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Co-production of a flexibly delivered relapse prevention tool to support self-management for long-term mental health conditions

A co-design and user-testing study

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Research Summary

Why was the research done?

Supported self-management interventions, which assist individuals to understand and manage their own health condition, have a strong evidence base for chronic physical illnesses but are not often used for long-term mental health conditions. This research was conducted to co-design a self-management intervention for mental health conditions and test the intervention with end users.

What were the key findings?

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 the individual's unique preferences and needs.

What does this mean for policy and practice?

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.

Citation

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Co-production of a flexibly delivered relapse prevention tool to support self-management for long-term mental health conditions: A co-design and user-testing study

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Abstract

Background: Supported self-management interventions, which assist individuals to actively understand and manage their own health condition, have a robust evidence base for chronic physical illnesses such as diabetes but have been underutilised for long-term mental health conditions.

Objective: This study aims to co-design and user test a mental health supported self-management intervention (MyPREP) that could be flexibly delivered via digital and traditional paper-based mediums.

Methods: This study employed participatory design, user-testing, and rapid prototyping methodologies, guided by two frameworks: the 2021 Medical Research Council framework for complex interventions and an Australian co-production framework. Participants were 18 years or older, self-identified as having a lived experience of using mental health services or working in a peer support role, and possessed English proficiency. The co-design and user testing involved a first round with six participants, focusing on a self-management resource used in a large scale randomised controlled trial in the United Kingdom, followed by a second round with four new participants to user test the co-designed digital version. A final round of qualitative feedback from six Peer Support Workers was undertaken. Data analysis involved transcription, coding, and thematic interpretation, as well as the calculation of usability scores using the System Usability Scale.

Results: Key themes identified throughout the co-design and user testing related to: (1) the need for self-management tools being flexible and well-integrated into mental health services; (2) the importance of language and how preferences varies between individuals; (3) the need for self-management to have the option of being supported when delivered in services; (4) the potential of digitisation allowing for greater customisation and features based on the individual's unique preferences and needs. The MyPREP paper version received a total usability score of 71 indicating C+ or "good" usability, whereas, the digital version received a total usability score of 85.63 indicating A or "excellent" usability.

Conclusion: There are international calls for mental health services to promote a culture self-management, with supported self-management interventions being routinely offered. The resulting co-designed prototype of the Australian version of the self-management intervention, MyPREP, provides an avenue for supporting self-management in practice in a flexible manner. Involving end-users, such as consumers and peer workers, from the beginning is vital to address their need for personalized and customized interventions, and

choice in how interventions are delivered. Further implementation-effectiveness piloting of MyPREP in real-world mental health service settings is a critical next step.

Background

Serious mental health conditions including schizophrenia, bipolar and major unipolar depression are associated with longer term use of mental health services [1]. Despite this substantial need, service provision is limited by funding and workforce constraints and additional ways of supporting individuals is required. Self-management programmes have been developed to assist individuals with serious mental health conditions to actively understand and manage their own health [2]. Core components of self-management include psycho-education, relapse prevention, identifying and avoiding stressors, developing effective coping strategies and often include a recovery element [3, 4]. There is now substantial meta-analytic evidence that the provision of supported self-management programmes (i.e., programmes with guidance from a health professional or other helper) alongside standard care improves outcomes for people experiencing serious mental health conditions – including significant reductions in symptom severity, shorter length of admissions, improved functioning and better quality of life [4].

As a result of this robust evidence base [4], global health policies increasingly emphasize the importance of self-management interventions to support individuals with severe mental illness to manage their own health [5, 6] and they are now included as a best practice recommendation in clinical guidelines (eg. UK's 2014 NICE Guidelines for Schizophrenia [7]). Despite this recommendation, self-management interventions are not always offered as standard in services for people experiencing serious mental ill health [4, 8]. This is in contrast to chronic physical illnesses such as diabetes [9], where self-management programmes are a core component of routine practice. Overall, self-management programmes have the potential to benefit the individual, reduce strain on health services, and have an economic rationale for reducing treatment costs [10] but implementation challenges remain.

Self-management programmes typically involve using a collaborative learning process that encourage people experiencing serious mental ill-health to become an expert in their own recovery [2, 11]. Evidence suggests that supported self-management programmes, with guidance from a health professional or other helper, are preferable to independent self-management for people with serious mental health conditions [2,

12]. Self-management programmes where support is provided by a peer support worker who has themselves experienced mental ill health, have demonstrated promising evidence of effectiveness [12-15].

One such example of a program that showed such effectiveness was the Crisis resolution team Optimisation and RElapse prevention (CORE) peer-supported self-management programme study [2, 12, 16], a large scale (n=441), UK-based, randomized controlled superiority trial. This found that peer support using a structured workbook aimed at helping consumers to develop self-management strategies to support their recovery beyond the immediate crisis led to significantly lower readmission to acute care within 1 year compared with self-management alone (29% peer-facilitated self-management vs. 38% self-management control)[12]. Replication of the CORE study findings in routine settings across the UK NHS services, and internationally, has the potential to substantially reduce the burden on the acute care system. However, it is recognised that different countries may have specific nuances based on their culture and systems [17, 18]. As such, delivering the intervention well in these different settings would benefit from consumer-driven consultation and co-production to translate and refine before any research and implementation occurs.

