



## Article

# In-Depth Co-Design of Mental Health Monitoring Technologies by People with Lived Experience

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**Abstract:** Advancements in digital monitoring solutions collaborate closely with electronic medical records. These fine-grained monitoring capacities can generate and process extensive electronic record data. Such capacities promise to enhance mental health care but also risk contributing to further stigmatization, prejudicial decision-making, and fears of disempowerment. This article discusses the problems and solutions identified by nine people with lived experience of being mental health care consumers or informal carers. Over the course of ten facilitated focus group format sessions (two hours) between October 2019 and April 2021, the participants shared their lived experience of mental health challenges, care, and recovery within the Australian context. To support the development, design, and implementation of 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.

**Keywords:** co-design; mental health lived experience; digital mental health; electronic medical records; health monitoring technologies



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## 1. Introduction

The potential advantages of digital technologies are widely recognized in clinical care [1–3]. A core aspect of their appeal in the context of mental health care is the granularity of the data, as well as the streamlined, unified processing of previously disparate information [4–6]. These data are critical to designing digital mental health interventions (DMHIs), which, while unable to replace therapeutic relationships with mental health workers, can nevertheless enhance access and personalize care well beyond the clinical consultation room. To achieve this enhanced oversight, DMHIs draw upon a range of electronic medical records (EMRs), thereby extending the range and type of data available to clinicians, potentially enabling more nuanced, accurate, and person-specific understandings of recovery and interventions [7]. DMHIs also generate new additions to those records so that engaging with DMHIs effectively amounts to engaging with EMRs. Thus, many DMHIs enact an extra layer of functionality that extends both the input and output of these data repositories.

To help inform the design of mental health monitoring applications, this article reports on an in-depth consumer and carer co-design consultation conducted by the Flinders University Digital Health Research Lab (DHRL).

### 1.1. Monitoring Technologies in Mental Health Care

Monitoring of consumer mental health and well-being is already a feature of contemporary clinical mental health care. Indeed, Australian community mental health clinicians have a legal responsibility to monitor the well-being and recovery progress of consumers in their care. Digital mental health interventions that streamline monitoring processes can reduce organizational labor and can also potentially scale up easily at a low cost [8].

Examples of monitoring within DMHIs abound, including:

- (1) Mobile applications that enable consumers to regularly self-monitor and report treatment outcomes, in turn helping to improve those outcomes [9,10];
- (2) Real-time, longitudinal collection of patient data to inform decision-making and facilitate early intervention [10–13];
- (3) Consistent and accessible, on-demand recovery support for remote communities enabled by ongoing digital monitoring of consumer wellbeing [14,15];
- (4) Objective measures of medication adherence, derived from electronic medical records (EMRs) [16,17];

However, such services are still not widely used in community care settings [18].

### 1.2. Why Co-Design Digital Mental Health Monitoring Interventions?

Despite the technology's potential value for consumers, public engagement is lacking [19,20]. Many technology-enabled mental health programs have failed [21–23]. This 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 mental health consumers and integrate poorly into their daily lives [24–26]. Examples of misfires include daily self-monitoring activities that might be easy to achieve in a single usability session but are time-consuming and hard to remember over longer periods [25]. Daily lifestyle tips that are not necessarily relevant to the consumer's own lived experience are another concern [25]. Problem areas include low usability, poor fit, lack of engagement, lack of knowledge, and the need for more implementation support [25].

Patient health-monitoring experiences are under-studied across public health care [7]. A scoping review of mobile post-operative self-monitoring interventions, for example, found that the most common outcome measure associated with patient experience was patient satisfaction, and only three out of thirty-four studies reported any sort of patient involvement in the design and development of the intervention [24]. Without a grounded understanding of the consumer's 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 not be served, or worse, that the consumer experience will be further challenged as a result of such implementations [27,28].

Monitoring technologies necessarily implicate issues regarding power and agency, raising concerns that when health systems involve forms of data surveillance, or "Dataveillance" [2,29], they objectify consumers by framing them as a form of data and transforming treatment into a form of data analysis. 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 [30]. Consumer agency is key to optimizing the benefits, as well as mitigating the risks, supported by co-design efforts. Agency is dependent upon the ability to make choices that have meaningful consequences or impacts, whereas co-design can support that capacity by ensuring that consumer "desire(s) are among those they can take" [1,31].

As yet, there are minimal extant legal requirements regarding the monitoring of consumer mental health and well-being at this granular level.

While the number of studies into the consumer acceptance of health monitoring technologies is growing [9,17,30,32–37], 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 they also encompass broader contextual concerns and service delivery considerations that can profoundly influence the consumer's lived experience of care [25]. A systematic review of studies that explored consumer engagement with digital mental health interventions found numerous issues that hamper engagement. Barriers include severe mental health challenges, as well as technical issues. Some apps were difficult to use or else failed to work as expected. In this regard, a lack of personalization options in some mental health apps and the inclusion of app content that is not directly relevant to the consumer's lived experience can be off-putting. For example, people who spend most of their time indoors are unlikely to be interested in exercise programs. In contrast, enabling factors included interventions that facilitated social connectedness, as well as access to increased health insights and the creation of a sense of control over one's own health [25].

