Patient and Public Involvement (PPI) in Digital Mental Health Research

A guidance document on how to involve people with lived experience in research on digital mental health interventions.

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Executive summary

This guidance can help guide and structure PPI consultations for a wide range of digital interventions and tools. This guide will act as a starting block to build upon when designing the activities and research plans. It provides insight into what has helped and hindered those with lived experience of mental health conditions in making significant contributions, as well as how to make PPI consultations meaningful and beneficial. Our guidance has been co-developed by mental health researchers and people with lived experience. It aims to help researchers designing PPI consultations for digital mental health intervention (DMHI) development and testing across a wide range of mental health service user groups. It also provides information on what are the key benefits expected and barriers encountered by service users in accessing DMHI so that these are appropriately addressed depending on the focus of the specific research.

Although our project is focused on the co-production of a guidance for PPI involvement in DMHI research, some of its key principles can be applied to the co-production of research more generally. This includes thinking about the type of people who are involved in a co-production project, at what stage they are involved, what can be done to include more underrepresented groups and how to navigate potential challenges.

Introduction

Digital technologies and interventions (defined as patient-facing or self-administered interventions delivered through a digital platform) have an increasing role in mental health care. It is key to ensure that appropriate patient and public involvement is not overlooked when developing new digital mental health interventions. The unique perspective offered by those with lived experience can improve study conduct and design, as well as ensure that interventions meet the needs of users, which may improve their quality and acceptability. The study aim was to produce a guidance for digital mental health usage to facilitate future collaborative projects. This guidance has been co-produced by researchers and people with lived experience of mental health issues.

Key:

DMHIs = Digital Mental Health Interventions

PPI = Patient and Public Involvement

Our objective was to develop a guidance for PPI involvement in designing and carrying out research on DMHIs. The activities undertaken to achieve this included a series of co-production online workshops with people with lived experience of mental health problems. The information from these workshops has been brought together to form this guidance on research involving DMHIs and tools in co-authorship with ten of the participants who had attended more than one workshop. The themes generated from the minutes of the workshop were validated with participants during the workshops and the drafting of this guidance.

We will discuss topics under the themes of: 'why do people become and remain involved in PPI?'; 'what areas should be discussed within PPI consultations?', including 'areas related to specific tyles of DMHI' and 'areas related to any type of DMHI', and; 'what can make a difference within DMHIs?'. In some cases, key elements could be viewed as either barriers or facilitators. We will then outline how these aspects can be identified and considered when developing new interventions, making sure that lived experience is harnessed effectively.

This guide is intended for researchers who are interested in utilising PPI for DMHIs and want information on where to begin or have already begun to involve PPI and want to learn more.

Why do people become and remain involved in PPI?

Participants who took part in the workshops all had experience of contributing to research as lived experience advisory members. They were asked about what influenced their decision to take part in the co-development of this guidance and in research projects. It emerged that members of the public engage in research for a variety of personal and social reasons, which can be summarised as: social motivations, positive experiences with DMHI and feeling a valued member of the research team.

Quotes within this theme and throughout the rest of the document are from participants who took part in the workshops.

1.1. Social motivations

Several social motivations for wanting to engage in PPI were given by those who attended the workshops. The issue of representation was given prominence throughout the workshops. It is therefore imperative when recruiting for PPI co-production that efforts are made to involve participants which are an expression of the diverse communities to which mental health service users belong. This will ensure that the intervention is felt to be relevant and accepted by those with lived experience, and meets cultural sensitivity needs. People reported wanting to engage with PPI to ensure there were diverse perspectives, experiences, and expectations. To ensure representation is met with PPI, recruitment strategies could include purposive recruitment and proactivity in reaching out to relevant communities.

Other social motivations included wanting to make use of their existing knowledge. Participants felt a sense of obligation to provide a perspective, particularly to represent those who cannot.

"I was drawn to take part simply because I felt it was an area that I and people I know have experience in, both in terms of digital interventions and in terms of mental health and also because it is an area of interest in me and also because I want to be as helpful as I can in contributing a PPI perspective to research"

1.2. Positive experiences with DMHI

People's prior experience with DMHIs shaped their willingness to be involved in PPI consultations. The ability to talk and listen to positive and negative views of these interventions and contribute to future developments were what influenced their decision to take part. People were more likely to engage in PPI when they were enthusiastic and passionate about developing effective DMHIs.