The peer-supported self-management intervention used in the CORE trial was systematically adapted in a step-wise co-production and piloting process in partnership with peer support workers [2] from recovery resources developed by Julie Repper, Miles Rinaldi, and their colleagues in South West London [19]. This paper-based resource “Taking back control” was itself co-produced with people with lived experience expertise, has a strong recovery focus, and incorporates self-management tools including relapse prevention planning, goal-setting, wellness planning, and recovery from a mental health crisis [2].

Since the original resource was developed in 2007, the proliferation and advancement of technology, particularly smartphones, has provided an opportunity for digital interventions to be more accessible and acceptable to people experiencing serious mental ill-health [20]. People experiencing psychosis have adopted digital technology comparably to the general population [21], and mental health interventions delivered via smartphones are acceptable and feasible for people with psychosis and have the potential to support recovery [22-24]. However, access to technology by people with schizophrenia has been found to vary by age and a proportion do not use technology to manage their condition [25]. There is therefore an imperative to allow people to choose between paper-based *or* digital self-management resource mediums depending on their preferences and circumstances. Further, as delivery of self-management interventions does not have a typical

medium (digital, paper based, verbal, or flexibly delivered) or delivery mode (face to face, digital, telephone, or hybrid) and support (self-directed, clinician, peer-supported, or blended)[4], offering a suit of flexibly-delivered personalised programs may help maximise the reach, acceptability and appropriateness of self-management interventions when delivered in real-world services.

This current study reports the translation of the CORE Study self-management resources from the UK to the Australian context, including the adaptation of paper-based resources used in the original CORE trial, and the development of digitally-based resources guided by the original paper-based tool to provide flexible delivery options for consumers. Following the strong tradition of co-production [2, 19], participatory design methodologies for this study were selected to adapt both the paper-based resources and develop the digital self-management resource. Integrating user feedback into the design of digital mental health interventions is gold-standard [26-30] and improves engagement with digital tools for serious mental ill-health [31]. Best-practice recommendations emphasise that researchers should publish descriptions of development work, which includes describing how design features are influenced by user feedback [32].

The overarching aims of this research study are to: 1) translate the paper-based CORE peer facilitated self-management resources to the Australian context for successful implementation; and, 2) co-design and user-test a digital prototype of CORE peer facilitated self-management resources.

Methods

Study design

This study uses participatory design, user-testing and rapid prototyping methodologies. Two frameworks provided an evidence-based structure for the co-design process: 1) the 2021 Medical Research Council framework for developing complex interventions [18], including identification and development of the intervention, feasibility, evaluation, and implementation; and, 2) the co-production framework [33] which seeks consumer leadership and input from the outset including co-planning, co-design, co-delivery and co-evaluation. In this study, co-planning included collaborators and researchers with lived experience informing the protocol and study design, ethics application, recruitment and were named investigators; co-design included people with lived experience being recruited to define, conceptualise, evaluate and design the prototype; co-delivery included lived experience researchers facilitating the aforementioned co-design research and co-evaluation included the knowledge transition team having representation from people and researchers with lived experience for analysis and write up of the results.

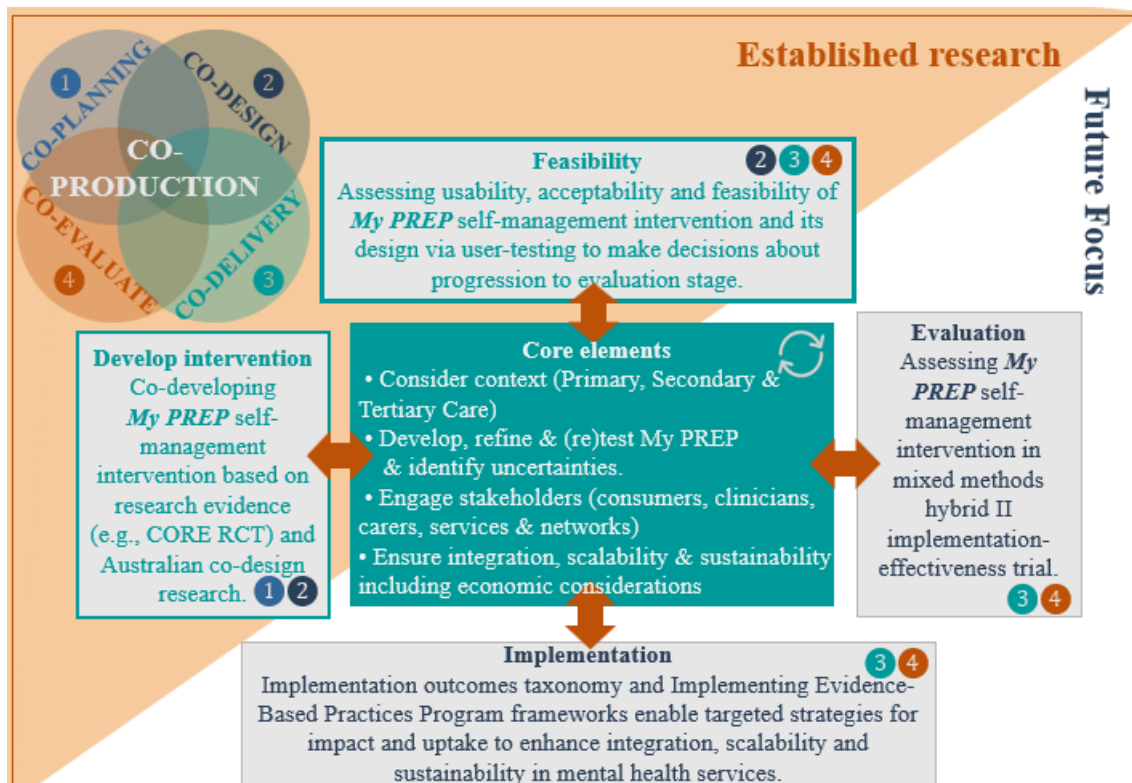


FIGURE 1. Co-production and MRC Framework used in MyPREP development

Participants

The inclusion criteria for study participation required participants to be 18 years old and over, self-identify as having a lived experience of using a mental health service, experiencing mental ill-health or working in a mental health peer support role, have English proficiency, and able to complete the informed consent processes.