As a result, the study concluded that co-design is a priority innovation for future digital mental health interventions.

Co-design invites the selected participants of designed processes to “become part of the design team as experts in their experiences” [6,38]. This collaboration gives service participants a central role in “knowledge development, idea generation, and concept development” [39–41], with a view to increasing consumer usability, usefulness, and, ultimately, engagement with technology [42]. Co-design, in its most optimal form, leads to results that capture the best aspects of consumer input—such as acceptability, utility, and novelty—while also being tempered by professional insights [43]. A co-design approach needs to validate consumers' experiences, while also being careful to achieve design constraints [44].

Co-design is especially important in this context because there is a growing demand for technology-enabled mental health services. However, so many digital mental health implementation efforts have previously failed, often due to a lack of consumer input in the design process. To counter this implementation failure trend, DHRL conducted an in-depth co-design consultation that unfolded over two years in total. The consultation explored beyond mere usefulness or feasibility, to instead reconsider the context provided by participants as foundational to the design of DMHIs, drawing upon normative theory [45–47], ethnography [48,49], and phenomenology [50,51].

The value of a broader perspective is reflected in the foundational decision to engage not only mental health consumers but also informal carers in this investigation. Informal carers, such as family members, provide care for people living with mental ill-health outside of a formal employment relationship [52]. Since clinicians are under-resourced, informal caregivers (CG) often provide vital support for mental health consumers. As such, they were invited to discuss their use of and willingness to use digital monitoring technologies to support someone living with a chronic mental health condition. Carers have unique insights into their loved ones' day-to-day lives that are just as valuable as theirs, but they are even more likely to be ignored within the design process. Carers may also have their own lived experiences of mental health challenges and social isolation that are unaddressed, despite being intertwined with their care provision. Thus, the carer perspective was an equally important concern within this co-design consultation process.

Amid a growing demand to redesign digital mental health services to be more usable, compelling, and implementable [53], this article reports findings from a co-design consultation study carried out in collaboration with people with a variety of lived experiences of mental health challenges. Potential problems and solutions regarding the use of digital monitoring processes within mental health care services are identified.

## 2. Materials and Methods

### 2.1. Consultation Context

The co-design consultation process informed the parallel development and implementation activities undertaken by members of the Flinders University Digital Health Research Lab (DHRL) on two DMHIs (digital mental health interventions). First, it involved the pilot implementation of the Actionable In-time Insights (AI<sup>2</sup>) project, a digital public health records monitoring tool designed to enable clinicians to proactively intervene in medication and appointment non-adherence with psychosocial support [16,17]. Second, it involved MindTick—an app designed to help track outcomes and undertake therapeutic tasks in-between sessions with a therapist [54]. During this study, the Consumer and Carer Advisory Group was consulted about the underlying design principles for consumer and carer engagement with these services. Some of the design principles that were identified as a result were implemented within these services, while others are intended to inform the design of future applications.

AI<sup>2</sup> (also known as CareMappr) processes the health records data contained in the Australian My Health Records database, such as the Medicare benefits schedule (MBS) data records collection of health events that qualify for a public health benefit, as well as prescriptions listed under the prescription benefits schedule (PBS) data scheme. New databases are being added to this records base, such as the PD database of dispensed prescriptions.

Once these data (sourced from the databases outlined in the previous paragraph) are gathered, the software processes that information using a set of system rules (such as: *if x event happens, raise an alert*). These algorithms will automatically flag potential anomalies that are associated with relapse risk, such as unfulfilled scripts or missed GP appointments.

MindTick, on the other hand, is a generic information recommendation and real-time nudging mobile application for health consumers. The app is designed to be modified and adjusted for different use cases or clinical contexts. Developed in Flutter, the app interface is compatible with both Apple iPhones and Android phones. Depending upon the condition being treated, the application provides treatment information and prompts consumers to fill out surveys about their treatment outcomes. Using Google Cloud, the consumer-documented results are processed and presented in a clinician's dashboard view. By enabling proactive consumer involvement in recovery and wellness maintenance efforts and encouraging shared decision-making, the MindTick suite of apps is designed to help improve consumer outcomes.

### 2.2. Participants

To join the consumer and carer advisory group (CCAG), participants submitted an “expression of interest” form in which they outlined their motivations, relevant qualifications, and expected contribution to the process of co-designing an automated well-being monitoring service. Since DHRL was developing digital monitoring services for chronic mental health care, the recruitment targeted people with lived experience of a chronic mental illness, as defined by the International Classification of Diseases, or via a Diagnostic Statistical Manual 5 (DSM-5) diagnosis. In other words, people with lived experience of a chronic mental illness that involved the risk of hospitalization and required ongoing medication were prioritized for recruitment to the DHRL consumer and carer advisory panel.