1.3 Being a valued member

People involved in these workshops reported that their reasons for continued involvement in the subsequent workshops included feeling as though they were listened to and played a meaningful role within the research. The workshops providing a friendly environment without feelings of judgement was a positive aspect which encouraged participants to attend week on week. Furthermore, knowing that their input was purposeful and would help others in the future as opposed to simply being a performative or "box-ticking" exercise encouraged participants to attend further workshops.

> *"Feeling it's a nice, warm and supportive environment and a non-judgmental one as well; that's really important! As well as feeling it will result in something great, helpful and positive!...making me feel it's NOT a box-ticking exercise; there's nothing worse! it's ok if not everything is accepted but at least you need to heard, listened to and occasionally appreciated!"*

> *"Feeling like my voice is heard and my opinions are taken on board would make me continue being involved"*

What areas should be discussed in PPI consultations?

In this section we discussed themes that emerged from the workshops, which described areas that participants felt would be important to discuss in PPI consultation on DMHI. These can be divided into areas relating to specific types of DMHI (such as online social networking, wearable devices and peer support) and general areas relating to any DMHI. Researchers may find these helpful to select the questions and topics they wish to discuss in PPI consultations, depending on the features of the DMHI they are developing or testing.

Areas related to specific types of DMHIs

The case studies presented below were selected to represent the variety of ways in which digital tools can be used in DMHIs and capture more specific ideas and concerns.

2.1. The use of Online Social Networking for mental health

Online social networking can bring benefits but also raise issues that require public and patient discussion, such as safety and trust.

There was discussion in the workshops about varying symptom levels and how they can influence how people engage with online social networking platforms. It was discussed that support could be provided for accessing social media and using them positively, especially when symptoms are more severe. Other important points brought forward included how certain patient groups are vulnerable to hyperstimulation from accessing online technologies and the negative consequences of blue light exposure on mood disorders.

Involving mental health professionals in discussions towards the development of such interventions was perceived to be helpful, provided they have a certain level or number of years of experience. A suggested minimum for this was two years' experience.

2.2. How to collect data on mental health outcomes through digital means

The development of wearable devices for assessing mental health outcomes can more precisely estimate the effects of interventions. Such devices may also help to deliver prompts and encouragements to improve those outcomes (ecological momentary interventions).

Those involved in the workshops were cautiously enthusiastic about the idea of such devices. Workshop participants felt it was an interesting idea which sounded similar to "my fitness pal" but for mental health needs. Suggestions were made for a "check-in" option like that of Facebook when interacting with friends (without names involved) on a wearable device such as a smart watch

would be helpful. These are discreet and widely used so would not make the user feel self-conscious as discretion and privacy are important. Another discussion was had about how this would aid users' own memory of interactions as often it is hard to remember how many positive interactions they have had. This would provide a concrete record to draw upon when talking to health professionals. Wearable devices were felt to have a potential to increase self-motivation. Users could set a goal for how many people they would like to interact with and receive the results either weekly or monthly. Suggestions were also made for heart rate detection to be able to monitor anxiety levels and ways to help and reflect upon that.

On the other hand, issues of data protection were discussed, comparing the device to "big brother" and to consider issues around disclosing to the other person in the interaction that there is a sensor device. There were also suggestions to consider how to record the difference between positive and negative interactions such as an argument and to define how much of an interaction will count i.e. if someone simply says hello and nothing more. Additionally, it was discussed whether home-based interactions would count towards a goal and how helpful interactions would be counted.

2.3. Providing online peer support to carers of people with severe mental health problems

Providing online support for carers might help to reduce the potential barriers experienced by this group such as time constraints and can increase their access to peer support.

Participants in the workshops felt as though education around mental health care would be particularly beneficial, especially for those who don't have English as their first language. They also felt it was important for carers to be able to digest the information in their own time. For those with hypersensitivity issues, online peer support was felt to be a positive idea due to struggles with face-to-face interactions and having felt forgotten when support was not available online. Suggestions were put forward to match people appropriately with peer supporters based on, for example culture, age and family member/ friends' diagnosis, although this is not an exhaustive list. Discussion was also had about whether the support would be local or national, highlighting issues around confidentiality if it were to be local.