Co-design and user testing stage 1

A first round of co-design and user-testing of the original co-designed UK version of the CORE self-management paper-based resource (which had 5 sections: 1) *Moving on again after a crisis* which focused on resuming routines and community support; 2) *Keeping well* which focused on activity scheduling and health promoting behaviours; 3) *Managing ups and downs* which focused on relapse prevention; 4) *Goals and dreams* which provided goal planning tools; and, 5) *Making a personal recovery plan* which provided psychoeducation in a recovery focused manner) [2, 19] was conducted with 6 participants in audio-recorded one-on-one 90-minute user experience sessions face-to-face or a digital video chat depending on participant needs. Interviews were conducted by either a lived experience facilitator or mental health clinician. In the sessions, facilitators engaged the participants in three phases of participatory design processes including discovery, evaluation and prototyping. In the discovery phase the facilitators used open and prompted discussion to explore participant

practices, goals, values and needs in relation to self-management of serious mental health conditions. In the evaluation phase participants user tested and evaluated the self-management resource focusing on their strengths and weaknesses. In this phase, think-aloud methodology [34] was used to gauge the usability and desirability of the design of the paper-based self-management workbook. After this, the facilitator focused on early prototyping with the participant, discussing what a digital version might look like to inform the build of a potential digital prototype. Before the end of the co-design/user testing session participants were asked about their basic demographics and their views on the usability of the paper based CORE resource – including, an adapted version of the System Usability Scale [35].

Knowledge translation stage 1

A Knowledge Translation Team (which included representative stakeholders with lived-experience, peer-support, clinical, research and technology backgrounds) was formed and regularly met with the lead researcher (first author) via digital meeting platforms. The Knowledge Translation Team updated the UK version of the CORE self-management paper-based resource to an Australian version based on the stage 1 feedback. Further, the Knowledge Translation Team used the participant co-design and user-testing feedback to build a high-fidelity digital (alpha) prototype. For this process to occur, the Knowledge Translation Team engaged in an interactive process of synthesizing, exchanging, and applying knowledge [36]. With the ultimate goal being that the user testing feedback is translated into practice, organizational management, technology development, and policy reform [36]. During Stage 2, the tool was also renamed “MyPREP” (My Personal Recovery Plan, which will be used henceforth) by the Knowledge Translation Team.

User testing stage 2

A subsequent round of user testing of the high-fidelity digital prototype took place with four new participants using think-aloud methodology to gauge the usability and desirability of the design of the Australian paper-based self-management workbook. After adaptations to the tool were made based on identified problems and suggestions, a group of six Peer Support Workers who would be piloting the tool in their community mental health service were provided with access to the digital and paper-based tools for a final round of qualitative feedback.

Data analysis

Audio recorded sessions were transcribed and anonymised. The qualitative data was subsequently interpreted using a previously established knowledge translation process for participatory design studies [37].

Specifically, the knowledge translation team developed a coding framework outlining all key concepts. Data were coded in NVivo 12 software using this framework. Interpretation of the data followed established thematic techniques [38], which involved an iterative and reflexive process of reading, coding, exploring the pattern and content of coded data, reflection, and discussion. Similarities and differences in opinion were examined, and differences dealt with through discussion to reach consensus. The knowledge translation team also identified themes and key learnings to inform the customization and configuration of the paper-based MyPREP program and the digital high fidelity prototype. The acceptability scores were calculated using standard SUS process [35]. Frequency and descriptive data analysis of quantitative data generating in user (acceptance) testing sessions was conducted in the Statistical Package for the Social Sciences (SPSS, IBM Corp 2013).

Results

Participant demographics

All 10 participants in the first two rounds of user testing identified as having lived experience of mental ill health and mental health service use, with 3 of the 10 participants identifying as male, 3 residing in regional areas of Australia, and six having a job as a peer support worker. This final prototype was then appraised by 6 additional peer support workers (3 male; 3 female) all working in urban/suburban areas of Sydney, Australia.

Main Themes

Key themes identified throughout the co-design and user-testing sessions related to: (1) the need for self-management tools to be flexible and well-integrated into the mental health services used by participants; (2) the importance of language and how preferences for this vary between individuals; (3) the need for self-management to have the option of being supported when delivered in services; (4) and how digitisation can allow for greater customisation and features based on the individual's unique preferences and needs. Further, the summaries of the full recommendations of adaptations to the MyPREP paper-based and digital prototypes are presented in Multimedia Appendix 1.

The need for integrated, flexible self-management tools

The majority of participants confirmed that there was a lack of self-management tools routinely offered in community mental services and self-management tools supporting people's recovery, and this should be offered as standard, as early as possible.