Applicants' lived experience and current engagement with the mental health system ranged from people within the first five years of treatment to those who had engaged in the mental health system long-term—with two participants reporting 20 years of experience, both caring for a loved one with a mental illness while being a recipient of care themselves. One applicant had undertaken advanced mental health-related studies, while others were serving in public-facing roles in the fields of mental health consumer and carer advocacy.

The consultation unfolded across ten workshops, with further follow-up reflective discussions regarding the thematic analysis and subsequent writing-up of results, both via facilitated focus groups and also via email. Focus group meeting topics and areas for shared inquiry—as outlined in the Appendix A—were determined by the research team

over the duration of the co-design phase (June 2019–April 2021, with supplemental reviews of summary reports in 2022 and 2023). Each group session lasted roughly two hours. Agendas, minutes, and preparatory readings were sent out in advance of the meeting, with participants encouraged to ask any questions or raise concerns between meetings via phone or email. Finally, since much of the consultation process took place during the COVID-19 pandemic, in-person attendance at focus groups was either optional or, if circumstances required, was entirely replaced by the ready alternative of virtual focus group attendance.

To ensure that participants were supported throughout the process, an experienced, appropriately registered mental health practitioner co-facilitated these focus groups. This ethical requirement promoted effective wellness monitoring. The mental health facilitator was able to support the welfare of participants and to manage or guide the forum process, with a view to minimizing distress.

As the consumer and carer advisory group became more familiar with the design and functionality of digital health monitoring technologies in collaboration with electronic medical records, they offered deep contextual grounding to researchers working on parallel implementation and development work, enabling them to ideate interaction designs (to enable reciprocal actions and communications) and real-life use cases or applications for the consumer- and carer-facing versions of the AI<sup>2</sup> and MindTick services.

### 2.3. Analysis

Workshop discussions were recorded, transcribed, and thematically analyzed in two stages. First, using a grounded qualitative content analysis approach [55], researchers described digital problems and solutions identified by participants in the area of mental health care. These problems and perceived potential solutions were then compared with the developing system design so that the design solutions were further refined among the research team.

Following this process, a thematic synthesis approach was used to meta-ethnographically synthesize research insights with those experiences common between participants, forming them into shared areas of inquiry—with discussion themes named using wording derived verbatim from the participants' contributions [56].

In order to double-check the researcher's design suggestions and overarching synthesized interpretations of CCAG discussion points, once these problem areas and discussion themes were identified, the CCAG was reconvened to further review and discuss these findings. Therefore, a progressive process of reflective analysis and validation was implemented with the initial list of problem areas, together with suggestions for potential solutions that were presented to the consumer and carer cohort for feedback and refinement, followed by a review and discussion of the thematic meta-analysis. In their review of these findings, the CCAG provided a crucial check to the accuracy of the researchers' summary of their contributions, with further insights and corrections, as appropriate.

Following a further redraft of the thematic summary and related discussions, taking account of any initial feedback from the consultation panel and peer review guidance, the consumer, carer, and advocacy group (CCAG) were invited to participate in post hoc discussions of these conclusions.

### 2.4. Ethics and Trial Registration

Ethics oversight and approval for this study were provided by the Southern Adelaide Clinical Human Research Ethics Committee (AK03478). This trial was registered with ANZCTR retrospectively (ACTRN12619000838112).

## 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, medication management, and self-monitoring. Examples codes for each theme are provided in Table 1; Tables 2–6 provide summaries of

findings for each theme, and the implications of these findings for digital mental health monitoring services.

**Table 1.** Summary of problems and the solutions identified, along with examples.

Access	(To the clinician of choice) (Consumer) "I didn't get diagnosed until I'd been in a severe manic episode . . . for about 11 weeks . . . and I had a doctor (GP) tell me that I had bipolar, and then he gave me a script for 60 Valium, and that's all I got . . . So it wasn't until I started seeing my newer psychiatrist in the last two and a half years and was put on lithium that I really had any treatment that was adequate for what I needed." (About different options) (Carer) "I think that Zoom has been great in lots of ways . . . But I think you should be given the choice whether you want to do it via Zoom, via phone, or whether you want to go in to [see] the GP. But I also feel that this has been an opportunity maybe for people to have a greater understanding of what it's like to be isolated."
Agency	(Consumer) "I was initially forcibly medicated in a locked ward, and the psychiatrist did afterwards apologize, acknowledge it wasn't necessary, and that he was overworked and couldn't be bothered negotiating with somebody who was thoroughly manic."
Interactions with Medical Professionals	(Consumer) "Medication-wise, I've had a doctor who's very clear that I'm in control of what I put in my body."
Medication Management	(Consumer) "The actual range of side effects has never been discussed with me on any drug that I've had. You've got to look up [on] the internet . . . which can be quite an excessive list . . . with some drugs."
Self-monitoring	(Carer) "I monitored [myself in a] diary, and that was something that the occupational therapist set up for her, but she was quite willing for me to be involved in that . . . They would discuss it and work out the medication really from what she was diagnosing. That worked well." (Consumer) "Yes, I make my own medication adjustments. This is after I've been taught how to . . . and so this really enables me to minimize my medication and minimize the side effects."

