MASTER THESIS

Best-Practices, Lessons Learned and Recommendations for the Participatory Design of eMental Health with People with a Severe Mental Illness: *A Qualitative Multiple Method Approach.*

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Abstract

Background: Long waiting times, costly therapy and stigma form barriers to access mental healthcare by people with a severe mental illness (SMI). eMental Health (eMH) may provide individuals with SMI with an effective and scalable way to receive care irrespective of time and location. However, adoption falls behind on expectations. A mismatch between the eMH interventions and the user's skills, abilities, context and preferences might explain this lack of adoption. Further, ill-fitted designs that do not accommodate the cognitive abilities of the target group result in poor usability. For the SMI population to reap the full benefits of what eMH has to offer, efforts need to be made to ensure that the technology fit the abilities and preferences of the SMI end-user. To optimize the fit between the technology and SMI patients, they should be included in the development process through participatory design (PD). However, vulnerable populations are often excluded or misrepresented. The active role of SMI patients in PD is relatively new and not yet clearly defined. Currently, there is a lack of knowledge or guidance on how to best involve individuals with SMI in PD.

Objectives: This research aims to gain insight into the best practices for doing PD with people with SMI.

Methods: A qualitative multi-method approach was used in accordance with the three pillars of evidence based medicine (i.e., scientific literature, practitioner's expertise and client values). First, a scoping review was performed to gather insight from the current literature on the best practices for PD with SMI patients. Second, a survey with open-ended questions was sent to people with experience in conducting PD with vulnerable target groups. Third, semi-structured interviews were held with SMI patients succeeding PD workshops to gather their opinions and preferences of being involved in PD. After conducting each method independently, relevant data was copied verbatim into a data extraction form. Herein an iterative coding process took place. The Grounded Theory Approach was used with a combination of inductive and deductive coding. Subsequently, the findings were combined to form a list of recommendations for future PD projects with SMI patients.

Results: The lessons learned that followed from the qualitative multi-methods, resulted in 23 actionable recommendations. The recommendations are divided into four categories: 1) plan and structure study, 2) create and maintain a participatory team, 3) accommodate participants and 4) strive for power balance. Each category contains four to seven recommendations. The first category concerns the necessary activities to carry out prior to the start of the data collection methods. The second category helps to ensure longevity in the fruitful collaboration of the participatory team. The third category targets the bespoke approach within PD that helps to accommodate participants in various ways such as their skills and abilities. The fourth category serves the mitigation of ethical challenges surrounding power balance.

Discussion/Conclusion: The recommendations provide a practical guidelines for conducting PD with the SMI population. Although diversity in people and methods, equal collaboration and communication can aid in the success of PD with people with SMI. The approach does not come with a one-size fits all approach. It calls for a flexible and bespoke undertaking that caters to skills and preferences of SMI participants. Researchers should always be aware of the context of their study. Future research may uncover the personal benefits of participation for psychiatric patients.

Keywords: *participatory design; severe mental illness; eMental Health; best practices; recommendations*

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1 Introduction

The Dutch Court of Audit observed that the more complex the mental healthcare needs of patients are, the longer they have to wait to access treatment [1]. Currently, 27% of patients in need of specialized mental healthcare have to wait longer than the acceptable norm, as opposed to the 8% of patients that require milder treatment [2]. People with a severe mental illness (SMI) are affected by this. In the Netherlands, around 210,000 people have an SMI (total population of 17.6 million) [3, 4]. SMIs include severe forms of mood disorders, anxiety disorders and non-affective psychoses (e.g., bipolar disorder, schizophrenia and major depressive disorder) [5-7]. These diagnoses must have persisted for at least two years, during which patients required care from various coordinated disciplines to treat their disability in functioning [8, 9]. Their access to care is reduced due treatment barriers, such as long waiting times [1], costly therapy and stigma [10]. The reduced access to care has negative effects on an individual's health outcome [11] and quality of life [1].

Further, this group increasingly relies on outpatient services due to the downscaling of inpatient facilities (85.7% undergo outpatient treatment) [3, 12]. Because of the barriers to access mental healthcare, people with SMI are expected to rely on self-care to support their own well-being [13]. Thus, innovative alternatives to in-person treatments should be considered and optimized to address the health disparities and barriers to mental healthcare experienced by people with SMI. eMental Health (eMH), such as websites, serious games and mobile applications [14], have the potential to offer an effective, accessible and scalable way to ensure access and quality care at a distance [15-19], as well as address the disparities in mental healthcare [20]. Although a general consensus of the definition is lacking [16], van Gemert-Pijnen et al. [15] defines eMH as *"the use of digital tools to treat and prevent mental health disorders and promote positive mental health"*.

In general, an increase in use of mobile devices and online services was observed in the SMI population [21]. The target group also sees eMH as feasible and acceptable [10, 21]. For example, a computerized cognitive behavioural therapy program for anxiety and depressive disorders [22], and a virtual reality cognitive behavioural therapy intervention for psychosis patients [23] were deemed to be (cost-)effective eMH solutions. Thus, eMH may provide individuals with SMI access to treatment while they are waiting to receive in-person treatment. It has the ability to be used irrespective of time and location [15, 18]. It may also improve the quality

of care [24]. However, despite the high level of acceptability, the implementation and adoption of eMH in practice falls behind expectation [25, 26].

A mismatch between the innovation and the user's skills, abilities, context and preferences might explain this lack of adoption [15]. Users with SMI have different design needs compared to the general public because of the effect their SMI-related cognitive deficits have on navigating and interpreting eMH systems (e.g., difficulty with abstract reasoning, decreased attention span and reduced working memory) [13]. Ill-fitted designs that do not accommodate the abilities of the target group, result in poor usability [13, 20]. More usable and effective designs were seen in eMH where a reduced cognitive effort was required of SMI end-users. Examples of such elements are a low reading level, minimal text, content grouping and memory aids [27]. By improving technology design, the developed eMH may show higher rates of adoption due to increased usability. Increased adoption will improve the access to care received by this population. So, for the SMI population to reap the full benefits of what eMH has to offer, efforts need to be made to ensure that the technology fit the abilities and preferences of the SMI end-user. To optimize this fit, tailored solutions should be made that incorporate the users' skills, abilities, context and preferences in the development process.

One way to include user preferences, is to develop the technology together with the end-user [20]. This can be done through participatory design (PD). PD facilitates a bottom-up approach to technology design that involves end-users [28] as equal partners [29]. This user-centered approach advocates for the collaborative effort between different stakeholders, such as designers, researchers, people with lived experience and end-users, throughout the development process [30, 31]. It aids developers to think outside their expertise by incorporating a wider range of perspectives from real-life user scenarios. Since this approach allows for the perspectives of end-users to be incorporated in the design of eMH technology from the start, a better fit between the user, technology and context can be achieved [15]. Additional benefits of PD include empowerment, ownership and skill-building for PD participants [32]. This may indicate that PD has the potential for positive personal impact, rather than solely epistemic benefits [33].

However, despite the benefits of PD, vulnerable populations are often excluded or misrepresented in PD projects [34]. Strict research criteria such as specific budget distributions and limited timeframes [35], along with lack of human or financial resources make the collaboration potentially less appealing to researchers [20, 34]. In addition, specific challenges to

PD with psychiatric participants such as power imbalance [34, 36], stigma and participant distress [37], make it even more daunting for researchers to include SMI participants. Moreover, the active role of patients in PD is relatively new and is not clearly defined [36]. Additionally, the role of researcher changes within PD [31]. Conducting PD with people with SMI creates an added responsibility of the researchers to maintain a flat hierarchy so vulnerable participants can thrive [38]. Currently, there exists a lack of knowledge or guidance documents on how to best involve people with SMI in PD [14, 20, 29, 34, 39].

This research aims to gain insight into the best practices for doing PD with people with SMI. The practical guidance document resulting from the findings may equip future researchers, developers and project owners with recommendations on how to best conduct PD studies with the SMI population. Once researchers and designers can design more effectively with the SMI population, the innovative output of their projects will hopefully become more successful and better adopted by the target group. The list of lessons learned is created through the findings of a qualitative multi-method research approach involving a scoping review, PD practitioner survey and participant interviews. The following research questions (RQ) will be addressed:

Sub-RQ 1: What relevant experiences, tips, best practices and lessons learned are reported in scientific literature by eHealth studies that conducted PD with people with SMI?

Sub-RQ 2: What are considered best practices and key recommendations for executing PD with SMI patients by people with experience in conducting PD with vulnerable target groups?

Sub-RQ 3: What are the experiences and preferences of SMI patients on how to be included in PD projects?

2 Methods

A qualitative multi-method approach was used for this study. The methods were in accordance with the three pillars of evidence based medicine, namely 1) scientific literature, 2) practitioner's expertise and 3) client values [40, 41]. First, a scoping review was performed to gather insight from the current literature on the best practices for PD with SMI patients. Second, a survey was sent to people with experience in conducting PD with vulnerable target groups. Third, semi-structured interviews were held with SMI patients succeeding PD workshops to gather their opinions and preferences of being involved in PD. After conducting each method independently, the findings were combined to form a list of recommendations for future PD projects with SMI patients.

2.1 Scoping review

A scoping review was deemed appropriate as the topic under review was broad and heterogenous [42, 43]. This review followed the process outlined in the guidance document by the Joanna Briggs Institute for conducting a scoping review in combination with the Arksey and O'Malley framework [43, 44]. To ensure completeness for the reporting of the results, the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews' checklist was used [45].

2.1.1 Sources and Search Strategy

Scopus, PubMed and three health design journals (i.e., CoDesign, Design for Health and The Journal of Health Design) were searched in February of 2021. These design journals were added as they were not incorporated in the databases of Scopus and PubMed. Inspiration for the search string was drawn from a study by Wang et al. [46], who conducted a similar scoping review that targeted people with dementia. The search string for this study was made up of two parts. One encompassed 'psychiatric patients' and the other 'participatory development'. The final search string and its operators were: "*("psychiatr*" OR "mental healthcare" OR "mental illness") AND ("participatory development" OR "co-creation" OR "co-design" OR "participatory design" OR*

"co-production" OR "generative design" OR "Scandinavian design" OR "participatory research")". For each source, the same search string was utilized.

2.1.2 Eligibility criteria and Selection Process

Due to the explorative nature of this scoping review, the only source characteristic used as eligibility criteria, was that the articles ought to be peer reviewed. There were no quality appraisals conducted. Different inclusion- and exclusion criteria were set at the title, abstract and full-text screening to allow for an increasingly narrowed focus. All search results were uploaded into an online systematic review management system called 'Covidence'. This system automatically removed all duplicates. After the screening process, a single round of snowballing was applied to the primary sources to look for additional titles. These titles followed the same screening process, in which the following criteria were applied:

1. **Title screening:** During the title screening stage, one researcher (SES) included all titles that concerned PD. Consequently, studies were included regardless of their target group and setting.
2. **Abstract screening:** The abstract screening was performed by two researchers independently with an even split (TD, SES). Before proceeding independently, an adequate inter-reviewer reliability Cohen's Kappa score of 0.84 was reached during a pilot screening [47]. If there were any doubts about an article's inclusion, the reviewers would consult one another to reach a consensus on its inclusion or exclusion. During this stage, studies with non-SMI participants were excluded. Only studies that involved psychiatric inpatients or SMI patients as study participants were included. Additionally, studies that were not written in English or Dutch were excluded.
3. **Full-text screening:** In the full-text screening, multiple criteria were applied by one researcher (SES). First, only studies that concerned the PD of eHealth were included. Second, only peer-reviewed studies were included. Third, studies where the abstract or full-text article could not be obtained, even after contacting the corresponding author, were excluded. Fourth, studies that only surrogated the preferences of psychiatric inpatients or SMI patients through other participants (e.g., caregivers, family members, friends or staff members) were excluded as those cases had no direct participation of people with SMI.

Fifth, non-primary studies were excluded such as systematic reviews and editorials. Thus, only studies that carried out the PD themselves were included. Sixth, studies where the diagnosis or severity of the participants' mental illness were not mentioned, were excluded.

2.1.3 Scoping review analysis

A data extraction form was created to determine which information would be extracted and how it would be categorized. See Appendix I for the categories and definitions. The main categories were study aim, technology, target group, goal, design framework, SMI involvement phase, methods, tools, environmental setting, organizational setting.

Relevant data was copied verbatim from the included studies into the data extraction form. The sub categories for the 'SMI involvement phase' were taken from the study by Wang et al. [46] The phases were divided into the *"pre-design"-, "generative-", "evaluative-", and "post-design"* stages, which in turn originated from a study by Sanders et al. [48]. The pre-design stage examines the context of the user prior to making the innovation, while the post-design stage examines the way the user interacts with the innovation once it is produced. The generative- and evaluative stage belong in the creative space where the innovation is designed and tested respectively. For this reason, it was decided to keep the methods 'usability testing' and 'beta testing' separate as one usually occurs in the evaluative stage and the other in the post-design stage. One category where items were merged was in the methods category. Here expert reference groups, group interviews and focus groups were grouped together in 'Focus Group'. Other methods included literature review, observation, interviews and survey. The categories were identified through in vivo coding (i.e., using words mentioned in the text).