Honestly, I think it might have been really beneficial to start [using self-management tools] while I was inside [the hospital]. You know that that way I'm not sort of just being discharged into sudden loss of support. I'm being discharged with a plan I have got a set of actions and a structure to go back to. (P3,UxRound1)

These participants expressed that there was a strong need for flexible delivery of self-management tools in Mental Health Service. That is, services should not just provide one type of medium to deliver interventions as the needs of an individual are not uniform.

"Individuals may experience barriers [to using self-management tools] due to their lack of use in technology. Or finding it challenging to adapt to technology this resulting in becoming fearful of using technology." (P4,UxRound2)

"From what I've observed, especially if it's like 60 and above, they love paper versions, even though like, I mean, some are tech savvy. Yeah, they do feel that comfort in what they know as well. But I guess it's just about educating them a little bit more about the technology and allowing them to adapt as well. So having both options is always, always better than not having an option." (P4, UxRound2)

Self-management tools also needed to be well integrated with other plans and documentation offered in services, and digital platforms may enable this integration.

"We get given a lot of stuff when we're coming out of the crisis, particularly for going to hospital discharge. You've got a discharge plan, you've got all your appointments, you got your medication sheets. You may even have a safety plan depending on which program you've gone through. So under a suicide attempt or you, we thought there might be a safety plan that's developed as well. So I think we just need to consider how this works in conjunction with all the other bits and pieces that might be provided." (P4, UxRound 1)

Language

A major theme identified was language. Some words need to be changed to reflect common language in Australia, compared to the UK. People held a preference for less formal and less clinical language. Participants also liked that the language used generally did not make assumptions about the person's situation.

"I like that it's like everyday language "the things I need to sort out". Yeah, I like that. (P1, UxRound 1).

"[when speaking about the 'people and places I can turn to' page] I really like it. And what I like about it is it's not assuming that those people are family members. You you're not making people feel worse by, you know, having to put down friends or colleagues or neighbours or whatever, because family is not in your life. So 'what support would I like?' Yeah, that's great. Nice basic phrasing there." (P4, UxRound 1)

Participants also discussed the importance of not having too much text on each page, as it can become overwhelming and distracting for users, especially as impaired cognition and concentration can be symptoms of mental ill-health. Decreasing the number of words on screen should be a priority to increase usability. This could be done through images, especially infographics and additional feature such as read out loud audio and using avatars.

"Language, is really, really important. The less that's on a screen or on a paper or on a document is better. Yeah, because you can't take it in. It's too much noise. It's too busy. And if my concentration is already impaired, it's not going to help me stay engaged. I'm just, I just won't get engaged." (P2, UxRound 2)

The name of the tool itself My Personal Recovery Plan, *"I don't like the words. Actually, at first I don't like the word recovery, I don't like the personal, and I certainly don't like plan (...) [the workbook needs] something more casual (...) it's the balance between not being too positive that can be invalidating too"* (P1, UxRound 1).

Further, participants emphasised that the language needed to be empowering, promoting self-agency, and sensitive to mental health situations of people as mental health can fluctuate. Although it was generally agreed the language was used in MyPREP was following this, there were few words identified such as 'recovery',

'triggers', 'moving on after a crisis', 'plans', 'goals' that were raised by some participants as having the potential to be disliked by some users of the tool.

"And now going back to the word recovery, if we're going to be changing it in certain instances, personal recovery. And it's interesting because now we are having this challenge around the word recovery. Yeah, some of us are now saying, hang on, many of us are not recovering from anything. If we want to look after health and wellbeing proactively, yeah." [...] "where are you on your journey? Exploring your health journey? Or your life journey, whatever it is that you want to use"
(P2, UxRound 2)

Views on language was mixed, with some reporting they liked the language that others did not *"oh I like the words 'moving on'"* (P1UT1), and some language should remain in the tool. For example, some felt that the term recovery should remain as it promoted autonomy.

You know, I think recovery is like very self-empowering. And that puts a lot of independence on people. (...) And so just thinking about perhaps placing the autonomy a little bit more on the individual as well. So that is self-directed, that is more self-directed yeah. (P1, UxRound 1)

The tool being worked on with support (particularly from a peer worker), would enable these conversations about language to occur.

Supported Facilitation

Self-management tools needed to be customised and personalised to the individual, many participants felt this needed to be carried out through conversations with facilitators/supporters, like peer support workers.

"Yeah, I think, um, this [using MyPREP] would be excellent to do again, through a conversation. Yes like where, if the person accessing the service would be talking with a peer worker and then, so, yeah, "I believe this is what recovery is", "what you think recovery is about", "what is recovery for you", that sort of thing. (P2, UxRound 1)

These conversations *"made it so much more human"* (P1, UxRound 1). Especially as facilitators such as peer workers can tailor the conversation based on the individual needs whilst using the tools as a guide.

Yeah, I would tailor it. So it's. Yeah, that is more for a conversation. Yeah, where the peer worker could be like, "So what are some signs that I could look for in you that might make me think you're not going so well?" (P2, UxRound 1)

Further to this, the accompanying psycho-education that helped contextualise the workbook was originally located at the end of the booklet in the original UK resource. Participants highlighted that this needed to be integrated in with the MyPREP module activities (noting this was actioned for both the digital- and paper-based Australian versions of MyPREP). Further, it was emphasised that this psycho-education component was an important discussion which could be held with someone such as a peer worker, a clinician and/or supportive other.