**Table 2.** Problems and solutions identified by participants regarding access.

Problems	Solutions
<ul style="list-style-type: none"> <li>Limited access to smartphones, since the Australian National Disability Insurance Scheme funds phones, but not data plans.</li> </ul>	<ul style="list-style-type: none"> <li>Provide options for paper printouts and scanned uploads of wellness monitors.</li> </ul>
<ul style="list-style-type: none"> <li>Limited access to clinical care and trusted clinicians, in particular, who may only be available for short periods of time, often with long waiting times between appointments.</li> </ul>	<ul style="list-style-type: none"> <li>Provide messaging facilities and ensure consumers have access to clear, relevant, accurate information as required.</li> </ul>
<ul style="list-style-type: none"> <li>Electronic medical records are dense and important information can be lost when clinicians need to quickly review lengthy case history notes.</li> </ul>	<ul style="list-style-type: none"> <li>Design a visual summary overview to enhance information exchange.</li> </ul>
<ul style="list-style-type: none"> <li>Mobile apps do not suit everybody.</li> <li>Levels of computer literacy differed and technical confidence was not always high.</li> </ul>	<ul style="list-style-type: none"> <li>Enable personalization options and design adaptable user interfaces to cater for diverse conditions, unique medication regimes, variable care plans, and diversified resources.</li> <li>Engage with different levels of technical know-how and medical proficiency.</li> </ul>
Implications for digital mental health monitoring services from Table 2	
<ul style="list-style-type: none"> <li>Technologies that accommodate flexibility enrich the participatory experience.</li> <li>Communication and information streams can increase access options.</li> <li>Visual digital record summaries can streamline clinician handover and avert miscommunication.</li> <li>Digital interventions need to be tailored to different needs and levels of support.</li> </ul>	

**Table 3.** Summary of problems and solutions relevant to agency.

Problem		Solutions	
Consumers			
<ul style="list-style-type: none"> <li>• Consumers often experience a sense of disempowerment when treatment is mandatory.</li> <li>• This can lead to concealment behaviors such as hiding medication and lying about adherence.</li> <li>• Numerous participants reported multiple reasons for non-adherence, however: losing insight due to illness, struggling with memory, concerns about side effects, a lack of perceived or experienced benefits from taking medication and wishing to avoid medication altogether.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants urged further investigation of the ways that digital health tools—and electronic health records—could emphasize the human in the system and, in turn, nudge treating clinicians towards providing more humanizing care.</li> <li>• To help avert the sense of blanket surveillance and heavy-handed enforcement approaches associated with police intervention, digital solutions ideally need to be grounded in ongoing, explicit consent. This links to the importance of personhood, which has been defined simply as, “People with a severe mental illness are people” [57].</li> </ul>		
Carers			
<ul style="list-style-type: none"> <li>• Carers found agency particularly challenging to navigate when consumer capacity was low. Seeing a loved one undergoing crisis treatment can be re-traumatizing.</li> <li>• Carers reported helping to manage medication—although the “permission” to do so diminished as consumers became more unwell.</li> </ul>	<ul style="list-style-type: none"> <li>• Relatedly, the need for ongoing consumer consent for carer access to their records and/or treating clinicians was repeatedly emphasized by participants.</li> <li>• However, one carer noted that this was complex, citing their experience caring for a young adult, where the lines between a desire for increased independence, psychopathology, and the capacity to self-manage were blurred.</li> </ul>		
Consumers and Carers			
<ul style="list-style-type: none"> <li>• Some panel members expressed concern that storing medical records, such as the Australian My Health Records (MyHR) database, was an opt-out rather than opt-in arrangement (in other words, the data are collected unless consumers request for them not to be). MyHR is a central public health database that tracks data relevant to each participating citizen’s publicly rebated medical events, such as prescriptions dispensed, and the medical appointments attended.</li> </ul>	<ul style="list-style-type: none"> <li>• Personalization options, such as editable account details, preferred names, notifications, and contact methods, even the allowance for “pauses” of self- or system-monitoring when appropriate, can help consumers to regain a sense of control over their mental health and electronic medical records.</li> </ul>		
Implications for digital mental health monitoring services from Table 3			
<ul style="list-style-type: none"> <li>• 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 care for themselves.</li> <li>• Optimal designs will enable consumers to set their own agenda regarding what is monitored, when that happens, and what that means.</li> <li>• Full transparency appears to be key to successful outcomes.</li> </ul>			