The sub categories for the tools were divided into *"make", "tell" and "enact"* tools [49]. Appendix I mentions the specific definitions on the (sub-)categories. These terms originate from a study done by Sanders et al. [49] where the terms respectively correspond to making things, stimulating dialogue and enacting scenarios. Lastly, the setting was divided into the environmental- and organizational setting. The former targets the environment in which the data collection methods were conducted, such as clinic, university, home, community center, online synchronous and online asynchronous. The distinction between the latter two is that online synchronous is online communication in real time such as a video conference and online asynchronous is online communication not in real time such as email. The organizational setting

concerned the grouping of people involved in the data collection methods, for example individual, group or combination.

Once this process was completed, the extracted data in the 'lessons learned' category were copied into a Microsoft Office Word document where it underwent an iterative inductive coding process according to the Grounded Theory approach [50, 51]. One researcher familiarized themselves with the content (SES), by repeatedly reading the data. This was done until overarching themes could be identified through in vivo coding. Data that encompassed similar concepts were grouped and further analyzed to come up with lesson themes. Once the themes were approved by two researchers (HK, TD), the data attached to each theme were analyzed, merged and translated into concrete lessons and recommendations for future studies by SES.

2.2 Participatory Design Survey

The aim of the survey was to collect the experiences, practical tips, best practices and recommendations on PD with vulnerable target groups from people that have experience in conducting such studies or projects. Ethical approval for the survey was obtained by the ethics committee of the 'Behavioural Management and Social Sciences' (BMS) faculty at the University of Twente in the Netherlands (#210121).

2.2.1 Participants and Setting

The respondents were recruited through convenience sampling within the networks of group members from a project in which a self-control training application was developed for the SMI population. In addition, the opportunity for snowball sampling was facilitated and encouraged as the respondents were asked to further distribute the survey among relevant members of their network.

The survey target group were adults (≥18 years) whom conducted PD with vulnerable participants. Appendix II includes the survey where vulnerable target groups are defined as "*people in (socially) vulnerable situations who, as part of this vulnerability and a lack of resources, have an increased risk or susceptibility to adverse (mental) health outcomes. For example, due to* poverty, *low literacy, poor housing, an immigrant background, frailty, or (severe) mental illness. This includes related terms such as "complex" target groups and "difficult-to-reach" target groups".* The scope of the research topic was broadened to vulnerable target groups to allow for an increased

amount of data that could be collected. This was deemed appropriate as the SMI population is a subsection of the vulnerable target group.

2.2.2 Materials and procedure

The web-based survey was administered via 'Qualtrics' during March and April of 2021. The survey consisted of three parts (see Appendix II). First, an introduction page that explained the aim and scope of the research was shown, followed by informed consent. Second, respondents were presented with a set of background questions (i.e., birthyear, sex, nationality, employment role, employer, experience level, and vulnerable target population). Third, a set of open ended questions were presented that covered the most common design challenges faced by researchers in healthcare. These challenges were categorized into *"challenges in practice", "challenges in project management"* and *"miscellaneous or generic challenges"* as per Groeneveld et al. [52]. Respondents were asked to reflect on specific challenges they faced in PD projects with vulnerable populations. Subsequently, they were asked to offer recommendations to overcome them. As this study was conducted during the COVID-19 pandemic, a specific section was added in order to cover remote PD research with vulnerable populations.

2.2.3 Analysis

The survey data was deductively coded according to the coding scheme of the scoping review. The individual recommendations that were mentioned by the respondents were added under the relevant scoping review lessons. This new respondent data either fully supported the existing recommendation, or offered minor changes to the lesson. For example, if a respondent mentioned the same thing as one of the lessons already stated, nothing was changed to the lesson. However, when a respondent mentioned a new insight that was related to an existing lesson, the lesson would be rewritten to encompass this new insight. Respondent data that was not covered by any existing lessons, were grouped under 'miscellaneous'. The miscellaneous category underwent the same inductive coding process as was performed during the scoping review (see section 2.1.3).

2.3 Participatory Design Interviews

The final pillar left to examine, were the client values. These were gained through group interviews that were held after a series of PD workshops of an eHealth development project for a self-control training smartphone application for the SMI population. Ethical approval for the interviews was granted by the ethics committee of the BMS faculty, domain Humanities and Social Sciences, at the University of Twente in the Netherlands (#210814).

2.3.1 Participants & setting

The interview took place straight after the final workshops. In total, five workshops were held during June and July of 2021 at two different care facilities. Each workshop lasted around 90 minutes. Overall, the workshops covered the topics of defining self-control, discovering user preferences and lo-fi prototype evaluation. Three workshops were held at a forensic psychiatric care facility that houses inpatients whom have been in contact with the judicial system (Forensic Psychiatric Clinic; FPC). The other two workshops were held at a regular mental health care outpatient facility (Flexible Assertive Community Treatment Center; FACT). Here patients were free to go as they pleased while receiving mental healthcare. For a complete overview of the workshops, a separate article will be published.

The participants of the workshops included 4 people with SMI undergoing treatment and 2 people with lived experience. Three of the participants were male forensic psychiatric patients and the remaining three were female. The age of all participants ranged from 29 to 57. Their recruitment was carried out in collaboration with care providers of both facilities through convenience sampling. Patients (≥18 years) were deemed eligible if they had a SMI diagnosis that required care in the last two years prior to their participation.

2.3.2 Materials and Procedure

Straight after concluding the final workshop, interview questions were asked as an evaluation of the PD process. The interview topics offered insight into the opinions and preferences of participants regarding participation, workshop activities, communication and continued involvement. An example of an interview question was “What did you like and dislike about the workshops with regards to activities and communication?”. For a complete overview of the

interview questions, see Appendix III. A semi-structured approach was chosen in the delivery of the interviews. The rationale for this decision was that the semi-structured approach enabled the maintenance of the informal and relaxed environment that was created during the PD workshops preceding the interview. The two group interviews were recorded and lasted 8 and 13 minutes.

2.3.3 Analysis

The recordings of the interviews were transcribed verbatim and analyzed using a deductive approach. For this, the lessons learned of the review and survey data were used as the coding scheme. The same approach as the survey analysis was applied to the interview data. If the lessons learned mentioned by interviewees fully supported any existing lessons, no alterations were made to the lessons. Whereas, when the data offered new insight to an existing lessons, they were rewritten to include the new insight. In the end, all lessons mentioned by the interviewees were categorized under the existing lessons; no new lessons resulted from the interview data.

3 Results

3.1 Summary of included literature

The identification of records resulted in 1224 hits. After the removal of duplicates, 950 studies remained for the screening process. After the application of the inclusion- and exclusion criteria, a final selection of 21 studies from the years 2008 to 2021 were included. Figure 1 displays the study selection process.

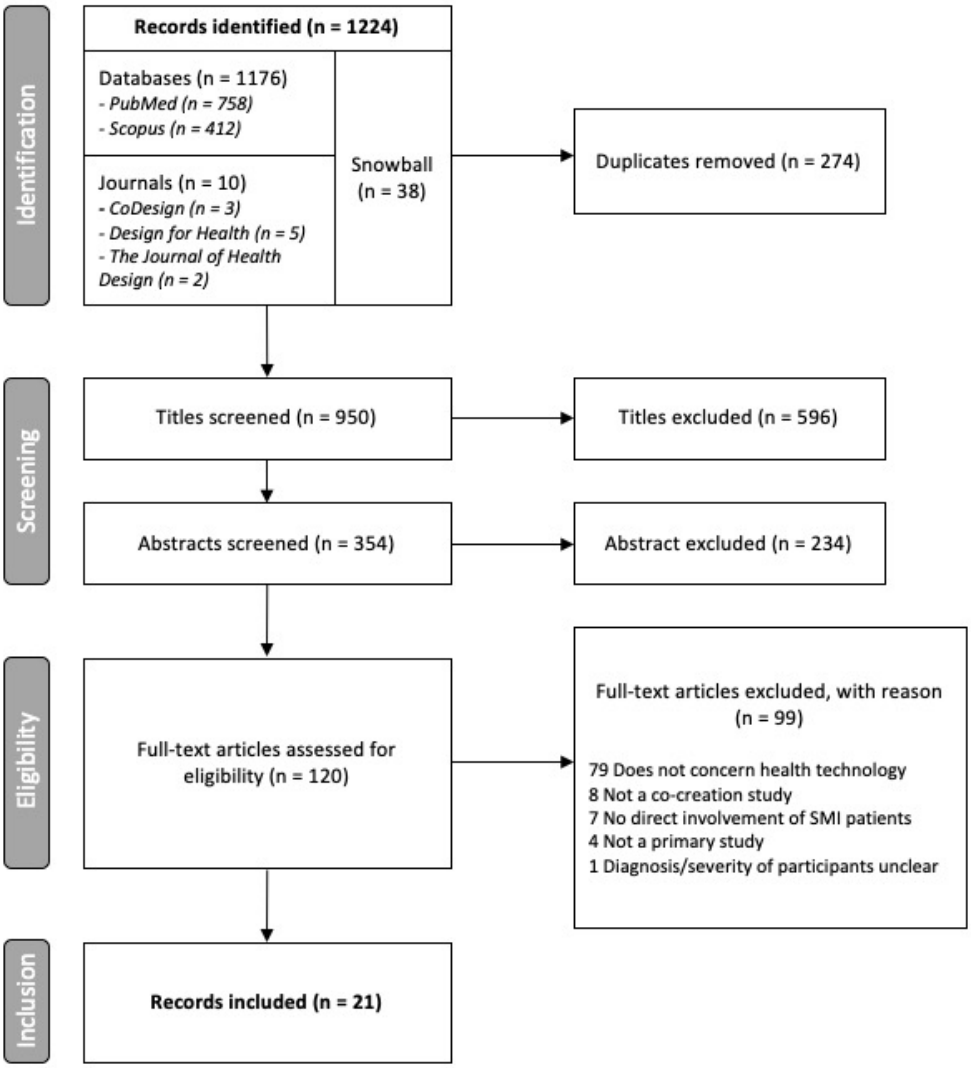

Figure 1: PRISMA Flow diagram of scoping review

The table in Appendix IV shows the study characteristics of the included articles. Nine studies developed e-health for people with psychosis (three specifically targeting early psychosis) [53-61], four for bipolar disorder [62-65], four for SMI patients [66-69] (one specifically targeting forensic psychiatric patients [66]), three for schizophrenia [70-72] and one for borderline personality disorder [73]. The most common innovation developed were applications (either smartphone or web). 15 studies were dedicated to the development of such applications. The three remaining innovations were websites (n = 3), virtual reality apps (n = 3) and decision aids (n = 1). The main difference between web applications and websites was the level of interaction: websites offered static resources, whereas web applications facilitated interaction with the end user.

Patients were mostly included in the evaluative stage (n = 14), followed by the generative stage (n = 13) and pre-design stage (n = 12). Participants were least involved in the post-design stage (n = 2). The methods in which SMI participants were included the most were interviews (n = 12) and usability testing (n = 11) followed by workshops and focus groups (n = 9 each). Other methods where SMI participants were included surveys (n = 6), observation (n = 1) and beta testing (n = 3). The tools that were utilized were tell tools (e.g., group discussions and storytelling) in 19 studies, make tools (e.g., sketches, wireframes and prototypes) in 12 studies and enact tools (e.g., scripting, role playing) in six studies.

The setting in which the studies took place were not specified in 11 out of 21 studies. From the ones that did, most were conducted in a clinical setting such as hospital or clinic (n = 9). Of these nine studies, five combined the clinical environment with additional settings: two added sessions in a community center, two complimented the clinical environment with (a)synchronous communication and one study also undertook their study in a university and at the patient's home environment. One study was conducted in a university setting combined with synchronous communication. Individual sessions were often combined with group sessions (n = 13), whereas four studies only conducted group sessions and the remaining 4 studies only conducted one-on-one sessions.

3.2 Survey respondent characteristics

The survey respondent characteristics can be viewed in Appendix V. 25 out of 29 respondents completed the survey (86.2% response rate). Respondents from five countries distributed over three continents (i.e., Europe, Oceania and Asia) filled out the survey. Most respondents came from the

Netherlands (n = 16), followed by New Zealand (n = 5), United Arab Emirates (n = 2), Belgium (n = 1) and Bulgaria (n = 1). The majority of respondents (n = 15) carried out their research in knowledge institutions, followed by non-profits (n = 5). Respondents mostly had little to moderate experience in conducting PD (n = 11 each). The roles in which they carried out their research were mainly that of researcher (n = 10), lecturer (n = 5) or student (n = 5). Three of the respondents were involved in research projects that targeted SMI or forensic psychiatric patients. Other target groups were people with a low-socio-economic status, people with dementia, people with Autism Spectrum Disorder and mothers of immigrant families. For the complete list of target groups, see Appendix V.

3.3 Workshop interviews

All six PD participants (see 2.3.1) participated in the interviews. In general, the overall opinion of workshop participants on PD was positive. Two participants found the process meaningful due to the sense of collaboration and teamwork. Another two participants valued their participation by creating something for people from the SMI target group. One participant did not necessarily find PD to be personally meaningful, but expressed the experience of participation as 'fun'.