"I think that [psycho-education] needs to be at the front [of the MyPREP tool]. Yeah, the way I would work with it is in that context, I'd be looking through it and go, oh okay, I'll go to the next page and then I've probably filled in a lot of that stuff before I've got to the end. It is where all the guidance around this. (...) It might not be read, so just all of this content could be put it in within the chapters. Yeah, that or a statement at the front of the elements that you feel from the information on how to help you fill it in was confined to the back of the book. A plain guide just say, Look, don't just launch into it. But there's some further guidance and support there on the back of the book that you can work with a friend or someone through it all with your worker. You know, because that is a lot of text there, and we are assuming the people have the ability to read and comprehend all that information. (P4, UxRound 1)

Additional desirable features and functions when digitised

Additional features and functions moving beyond the paper-based MyPREP workbook were highlighted by participants as part of the co-design process. Exemplar additional features and functions are displayed in Figure 2 and described in detail below (See Multimedia Appendix 2 for enhanced visibility of each page feature).

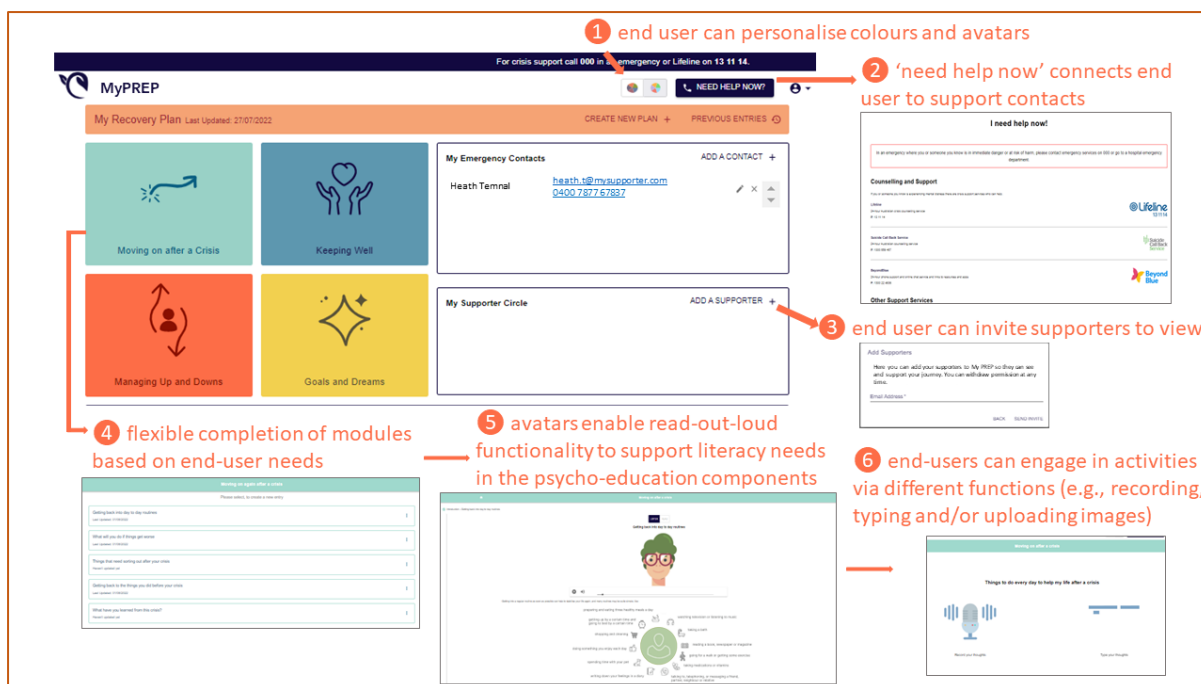


Figure 2. Exemplar of MyPREP additional features and functions

Based on feedback in the user testing phases, *customisation* (which is done by the user) was enabled through the digital version so end users could adapt the content to their preferences. End users could make changes by configuring the colour pallet, the voice and image for their avatar, and were able to alter and flexibly select the MyPREP modules. The ability for end users to customise was seen as very important as it enabled a feeling of ownership over MyPREP. For example, the colour pallet could be changed to reflect not only the preference, but the mood of the participant, which was seen as important in mental health.

“I think it's like there's dark colours and light colours pastel. Yeah, I like that. I think that's really nice because it's like I said, you're going towards personal, like being personal. And this gives choice of being personal as well. It's cool.” (P4, UxRound 2)

“when you are unwell, you only see fog, colour can break through.” (P1, UxRound 2)

The customising of the avatar images and voices in the program was seen as trauma informed (as it had the potential to decrease inadvertent traumatization if someone had a previous traumatic experience with a person of a particular sex), gender inclusive (as voice and image could be changed), and helped tailor for the individuals’ background such as their age. In the future, this was seen as an important feature so additional languages could be easily integrated into the MyPREP package.

You just have to think of the LGBTQ plus community as well (...) I think that's because if you do like a said male or female, it's just like 'why only two?' Yeah, you know, but then if it's like I said a plant [an alternative avatar on MyPREP], it's very cute and it has a smiley face. And I really like that because I think especially in the new generation, if you think about it, a lot of like animations are popping up as well. So, if you want to adapt to the younger generation, they might really enjoy this thoroughly." (P4, UxRound 2)

A new feature, not possible in a paper version but enabled through digitisation was including a “need help now” button suggested by participants, providing the contact details of crisis support and additional mental health support service. This feature was developed after user-testing participants recognised and acknowledged that creating a MyPREP plan potentially could be confronting, and the individual may want additional support from others to process the information, or, obtain additional mental health crisis support.