**Table 4.** Summary of problems and solutions relevant to interactions with medical professionals.

Problems		Solutions	
Consumers			
<ul style="list-style-type: none"> <li>• Discontinuity of care is a common experience and is potentially damaging. Difficulties getting appointments with trusted clinicians can result in catastrophic care-plan changes in the consumer’s medication, therapies, and life.</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative and/or supplementary formal care pathways include interventions that are led and co-designed by members of the lived experience workforce (such as peer-support workers). Such interventions have the potential to embody recovery in encouraging and affirming ways.</li> </ul>		
Carers			
<ul style="list-style-type: none"> <li>• Exclusion from discussions about the treatment of their loved ones was identified as a traumatic barrier for carers that could become catastrophic in crisis situations. This sense of disempowerment reflects findings from previous studies of family involvement in mental health care [58].</li> </ul>	<ul style="list-style-type: none"> <li>• Carers noted the importance of their own advocacy role, and how this can also be integrated into digital solutions (including reminders) to potentially enable more positive experiences.</li> </ul>		
Implications for digital mental health monitoring services from Table 4			
<ul style="list-style-type: none"> <li>• The more that digital interventions can emphasize recovery and wellness, as opposed to illness, the more transformative they can become.</li> <li>• Carer contributions are often overlooked and under-recognized, but digital interventions can actively network with and include carers (with consumer consent) to empower both the carers and their loved ones.</li> </ul>			

**Table 5.** Summary of medication management problems and solutions.

Problems	Solutions
<ul style="list-style-type: none"> <li>• Mental health medications can be lifesaving; however, they can also have life-altering side effects, with disappointing quality-of-life improvements.</li> <li>• Multiple participants had been prescribed drugs to manage the side effects of other drugs.</li> <li>• Medication effects that undermine a consumer’s social or public presentation, such as weight gain, tremors, and hair loss, can be particularly devastating.</li> </ul>	<ul style="list-style-type: none"> <li>• Accessible information about medication effects and potential drug interactions aimed at both clinicians and consumer-users.</li> <li>• Linked to the above solution, tools to track and identify the signature patterns of thriving, in addition to unwell behaviors, can help consumers gain greater insight into their own well-being and make medication management efforts more meaningful.</li> </ul>
<ul style="list-style-type: none"> <li>• Forgetfulness was a particularly sensitive issue—for some consumers, it had been interpreted as treatment resistance, with serious impacts including interaction with law enforcement.</li> </ul>	<ul style="list-style-type: none"> <li>• Tasks identified as key targets for digital enhancement include reminders or feedback.</li> </ul>
Implications for digital mental health monitoring services from Table 5	
<ul style="list-style-type: none"> <li>• Digital monitoring technologies can support consumers by enabling checks for drug interactions and medication reviews, along with providing tools to help consumers manage complex prescriptions.</li> <li>• Building an understanding of what is “normal” is useful for establishing whether a physical health concern is worthy of further investigation.</li> <li>• Automated digital reminders and acknowledgments of tasks achieved can help consumers and carers to manage numerous medications and medical appointments.</li> </ul>	

**Table 6.** Summary of self-monitoring problems and solutions.

Problem	Solution
<ul style="list-style-type: none"> <li>• Self-monitoring is linked to agency, personal responsibility, and the positive potential for shared decision-making.</li> <li>• These benefits are balanced against the potential for self-obsession and harmful use.</li> <li>• There is some concern that consumers might feel pressured to self-monitor, in order to be perceived as compliant.</li> <li>• Sustainability is a challenge.</li> </ul>	<ul style="list-style-type: none"> <li>• The monitoring process needs to be minimized, relatively easy to maintain, and meaningful.</li> <li>• Feelings about whether carers should be involved in monitoring their loved ones were ambivalent among the CCAG—some felt that this may damage the relationship, while others felt that it might result in something that consumers found genuinely useful.</li> </ul>
Implications for digital mental health monitoring services from Table 6	
<ul style="list-style-type: none"> <li>• Clinical engagement is key to a meaningful self-monitoring practice, or at least the provision of some form of useful digital feedback (through pattern identification, for example) to reward consumer input.</li> <li>• When strong consent boundaries are in place, carer access to a wellness monitoring process can provide a valuable backup source of information about a loved one’s wellbeing when consumers are unable to actively participate.</li> </ul>	

These challenges are reviewed in the following section, alongside proposed solutions and implications for digital mental health monitoring services.

#### 4. Discussion

Key findings from this paper include the importance of the consumer and carer co-design of DMHL, 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.

The DHRL Consumer and Carer Advisory Group emphasizes that carer involvement, as well as the sort of support available through lived experience peer connections, are invaluable for mental health wellness recovery and maintenance efforts, tempered by the need for strong and sensitive boundary setting, and the appeal of a design approach that emphasizes the mutual responsibility of care, rather than an expectation of compliance.

#### 4.1. Thematic Discussion

This co-design consultation study explored what sort of digital mental health monitoring technologies consumers and carers might want. The themes emerging from the identified problem areas relevant to the experience of mental illness and potential design solutions, as discussed with the panel, include adaptability and flexibility, optimizing the record, humanizing the record, and enhancing the digital therapeutic relationship.