3.4 Lessons learned

The lessons learned that followed from the three qualitative studies, were categorized into four inductively created categories, namely, 1) plan and structure study, 2) create and maintain a participatory team, 3) accommodate participants and 4) attain power balance. Each category consists of four to seven recommendations. An overview of the lessons is provided in Table 3. Subsequently, examples are provided for each lesson to illustrate how the lessons may be operationalized. Some concrete examples derived from the workshops are incorporated into the lessons learned. For an overview of key points per lesson separated by source, view Appendix VI.

The order of the lessons within each category are in descending order in line with the literature support. The lesson most frequently supported by literature are on top. Note that within lessons 'team members' refer to the stakeholders involved in the research team, which may include individuals with SMI. Whereas 'participants' refer to stakeholders involved in separate data collection methods, which always include SMI patients.

Table 3: Lessons learned for doing PD with people with SMI

Lessons learned		*Sources*		
Plan and structure study		***Review***	***Survey***	***Interview***
1	**Combine multiple methods** (e.g., focus groups, interviews and design workshops) to gain different types of data and completeness of information.	*[53, 57, 58, 60, 64, 66, 73]*	*R5, R18, R20*	
2	**Set up a flexible study design** to allow for an iterative and adaptive development approach.	*[54, 57, 62, 67, 71]*	*R3, R19, R22*	
3	**Determine the recruitment strategy** in collaboration with stakeholders (e.g., vulnerable members, care organizations, supervisors, people with lived experience).	*[53, 70]*	*R1, R3, R4, R5, R8, R9, R10, R11, R12, R13, R15, R20, R22, R25*	*P6*
4	**Secure the availability of sufficient resources** (i.e., time, budget, materials and participants) in the early preparation phase of the study.	*[53, 66]*	*R6, R11, R18, R19, R20, R21, R22, R23, R24, R25*	*P6*
5	**Provide and coordinate a clear structure** between and within study activities (e.g., setting regular meetings).	*[66, 70]*	*R5, R11, R15, R17*	
6	**Reflect with a critical and open mindset** on the chosen methodologies.	*[57]*	*R4, R6, R11, R12, R15, R16, R22*	
Create and maintain a participatory team		***Review***	***Survey***	***Interview***
7	**Collaborate with multiple stakeholders**, including patients, to incorporate all relevant perspectives in the design-, development- and delivery process.	*[53, 54, 56-58, 64, 66, 72, 73]*	*R2, R5, R7, R17, R19, R23*	*P6*

8	**Ensure informed participation** by briefing participants on study goals and set-up through clear introductions and handing out flyers to ensure voluntary and informed participation.	*[58, 66, 70]*	*R1, R2, R3, R5, R7, R9, R10, R12, R13, R15, R17, R18, R19, R20, R21*	
9	**Communicate with participants** in between sessions to secure participation, send reminders and updates, and provide support for their role as contributor.	*[53, 66, 70]*	*R1, R3, R9, R10, R12, R13, R15, R19, R20, R21, R23, R24*	
10	**Stimulate a collaborative work relationship** between team members and participants through ice-breaker activities and mediation in case of differing opinions between members.	*[53, 57, 64]*	*R1, R8, R9, R16, R18, R19*	*P3*
11	**Provide transparency in design decisions** by showing (concept) designs and explaining decision rationale.	*[53, 57]*	*R8*	*P2, P5, P6*
Accommodate vulnerable participants		***Review***	***Survey***	***Interview***
12	Use concrete tools (e.g., scenarios, personas and prototypes) that **account for the cognitive abilities** (e.g., abstract reasoning and decreased attention span) of the participants.	*[53, 57, 66, 70]*	*R3, R4, R9, R11, R12, R13, R15, R17, R19*	*P2, P3, P6*
13	**Adapt (the order of) research activities in a bespoke manner** during data collection, according to the state and preference of the SMI participants.	*[57, 58, 70]*	*R1, R5, R13, R17*	
14	Determine with participants how to **solve practical barriers** that might affect participation prior to the study to improve (repeated) attendance.	*[53, 66]*	*R11, R21*	
15	**Offer incentives** (e.g., money, coupons, personal goals) that are intrinsically valuable to the participants.	*[57, 66]*		*P6*
16	**Employ skilled researchers** for conducting qualitative research (e.g., ask effective probing questions) to guarantee quality of data.	*[66]*	*R6, R8, R9, R10, R13*	
17	Put measures in place that **minimize the risk of harm or distress** of vulnerable participants, such as having psychologists in attendance and offering ample opportunity for breaks.	*[58]*	*R3, R4, R7, R11*	

Strive for power balance		*Review*	*Survey*	*Interview*
18	**Approach participants with lived experience as experts and equal partners** to minimize sense of power imbalance.	*[53, 57, 58, 66, 70]*	*R5, R6, R9, R13, R20*	*P5, P6*
19	**Stimulate equal dialogue and interaction** by encouraging reserved members to provide input**.**	*[53, 58, 66, 67, 70]*	*R16, R24*	
20	**Conduct formal evaluations** (e.g., brief interviews, exit questionnaires) with vulnerable participants to reflect on both the co-creation process and designs.	*[53, 57, 67]*	*R9*	
21	**Create an informal and relaxed physical environment** by altering artefacts (e.g., decorations and refreshments) during data collection sessions.	*[53, 57, 70]*		
22	**Enhance accessibility** to participation by offering remote research methods to vulnerable participants.	*[53]*	*R4, R5, R8, R11, R13, R14, R15, R16, R20, R21, R22, R23, R25*	
23	**Provide skills training** on digital literacy and research methods to promote equal participation.		*R8, R11, R20, R25*	

3.4.1 Plan and structure study

The following recommendations relate to activities to carry out or consider prior to the start of the data collection methods.

1. ***Combine multiple methods***

The literature and survey respondents indicated that multiple methods should be utilized in PD projects to bring forth different types of information. For example, focus groups where multiple stakeholders participate in group discussions could be used for the exploration of broad topics and reaching consensus [58, 66]. These could be supplemented by creating bespoke sub-groups or conducting one-on-one interviews, to dive deeper into specific or sensitive topics [53, 58, 64, 66].

2. ***Set up a flexible study design***

A flexible and iterative research design facilitated the continuous generation of ideas [54, 62, 71]. Simultaneously, flexibility to the development process may enable spontaneous bottom-up opportunities [R19]. It also created the ability to take a step back in the design process in times where the project experienced drawbacks or required concepts to be revised [R22]. Lastly, Matthews et al. [62] suggested that *"An approach which combines both participatory design workshops early on to identify needs and early design directions followed by in situ design later might be ideal."* This would enable the design team to rapidly respond to feedback [62].

3. ***Determine recruitment strategy***

All three sources stated the benefit of establishing partnerships with stakeholders in close ties with the target group (i.e., care organizations, supervisors, people with lived experience). First, it allowed for access to vulnerable participants due to the personal networks of such stakeholders. For example, mental healthcare institutions have access to patients on therapy waiting lists that could be contacted for participation [53]. Second, such partnerships allowed for the involvement of vulnerable members in the creation of the recruitment materials [53], which in turn made the vulnerable group feel more addressed [R4, R13, R20]. To elaborate, respondent 4 suggests that the use of less intense terms made participants feel more included and less intimidated. An example towards caregivers was provided: terms such as *"caregivers"* could be replaced with *"people who provide unpaid care for a spouse/family member"*.

4. ***Secure sufficient resources***

The literature, survey respondents and interviewees emphasized the importance of securing resources (i.e., time, budget, materials) to facilitate the involvement of vulnerable end-users and non-researchers in the development process. For example, funding for the contributions of team members such as a study ambassador (i.e., co-investigator, care staff) to arrange the study logistics (e.g., organizing a room, promote the study, contact participants) [53].

5. ***Coordinate study structure***

A consideration valued by Kip et al. [66] was to appoint a dedicated project manager to coordinate the different stakeholders and monitor the study structure. The structured approach may be seen within the sessions (i.e., setting an explicit agenda, and choosing appropriate generative tools and techniques) [70] and between the sessions (i.e., setting regular meetings) [66].

6. ***Adopt an open and critical mindset***

The mindset shift from 'participation' (i.e., contribution according to the needs of the researchers) to that of 'co-design' (i.e., serving the vision of the participant) was challenging and required researchers to step out of their comfort zone [R15, R16]. An open mindset of (co-)researchers towards unconventional research methodologies was deemed essential to the success of letting the future users shape the innovation [57]. Simultaneously, a critical mindset and moral sensitivity was seen as necessary to evaluate whether the chosen methods, tools and materials were optimal for the abilities of the target group [R6].

3.4.2 Create and maintain a participatory team

The following recommendations regard strategies to ensure longevity in the fruitful collaboration between the PD team members and participants.

7. ***Collaborate with multiple stakeholders***

Collaboration with multiple stakeholders was reported by all source types. In addition to patients [P6] and designers [73], it was advised to also include clinicians [64], management [R5] and caregivers [R7] as they played an important role in the implementation and success of the innovations. On one hand, involving a range of stakeholders in the data collection

methods was seen as beneficial to account for all relevant perspectives in the design, such as patient needs regarding usability or clinician's expertise regarding theoretical background [53, 66]. On the other hand, the a multi-disciplinary project team profited from the increased empathy and mutual understanding that patients could bring to the research set up and delivery of research methods [53].

8. Ensure informed participation

Prior to participation, transparent communication about participation could be achieved through session introductions [70]. Briefing participants prior to the data collection could aid the alignment of participants [R5] and improve team functioning [58]. Two main areas for briefing were found. The first topic was the added value of the research and methods [R2, R7, R9, R13, R15, R17-R20]. This could be presented by explaining the relevance of the research and chosen approaches. The second area was to inform participants on the practicalities of the data collection process. Examples of information to include in the latter overview are: agenda [70], aim [58, 66, 70], content [70], timeframe [70], design artifacts [70], roles [58, 66], tasks [66], responsibilities [58, 66], procedure [58], data handling [R10] and an explanation of the voluntary nature of participation [70]. (Co-)defining the roles, tasks and responsibilities of the project members kept participants motivated and actively involved in the process as everyone knew what to expect [66]. Finally, the following strategies could be adopted to further ensure informed participation: send information booklets prior to the meeting that include the study and session aims [R12, R21], have meeting minutes readily available at any point in time that include relevant information and decision rationale [66] and provide participants with the ability to ask questions throughout [R10].

9. Frequently communicate with participants

Throughout participation frequent communication in between sessions may be used to inform members on updates and activities, or provide them with support for their role as contributor [53]. It may also serve as a way to remind members of the importance of the study [R19] and to secure participation with participants [R10]. In addition, Terp et al. [70], suggested for researchers to use an appreciative tone towards participants and *"use graphical representations and metaphors"* as a way to establish a relationship and sense of trust.

10. Stimulate a collaborative work relationship

The literature and survey brought forth the importance of acknowledging the differing skillsets between the participants to create empathy towards one another [53, R8]. A helpful exercise to let the participants experience how they could communicate with each other and witness the value of everyone's contribution, was to start the sessions with an ice breaker activity (e.g., *"co-designing a pizza")* [57]. If a situation arose where stakeholder opinions conflicted, mediation could be achieved by having an experienced psychologist (i.e., lead researcher) or trustees of the participants present. Within the workshops of this study, the tone was kept light and informal during discussion to come to a consensus between participants.

11. Provide transparency in design decisions

Incorporating the input of vulnerable participants into (concept) designs helped to show participants their input was valued and increased participant engagement [57, R8]. In the current study's workshops the design results were shown to participants at the start of each following session. This insight was viewed as positive by participants as they could see the impact of their input on the designs [P2, P5]. These intermediate design outcomes were used to generate further discussion. However, if participants' input could not be processed in the design during the ongoing PD process, two alternative actions were reported. First, find compromises within the abilities of the project (i.e., budget, time) [53, 64]. Second, provide an explanation on why such changes were not possible *[53]*.

3.4.3 Accommodate participants

SMI patients require a specialized approach within PD that accounts for the abilities and challenges the target groups faces (e.g., abstract reasoning, reduced memory capacity, low concentration). The following lessons target strategies to include in the communication and organization of the data collection methods to offer the target group a bespoke approach.

12. Account for vulnerable participants' skills and abilities

To limit the need of abstract reasoning, concrete examples (e.g., scenarios, personas or prototypes) were experienced as effective [66, R4, R13], along with familiar examples, storyboards, visualizations, and graphics [66, 70, R4, R13]. Further, to comply with the concentration levels of SMI patients, it was preferred to keep methods such as interviews short [66, P2, P3, R12]. Moreover, general suggestions to not overwhelm participants were to limit

the materials presented to vulnerable participants [P2], to introduce the materials in increments [P2], to limit the amount of text displayed on materials [R9] and to include vulnerable participants in a development phase that suits their capabilities [R4]. For example, if a low fidelity prototype is too challenging for testing by vulnerable groups, it may be worth considering their involvement when high fidelity prototypes become available [R4]. When unable to include the vulnerable members early on in the PD process, non-vulnerable target groups (e.g., caregivers, care staff) could be used to find usability and design flaws early on [R3].

13. Adjust activities in a bespoke manner

A flexible and tailored approach to research activities (i.e., pace and activities) helped to accommodate the varying needs and different stages of recovery of the vulnerable participants [57, 58, 70]. This was also seen during the workshop activities of this study. The order of activities was adjusted once a decreased comprehension of an exercise was noticed. Another exercise that was deemed better suited for the participants in that moment was carried out instead.