Users felt there ought to be a professional present in any peer support sessions and/or peers should be trained to provide support so as not to cause potential harm.

The participants in the workshops viewed this to be a positive idea as there are time benefits to online peer support including a reduction in travel and its associated costs, as well as increasing accessibility to support.

Areas related to any type of DMHI

3.1 Safety and Trust

Failure to reassure people about safety can affect their willingness to use DMHI and reduce acceptability of these interventions. Trust in relation to the privacy of data and content is considered to be particularly difficult to establish. Concerns were also formulated in relation to interactions through digital social media. Trust around interacting with individuals within DMHIs varied depending on the type of individual and platform, whether it was a forum, self-help or therapy. Users reported feeling as though trust could be achieved, although it may take some time. However, this might not be much different to face-to-face scenarios.

For users to trust an intervention and become fully involved with DMHIs they reported needing to feel safe. Concerns were brought up in the workshops about the sharing of information in discussion pages of DMHIs outside of these interventions, particularly when discussing sensitive topics. Participants felt that it is helpful when sets of rules (in lay terms) appear each time the user accesses a DMHI that require the user to 'accept' them before logging in.

"There are apps where they will have the safety come up every time you log in, so that when you are not well you don't forget. Needs to be very plain language and short"

3.2 Security and Data Protection

Reassuring users of privacy of data and being transparent about how data will be used and protected is of great importance when communicating through digital health innovations or online platforms generally.

Data protection was described as imperative in encouraging meaningful PPI and engagement with DMHIs. Having security measures in place such as 'limited access' or 'membership only' was seen to be of high importance for workshop participants.

"Some form of safety i.e., security through membership so not just anyone can view sensitive data written in forums"

3.3 Moderation

Having a moderator in place was a reoccurring topic within workshops, both for helping to manage difficult responses in DMHIs as well as to provide aid and support. A moderator would also ensure that those people who are vulnerable are not taken advantage of. In addition, it was highlighted that moderators were welcoming/reassuring to those posting for the first time, and that a response from a moderator could avoid someone feeling ignored if no one else responds to them. The information given to people by moderators must be clear and from accurate sources. Staff who provide or moderate the DMHI may also need to receive extensive training to guide patients.

However, the importance of finding the right balance with moderators was identified as at times platforms were considered to be over moderated. An example was made of a moderator removing an entire thread that could have been helpful rather than only the few concerning/unhelpful comments on the thread) (see quote).

> *"Lose a conversation because of a couple of comments which then is counterproductive, other people could have used that conversation for helpful hints"*

3.4 Digital Exclusion

Digital exclusion in this guide refers to a proportion of the public having unequal opportunities or scarce literacy to use online or digital technology.

3.4.1 Limited access to devices and/or internet

People may be out of work or on reduced income, and therefore may not be able to afford Wi-Fi/data or may not have access to newer devices where specific DMHIs may be made available. Building on this, some apps also require a subscription which can be too costly. This can prevent involvement opportunities and lead to a potential bias around innovation and evaluation. Where possible, DMHIs should be available across visually attractive online platforms to reach a larger number of users.

> *"DMHIs need to work across online platforms and they need to look good. They should be accessible, practical and have visual appeal"*

3.4.2 Limited digital literacy and/or support

Some people have poor IT literacy and need support to access digital technologies; this support may need to be ongoing to build confidence and reassurance to access digital technology. It is important to be aware of this digital inequality otherwise the usefulness, acceptance, and effectiveness of DMHIs might be limited only to proficient users. It would be helpful to invest time to provide education/training and offer support to these people to increase their digital literacy skills before they begin to use any DMHI and therefore encourage the efficient use of a digital intervention.

3.4.3 Language

DMHIs with a lack of alternative languages are viewed as a considerable barrier. People who engaged with these workshops reported they had not seen any provisions for those with a lack of proficiency in the language in which the intervention was originally developed. This applies both to a lack of ability to choose a language other than English, and to situations where other languages cannot be translated on forums. Therefore, the option to choose a language or automatic translation to a chosen language is important to include in DMHIs.