##### 4.1.1. Adaptability and Flexibility

The more that digital interventions can meet individuals on a person-by-person basis, the more likely they are to succeed. Options for face-to-face or remote participation, as well as the choice between printouts or digital records, were flagged as useful. Other targets included flexible self-management strategies that may be simple at first, perhaps prescribed, with an emphasis on clarity and credibility, supported by human touchpoints and accessible training resources. However, over time, it would be ideal if consumer applications provided the ability to evolve controls and enable consumers to collaborate on treatment changes over time (such as the ability to flag the need for medication dosage changes). Albeit optional, this sort of multi-level, evolutionary provision was identified as key to encouraging ongoing engagement. Crucially, it was felt that such adjustments would help to acknowledge that illness and health are not monolithic entities and instead change over time.

##### 4.1.2. Optimizing the Record

Such an evolution is likely to involve the development of the consumer's documentation of their personal wellness experience over time, as a way to help them gain insight into their own wellness patterns. By enabling consumers to track their own EMR in a way that enables them to detect and reinforce "signature patterns" of thriving, rather than a deficit, DMHIs can empower consumers to regain a sense of their ideal identity. Participants noted the importance of tracking times when challenges had been resolved positively, which could be used to prompt more helpful actions in future crises.

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

##### 4.1.3. Humanizing the Record

One panel member advocated for a greater appreciation of mental health care as a consumer service. Feedback from the advisory group indicated that an enhanced wellness monitoring service that emphasizes the human in the system is more likely to emphasize the experience of care over that of expected compliance. Shifting toward ontologies of design that emphasized mutuality and collaboration—that is, moving from treatment directives toward treatment agreements that are built upon trust and mutual respect—was identified as key to this process and was especially prevalent in how participants spoke about models of consent. Indeed, we would assert that these models of consent—including how to ensure that boundaries and expectations are set in advance by all involved—should be considered a core priority for future research into DMHIs.

##### 4.1.4. Strengthening the Digital Therapeutic Relationship

This mutuality was extended into the types of digital therapeutic relationships that DMHIs enable; using technology in these contexts was seen as useful to encourage adherence more broadly to the agreed care plan, not only by consumers but also by their medical professionals and health systems. Indeed, the advisory group notes that "adherence" is not the sole responsibility of consumers. It emerges from an exchange of responsibilities, which implies that medication monitoring processes will need to both track and enable a consumer's mental health care.

Another core aspect of humanizing these technologies that was identified with some urgency by the advisory group was ensuring that the consumer's own informed judgments about their medications' effects on their lives—for better or worse—and the value of other treatments recommended by their clinical team should be heard and enabled through these technologies, rather than that these regimes are simply being monitored and enforced.

#### 4.2. Discussion in Light of the Wider Literature

As reported in an earlier study [58], in order to ensure that digital mental health interventions are relevant, meaningful, engaging, and empowering for consumers and carers with lived experience of mental illness, this co-design consultation study involved an in-depth exploration of consumers' and carers' lived experience of mental health care in Australia. By identifying priority problem areas in mental health care and considering how digital mental health interventions might be designed to help solve these problems, this study contributes foundational consumer evaluation frameworks for digital mental health interventions [57]. Our findings extend previous mental health consumer co-design studies [24–26] highlighting the broader contextual considerations that can impact the implementation of digital mental health services within Australia.

##### 4.2.1. Monitoring Technologies in Mental Health Care

Digital health monitoring interventions tend to incorporate and generate electronic medical records. Electronic medical records are tools as much as artifacts of digital mental health care that both articulate and shape the experience of mental illness and recovery. In the context of mental health care, it is crucially important that these interfaces—through their shaping of these data into a form useable and interpretable by clinicians—do not misrepresent or otherwise make subservient these human experiences in the name of simplicity of interpretation or integration [59].

This emphasizes the importance of developing system protocols that foster respect for the patient's dignity, appreciation for patient uniqueness, and humanity [60]. 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 [61]. Such results are linked to the promotion of mutual decision-making, as well as improvements in both patient and clinician satisfaction, consultation time, medication adherence, and symptom severity.

##### 4.2.2. Why Co-Design Digital Mental Health Monitoring Interventions?

There are numerous reasons why shared decision-making is still an emerging model of care within mental health care contexts, including risk aversion [62], the need for greater training and guidance, and the still-emergent approaches transitioning from research into practice that encompass the value of informal care network engagements within care processes [63].

To be genuinely time-saving and treatment-enhancing for clinicians, DMHIs need to be integrated into clinical workflows in a way that is relevant and has utility in meeting practice expectations, while encouraging the consideration of individual needs and, in turn, enabling more humanizing and accurate reporting of service users' needs when (re)developing models of care. For consumers, this has the potential to enable better self-advocacy within services. In the long term, these approaches may enable in-clinic monitoring processes that are subsidized by Medicare, to potentially minimize GP visits and streamline medication adjustments.