14. Solve practical barriers

Practical barriers such as time constraints can negatively affect participation [66]. By mapping out ways to mitigate barriers, prior to the data collection, their effect on the PD process may be minimized. Examples of strategies are to 1) consult participants in the scheduling process to find suitable times rather than offering pre-specified times [53], 2) observe participants in their home environment to determine best ways to include them [R21] and 3) offer remote research methods for participants that are unable to attend in person due to time constraint or participation anxiety [53]. Also, ensure that the preconditions necessary for conducting virtual methods (e.g., ownership of devices, work surface, good quality internet) are available or provided [R4, R12]. Further, in the workshops of this current study, it was perceived as helpful that researchers provided all the tools/materials necessary and that the research took place at a location convenient for participants [P6].

15. Offer personally relevant rewards

Kip et al. [66] placed value on the identification of *"personally relevant rewards for participants"* prior to the data collection. Such rewards may be extrinsic (e.g., materials, grocery vouchers and refreshments) or intrinsic (e.g., being endorsed as experts, working in a

team environment and sharing personal stories) [57]. Additionally, interviewee 6 encouraged researchers to provide a token of appreciation (i.e., money, sweets) to participants after each study session to help with motivation for participation. After each workshops of this particular study, a small gift in the form of chocolates or goodie bag with university paraphernalia were provided to the participants. One participant group even returned the favour and provided the researchers with flowers as a way to show their appreciation for their inclusion and participation.

16. Employ skilled researchers

Respondent 8 indicated that, as a researcher, it was difficult to switch between the role of researcher and creating space for vulnerable participants to share anecdotes regarding their personal experiences. When lending an ear, data could become less relevant and meaningful with respect to the research aims. A way to uphold the integrity of data and maintain the open and explorative nature of PD, was to employ researchers skilled in qualitative methods to carry out the data collection. Examples of such skills were good interviewing practices (e.g., ability to ask effective probing questions) [66], the ability to interpret what the participants were trying to say [R13] and to remain unbiased and neutral [R10]. Further, to achieve a balance between openly listening to participants' stories and obtaining relevant data between researchers, a replicable procedure was beneficial [R9].

17. Minimize risk of harm and distress

Some research activities may cause distress for vulnerable participants. For example, in the study by Knight et al. [58], participants were exposed to-, thought of- and discussed psychosis through the use of virtual reality. The lessons learned of their study, along with that of some survey respondents, were to implement protective measures against any potential distress. It is unclear if a participants experienced distress or if the methods were utilized in the study by Knight et al. [58]. Such measures could be to have psychologists, family and support workers in attendance [58], to offer ample opportunities for breaks between research activities [R11] and to exclude participants whom experienced negative effects caused by the research activities [R3, R7].

3.4.4 Attain power balance

PD with the SMI population creates an environment where stakeholders with various knowledge- and skill levels collaborate. Therefore, measures to mitigate challenges surrounding the creation and maintenance of power sharing are relevant. Otherwise, there is an increased risk of vulnerable participants not being taken seriously or adequately involved. Thus, the following recommendations offer ways in which the ethical challenges and considerations for power attainment can be established.

18. Promote equal partnership

Terp et al. [70] illustrated that power balance and equality created a shift in identity for SMI participants from that of a *"patient in need"* to a *"designer of need"*. Prerequisites for creating a collaborative environment absent of power imbalance, were a flat democratic structure [R5], trust [57, 66, R6, R13] and respect [66]. Tactics that helped to establish such informal atmosphere were the use of posture (e.g., sit amongst the participants) [57], appearance (e.g., dress casually) [57], appropriate language (e.g., avoid jargon) [53], manners [53] and first name introductions by all participants and team members [57] and active involvement of researchers in ice breaker activities. In the PD workshops of this study, the researchers actively took part in the design activities to promote the equal partnership. They also engaged in casual conversation and emphasized the essential aspect of teamwork.

19. Facilitate involvement of vulnerable participants

Vulnerable participants might feel hesitant or uncomfortable to express their opinions due to the experience of power imbalance or personal reasons [67]. To combat this, a facilitator (i.e., co-researcher) could speak on behalf of reserved participants [58]. To help facilitators determine when to speak up for vulnerable participants, it was put forward by Berry et al. [53] for co-researchers to sit amongst group members. This would enable the facilitators to observe group interactions and intervene accordingly.

20. Conduct formal evaluations

The literature [53] and survey [R9] highlighted that formal evaluations could enable researchers to determine whether participants were satisfied with their experience, the pace, frequency and intensity of the sessions. The given feedback could be implemented in future sessions. To enable participants to express their full and honest opinion on decisions that were

made during research activities, Grim et al. [67] suggested that researchers offer *"a concrete opportunity for reflection from the user following the meeting, one which would be clearly documented in the digital support and preserved as an aspect of the next decision or meeting"*

21. Alter physical environment

To establish an environment that stimulates creativity and interaction, an informal physical surrounding was viewed as desirable [70]. Strategies were to alter the environment in which PD takes place with the use of physical artefacts such as music, flowers and coloured drawings for decoration, along with providing food (i.e., meals, snacks, fruit) supported a relaxed ambience [70].

22. Enhance accessibility

Remote methods were proposed as a way to enhance accessibility for participation when people are unable to attend in person [53]. Respondent 25 notes that *"it [remote methods] has the potential to enhance accessibility, reduce power imbalances and increase confidence to participate. People can participate in the project from an environment where they feel comfortable, with reduced pressure for social interaction which may be present during in person interactions."* Ways to make the virtual engagements a success were to conduct such methods in smaller groups [R20], to test (mature) virtual prototypes [R23], to use straightforward language [R5] and to use accessible tools for people with low (digital) literacy [R4].

23. Close knowledge gap

As equal participation may be complicated for participants that do not possess the necessary skills or experience (i.e., digital, research, technical) to participate, attention can be paid to broaden the abilities of participants [R8, R25]. Respondent 20 proposes the following three tactics to mitigate the knowledge gap: 1) send participants the materials and information prior to the session so they can prepare for the session beforehand, 2) dedicate time within sessions to teach participants the necessary skills to adequately use the necessary tools, and 3) provide participants with a phone number to call for additional support and have questions answered.

4 Discussion

This study aimed to uncover the best practices for conducting PD with a vulnerable and complex target group: people with SMI. Multiple qualitative methods were used to compile a list of recommendations for future researchers and designers. In total, 23 actionable recommendations were identified. When conducting PD projects, practitioners should pay close attention to four distinct categories: 1) plan and structure study, 2) create and maintain a participatory team, 3) accommodate vulnerable participants, and 4) strive for power balance. Each category consists of four to seven recommendations. In the following section, the answer to the RQs will be answered. Thereafter, the implications of this study, the strengths and limitations, and future research opportunities will be reported.

4.1. Principle Findings and Summary

The RQs were used to uncover 1) the best practices and lessons learned of PD reported in scientific literature, 2) the best practices and key recommendations according to PD practitioners and 3) the experiences and preferences of SMI patients for PD participation. In short, It seems that diversity, flexibility, equal collaboration and communication were central themes to what makes PD with people with SMI successful. Diversity in people and methods that are incorporated in the process were important to gain as much insight as possible. While flexibility was necessary to adapt the tools and activities to allow for efficient partnership with the SMI target group. Finally, equal collaboration and communication allowed for every person to contribute and feel respected throughout the process. Since the data of each method was combined into the final guidance document, the recommendations supported by all three data sources will be outlined below.

The first category concerned the necessary activities to carry out prior to the start of the data collection methods. At the early phase of the project, the securing of sufficient resources (i.e., time, budget, materials and participants) and co-designing the recruitment strategy with stakeholders were key considerations.

The second category helped to ensure longevity in the fruitful collaboration of the participatory team. It was recommended that the team consists of multiple stakeholders, including patients. This ensured that all relevant perspectives were covered in the design-, development- and delivery process. Due to the multi-disciplinary partnership, it was important to stimulate a

collaborative work relationship between team members and participants through ice-breaker activities.

The third category concerns the bespoke approach within PD that helps to accommodate participants' skills and abilities. The use of concrete tools was a useful strategy for the support of the cognitive abilities of participants.

The fourth category serves the mitigation of ethical challenges surrounding power balance. The main take was to approach participants with lived experience as experts and equal partners.

4.2 Implications for Participatory Design

This study adds novel insight to the current literature on best ways to conduct PD with the SMI population. The recommendations are expansive, but not exhaustive. Due to the focus on the SMI population, specialized considerations were included in the recommendations. Addressing stigma and distress were important points to consider within PD with people with SMI [74]. These aspects were not included in guidelines that were geared towards the general public [75] or a broad range of vulnerable groups (e.g., asthma, spinal cord injury, caregivers) [76]. These topics alone warrant that the SMI population requires a specialized approach as the consequences of not taking such aspects into account may have direct impact on the participants well-being. The next section covers four implications that garner further attention: 1) there is no one-size fits all approach to PD, 2) gather client values, while giving clients value, 3) all-purpose practitioners and 4) communication as a key to power equity.

4.2.1. There is no one-size fits all approach to PD

PD studies should be tailored to the context of the research. To elaborate, there were differing opinions and discrepancies within the data on when to include participants (i.e., stage of involvement) and how to include participants (i.e., participant roles). A study done by Ramírez-Galleguillos et al. [39] even identified 6 different roles for participant involvement: informants, partakers, validators, learners, research partners and design partners. The appropriate role depends on the project, its aim and the abilities of the participants. Each development environment comes with their own nuances that require an adaptive mindset of researchers [29]. The strategies should fit the environment in which the PD takes place and fit the people that are involved in it.

The recommendations in our study actively encourage researchers to adapt any research activities according to the skill levels and state of mind of the participants during the research

activities. PD with SMI warrants an approach that is tailored and attentive to the vulnerabilities of the target group. However, one aspect that was not included in the recommendations was the process of informed consent. The psychiatric population can face difficulty with understanding the information provided to them and may lack autonomy in decision making [77]. Perhaps continued consent is a better approach for psychiatric research [77]. The information provided to the target group should be adjusted to fit their level of comprehension and asked throughout the research activities.

It should be acknowledged that adopting a personalized approach to PD is labour intensive and requires ample resources (e.g., time, human, budget). This poses a challenge as PD in and of itself is already a costly endeavour [20]. Affordable and efficient ways to achieve bespoke research will be important within PD.

4.2.2. Gather client values, while giving clients value

Even though PD allows for participants to be actively involved as collaborators within research activities, the approach mainly targets the epistemic benefits. This leaves patients as contributors rather than beneficiaries. Some participants from our workshops expressed the sense of teamwork and participation as valuable, while all experienced PD as fun. This might suggest that PD has other benefits than solely those related to study outcomes. It could have impact on the overall mood of participants. The ability to act on their self-efficacy and self-determination could have something to do with it [78].

Although the recommendations prompt researchers and participants to determine intrinsically valuable incentives for participants, it mainly concerns the direct participation in the project itself. Ideally, long term benefits for SMI participants could be identified, such as ways to increase sense of empowerment and skill development [39]. That way, PD participants are also able to benefit from the projects. Potential skill development could further aid participants in their personal lives and empower them to partake in other activities that influence their care.

4.2.3. All-Purpose Practitioners

PD practitioners should be aware of the multitude of responsibilities that come along with conducting PD. As was established by Sanders et al. [31], PD creates a shift in the researcher profile from translators to facilitators. Within this study 23 multi-faceted recommendations were written as action points towards the responsibilities of PD practitioners. It seems that PD with people with SMI requires practitioners to be all-rounders. Examples of added

responsibilities were the creation of a collaborative and informal environment, mitigating power imbalance and fulfilling different roles such as researcher, confidant, project manager, mediator and participant.

It was argued by Orlowski et al. [29] that PD in the health research context is best executed by highly skilled and experienced researchers as the approach may otherwise lose its effectiveness to create innovative solutions. This counts in particular towards working with people with SMI. Not only do PD practitioners need to apply an array of tools and methods, they need to be sensitive to the vulnerabilities of this group and be equipped with the right competencies to handle situations where the participants might experience distress. Perhaps in addition to focusing on skill development of participants, skill development of PD practitioners is just as important to ensure effective execution of the approach.

4.2.4. Communication as a key to power equity

Establishing a true flat power hierarchy might be unattainable due to the underlying power structures imposed onto the target group [79]. Even though the input of SMI participants directly influences the outcome of the PD activities, the supposed 'power balance' achieved in the PD context could vanish outside of. Within PD, the research environment is set up by certain individuals that carefully plan and distribute resources which enables for a momentary power sharing. It might not be possible to achieve power balance through the application of a list of recommendations. But, power equity may be achieved through transparent communication, clearly defined roles and responsibilities, and a genuine sense of community and collaboration. The ability to adapt the tools and activities according to the need of the participants, and provide them with skills training will empower them so they can contribute to the process equally [80].

4.3 Strengths and Limitations

A considerable strength of this study was the qualitative multi-method approach. This allowed information to cover multiple perspectives. The methods were meticulously chosen to suit the context of the target groups. For example, a survey seemed best suited for PD practitioner as they were able to complete it in their own time, while shorter interviews were deemed appropriate for the SMI participants to accommodate their levels of concentration and motivation.