3.4.4 Awareness of people's religious, spiritual, and cultural beliefs and values

It is essential when designing digital health innovations to consider users' spiritual, religious and community values, particularly when working with under-reached groups. People have a diverse range of beliefs, perspectives, experiences, and expectations which need consideration in relation to the purpose, aims and context of any proposed intervention. Online forums might provide opportunities to tackle these issues, bringing together like-minded people who cannot travel and provide opportunities to talk freely outside of their immediate communities. It is felt that people from outside of these backgrounds may not understand the impact on illness from these aspects of life, leading to feelings of exclusion. Steps therefore need to be taken to generate awareness within under-reached communities to help reach out/spread the message.

> *"Thinking of faith support as well. People of colour and of organised religion are disproportionately affected with mental health problems yet when we go to these apps there's actually nothing for spiritual needs. It is something that gets ignored"*

> *"there is an issue around it not being spoken about or recognised in our communities…It would be good for steps or actions to be taken to generate awareness or understanding in Muslim communities"*

> *"Sometimes online would be a really good place because there is that level of anonymity or connecting with people who are not in your own community so you can be a little more open…you can at times discuss with likeminded people from other communities who understand and feel open because they are not in your local community"*

3.5 Impact of symptoms on use of DMHIs

A key barrier identified was that of an individual's mental health status. Severity of symptoms and its possible variation over time could affect how people engage with DMHIs. It was felt by those in the workshops that people with higher severity of symptoms would be more vulnerable and likely to regret any comments made on a platform. The permanence of online messages compared to verbal interactions is a key issue for DMHIs and thus is something to be aware of when developing these interventions. Some posts may also not make sense when a person is unwell. Increasing or adding advice surrounding mental health literacy (an individual's knowledge about mental illness to aid their recognition and management) specifically during the use of a DMHI could be a solution to address this. This barrier also emphasises a need for anonymity for those users who tend to overshare when they are unwell. The ability to choose a username for anonymity might reinforce feelings of comfort with sharing online.

What can make a difference within DMHIs?

Participants within the workshops reported what they believe to be the key elements of intervention design. These can guide and inform those designing interventions that address key users' needs.

4.1 Communication

Communication in this guidance refers to the way in which the subject matter of DMHIs may be communicated to users, as well as how users may communicate within DMHIs and how this might affect treatment. Both verbal and non-verbal communication were highlighted as important to consider.

4.1.1 Verbal

Effective verbal communication, which is presented using lay language (provided in plain English) is felt to be essential for aiding people's understanding. The information should be in bitesize chunks that are easily digestible. Technical jargon should be avoided. Intervention developers should also consider accessible dissemination approaches targeting individuals with different abilities and preferences, using appropriate language.

> *"Easy to understand, mention it is for everyone not just certain people and say who it is inclusive for and list the minority groups. No chunks of text as that can be off-putting"*

4.1.2 Non-verbal

The absence of non-verbal communication in DMHIs could result in some users feeling significantly more distressed than they indicate online, which may be missed or overlooked. This lack of non-verbal information could also hinder emotional understanding and the development of a therapeutic relationship that mental health professionals share with a person, or the ability to replicate empathy between peer-to-peer interactions. Poor use of language or lack of punctuation between a professional and user, or between users in a forum, can lead to misunderstandings about the message that is trying to be conveyed. There is also the potential for misunderstanding because of a lack of body language and tone of speech. However, for some people the lack of non-verbal communication can make interactions online more comfortable, due to issues with hypersensitivity and struggles with social cues in face-to-face interactions.

4.2 Encouragement

Encouragement in this guide refers to a user's need to receive words of support throughout the intervention, which may help to motivate engagement with DMHIs. Encouragement could be provided via human or computer-based interaction.

4.2.1 Computer-generated

Words of encouragement provided through an automated/artificial system were considered beneficial for user engagement with DMHIs as well as the development of healthier mental outlooks and improved well-being.

4.2.2 Human encouragement

Empathetic encouragement provided from health professionals, even in a simple message such as 'you're doing a good job', was felt to be of importance. Such words might offer emotional support, reassurance and validation during their mental health journey.

4.3 Flexibility in accommodating for individual and collective needs

Accommodating for individual and collective needs will help to ensure inclusivity. Flexibility is needed in how support is provided, as users can act differently and have various ways of coping.