"If I'm not in a good space and I'm trying to read it, I want to know I've got a safety button. I can go to hey, look, I'm feeling like shit, OK, and I might be reading this and you know what? I actually want to talk to someone, or I want to write to someone or chat to someone. Yeah, and I get blocked. Yes. I think, you need to have a safety, safety spot, do you need help now? Something. The hope is you read it, but it's also a risk thing that, yeah, I think you need this." (P2, UxRound 2)

Another new feature was the “my emergency contacts” and “supporter circle”. The emergency contacts feature allows users to enter contact details of people and services they can contact during a mental health crisis. Additionally, the supporter circle function was designed for users to be able to share their recovery plan entries with people in their support circle (such as carers, health professionals, peer workers) so they could view their MyPREP entries. For one participant, it was important that the user be prompted to input contacts for both of these features when signing in for the first time, in order to provide a safety net if users became distressed in the process of completing the plan and suggested displaying these important contacts on the dashboard at all times to provide a sense of support to users.

P3: "OK, I would want them to have their emergency contacts sorted and their support circle sorted because they can't move on after a crisis. If they don't, if they're unaware of their support circle,

then we can't help them to do that either if we don't know. Especially and then managing up and ups and downs like they're going to need their support circle and their emergency contacts". (P3, UxRound 2)

All participants acknowledged the usefulness of the feature in giving access to user's professional support network including psychologists and support workers if the end user wanted his to be shared.

"People that are supporting you that you want to know what's going on? Mm-Hmm. Yeah. So. I mean, you can have them invited by, or you can share a copy, so I mean, that would be really useful for clinicians and obviously peer workers and mental health workers..." (P3, UxRound 2)

It was emphasised that some may not use this feature because of privacy concerns, particularly with family or carers: *"Some people really don't like family seeing this stuff."* (P3, UxRound 2). Importantly, permission for view access could also be withdrawn by the end user at any stage.

The major function of the online self-management tool is assisting users to systematically map out and record personalised self-management strategies in response to prompts in order to assist in their recovery from a mental health crisis. A feature that facilitated this was the avatar for read-out-loud functionality, which was viewed as especially important for those who held a preference for this, or who had lower literacy skills. Further, each activity was able to be completed in a variety of different ways based on the individual's needs. Specifically, end users can engage in the MyPREP activities by uploading voice recordings, images, emojis and text. This was seen as a highly inclusive feature.

"Oh, we got little icons. I would probably put a smiley face. Awesome, and then you can upload stuff. That's cool, that's like really personalized. Awesome! (...) I think people get really anxious when they feel like they're being recorded or they don't like hearing their voice playing back, I know I don't. So I would always go for the text. (...) I think some people might like it. Some people might not want to type." (P3, UxRound 2)

These features were also seen as an important motivating factor to promote better end-user engagement with MyPREP.

I don't know if people are going to struggle with doing these entries, because if they might think, OK, what is the purpose of it? But if it's more fun and personal, it's more fun. So, it's like okay, I'm going to do this one. I might even put a photo of me in it and get that done. But if it's always just bland, I don't know. People might be like, well, especially, you know, you want that motivation. But I think this is really cool. (P4, UxRound 2)

MyPREP module activity entries made by the end user were also editable, and there was a function where entries could be saved so they could keep a record of change.

This is really awesome. And it will keep the track as well. You can kind of say you can kind of go back, it can be like okay I was feeling not great on this day, what happened that day as well? (...)
Yes. So, you can kind of see that progress, especially for consumers who do enjoy that progress. (P4, UxRound 2)

System Usability Scale (SUS)

At the end of each user testing session, participants completed the SUS. The mean and range are presented in Table 1. The MyPREP paper version received a total SUS score of 71 indicating C+ or “good” usability. The digital version received a total SUS score of 85.63 indicating A or “excellent” usability.

Table 1. SUS usability scores for the paper-based and digital versions of MyPREP

| SUS Items | MyPREP Paper-based Version | MyPREP Digital Version |
|---|----------------------------|------------------------|
| | Mean (range) | Mean (range) |
| N | 5 of 6 | 4 of 4 |
| 1. I think that I would use the Personal Recovery Plan frequently. | 2.4 (0-3) | 3.25 (3-4) |
| 2. I found the Personal Recovery Plan unnecessarily complex. ^a | 2.4 (0-3) | 3.75 (3-4) |
| 3. I think the Personal Recovery Plan would be easy to use. | 3 (0-5) | 3.5 (3-4) |
| 4. I think I would need the support of a support person (e.g., a peer support worker) to use the Personal Recovery Plan. ^a | 2.2 (0-4) | 2.75 (2-4) |
| 5. I felt the various sections in the Personal Recovery Plan were well integrated. | 3.6 (3-4) | 3.5 (3-4) |

| | | |
|--|-------------|-------------|
| 6. I thought there was too much inconsistency in the Personal Recovery Plan. ^a | 3.2 (1-4) | 3.5 (2-4) |
| 7. I would imagine that most people would be able to use the Personal Recovery Plan easily. | 2.2 (0-3) | 3 (2-4) |
| 8. I found the Personal Recovery Plan very cumbersome. ^a | 2.8 (1-4) | 3.5 (2-4) |
| 9. I would need to learn a lot of things before I could start using the Personal Recovery Plan. ^a | 3.2 (1-4) | 3.25 (2-4) |
| 10. I would feel very confident using the Personal Recovery Plan myself. | 3.6 (2-4) | 3.75 (3-4) |
| Total SUS | 71.5 | 84.4 |

^a Indicates reverse scored items

In a final meeting before endorsing MyPREP for piloting, the researchers met with six peer support workers, where the tool was presented and discussed, these peer workers were then given access to the MyPREP intervention to provide feedback. At this meeting and at follow-up only positive additional feedback was relayed, and the peer workers emphasised that they were excited for it to be used in their service.