The findings of other studies, such as Ramírez Galleguillos et al. [39] and Ozkaynak et al. [76], were solely supported by literature. Therefore, the multi-method approach adds a novel methodological approach to the current literature. It proved beneficial as one of the recommendations (i.e., skills training) was generated solely from the respondent data. In addition, including a heterogenous group - PD practitioners and people with SMI - allowed for the recommendations to be supported by real-world scenarios. Consequently, the list includes the views of people directly affected by the list of lessons learned or the final eMH innovation.

Further, the systematic undertaking of the research methods and analysis was also seen as a strength. It provided a sense of transparency and trustworthiness of the study results. Future researchers are able to replicate the procedures. Finally, the setting in which the interviews took place was seen as another strength. All interviewees were participants of PD workshops. The interviews were conducted straight after the final workshop. This ensured that the SMI participants did not have to put a claim on their long-term memory to answer questions. It also ensured that the opinion of participants was based on real life experiences, which decreased the need for abstract reasoning.

Some limitations of this study may offer useful insight into possible improvements for future studies. First, the coding process was carried out by one researcher. It would have been beneficial for at least two reviewers to carry out the coding process, to offer increased transparency and trustworthiness of the analysis through an inter-coder reliability score [81]. However, two independent researchers repeatedly provided feedback on the produced codes. Therefore, the negative impact on the trustworthiness of the results were believed to be minimal.

Second, due to time constraints, the interviews with patients were short. Thus, the amount of information that could be obtained from patients was limited. Perhaps in future studies, more extensive interviews may be carried out to gather additional information so that the participant perspective is better heard and incorporated in future best practices. Additionally, the interview participants were involved in one single development process. This could result in bias as their values only reflect the experience of one PD project.

Third, there is a potential for self-selection bias within the survey and interviews, which can lead to a misrepresentation of the target group [82], as it is often seen that the most willing and able people are most likely to participate [30]. This possibly creates a skewed view of the preferences of the target group as the voices of patients with more severe disabilities or fewer interest in eMH remain unheard. Although it is not expected to have influenced the

generalizability of the study results, it would have been interesting to compare the opinions and concerns for participation of the study sample, to the group whom opted out of participation.

Fourth, there was a minority (3/25) of survey respondents that had extensive experience in conducting PD with vulnerable target groups. Although it would have been an improvement to have more researchers with extensive experience as survey respondents, there was still ample useful information in the submitted forms. It may also be the case that people tend to be humble about their status and choose a moderate label over a very experienced one.

4.4 Future Research

The main suggestion for future research would be to validate the list of recommendations generated in this study. Several studies advocate for the execution of more research on the effectiveness of PD approaches and overall efficacy [14, 34]. Thus, researchers may try to determine under which circumstances the list worked or did not work and if it made the overall PD process more effective. However, as mentioned in the implications of the study, it would be a valuable step to determine ways we can offer participants more personal benefit to participation. Follow up research should choose the right determinants to define quality of participation. The focus should not only concern how the participation benefited the project (i.e., epistemic improvement), but also how it benefitted the participant (i.e., sense of power, skill development and personal impact) [33].

As a first step to validate the list, the opinions of designers, non-scholars and participants could be gathered on the comprehensiveness and understandability of the recommendations. In order to compensate for the majority of respondents with low to moderate PD experience, a focus group may be conducted with PD experts with extensive experience. Methods such as focus groups or interviews would seem preferred over surveys due to the ability to ask probing questions. Other ways of evaluating and further solidifying the list of best practices and recommendations is to carry out PD case studies with the use of this list to reflect on their added value and effectiveness.

Overall, the studies showed inconsistent reporting with regard to lessons learned. Certain information, such as setting and type of participation, was often left out [20]. Moore et al. [14] also noticed poor reporting among PD studies and stated that each study they included had a unique way of reporting. This makes PD somewhat of a black box where it becomes difficult for researchers to make informed decisions on which methodologies to apply in certain contexts

[14]. The recommendations were formulated based on 14/21 (66,7%) of the included studies. This shows that a fair amount of studies did not even report any lessons learned.
In addition, our study noticed that within the documentation of study's lessons learned, most statements were general recommendations towards a certain concept; the papers lacked concrete examples. It was regularly suggested 'what' should be done, but not 'how'. Therefore, a recommendation would be to define criteria for reporting PD studies to increase coherence and transparency of such studies. An example so far is the GRIPP2 [34], which is an evidence based check-list for reporting patient and public involvement studies [83]. It can offer a blueprint to expand on towards the creation of an eHealth specific check-list. The GRIPP2 check-list addresses items such as type of involvement. However, setting and sampling procedure are not. Especially the sampling procedure would have offered useful insight as recruitment with this hard-to-reach target group was seen as a significant challenge by the survey respondents.

Due to the cross-disciplinary nature and the involvement of diverse stakeholders, it is important for dissemination strategies to target non-scholars (e.g., designers, care staff). Traditional means such as scientific journal entries will, most likely, not suffice. To aid in this process, Ross-Hellauer et al. [84] provides ten helpful tips to compose a purposeful dissemination strategy. For this particular study, an infographic was produced of the lessons learned (see Appendix VII). This sheet was handed out during a design conference in the Netherlands that attracts a large range of attendees. Future research could focus on effective ways to convey (practical) scientific findings in digestible ways to non-scholars and research the effectiveness of reaching the desired target groups.

5 Conclusion

This qualitative multi-method study adds insight to the field of PD by providing an actionable list of recommendations for conducting such projects with the SMI population. Central themes such as diversity in people and methods, equal collaboration and communication can aid in the success of PD with people with SMI. But, PD with people with SMI does not come with a one-size fits all approach. The overall approach calls for a flexible and bespoke undertaking that caters to the context, skills and preferences of SMI participants. Before embarking on a PD project, researchers ought to be aware of the many roles they need to fulfill and equip themselves through proper training or education. Future research may uncover the personal benefits of conducting PD with psychiatric patients.

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Appendix I: Data extraction form with categories and definitions

Main category	Sub category	Definition
Study aim	-	The aim of the study.
Technology	-	The e-health innovation (to be) developed in the study.
Target group	-	The target group of the e-health innovation.
Goal	-	The goal of the e-health innovation.
Design Framework	-	The design framework used to guide the design of the e-health innovation.
SMI involvement phase	Pre-design stage	A stage dedicated to familiarize oneself with the context of the users' lives and determine their preferences for the innovation.
	Generative stage	A stage dedicated to share design ideas and create the innovation/prototype.
	Evaluative stage	A stage dedicated to assessing the effectiveness of the low fidelity design and to collect feedback.
	Post-design stage	A stage dedicated to assessing the effectiveness of the high fidelity design and to collect feedback.
Methods	Literature review	A review of the current (scientific) literature on a certain topic.
	Observation	Observing the users in the environment where the innovation will be used.
	Interviews	One-on-one interviews with certain stakeholders.
	Survey	Survey data gathered from certain stakeholders.
	Focus groups	Guided group discussions with (various) stakeholders which also includes expert reference groups and group interviews.
	Workshops	PD workshops where group of (various) stakeholders come together to create (aspects of) the innovation.
	Usability testing	Product testing in the evaluative phase of the project, often in a more controlled setting with a prototype.
	Beta testing	Product testing in the post-design phase of the project, often in the user's own environment with a mature version of the prototype/innovation.

Tools	Make	Participatory design tools that enable the participants to 'make things' (e.g., prototyping, generative tools and probes).
	Tell	Participatory design tools that facilitate dialogue amongst the participants (e.g., discussion, brainstorming).
	Enact	Participatory design tools that enable the participants to envision the future design and enact various scenarios (e.g., storytelling).
Environmental setting	Clinic	Sessions that took place in a clinical setting (i.e., hospital or clinic).
	University	Sessions that took place in a university.
	Home	Sessions that took place in the user's home environment.
	Community center	Sessions that took place in a community/activity center.
	Online synchronous	Online communication occurring in real-time (e.g., teleconferencing, phone calls).
	Online asynchronous	Online communication not occurring in real-time (e.g., email, text messages).
Organizational setting	Individual	Whether the sessions were conducted in an one-on-one setting.
	Group	Whether the sessions were conducted in a group setting.
	Combined	When the sessions were conducted both through individual- and group sessions.

Appendix II: Survey to people experienced in PD

Dear participant,

Welcome to this short online questionnaire on experiences with participatory design research in vulnerable target groups.

The questionnaire is currently set to English (Engels). If you want to switch to Dutch (Nederlands) instead, you can do so in the upper right corner of this screen.

Welcome to this research study on experiences in participatory design research in vulnerable target groups. This study is being done by dr. Tessa Dekkers (t.dekkers@utwente.nl) & Hanneke Kip (h.kip@utwente.nl) from the Faculty of Behavioural, Management and Social Sciences at the University of Twente.

The goal of this research study is to collect and share experiences, practical tips, best practices and recommendations on participatory design research in vulnerable target groups. Ultimately, we hope to build collective resources that can support researchers when conducting participatory design research in vulnerable target groups.

The research study consists of an online survey and will take you approximately 10-20 minutes to complete. During the survey, you will be asked to briefly reflect on practical, project management, and overarching challenges of the field. After that, you are asked to share your best tips and recommendations.

We want to emphasize that your participation is not just to benefit us: our goal is to collect, publish, and share these experiences with you so that we can all learn from each other's insights. For this reason, you can indicate whether you want to receive a report with the results at the end of the survey.

Your participation, possible risks and reimbursement

Your participation in this study is entirely voluntary and you can withdraw at any time. You are free to omit any question. We believe there are no known risks associated with this research

study. You will not receive reimbursement for your participation in this study. If you want to withdraw from the research or have questions or concerns, please contact the principal investigator, Tessa Dekkers (t.dekkers@utwente.nl).

Confidentiality, privacy and data use

To the best of our ability your answers in this study will remain confidential. The information that you share as part of this research will be stored on a secured, local drive of the University of Twente. We will minimize any risks by anonymizing your data before the research data is stored or used. No confidential information or personal data from or about you will be disclosed in any way that will allow anyone to recognize you in publications, unless you explicitly consent to this in the consent form (for example, a quote). In all other cases, anonymous data or pseudonyms will be used in publications. Finally, you have the right to request access to, change, delete or adapt your data. To do so, please contact the principal investigator, Tessa Dekkers (t.dekkers@utwente.nl).

Additional information and complaints

This research has been assessed and approved by the ethics committee of the Behavioural, Management and Social sciences (BMS) faculty of the University of Twente (registered as study #210121). If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-bms@utwente.nl.

By signing this informed consent form I agree to the following:

I have read and understood the study information. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	Yes	No
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	Yes	No

I understand that information I provide will be used for publication. The publications will not include any information that can directly identify me. I give permission for the information that I provide to be archived on a local drive of the University of Twente so it can be used for future research and education.	Yes	No

Next to the previous agreements, we ask consent for the following **specific requests.** You are asked consent for each request separately and may choose to provide consent for some requests but not others.

I agree that my information can be quoted verbatim in research outputs.	Yes	No
I agree that the name of the organization where I work may be stated in the above-mentioned quotes, if the organization's name is provided by me.	Yes	No
I agree that my information may be shared with (other) researchers for future research studies. The researchers will not contact me for additional permission to use this information. This includes use of my information for educational purposes. The information shared with other researchers will not include any information that can directly identify me.	Yes	No

- Do you or have you ever conducted participatory design research with people from vulnerable target groups?

  *By **participatory design research** we mean the active involvement of end users in design activities, to help ensure that a product (or service, or technology) will meet their needs and be usable by them. This includes related terms such as co-design, co-creation, formative and generative design research, and human- / user-centered research.*

  *By **vulnerable target groups** we mean people in (socially) vulnerable situations who, as part of this vulnerability and a lack of resources, have an increased risk or susceptibility to adverse (mental) health outcomes. For example, due to* poverty*, low*

literacy, poor housing, an immigrant background, frailty, or (severe) mental illness. This includes related terms such as "complex" target groups and "difficult-to-reach" target groups

- Yes
- No, because...
- I'm not sure, because...

- What is your gender?
  - Male
  - Female
  - Non-binary or prefer to self-describe:
  - Prefer not to answer
- What is your year of birth?
- What is your country of residence?
- With which vulnerable target groups have you conducted participatory design research?
- In which (type of) organization do or did you conduct this research?
  You can select multiple answers. You may choose not to disclose the name of the specific organization.
  University (of applied sciences) or a comparable knowledge institution, namely:
  - Government, non-profit, or NGO, namely:
  - SME or self-employment, namely:
  - Large company, namely:
  - Privately, namely:
  - Different, namely:
- What is/was your job title within this organization?
- How experienced would you say you are in participatory design research with vulnerable target groups?
  - No experience
  - Little experience
  - Moderate experience
  - Extensive experience

Conducting participatory design research with people from vulnerable target groups may present challenges. In this part of the survey, we ask you to reflect on these challenges.

To help you reflect on challenges we will ask you to successively consider practical, project management, and overarching challenges. However, the focus of the research is on the challenges you experience and not on how these fit these categories. So if you don't know which category best fits your challenge, you can write it down anywhere.