Suggestions made by those participating in the workshops included:

- **Content and design –**

It is important to ensure that the use of methods and activities fully engage users. Use of enticing colour is needed regarding the design of an intervention, and accounting for the range of interests and tastes. Additionally, it is recommended that font types are clear and easy to read. One way to deal with this could be to offer people the ability to customise their DMHI interfaces. Regarding content, the use of interactive elements such as quizzes, games and videos were suggested to facilitate understanding of information and get "people more engaged".

> *"I'm quite a visual person who likes light bright colours, it feels really nice and there's nothing dark there. Mental health always has dark colours and lots of black"*

> *"I do think the website needs to be clear, concise. It should not be unnecessarily wordy. I think having short videos is quite useful too"*

- **Peer-to-peer interactions –**

The ability to connect with peers is important for sharing experiences and coping strategies as well as the ability to form emotional connections. Online peer interactions can provide flexibility by allowing people to access support at their convenience, and for as much or as little time as is necessary. There is also the ability to remain anonymous if they choose.

> *"I think having a chat option on the forum would be quite good too, for example members would be able to talk to each other in real time. This should still be moderated of course"*

- **Reducing stigma –**

It is important to ensure that DMHIs are inclusive of all of those with mental health conditions, including those which are more heavily stigmatised. It should be stated at the beginning of the intervention that everyone will be treated equally. Measures should also be put in place to ensure no unequal treatment of those with varying mental health conditions, including those whose mental health conditions may be more heavily stigmatised.

4.4 Goal setting

Self-help was reported by some to be potentially overwhelming and that instead specific, manageable goals should be provided, and users should be able to track their progress of completing these goals. It was felt that, on the whole, those existing interventions containing self-training with lone activities like homework reduce motivation. However, homework could encourage the habit of carrying on the intervention activities independently. The ability to set and track goals was deemed to be helpful, although such a feature should be an opt-in system so that being unable or lacking in confidence to achieve goals is not demotivational and people can join when they feel ready.

4.5 Structure

It is considered helpful for users' progress when DMHIs such as apps have a sequential programme to follow so they can monitor their own progress and be able to see where it will lead. Having email reminders or push notifications was quite important to help remind users to keep up with their programmes. However, if this were provided, the ability to choose to opt-out would also be required in case the reminders become too overwhelming for users.

Summary of key points

In the final section of this guidance, we would like to summarise the key points established during our co-development work.

The use of digital technology within mental healthcare is rapidly increasing, indicating a promising scope for the development of DMHIs. The benefit which these interventions can offer is far-reaching, provided they are designed in a way that meets the needs and concerns of users. To ensure that user's needs are met, it is integral that researchers involve PPI in the development of DMHIs. This guide provides an insight into how to promote and maintain PPI, what to discuss during PPI consultations and what is important to include within DMHIs from those with lived experience of mental health conditions.

In terms of **promoting and maintaining PPI**, researchers should consider:

- Utilising a purposive recruitment strategy to ensure that all relevant communities are reached, and cultural needs addressed.
- Providing a non-judgemental space for users to openly discuss any concerns.
- Ensuring that participants feel listened to, and their inputs valued during consultations.

When doing **PPI consultations around the development of DMHIs**, researchers should consider discussing:

- Providing safety and security in DMHIs.
- Providing moderators within DMHIs (including potential training to be provided to these moderators).
- Potential issues around digital exclusion (for example digital literacy, language and culture).
- The potential impact of people's symptoms on their use of DMHIs, and ways to address this.
- The potential for DMHI to cause hyperstimulation for certain patient groups.
- Involving mental health professionals in discussions towards this type of DMHI.

Finally, the points highlighted as **important to consider within DMHIs are**:

- Providing safety and security in DMHIs.
- Addressing potential issues around digital exclusion (for example digital literacy, language and culture).
- Understanding the influence of online interactions on communication.
- Offering encouragement throughout DMHIs.
- Accommodating for individual and collective needs within DMHIs.
- Having a structure and achievable goals within DMHIs.

These points are made to inform those who may be designing PPI consultations for DMHI development or have already begun using PPI and want to learn more about how to get the most out of their consultations. The information provided within this guidance document can be used to direct and initiate discussions with those with lived experience to develop DMHIs that meet the needs of a wide range of mental health service user groups.