“I have reviewed the Workbook and honestly couldn’t find much wrong with it at all!! It’s great and I am very excited to put it into practice.” “My team had no feedback to give on the digital version other than it looks great and can’t wait to see it used with clients in practice!!” Peer worker 1

Discussion

In this study, we present user-testing of an Australian version of the paper-based My Personal Recovery Plan (MyPREP), and co-design and user-testing of a digital version. Key themes identified throughout the co-design and user-testing sessions related to: (1) the need for self-management tools being flexible and well-integrated into mental health services; (2) the importance of language and how preferences varies between individuals; (3) the need for self-management to have the option of being supported when delivered in services; (4) the potential of digitisation allowing for greater customisation and features based on the individual’s unique preferences and needs. The resulting tool was subsequently rated using the SUS which indicate that the end-users involved in this study rated the paper-based tool as “good”, but the digital version as “excellent”. Combined, these results suggest that the prototype has valuable potential for use in mental health services, and support the progressing of research to piloting in mental health services to inform a future large-scale RCT. This early research providing detailed descriptions of intervention development is called for now as best practice [32]. Specifically, it important to include details such as: the important decision-making steps across all stages

of development; explanations of how the information gathered from intended end-users was carried out; and, how intended end-user input influences how design features were incorporated into the design.

The need for implementation research

Participants in our research also highlighted the need for integration and co-ordination of self-management interventions and tools within services as there can be a multitude of staff involved, and a multitude of documents and plans (such as suicide prevention plans, discharge plans, wellness plans, medication adherence plans) at various points throughout a consumer/service-users journey in a mental health service. Further, although the digital version of MyPREP was seen as being able to be used independently by end users at their home or within health settings, participants emphasised a need for such tools to be delivered with support from others, particularly peer support workers. While this may be explained by many of the participants being peer-workers or consumer advocates themselves, this finding mirrors the current movement within mental health services towards the holistic inclusion of lived experience expertise [39]. Further, integrated staffing models may also be associated with better recovery, including social functioning [40]. Taken together, implementation-focused research is needed to determine how MyPREP is actually delivered, and how it can be optimised, once it is introduced in real-world settings.

A recent systematic review of supported self-management interventions for people with serious mental health conditions found that there is a current lack of research focused on implementation and even fewer studies are based on implementation science theories [8], which are summarised in the taxonomy of implementation outcomes [41]. Although randomized controlled trials (RCTs) remain the gold-standard approach to informing clinical decision-making and drawing causal inferences [42, 43], there remain unacceptable research-to-practice gaps and a disconnect in generalizability and performance between an extremely controlled clinical trial environment to highly complex real-world mental health environments [44]. Implementation science, which is the formal study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, can bridge the clinical evidence-to-practice gap as it can improve the quality and also the effectiveness of health services [44]. The hybrid effectiveness-implementation design is an innovative and rapid solution to providing high quality evidence on effectiveness and implementation simultaneously [44, 45], making it the ideal next stage of the research pipeline for the

MyPREP project to determine effectiveness and implementation. This is particularly important in this case, as the basic content of MyPREP is already tested successfully in the CORE trial in the UK [16].

Accessibility of MyPREP

The digitisation of MyPREP may have allowed it to become more accessible to end users when compared to the paper-based version, and this may go some way to explaining the increase in usability scores as rated by the SUS. For example, the use of read-out-loud feature via the avatar was viewed by participants very positively, as was providing options for writing, recording their voice, or uploading images when completing MyPREP module activities. A recent systematic review suggests that developers of self-management interventions should adapt interventions to ensure greater inclusivity for participants with less formal education, as it was found that educational level was associated with engagement [8]. This is particularly critical for individuals with severe mental ill-health given the increased rates of lower education in this cohort [46]. Indeed, participants in our study repeatedly emphasised that plain and informal language was preferred. Further to this, we used Design for Dignity Principles, web content accessibility guidelines and International Organization for Standardization (ISO standards) for process improvement, safety, and quality (e.g., 9241-11 ISO standard) to promote digital accessibility and ensure features are useable and acceptable for people with accessibility issues.

Customisation of MyPREP

Customization embedded within MyPREP was a clear theme throughout the co-design process, and was rated very positively in user testing sessions of the digital tool such as the ability to change the colour pallet and chose their avatar. This was important, as it is a self-management tool, participants emphasised that these self-directed changes to MyPREP fostered a sense of autonomy, control and choice and ownership, and this should be embedded as standard in all features. Reviews in this area recommend that the content of self-management intervention should be tailored to the service users and have flexibility to be personalised and customised, especially as interventions were found to not always fit end user needs [8].

In the future, there are plans for MyPREP to be customised further. A major example is enabling control over language. Specifically, the feedback concerning the language used for the names of modules (eg. “my recovery plan”, “moving on after a crisis” and “goals and dreams”) was liked by some in user testing sessions,

but not by others. This was despite MyPREP being co-produced and going through iterative co-design cycles with people with lived experience of serious mental ill-health [2, 19]. The solution to this lies in customisation, where end users can adapt the names of the modules to suit their own set of beliefs, and even remove modules that are not relevant to them on their MyPREP dashboard.