- **Practical challenges** refer to challenges experienced in practice and in the field. For example, challenges in adapting material to participants, restrictions and unexpected circumstances during fieldwork, effectively involving participants throughout a session and keeping them engaged, etc.
- **Project management challenges** refer to challenges in setting up, planning, and managing a participatory research project. For example, challenges in connecting with relevant stakeholders, maintaining enthousiasm in the project team, etc.
- **Overarching challenges** refer to challenges that do not fit the previous categories. They may be related to both pratical and managerial aspects of participatory design research, or be more generic challenges. For example, challenges in generating funding, time, and attention for participatory design research.

- What are the main **pratical** challenges in participatory design research with vulnerable target groups according to you?
  For example, consider challenges in adapting material to the target group, continuously *engaging participants in a workshop, handling sensitive data, or managing your own reaction to negative experiences that may be shared during sessions.*
- What are the main **project management** challenges in participatory design research with vulnerable target groups according to you?
  For example, consider challenges in coming into contact with relevant stakeholders, maintaining enthusiasm in a project team, reporting findings in an accessible manner, recognizing and responding to differences in people's expertise, conveying the added value of participatory research to stakeholders.

- What are the main **overarching** challenges in participatory design research with vulnerable target groups according to you?
  For example, consider challenges in obtaining funding, generating interest in participatory research in general, or challenges related to your or other stakeholders' (organizational) culture.

You stated ___ as main challenges.

- Which concrete tips, best practices or recommendations can you share with other researchers and designers to (partially) address these challenges?
- If possible, can you provide a concrete example and/or a link or reference to additional information for each tip?

Finally, the global Coronavirus (COVID-19) pandemic has had an unprecedented impact on the way research is conducted, including participatory design research. Research methods had to be adapted to meet social distancing and various other measures.

- Can you share any concrete tips, best practices or recommendations that specifically relate to **online, remote, or otherwise adapted to the pandemic** participatory design research with vulnerable target groups?
- Do you have any remarks about participatory design research with vulnerable target groups or this survey which have not yet been addressed?

Thank you for your participation! If you would like us to share the results with you, please leave your email address below. Your email address will be used for the sole purpose of sending the final report and will not be linked to or saved with your answers to the survey.

Please use a professional (work) email address or other public email address instead of your private email address.

We invited you to this survey because of your experience in participatory (design) research with vulnerable target groups. Perhaps you know other experts in this area who we should invite for the survey?

It would be greatly appreciated if you can leave their email address below. Again, these addresses will be used for the sole purpose of sending the invitation and will not be linked to or saved with your answers to the survey.

Please use a professional (work) email address or other public email address instead of a private email address.

Thank you for participating in this survey. Your answers have been saved successfully.

Do you know others who have experience in participatory design research with vulnerable target groups? Please invite them to participate in the study! You can do so by sharing the survey url: https://utwentebs.eu.qualtrics.com/jfe/form/SV_elnA8w59ZhrIEmh.

Appendix III: Interview questions

	Dutch (original)	English (translated)
1	Hoe vonden jullie het om mee te doen?	What did you think about participating in the study/workshops?
2	*Even samenvatten wat we hebben gedaan* Wat vond je leuk en minder leuk aan deze workshops? • Activiteiten • Communicatie	*Provide a brief summary on what we have done* What did you like and dislike about the workshops? • Activities • Communication
3	Heb je nog tips voor ons? Wat zouden we anders kunnen doen?	Do you have tips for us? What could we have done differently?
4	Wat betekende het voor jou om mee te doen?	What did it mean for you to participate?
5	Hoe zou je verder nog betrokken willen blijven?	How would you like to stay involved?

Appendix IV: Characteristics of Included Articles Scoping Review

Author (year), country	e-health Innovation	Design approach	Study design	Setting	Lesson(s)
*[65] - Bardram et al. (2011), United States of America, Denmark *Study aim:* The paper presents and discusses the design and technical implementation of a persuasive monitoring system for mental illness.	*Technology:* MONARCA system, a smartphone and web application *Target group:* Patients with bipolar disorder and their clinicians and relatives *Goal(s):* (i) to provide an input mechanisms for patients to fill in their self- assessment data; (ii) to collect objective sensor data from the phone; (iii) to provide a simple historic visualization of the data entered; (iv) to provide feedback and suggest actions to take in situations that presents risks; and (v) help patients to keep track of their prescribed medication.	*Design Framework*: User-centered design ***SMI involvement phase***: Pre-design stage Generative stage	*Methods (objective)*: **Workshops** (to gain knowledge, ideas and feedback, based on the participants' daily life and prototypes) *Tools*: Make; Tell	*Environmental setting*: Clinical *Organisational setting*: Group	-

[71] - Ben-Zeev et al. (2013), United States of America *Study aim:* The study describes the development of a smartphone illness self-management system for people with schizophrenia.	*Technology:* FOCUS, a smartphone system *Target group:* People with schizophrenia *Goal(s):* To support self-management of illness among people with schizophrenia.	*Design Framework*: Flat Explicit Design Model ***SMI involvement phase***: Pre-design stage Evaluative stage	*Methods (objective)*: **Survey** (to assess needs and explore mHealth options for treatment provision in community settings) **Usability testing** (to evaluate the learnability of the system and to provide feedback on design artefacts) Focus group (to consider how an mHealth intervention could be of greatest utility to users, to identify a clinical population and treatment modality that would benefit from an mHealth resource, and to suggest points for consideration in the development of a mobile system intended for individuals with severe psychiatric disabilities.) *Tools*: Tell	*Environmental setting*: Clinical *Organisational setting*: Combined	3
*[53] - Berry et al. (2020), United Kingdom	*Technology*:	*Design Framework*:	*Methods (objective)*:	*Environmental setting*:	1, 2, 5, 6, 8, 9, 10, 14, 17,

Study aim: This article describes how a multidisciplinary team designed and developed Actissist.	Actissist is a CBT-informed and self-guided smartphone app *Target group*: Early psychosis patients *Goal(s):* To help scale up access to CBT-informed information and strategies	A person centered design approach ***SMI involvement phase***: Pre-design stage Post-design stage	**Interviews** (to identify needs and provide feedback); **Focus groups** (to provide feedback); **Beta Testing** (to provide feedback and suggest changes to the app) *Tools*: Tell	University; Online synchronous *Organisational setting*: Combined	18, 19, 21, 22, 23
*[61] - Bucci et al. (2019), United Kingdom *Study aim:* This paper describes the development of Actissist.	*Technology:* The Actissist app functions as a standalone app. *Target group:* Early psychosis patients *Goal(s):* To deliver a CBT theory-informed, in-the-moment intervention targeting distressing psychotic and psychosis-related experiences. Actissist supports	*Design Framework*: Iterative Scrum Methodology ***SMI involvement phase***: Generative stage Evaluative stage	*Methods (objective)*: **Focus groups** (to gather ideas for improvement and understand what features were deemed necessary); **Interviews** (to provide suggestions for improvement and measure satisfaction) **Usability testing** (to find and eliminate defects and to ensure that the platform was accessible, clear and functional prior to commencing the clinical trial)	*Environmental setting*: Not specified *Organisational setting*: Combined	-

	self-management and can facilitate shared decision- making in treatment.		**Survey** (to measure satisfaction) *Tools*: Not specified		
[73] - Derks et al. (2017), Netherlands *Study aim:* This study describes an attempt to develop and apply a scientifically grounded approach when designing and implementing an mHealth e-coaching app.	*Technology:* Sense-IT, an ambulatory biofeedback e-coaching intervention application *Target group:* People with borderline personality disorder with low emotional awareness *Goal(s):* To learn to better recognize and monitor one's own emotional arousal.	*Design Framework*: Elements-Methods-Products Framework ***SMI involvement phase***: Generative stage	*Methods (objective)*: **Interviews** (to determine content) *Tools*: Tell	*Environmental setting*: Not specified *Organisational setting*: Individual	5, 6
[67] - Grim et al. (2017), Sweden *Study aim:* The aim of this study was to use a participatory design in	*Technology:* A web-based decision aid *Target group:* Individuals receiving psychiatric services	*Design Framework*: Service Design Approach	*Methods (objective)*: **Interview** (to gather feedback on the prototype and express possible barriers for use)	*Environmental setting*: Not specified *Organisational setting*:	3, 21, 23

order to facilitate the development of a user-generated decision aid for individuals receiving psychiatric services.	*Goal(s):* To strengthen service users' experience of self-efficacy and control as well as provide staff access to user knowledge and preferences.	***SMI involvement*** *phase*: Evaluative stage	**Usability test** (to elicit overall comprehension and acceptability and to obtain feedback on content, form and sequencing as well as collecting suggestions for improvements, prior to proceeding with an electronic version) **Beta testing** (to evaluate the decision aid in clinical situations and community settings in order to obtain further input on usability and insight into barriers and facilitators for implementation) *Tools*: Tell	Combined	
[55] - Hardy et al. (2018), United Kingdom *Study aim:* This study aimed to optimize the usability of an existing psychological intervention, Thinking Well, which targets	*Technology:* SlowMo is an innovative blended digital therapy web application *Target group:* People with psychosis and those experiencing paranoia who fear harm from others	*Design Framework*: Design Council's Double Diamaond Method; Inclusive User Centered Design Approach	*Methods (objective)*: Literature (to map out existing innovations) **Observation** (to gain insight into therapists' roles and service user journeys through the system)	*Environmental setting*: Not specified *Organisational setting*: Combined	-

reasoning processes in paranoia using a basic digital interface.	*Goal(s):* To help people notice their worries and fast thinking habits, and encourages them to slow down for a moment to find ways of feeling safer by targeting jumping-to-conclusions and belief inflexibility which are the reasoning styles that contribute to paranoia	***SMI involvement*** *phase*: Pre-design stage Generative stage Evaluative stage	**Interviews** (to gain insight into users' attitudes, needs and to elicit feedback regarding acceptability, usefulness, and usability) Workshop (to synthesize findings and generate the design brief) **Usability test** (to elicit feedback and to test a low fidelity version of the therapy redesign) *Tools*: Make; Tell; Enact		
[66] - Kip et al. (2019), Netherlands *Study aim:* The two main objectives of this case study were to present and reflect on the (1)	*Technology:* A virtual reality application *Target group:* Forensic psychiatric patients *Goal(s):*	*Design Framework*: CeHRes Roadmap ***SMI involvement*** *phase*: Pre-design stage	*Methods (objective)*: **Focus groups** (to identify the ideas of therapists and patients about potential ways of using VR in treatment) Literature study (to gain an overview of all studies and current initiatives	*Environmental setting*: Clinical *Organisational setting*: Combined	1, 4, 5, 6, 7, 8, 12, 13, 14, 17, 18, 21

methods used in the development process of a virtual reality application for forensic mental health care and (2) the development model that was used: the CeHRes Roadmap (the Centre for eHealth Research Roadmap).	To support therapists and patients in identifying triggers that can elicit undesired behavior and search for helpers that can support the patient in dealing with these triggers and to practice coping skills	Generative stage	concerning VR in treatment of (forensic) psychiatric patients) **Workshops** (to generate multiple ideas on the use of VR in forensic mental health care, based on the outcomes of the contextual inquiry) **Survey** (to identify the preferences of stake- holders of the 6 ideas and stakeholders' values regarding VR in forensic mental health care) **Interviews** (to examine opinions and preferences and identify points of improvement in the existing forensic mental health treatment of in- and outpatients and possible applications of VR) *Tools*: Make; Tell;		