##### 4.2.3. What the Existing Literature Tells Us about Consumer Engagement with Mental Health Monitoring Technologies

Consumer attitudes towards technology adoption represent a widely developed area of inquiry within digital health consumer research. It consists of a number of theories, such as the theory of planned behavior or TPB [64], the technology acceptance model [65], and

the unified theory of technology acceptance or UTAUT [66], which synthesized previous technology adoption theories to highlight the influence of key contextual factors, such as performance expectations, perceptions about ease of use, and usability expectations, as well as social influence and facilitating conditions, such as the task–technology fit [37].

Studies that explore consumer engagement with digital mental health interventions [7,8,18,23,25,67,68] indicate that these interdependencies are mediated by consumer demographic characteristics, such as gender (females tend to be more anxious about privacy, more risk-averse, and more concerned about ease of use, meaning that trust and access are more important considerations for them), age (young people tend to be more comfortable when adopting new technologies than older people), technology usage experience, education, and the consumer’s current employment, housing context, and medical history (since depressive symptoms and low mood have been identified as particular barriers for engagement, along with tiredness and the severity of symptoms) [7]. Mental health literacy is a sensitive determinant of mental health service engagement. Negative past experiences with mental health services, for example, when a consumer believes that treatment has been forced upon them, may significantly hamper trust, whereas positive past experiences with mental health services and a positive perception of mental health help-seeking practice greatly facilitate engagement [7]. Other privacy considerations relate to the potential stigma of mental illness, factors that traditionally inform consumer trust in digital services, such as ease of use, will generally require additional privacy safeguards such as the discreet naming of mental health mobile apps and the sensitive wording of text message reminders, since these online tools may be used in public [18].

#### 4.2.4. What This Study Tells Us about Consumer Engagement with Mental Health Monitoring Technologies

Beyond these broad population-based indicators, our smaller consultation study emphasizes that interactions between the various factors that influence consumer engagement with DMHIs, including trust, consumer and service capacity, confidence, and well-being are complex and, ultimately, individual. This reaffirms the assertions highlighted in the recovery literature [69–73] that the acknowledgment and integration of individual experiences, needs, and contexts into a consumer’s care are crucial to recovery-oriented practice.

Additional themes revealed in this consultation process that have not been highlighted in previous studies include the consumer’s desire to shift the focus of digital mental health care towards wellness maintenance, thriving, and recognizing the human within the system in a way that enhances the digital therapeutic relationship. The importance of providing comparative benchmarks to help consumers compare and evaluate “normal” treatment outcomes, as well as the therapeutic utility of providing ways to help identify and manage a consumer’s signature wellness signs and triggers, are unique to this study, being specifically informed by mental health lived experience.

Our study recognizes the (often) undervalued role that informal carers can play in recovery. Shared engagement within DMHIs between carers and consumers can potentially help to support consumer self-advocacy within services, through the provision of additional external insights into their day-to-day life, and can, in turn, lower the burden associated with self-monitoring for consumers. These interventions can enable informal carers supporting consumers to engage in interventions and in their recovery plans; this is a potentially potent strategy to embed a digital mental health care service in daily life, previously recognized as being key to the successful implementation of interventions [25]. Integration of the consumer and carer relationship within DMHIs can enable pathways for carers to access ongoing peer support, psychoeducation, and networking functionalities that digital technologies can provide at scale with relative ease. However, the participants made it clear how important it is to protect consumer independence and privacy equally and to ensure that all consumer–carer involvement is voluntary and is supported by strong boundary-setting options.

Independence and privacy emphasize the need to develop system protocols that foster respect for the patient's dignity, appreciation for patient uniqueness, and humanity [60]. Previous studies show that highlighting the humanity of both the consumer and the context of health care can influence the perceived quality of care and the rate of healing [61]. Shared outcome measures are linked to improvements in both patient and clinician satisfaction, consultation time, medication adherence, and symptom severity.

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 that is complicated by broader systemic issues. In the context of mental health care, adherence is likely to be as much about relationships as it is about directives [74]. Indeed, these relationships are key to building trust, which is so important for DMHI success.

Enhancing the consumer's engagement with patient-centered care through the use of mobile digital technologies can improve clinician–consumer relationships as well [75]. The ready provision of digital extension services, such as real-time symptom assessments, pre-programmed reminders, and personalized feedback, can supplement clinical care for better health outcomes [76].

It is essential to consider the limitations of self-management in addressing a mental health consumer's emotional and psycho-social recovery needs [25,68,77]. For that reason, DMHIs are unlikely to enable the wholesale replacement of the therapeutic relationship. Nevertheless, DMHIs can enhance that therapy by enabling different types of collaboration. In this context, it is important to avoid excessive prompts to engage [18] and, in turn, potentially overload the end-users of these technologies [16], instead stressing the importance of ongoing, close work between end-users and clinical stakeholders to enable and manage optimal communication flows.