Limitations

This is a preliminary iterative co-design and user testing study, and should be viewed as such. Like most user-testing studies, our sample of service users was small (eg. [47]). Further, we used both advertisements across networks and services but also snowball sampling, which is a type of convenience sampling. A major disadvantage of such convenience sampling is that it risks a non-representative study sample. In our case, the study sample was quite diverse in age and sex. However, a large proportion of participants were consumer advocates and peer-workers, having considerable mental health knowledge and expertise. Further, those recruited for this study might have had a particular interest in working with digital health tools, which may introduce avidity bias, and may explain the very high acceptability scores on the SUS when scoring the digital version of MyPREP. The next stage is piloting MyPREP in services to increase the representativeness of our sample and make iterative adaptations to MyPREP based on user feedback. Overall, however, as the original 'My Personal Recovery Plan' was trialled in the UK with at least 275 crisis care service users in a large-scale RCT (with 441 service users enrolled in the trial), this may suggest that the representativeness of our sample at this point does not pose concern for the next stage of piloting of the Australian version in real world mental health services.

Another limitation that is common in user-testing (e.g. [47]), is that the presence of the facilitators over a digital meeting platform during the testing session may have affected the views of the participants as they might have felt reluctant to be critical. We do not expect that this was a major limitation, however, as continuously throughout the session, facilitators emphasised that this was the opportunity to improve the paper-based and digital prototypes and encouraged discussion around problems and areas for improvement.

Conclusions

The co-production of the MyPREP self-management intervention and associated research in Australia is currently in its early stages. However, this co-design and user-testing phase is a crucial step in adapting the MyPREP to the Australian mental health setting and digital context. Noting the current findings may remain

relevant to implementation in any setting. Overall, the co-production process is vital, as service-wide implementations that fail to consider end-user needs and organisational structures often encounter problems. Indeed, Killikelly and colleagues [31] suggest that both co-design and support from mental health staff or researchers when using the tool are two features that are associated with successful implementation and improves engagement with digital tools for people experiencing serious mental ill-health. To avoid implementation issues, it is essential to involve consumers and peer workers who may support the delivery of MyPREP from the outset. In this study, feedback from these end-users has highlighted a strong desire for personalised delivery of self-management interventions that offer choice and options, considering individual end-users' different needs and circumstances. MyPREP has worked towards addressing this need by offering digital and paper-based mediums, providing options for how delivery is supported (i.e., individuals can choose their supporters), increasing accessibility (e.g., avatars, voice-recording options) and customisation (e.g., colour pallet, choice of avatars) based on their preferences and needs. To strengthen MyPREP's implementation in real-world Australian mental health service settings, implementation-effectiveness piloting and robust trialling is now required to test and refine the tool.

Lived experience commentary

In our view, co-production is the umbrella term for the co-family; co-creation, co-planning, co-implementation and co-evaluation. This is a concept and philosophy where collaboration with the lived experience is paramount. It is a way to co-create new interventions, improve systems and solve problems, and is now being adopted in many public health policy arenas — including research.

This has moved far beyond “consumer participation”, which was enshrined in 1992 in Australian mental health policy (1992 Australian Health Ministers, National Mental Health Policy). Back then, this was ad hoc and tokenistic. Now, as “co-” is becoming more widespread, there are more genuine attempts to learn to integrate co-production as a way of doing research across the board.

In research, with co-production we are witnessing a move from consumers and carers (or those with lived and living experience) voices from being “subjects of” to equal collaborators — working with researchers to influence change that benefits the service and system user. This research project has done just that. By having lived-experience experts lead, participate and contribute to the design and facilitation of the research, we are actively using Lived Experience knowledge and expertise in recovery planning through various stages. The

recruitment of participants, data collection, workshop, one-on-one interview formats and question were developed and lead by Lived Experience.

In this project, a trusting respectful alliance between research and lived experience evolved organically and naturally, providing a solid foundation to “do” this project with passion and enthusiasm, creating a safe and supportive atmosphere which was emulated in dealings with others. Interviewees felt more than comfortable to give their time generously sharing their insights and thoughts to what would work well and be improved to increase engagement and use of this recovery-based intervention.

Through different phases of this project, reciprocal positives emerged for the research team. Empowering and enabling each member to consider different perspectives and interpretations. Embracing new ways of thinking created richer understanding of issues not considered previously. This was articulated in ways in which the research was focused and conducted. On reflection, lessons for how this research approach will inform similar ongoing collaborations should be considered — where research projects embrace and welcome different skills sets, experience and knowledge.

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Competing interests

The authors declare that they have no competing interests.

Availability of data and materials

The qualitative datasets generated and analysed during the current study are not publicly available: they are lengthy interview transcripts, from which quotations used in this publication have been selected to ensure that individual services or participants cannot be identified. The datasets are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Ethical approval for this study was obtained from the University of Sydney's Human Research Ethics Committee (HREC reference number 2019/571). Informed, written consent was obtained in advance from all participants in qualitative sessions for this study. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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Author contributions

AM and NG conceived this phase of the research and its design, with support from BLE and SJ based on the original UK CORE study work. AM, IO and DP conducted the data collection. AM, DJ, DP, IO synthesised and analysed the data. AM drafted the manuscript with support from IO, TC, EB and UA. DP, JC and AM oversaw the digital build of the resource for user testing. All authors read and approved the final manuscript.

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