			Enact		
[68] - Klein et al. (2019), Australia *Study aim:* This study aimed to explore the feasibility, acceptability, and utility of adapting a novel smoking cessation app (Kick.it) to assist smokers with SMI to prevent smoking relapse and quit.	*Technology:* Kick.it, a smoking cessation application *Target group:* People with a severe mental illness that want to quit smoking *Goal(s):* To enable app users to create a profile (i.e., input information about their psychiatric diagnoses and smoking) and receive a personalized quit program that offers smoking cessation approaches tailored to meet their unique needs	*Design Framework*: Intervention Mapping; Co-design methodology ***SMI involvement*** *phase*: Pre-design stage Evaluative stage	*Methods (objective)*: **Interview** (to explore participants' smoking-related experiences and perceptions of social support for smoking cessation and to explore participants' perceptions of the feasibility, utility, and acceptability of the app features for SMI populations) *Tools*: Tell	*Environmental setting*: Not specified *Organisational setting*: Individual	-
*[58] - Knight et al. (2021), United Kingdom *Study aim:* This paper discusses the methods used in the	*Technology:* The gameChange application is an automated, standalone VR cognitive therapy *Target group:*	*Design Framework*: Iterative Transdisciplinary Participatory Design Approach	*Methods (objective)*: **Focus groups** (to input and give feedback into the designs relation to their practical development, clinical and user needs.);	*Environmental setting*: Not specified *Organisational setting*:	*5, 6, 7, 15, 16, 18, 21*

transdisciplinary participatory design process with people with lived experience of psychosis to develop an automated VR therapy and illustrates some of the results of these methods. It describes the working structures, and outlines the reasons for some of the design decisions.	People with psychosis who feel anxious in everyday situations. *Goal(s):* The aim of the therapy is to help people with psychosis to overcome anxiety and feel confident in everyday social situations by adopting a new set of actions they can use when anxious.	***SMI involvement*** *phase*: Generative stage Evaluative stage	**Workshops** (to design specific areas of the VR therapy); **Survey** (to give feedback and refinement on designs); **Usability testing** (to make sure the application satisfied the success criteria: immersive, easy to use, and engaging) *Tools*: Make; Tell; Enact	Combined	
[60] - Laine et al. (2015), Finland *Study aim:* The aim of this study is to produce a user-friendly and high-quality internet-based patient education program for adolescents with psychosis	*Technology:* MentalNet, an internet-based education program *Target group:* Patients with psychosis and their relatives and nurses *Goal(s):*	*Design Framework*: Cyclic, Recurring, Repeating Method; Iterative Design Process *SMI involvement phase*:	*Methods (objective)*: **Interview** (to elicit the needs of adolescents for patient education and internet use and to gather feedback on the existing program) Focus group (to discuss the possible strengths, weaknesses, opportunities and threats of internet-based patient	*Environmental setting*: Clinical; Asynchronous communication *Organisational setting*: *Combined*	5

through modification of an existing program originally developed for adults with schizophrenia.	The purpose of MentalNet is to provide information and to enhance treatment processes in health care.	Pre-design phase Evaluative phase	education, and to gather nurses' needs and expectations regarding patient education and internet use in it.) Survey (to receive feedback from healthcare professionals about the content and usability of the program) *Tools*: Tell		
*[59] - Lambe et al. (2019), United Kingdom *Study aim:* This paper describes the process of development of an automated VR cognitive therapy targeting anxious avoidance of everyday social situations by patients with psychosis.	*Technology:* gameChange, an automated virtual reality cognitive therapy *Target group:* People with psychosis *Goal(s):* To target the treatment of anxious social avoidance in psychosis.	*Design Framework*: Iterative Person-Centered Design Process ***SMI involvement phase***: Pre-design stage; Generative stage; Evaluative stage	*Methods (objective)*: **Focus groups** (to provide feedback on the application and design artefacts) **Workshops** (to choose between different design artefacts) **Survey** (to provide feedback on the application) **Usability test** (to provide feedback on the application)	*Environmental setting*: Not specified *Organisational setting*: Combined	-

			Tools: Tell; Enact		
*[64] - Marcu et al. (2011), United States of America; Denmark; Italy *Study aim:* This paper describes the approached and the challenge of designing persuasive systems for mental illness using a framework that we developed for this purpose – the Patient- Clinician-Designer (PCD) Framework.	*Technology:* The MONARCA system – a mobile phone application *Target group:* People with bipolar disorder *Goal(s):* To support the treatment of bipolar disorder through persuasive data collection and feedback.	*Design Framework*: User-centered design; Patient-Clinician-Designer Framework ***SMI involvement phase***: Generative stage	*Methods (objective)*: Literature review (to provide the domain knowledge required to embark on the design of a system for bipolar disorder); **Workshops** (to make decisions about system features); **Interviews** (to provide the domain knowledge required to embark on the design of a system for bipolar disorder and to ask for user input and opinions) *Tools*: Make; Tell	*Environmental setting*: Clinical; Home; University *Organisational setting*: Combined	5, 6, 9
*[62] - Matthews et al. (2015), United States of America	*Technology:* MoodRhythm, a cross-platform mobile application	*Design Framework*:	*Methods (objective)*: **Usability test** (to report on user experiences each week, and to suggest	*Environmental setting*: Clinical;	3

Study aim: This study aimed to provide evidence of the value of in situ design: and presents the design of MoodRhythm, a support system for patients with BD that reflects intentional design choices informed by low-level cognitive and physiological understandings of the disease and grounded in a clinically validated, evidence-based social therapy treatment from the field of clinical psychology.	*Target group:* People with bipolar disorder *Goal(s):* To enable users to reflect on their momentary experiences throughout the day and to help patients maintain consistent circadian and activity rhythms in their day-to-day lives.	In-Situ Participatory Design ***SMI involvement*** *phase*: Generative stage Evaluative stage	novel ideas that might better support self-management) **Interview** (To provide feedback) *Tools*: Make; Tell	Online synchronous; Online asynchronous *Organisational setting*: Individual	
[63] - Matthews et al. (2016),* United States of America *Study aim:* In this paper we describe how biological characteristics of	*Technology:* MoodRhythm, a smartphone and web app, designed to support patients in tracking their health passively and actively over a long period of time. *Target group:*	*Design Framework*: Not specified ***SMI involvement*** *phase*: Evaluative stage	*Methods (objective)*: **Usability test** (to assess the impact of MoodRhythm) *Tools*: Not specified	*Environmental setting*: Not specified *Organisational setting*: Individual	-

bipolar disorder can be taken into consideration when developing systems to detect and stabilize mood episodes. We describe the co-design of MoodRhythm, a smartphone and web app, with patients and therapists.	Individuals with bipolar disorder *Goal(s):* To provide a combination of active and passive methods to track daily rhythms, to relay this information to clinicians, and to provide feedback to patients to enable them to improve their moods by establishing more regular daily rhythms.				
[57] - Nakarada-Kordic et al. (2017), New Zealand *Study aim:* This case study describes the challenges involved in developing, designing and employing novel methods and activities to meaningfully engage young people who have experienced psychosis, in the co-creation of an online	*Technology:* An electronic (website), patient-centered educational resource *Target group:* People experiencing psychosis and their families/clinicians *Goal(s):* To effectively support and guide patient medication education in mental health and to help facilitate communication between a young	*Design Framework*: Co-Design Methodology *SMI involvement phase*: Pre-design stage Generative stage Evaluative stage	*Methods (objective)*: Interviews (not specified) **Workshops** (to explore information needs and preferences for an online resource and to generate/evaluate specific solutions for the design of the content and look-and-feel of the new online resource) **Usability testing** (to bring 'form' to the initial insights identified by the co-design group, and to use these	*Environmental setting*: Clinical; Community center *Organisational setting*: Group	3, 5, 6, 9, 10, 11, 13, 15, 17, 18, 19, 23

resource to support their informational and experiential needs and wellbeing.	person [experiencing psychosis] and a clinician		prototypes as a way to facilitate the unpacking of further understanding for evaluation and further input) *Tools*: Make; Tell		
[56] - Realpe et al. (2019), United Kingdom *Study aim:* This study aimed to adapt existing manualised social cognition intervention for people with a first episode of psychosis to a virtual world environment through co-design with service users.	*Technology:* A virtual environment *Target group:* Early psychosis patients *Goal(s):* To deliver an accessible social cognition intervention to a hard to engage service user group.	*Design Framework*: Methodological Guideline for the Implementation of Participatory Design of Online Treatment for Young People ***SMI involvement phase***: Pre-design stage; Generative stage; Post-design stage	*Methods (objective)*: **Focus groups** (to seek their advice on how the intervention needed to be framed to be meaningful and relevant) **Workshop** (to create an intervention that young people felt motivated to use) **Interviews** (to gather young people's views about how they found the environment and how to improve the intervention) Usability test (to gather information about the technical usability of the	*Environmental setting*: Not specified *Organisational setting*: Combined	6

			environment to deliver specific aspects of the intervention) **Beta testing** (to rate various aspects of the system) *Tools*: Make; Tell; Enact		
[54] - Sin et al. (2019), United Kingdom *Study aim:* This study reports the intervention building/modeling phase of the overall E-support for Families and Friends of Individuals affected by Psychosis project	*Technology:* COPe-support is a Web-based intervention *Target group:* Carers of individuals affected by psychosis *Goal(s):* To provide psychoeducation and emotional support using health care professional contribution and peer support.	*Design Framework*: Participatory Research Methodologies; Agile methodology; UK National Institute for Health Research Online Resource Development Cycle;	*Methods (objective)*: **Workshops** (to design and build the intervention); **Focus groups** (to seek consultation on end users' views and ideas to optimize the intervention design and usability); **Usability Testing** (to provide feedback and determine usability issues) *Tools*: Make;	*Environmental setting*: Not specified *Organisational setting*: Combined	3, 6

		Coproduction in Mental Health Improvement Work Method ***SMI involvement*** *phase*: Generative stage Evaluative stage	Tell		
[70] - Terp et al. (2016), Denmark *Study aim:* The aim of this paper is to describe if, and how, PD thinking and tools can help construct a room for design – a fertile environment that enables participation and engagement in the development of participatory mental health care for young adults with schizophrenia.	*Technology:* MindFrame, a smartphone application for use in early phase schizophrenia care. *Target group:* Young adults with schizophrenia *Goal(s):* Collaboration and self-management	*Design Framework*: A three phased participatory design process: (1) identification of needs; (2) design and development;** (3) pilot-test ***SMI involvement*** *phase*: Generative stage	*Methods (objective)*: **Workshop** (to formulate and sketch visions, generate users insights and manifest design ideas) *Tools*: Make; Tell; Enact	*Environmental setting*: Community center; Clinical *Organisational setting*: Group	2, 4, 7, 8, 15, 17, 18, 19, 21

[72] - Välimäki et al. (2008), Denmark *Study aim:* The aim is to describe the design and development process of patient-centered computer based support system (Mieli.Net portal) for patients with schizophrenia spectrum psychoses.	*Technology:* Mieli.Net portal, a computer-based self-management system *Target group:* Patients with schizophrenia *Goal(s):* To support self-management among patients with chronic illness	*Design Framework*: Not specified ***SMI involvement phase***: Pre-design stage Evaluative stage	*Methods (objective)*: Literature review (to find the most effective and appropriate methods concerning different solutions for patient's needs) **Survey** (to ascertain the needs for development of patient education and to gain insight into inpatients' satisfaction with care) **Interview** (to ascertain spheres of information rated important by patients, realization of information supply, and the methods through which patients wanted to access information. Patients also described the problems of information supply in their own words and offered suggestions for the development of successful information supply)	*Environmental setting*: Clinical *Organisational setting*: Combined	6

			Focus groups (to evaluate the content, structure, visual appearance and usability of a prototype of the computer-based support system) *Tools*: Tell		
[69] - Vilardaga et al. (2018), United States of America *Study aim:* The objective of this study was to report the rationale, ideation, design, user research, and final specifications of a novel smoking cessation app for people with serious mental illness that will be tested in a feasibility trial.	*Technology:* Learn to Quit, a smoking cessation application *Target group:* Individuals with a severe mental illness *Goal(s):* To attain smoking cessation.	*Design Framework*: User-centered design Framework ***SMI involvement phase***: Pre-design stage Evaluative stage	*Methods (objective)*: Literature (to ensure the theoretical grounding and evidence-based foundation) **Focus groups** (to better understand the needs of the target population) **Usability testing** (to gather meaningful and concrete feedback from users) *Tools*: Make; Tell	*Environmental setting*: Not specified *Organisational setting*: Combined	-

* = non-unique studies

* = only phase described in paper

Appendix V: Survey Respondent Characteristics

ID	Country	Setting/employer	Role/profession	Experience	Target group
R1	Netherlands	Knowledge institution	Researcher (Junior/Senior/PhD); Research coordinator	Little experience	Low-socio-economic status; Intellectual disabilities
R2	Netherlands	Large company	Policy advisor; Project Manager	Little experience	Forensic psychiatric patients
R3	Netherlands	Knowledge institution	Head of Innovation Studio	Moderate experience	Forensic psychiatric patients
R4	New Zealand	Knowledge institution	Researcher (Junior/Senior/PhD)	Moderate experience	Older adults; Informal caregivers of people with dementia
R5	Belgium	Knowledge institution	Researcher (Junior/Senior/PhD)	Extensive experience	Young cancer patients
R6	New Zealand	Knowledge institution; Non-profit	Lecturer	Little experience	Low-socio-economic status (families)
R7	New Zealand	Knowledge institution	Researcher (Junior/Senior/PhD)	Moderate experience	People with dementia
R8	Netherlands	Knowledge institution; Non-profit	(Thesis) student (BSc/MSc)	Little experience	Young cancer patients
R9	New Zealand	Knowledge institution; Large company	Researcher (Junior/Senior/PhD)	Moderate experience	Young autistic adults
R10	New Zealand	Knowledge institution; Non-profit	(Thesis) student (BSc/MSc)	Little experience	Mothers of immigrant families

R11	Netherlands	Non-profit; Other	Chairman of Foundation; Project Manager	Little experience	Severe mental illness
R12	Netherlands	Knowledge institution	Researcher (Junior/Senior/PhD)	Little experience	Autism Spectrum Disorder
R13	Netherlands	Knowledge institution	Researcher (Junior/Senior/PhD)	Moderate experience	Low health literacy; Low socio-economic status
R14	Netherlands	Knowledge institution; Privately	Researcher (Junior/Senior/PhD)	Extensive experience	Elderly; Sick people; Teenagers; Prostitutes
R15	Netherlands	Knowledge institution	Researcher (Junior/Senior/PhD); Research coordinator	Moderate experience	Elderly; Low socio-economic status
R16	United Arab Emirates	Knowledge institution; Non-profit; Self-employed	Founder-Director; Director; Participation Lead; Researcher (Junior/Senior/PhD); Consultant; Lecturer	Extensive experience	People with intimate lived experience of dementia; People living with mental distress or mental diversity; People who use noises signs and sounds to communicate; People in the last months of life; People with multiple profound disabilities; Learning disabled survivors of sexual abuse; Older men who need and choose to street drink;

