell behaviours could be particularly helpful.

Medication management was an area that carers found particularly difficult to navigate. Feelings about the extent to which carers should also have access to digital monitoring information were ambivalent — some felt this may damage the relationship, others felt it might result in something genuinely useful. Carers nevertheless noted their own strength in identifying when patterns of regularity in their loved one's lives were broken, and how this awareness could also help to prompt a pre-crisis intervention.

3.5 SELF-MONITORING

3.5.1 Problems

Whilst the potential benefits of digital mediation of self-monitoring for health management were readily acknowledged, they were balanced against the potential for self-obsession, harmful use, and the impact of surveillance on consumer agency. Sustainability was also a challenge.

3.5.2 Solutions

Perceived relevance and clear benefits were important considerations. The monitor needed to be minimised, relatively easy to maintain and meaningful, which implicates the importance of clinical engagement, or at least some form of useful feedback (through pattern identification, for example), as much as consumer input.

Feelings about whether carers should be involved in monitoring their loved ones were ambivalent – some felt this may damage the relationship, others felt it might result in something consumers found genuinely useful. As such, carers argued strongly for facilitating carer access to a wellness monitor – both as a backup if their loved one was unable to actively participate, and as a valuable additional information source. However, this function was understood in the context of consent considerations, and the acknowledged need for strong boundary setting facilities.

4 Discussion

Key findings from this paper include the need for adaptability and flexibility, the importance of a focus upon wellness maintenance and thriving, as opposed to illness, the need to ensure that consumers are humanised by design, rather than objectified as data, the value of carer involvement, as well as peer connections in digital mental health care services, tempered by the need for strong, and sensitive boundary setting, and the appeal of a design approach that enhances the digital therapeutic relationship by emphasising the mutual responsibility of care, rather than the expectation of compliance.

Themes emerging from these identified problem areas and potential design solutions include adaptability and flexibility, optimising the record, humanising the record and strengthening the digital therapeutic relationship.

4.1 Adaptability and Flexibility

The more that digital interventions can meet individuals on a person-by-person basis depending on what supports their need at that moment the more likely they are to succeed. For example, flexible self-management strategies can be simple at first, perhaps prescribed, but the ability to also evolve controls and even enable consumers to collaborate on treatment changes over time (such as the ability to flag the need for medication dosage changes) was identified as crucial to encouraging ongoing engagement motivation, but also — more practically — as an acknowledgment that illness and health are not monolithic entities and change over time.

4.2 Optimising the Record

Such evolution is also likely to involve the development of the consumer's documentation of their personal wellness experience over time as a way for them to detect and reinforce "signature patterns" of *thriving*, rather than deficit. Such approaches can empower consumers by giving them back a sense of their ideal identity. Participants again noted the importance of tracking times when a crisis had been resolved positively — which they suggested could also prompt more helpful action in future crises.

4.3 Humanising the Record

Related to this shift in focus, one panel member advocated for a greater appreciation of mental health care as a consumer service. This emphasizes the push to develop system protocols that foster respect for patient's dignity, appreciation for patient uniqueness, and humanity (Busch et al. 2019). Previous studies show that highlighting the humanity of both the consumer and the context of health care can influence not only the perceived quality of care, but also the rate of healing (Hudon et al. 2011) (linked to improvements in both patient and clinician satisfaction, consultation time, medication adherence and symptom severity)

Enhancing the consumer's engagement with patient-centred care through the use of mobile digital technologies can improve clinician consumer relationships as well (Qudah and Luetsch 2019). Importantly, the ready provision of digital extension services like real-time symptom assessments, pre-programed reminders, and personalised feedback can supplement clinical care for better health outcomes (Lee et al. 2018).

Group feedback also indicates that an enhanced wellness monitoring service that emphasizes the human in the system is more likely to privilege the experience of care rather than compliance, shifting the emphasis from treatment directives, towards treatment agreements built upon trust and mutual respect.

(re consent) Design solutions in this space need to be considered sensitively. Ongoing discussions about models of consent were identified as a priority of future research into these tools — including how to ensure boundaries are set in advance.

4.4 Strengthening the digital therapeutic relationship

Using technology in these contexts was seen as useful to encourage adherence not only of consumers, but also medical professionals and health systems more broadly to the agreed care plan. The advisory group notes that "adherence" is not the sole responsibility of consumers (Marrero et al. 2020). It emerges from an exchange of mutual responsibilities, which implies that medication monitoring processes will need to both track and enable a consumer's mental health care. Humans are complex, which is why collaboration is not always a simple exercise, nor is it necessarily equal. Negotiating the borders between wellness and crisis care, for example, can be a highly sensitive matter, complicated by broader systemic issues. In this context, adherence is likely to be as much about relationships, as directives (Pérez-Revuelta et al. 2018).