#### *4.3. Limitations and Future Research*

The present study has several limitations, which could be addressed in future work. Since it was focused upon a stakeholder consultation, the panel size was comparatively small, comprising 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 be checked against a wide range of demographics, such as gender and age, and diverse user characteristics. Pertinent topics for further experiential research include an exploration of optimum designs to help support digital therapeutic relationships and consumer/carer/clinician information flows in digital mental health care. Equally, it would be valuable to explore optimum strategies to help cater to multiple participants with varying digital literacy levels.

### **5. Conclusions**

Electronic medical records are integral to the experience of digitally enhanced mental health care; therefore, it is important that their potential applications are co-designed with mental health consumers and carers, as well as with clinicians. Whereas user experience studies might only explore practical usability questions within a controlled study, co-design research and development protocols can extend those studies to also incorporate the in-depth lived experience of mental health care, which is complex, emphasizing the key issues of trust, capacity, confidence, and wellbeing that are all highly pertinent to the success of DMHIs.

Over the course of an extended two-year consultation, participants of the Flinders University Digital Health Research Lab's Consumer and Carer Advisory Group identified the broad problem areas of agency, access, interactions with health professionals and health systems, medication management, and (self-) monitoring. The group flagged a range of potential solutions to accompany the identified problems within these categories. Priority sites for design intervention include the strengthening of social and interpersonal support,

on the proviso that these personal and social connections are balanced by strong consent procedures and boundary-setting. Key engagement principles include accessible design, as well as understandable content. Equally, it is essential to provide support for different technology-use access capacities and preferences. Valuable enhancements for DMHIs include drug and health education, as well as tools that help participants to identify and better manage signature triggers and behavior patterns.

User-experience-designed research and development approaches may pick up some of these issues; however, in the context of DMHIs, more in-depth consumer inquiry is essential. Incorporating in-depth knowledge of the lived experience of mental illness and the broader contexts of mental health care through consumer and carer co-design is strongly recommended.

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**Data Availability Statement:** The data from this study includes transcripts of in-depth focus group discussions that are difficult to anonymise and involve sensitive topics. For privacy reasons the data is not available.

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## Appendix A

Table A1, below, outlines the relevant agenda items for discussion, preparatory readings, and attendance at each focus group meeting of the DHRL Consumer and Carer Advisory Panel between 2019 and 2022.

**Table A1.** Agenda topics, homework, and attendance at meetings.

Date	Agenda Topics	Homework	Number of Consumers and Carers in Attendance	Number of Researchers in Attendance
3 October 2019	Welcome and Introductions Consent to the recording of voices; terms of reference review. Brief presentation of AI <sup>2</sup> : a service to automatically collate and process My Health Records data Relevant technology: AI <sup>2</sup>	NA	9	2

Table A1. Cont.

Date	Agenda Topics	Homework	Number of Consumers and Carers in Attendance	Number of Researchers in Attendance
7 November 2019	Review of Research Impact Statement for AI <sup>2</sup> Review of notice informing clinicians about the use of AI <sup>2</sup> Discussion of how consumers are likely to react to AI <sup>2</sup> Introduction to the existing consumer-facing mental health-monitoring app—MindTick. Relevant technology: AI <sup>2</sup> public medical records processing and MindTick mobile patient self-monitoring app	Review of documents pre-session.	6	2
5 December 2019	MindTick presentation with Q&A MindTick posters and feedback. Relevant technology: MindTick mobile patient monitoring app	AI <sup>2</sup> room notice review	8	4
6 February 2020	Recruitment protocol and methods for AI <sup>2</sup> call center trial. Consumer concerns about AI <sup>2</sup> —best-practice protocol MindTick review focused on problem questions feedback Relevant technologies: MindTick and AI <sup>2</sup>	Participant diversity recruitment reviewed.	8	4
5 March 2020	AI <sup>2</sup> waiting-room notice accepted. M3Q questionnaire discussed. Pharmacogenomics presentation, with a Q&A session Relevant technologies: AI <sup>2</sup>		9	1
6 August 2020	Data collection for the COVI multi-country project on changes in healthcare in the context of COVID Relevant technologies: MindTick and AI <sup>2</sup>	NA	8	2
3 September 2020	Medication management, background (two perspectives—consumers and carers) Relevant technologies: MindTick and AI <sup>2</sup>		8	2
1 October 2020	Discussion of medication management Part 2—Medication decision-making. Carer groups and COVID Relevant technologies: MindTick and AI <sup>2</sup>	Research on Medication Management—Part 1	7	2
4 February 2021	Medication management part 3: Concrete solutions—IT-based solutions for consumers/carers and medication management. Relevant technologies: MindTick and AI <sup>2</sup>		7	2
1 April 2021	Further exploration of solutions with regard to personal goals, frustrations/problems/barriers, behavior, motivation, and device usage. Relevant technologies: MindTick and AI <sup>2</sup>		7	4
22 March 2022 (mix of face-to-face and email)	Review of consultation findings and thematic analysis	Review of a document summarizing problems, solutions, and thematic design insights	6	3

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