					Gypsy Roma groups; Asylum Seekers and Refugees; Black and minority ethnic carers; Deaf communities; Inmates of secure institutions (prisons and locked hospital wards); Women survivors of domestic abuse; Disabled children;
R17	Netherlands	Non-profit	Researcher (Junior/Senior/PhD)	Moderate experience	Vulnerable psychiatric patients
R18	Netherlands	Non-profit	(Thesis) student (BSc/MSc)	Little experience	Slight intellectual disability
R19	Netherlands	Knowledge institution	Lecturer	Moderate experience	Severe intellectual disability; Personality disorder; Autism spectrum disorder; Criminals; Alcohol addicts
R20	Netherlands	Knowledge institution	Researcher (Junior/Senior/PhD)	Moderate experience	Obesity; Low socio-economic status; Huntington's disease; Hospitalized children
R21	Netherlands	Knowledge institution	(Thesis) student (BSc/MSc)	Little experience	Visually, hearing and physically impaired
R22	Netherlands	Knowledge institution	Industrial Designer	Little experience	Visually, hearing and physically impaired
R23	Netherlands	Knowledge institution	(Thesis) student (BSc/MSc)	Little experience	Slight intellectual disability
R24	Bulgaria	Knowledge institution	Research coordinator	Moderate experience	Hip osteoarthritis;

					Low literacy; Low economic status
R25	United Arab Emirates	Knowledge institution	Lecturer	Moderate experience	Drug and alcohol users and their affected family members; Victims/survivors; Perpetrators of domestic violence; Families under stress and those at the edge of care

Appendix VI: Detailed information lessons learned

1. Combine multiple methods		
Scoping review	***Survey***	***Interviews***
- Form bespoke subgroups (within and between discilines) or individual interviews to have in-depth discussions and discuss sensitive topics [53, 58, 60, 64]; - Have group discussions to generate new ideas, discuss broad topics [58, 66]; - Use multiple methods to collect different types of information [57, 66, 73];	- Use generative tools [R5]; - Engage in group discussion to reflect on design decisions [R18]; - Ensure small group sizes for virtual methods [R20].	

2. Set up a flexible study design		
Scoping review	***Survey***	***Interviews***
- Apply (iterative) in-situ design to rapidly respond to feedback [62]; - Follow an iterative process (e.g., design sessions, usability testing) to continuously generate new ideas/insights/preferences [54, 57, 67, 71].	- Use an iteratively process to test prototypes, re-evaluate prior design decisions [R3, R22]; - Conduct PD research systematically but allow for spontaneous opportunities [R19].	

3. Determine recruitment strategy		
Scoping review	***Survey***	***Interviews***
- Co-create recruitment material with SMI participants [53]; - Contact people from therapy waiting lists [53]; - Communicate appropriately [70].	- Collaborate with stakeholders in close ties with participants (e.g., clinics, community centers, family, care organizations) [R1, R3, R5, R10, R11, R13, R15, R20, R22]; - Make participants feel addressed in recruitment material (e.g., use less intense terms) [R4, R13, R20]; - Thoroughly plan and structure recruitment [R5]; - Offer incentives to participate [R10]; - Recruit as early as possible [R10]; - Communicate early and clearly (with aids such as leaflets) [R12, R13].	- Offer incentives to participates [P6]; - Conduct study at location convenient for participants [P6]; - Collaborate with stakeholders in close ties with participants (e.g., care providers, daily supervisors, people with lived experience) [P6]; - Minimize effort needed for participation (e.g., convenient location, supply tools/materials) [P6].

4. Secure sufficient resources		
Scoping review	***Survey***	***Interviews***
- Funding for stakeholder involvement and co-investigators (to coordinate project and to carry out research methods) [53]; - Map out available resources [53]; - Time, budget, motivated members [66].	- Time [R6, R11, R18, R19, R20, R21, R22, R23]; - Ambassador in care organization [R19]; - Budget (for stakeholder engagement) [R19, R24, R25].	- Ensure minimal effort participation [P6]; - Organize a room [P6]; - Conduct study at location convenient for participants [P6]; - Tools and materials [P6]; - Employ co-investigator [P6].

5. Coordinate study structure		
Scoping review	***Survey***	***Interviews***
- Let a dedicated coordinator carefully plan/structure PD (e.g., choose appropriate tools/materials/activities) [66, 70]; - Set regular meetings [66].	- Use evidence based methods [R5]; - Incorporate a few methods [R11]; - Prepare PD sessions well [R15]; - Structure sessions appropriately to the environment/people [R17].	

6. Adopt an open and critical mindset		
Scoping review	***Survey***	***Interviews***
- Employ open-minded researchers that consider progressive research methods to let the user lead [57].	- Be critical and show moral sensitivity to determine if tools/methods suit the participants (e.g., caution with digital methods with low digitally literate participants) [R4, R6, R12]; - Step out of your comfort zone as researcher [R15].	

7. Collaborate with multiple stakeholders		
Scoping review	***Survey***	***Interviews***
- Include the perspective of multiple stakeholders with different skills/interests: patients, therapists, clinicians, managers, researchers, developers, designers, financial controllers [53, 54, 57, 58, 64, 66, 72, 73]; - Consistent participation in design sessions of the same stakeholders [56]; - Include vulnerable participants in the delivery of data collection methods for increased empathy and understanding [53].	- Include multiple stakeholders [R17]: management (implementation) [R5], caregivers (directly affected) [R7], care professionals [R19];	- Include end-users [P6]; - Let participants work together [P6].

8. Ensure informed participation		
Scoping review	***Survey***	***Interviews***
- Workshop introductions to increase transparency and clarify agenda, aim, content, timeframe, design artefacts, roles, task, responsibilities [58, 66, 70]; - Ensure voluntary nature of project [58, 70]; - Clarity on roles, tasks, responsibilities [58, 66]; - Make meeting minutes [66].	- Transparent communication to ensure informed participation (e.g., use leaflets) [R1, R3, R5, R12, R21]; - Explain importance and intended impact of study [R2, R7, R9, R13, R15, R17, R18, R19, R20]; - Clear roles/responsibilities [R5, R17]; - Consistent in definitions [R5]; - Transparency in data handling [R9, R10]; - Ensure voluntary nature of project [R10].	

9. Frequently communicate with participants		
Scoping review	***Survey***	***Interviews***
- Employ a co-researcher to clearly communicate practical information with participants [53, 66, 70]; - Ensure communication is appreciative and visual [70].	- Provide transparent and frequent communication [R3, R19]; - Secure participation by calling participants several days before sessions [R9, R10]; - Use simple and appropriate language [R13, R20, R23]; - Send information leaflets prior to sessions [R20]	

10. Stimulate a collaborative work relationship		
Scoping review	***Survey***	***Interviews***
- Acknowledge and negotiate what is possible within the abilities of participants and research constraints [53, 64]; - Start the session with an ice-breaker activity (e.g., co-designing a pizza) [57].	- Be aware of conflicting opinions and find ways to navigate those [R2, R9, R16, R18]; - Openly communicate with participants about their abilities and boundaries [R8]; - Allow for time to be spent on communication between stakeholders [R19].	- Enable and encourage team work [P3]

11. Provide transparency in design decisions		
Scoping review	***Survey***	***Interviews***
- Validate user input by implementing it in (concept) designs [57]; - When feedback cannot be implemented, negotiate what adjustments can be made and provide feedback to reflect back why certain things were not possible [53].	- Incorporate participant feedback into designs to validate input and to avoid tick-boxing [R8].	- Offer insight into (concept) designs to elaborate on design decisions [P2, P5]; - Give credit for participation (e.g., "made by" page) [P6].

12. Account for vulnerable participants' skills and abilities		
Scoping review	***Survey***	***Interviews***
- Minimize need for abstract reasoning, for example with the use of concrete aids : visualizations, low/high fidelity prototypes, existing examples, scenario-based videos, personas, graphics [57, 66, 70]; - Accommodate reduced concentration/motivation levels and keep methods as short as possible [66];	- Test more mature/concrete prototypes or involve close relatives in the early stages when participants are unable to participate [R3, R4]; - Include in appropriate development/design phase [R3, R4, R17]; - Adjust materials/methods according to the abilities of the participants (including accessible tools with virtual methods) [R9, R12, R19]; - Short methods [P12];	- Minimize examples/options shown to participants [P2]; - Shorter methods [P3]; - Build confidence to participate [P6].

	- Use concrete, visual examples (e.g., storyboards, prototypes) [R13]	

13. Adjust activities in a bespoke manner		
Scoping review	***Survey***	***Interviews***
- Customize data collection activities in accordance to the daily condition of the participants [57, 58, 70].	- Adjust methods/materials in accordance to skills/abilities participants [R1, R5, R17].	

14. Solve practical barriers		
Scoping review	***Survey***	***Interviews***
- Keep methods short [66]; - Identify barriers to participation and ways to overcome them prior to data collection (e.g., virtual meetings, scheduling in collaboration with participants rather than offering pre-specified times) [53, 66];	- Call/text instead of email [R11]; - Observe participants in their home environment to determine best ways to communicate with them [R21].	

15. Offer personally relevant rewards		
Scoping review	***Survey***	***Interviews***
- Identify personally relevant rewards [66]; - Provide external motivators (e.g., gift cards, food) [57]; - Determine internal motivators (e.g., being endorsed as experts, expressing their needs, social interaction, being part of a team) [57].		- Offer incentives, after each session, to participate (e.g., money, gift card) [P6]; - Make it as easy for participants to participate as possible (e.g., location convenient to them) P6.

16. Employ skilled researchers		
Scoping review	***Survey***	***Interviews***
- Employ researchers skilled in qualitative research methods [66].	- Listen carefully and interpret what the participants are saying while speaking freely [R6, R8, R13]; - List a protocol so multiple research end with comparable data [R9]; - Remain unbiased [R10].	-

17. Minimize risk of harm and distress		
Scoping review	***Survey***	***Interviews***
- Choose research activities appropriate to the needs and abilities of the participants to minimize the risk of harm and distress [58]; - Ensure the availability of a private room, attendance of psychologist/support workers/family, ample opportunity for breaks [58].	- Monitor participants on negative effects caused by research activities, exclude them if found and provide aftercare [R3, R7]; - Include participants in the stage of development that best suits their abilities to not overburden them [R4, R11]; - Offer ample opportunity for breaks/relaxation [R11].	

18. Promote equal partnership		
Scoping review	***Survey***	***Interviews***
- Ensure participants have equal importance [53, 57, 58]; - Use appropriate language and avoid jargon [53]; - Establish manners for collaborative participation [53]; - Build a dynamic with trust and respect [66];	- Keep a flat democratic structure (i.e., prevent power imbalance) [R5, R13]; - Build trust [R6]; - Sit amongst participants [R9].	- Communicate with participants that their input is valuable and important [P5, P6]

- Ensure vulnerable participants feel comfortable and valued [58, 70]; - Dress casually, arrange seating informally, first name introductions, view participants as experts [57].		

19. Facilitate involvement of vulnerable participants		
Scoping review	***Survey***	***Interviews***
- Facilitate dialogue and participant interaction within workshop activities [67, 70]; - Prevent oversteering of the content and let participants think openly and freely, but ensure this process is still well facilitated through excellent interviewing skills [66]; - Let co-researchers and facilitators sit amongst the members to quickly notice group interactions and intervene accordingly [53].	- Facilitate the involvement of vulnerable participants [R16, R24].	

20. Conduct formal evaluation		
Scoping review	***Survey***	***Interviews***
- Conduct formal evaluation to understand the experience of participants [53]; - Obtain ethical approval/consent to identify and publish reasons for non-attendance and impact of participation [53]; - Let participants share feedback (individually) straight after sessions rather than long-term retrospective reflections [53, 57]; - Document individual private feedback to include it in the following decision/meeting [67].	- Ask participant satisfaction with pace, frequency and intensity of sessions [R9].	

21. Alter environment		
Scoping review	***Survey***	***Interviews***
- Set up an informal and relaxed atmosphere [70]; - Place physical artefacts (e.g., music, flowers, coloured drawings) [70]; - Offer refreshments (e.g., meals, snacks, fruit) [70]; - Include an experienced participant [70]. - Dress casually [57]; - First name introductions [57]; - Arrange seating informally [57].		

22. Enhance accessibility		
Scoping review	***Survey***	***Interviews***
- Incorporate virtual methods to accommodate anxious participants [53].	- Use online research tools with good usability for low digital literate participant [R4, R5, R20, R25]; - Use video/audio software (e.g., Zoom, Skype) [R5, R8, R13, R21, R22];	

	- Use explicit language with virtual methods [R5]; - Send questionnaires through email [R13]; - Keep virtual sessions simple [R15]; - Ensure all prerequisites for virtual methods are met (e.g., software, hardware, Wi-Fi, log in credentials) [R15]; - Conduct virtual methods with smaller groups [R20]; - Use mature virtual prototypes [R23].	

23. Close knowledge gap		
Scoping review	***Survey***	***Interviews***
	- Support participants that lack experience/knowledge to fully participate [R8, R25] by 1) spending time within sessions to teach them the necessary skills (e.g., digital tools) [R20], 2) send research/design documents prior to session [R20] and 3) provide a phone number to act as help-line [R20].	

Appendix VII: Infographic Recommendations