Digital processes can be designed to support collaboration. Using systems to enable such conversations requires that those systems give participants the capacity and motivation to take part in a dialogue. For example, the consumer group urged that the consumer's own informed judgements about medication effects, and the value of recommended treatments be heard, and enabled. There are numerous reasons why shared decision making is still an emerging model of care within mental health care contexts, which include the need for greater training and guidance, and the value of informal care network engagement within the process (Ashoorian and Davidson 2021).

For clinicians, this means that digital mental health care services need to be genuinely time saving and treatment enhancing, rather than merely more information to check. For consumers, this same service will ideally save just as much time and effort (perhaps by providing automated medication reminders or enabling alternate monitoring processes to potentially minimise GP visits and streamline medication adjustments, or even perhaps by the introduction of Medicare rebates for consumer monitored data) whilst also genuinely enabling care improvements.

This study extends previous mental health consumer co-design studies (Borghouts et al. 2021; Lavallee et al. 2019; Simblett et al. 2018) by highlighting the broader contextual considerations that can impact the implementation of digital mental health services within Australia. Additional themes revealed in this review, which have not been highlighted in these previous models include the consumer desire to shift the focus of digital mental health care towards wellness maintenance, thriving, and the human within the system in a way that enhances the digital therapeutic relationship. The importance of providing comparative benchmarking capacity with “normal” treatment outcomes, as well as the therapeutic utility of providing ways to help identify and manage a consumer’s signature wellness signs are also unique to this study, specifically informed by mental health lived experience. Importantly too, our study recognises the undervalued role that informal carers can play as part of that effort. Shared engagement with carers can potentially help to support consumer training efforts, balance mental health engagement challenges, plus potentially reduce individual monitoring burden. In some ways, extending involvement to informal carers as much as consumers is a potent strategy to embed a digital mental health care service in daily life, a factor which has also been previously recognised as key to a successful implementation (Borghouts et al. 2021). Equally, whilst being mindful not to overly burden either carers, or consumers (by asking carers to manage compliance, for example) involving carers more closely within their loved one’s wellness maintenance journey ensures that they also gain access to the ongoing educational support and networking functionalities that digital technologies can provide, relevant to their loved-ones wellness journey. At the same time, it is equally important to protect consumer independence, and privacy, and ensure that all consumer-carer involvement is voluntary and supported by strong boundary setting options as and when required.

The present study has several limitations, which could be addressed in future work. Focused upon a stakeholder consultation, the panel size was comparatively small, comprised of many high-functioning consumer and carer advocates. Future co-design studies would benefit from engaging a wider variety of mental health consumer and carer co-designers over time to build a more representative sample selection of viewpoints that can also be checked against a wide range of demographic and user characteristics.

Pertinent topics for further experiential research include an exploration of optimum designs to help support digital therapeutic relationships, including providing support for consumer/carer/clinician information flows in digital mental health care. Pursuant to calls for consumer evaluation frameworks of digital mental health services (Fortuna et al. 2019), going forward this study also points to the value of developing model frameworks for consumer co-design within digital mental health care research and development efforts.

5 CONCLUSION

Learning to self-manage chronic health conditions can be a challenging process for patients. Even though personal healthcare management can improve health and wellbeing outcomes, nevertheless self-management may not always serve a health consumer’s considerable emotional, psycho-social recovery needs (Borghouts et al. 2021; Greer et al. 2019; Jeffrey et al. 2019; Torbjørnsen et al. 2019). User experience design approaches may pick up some of these issues, but consumer and carer co-design of future digital mental health care research and development efforts are recommended to help find the optimum working solutions for each target engagement group.

Over the course of an extended two-year consultation participants identified the broad problem areas of Agency, Access, Interactions with Health Professionals and Health Systems, Medication Management, and (Self)Monitoring — with a range of solutions accompanying the identified problems within these categories. Priority sites for design intervention include the strengthening of social and interpersonal support, balanced by strong consent procedures and boundary setting, accessible design as well as understandable contents, support for different technology-use access and preferences, the inclusion of drug and condition education, and the facility to more easily identify and better manage signature patterns.

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