Service user's actual involvement in mental health research practices

A scoping review

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Published in:
International Journal of Mental Health Nursing

DOI:
10.1111/inm.12594

Publication date:
2019

Document version
Accepted manuscript

Citation for published version (APA):

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Download date: 03. Apr. 2020
Manuscript category: Review article

Title: “Service user’s actual involvement in mental health research practices: A scoping review”

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Acknowledgements: The authors would like to acknowledge the significant contributions from Dr. Katherine Gill, Ms. Yvette Quinn, Ms. Cath Roper, Dr. Richard Schweizer and the Service user panel of Region Zealand mental health trust.

Disclosure statement:
We have no conflicts of interest to disclose.

Funding:
The project has received funding from Psychiatry Management’s Research Pool, Mental Health Services Region Zealand, Denmark.

Word count: 6224 words including abstract and acknowledgements.
User involvement in mental health research: A scoping review

Abstract

User-involvement in mental health research is on the international political agenda, e.g. mirrored by an emphasis on user involvement in funding of research. The idea is that user involvement can contribute positively to research. The purpose of this study is to identify empirical research of how mental health service users are involved in collaborative research processes and to summarize this research in dialogue with mental health user-researchers. A scoping review was carried out and 32 studies were included. Main findings indicated that actual involvement of user-researchers in research processes was based on a complex set of precarious negotiation practices, where academics and user-researchers were positioned and positioned themselves in novel ways. The review accounts for how mental health service users were involved in collaborative research processes. The extracted themes concerned: Expectations to research processes, Contribution to research processes, and Training and learning from research processes. The study reveals that collaborative research in mental health requires changes to traditional research practices to secure genuine collaborative partnerships and thereby avoid tokenism and power inequalities.

Keywords [MeSH]:
Community-Based Participatory Research; Mental Health; Patient Participation; Rehabilitation Research; Review [Publication Type]
Introduction

‘The participatory turn’ is a general shift in political agendas that emphasizes user participation in all aspects of health care and social care (Groves 2017). The slogan, ‘Nothing about us, without us’, guides national goals for increased user involvement in mental health in several Western countries, including, for instance, Australia, Denmark and UK (Department of Health 2010; Gill 2018). The participatory turn challenges scientific communities to rethink research processes as it aims at shifting the power relationships between mental health care service users and the traditional scientific experts (Groves 2017). However, little is known about how users are actually involved in research processes as partners and how such partnerships might shape research processes. This paper reviews the research literature on the actual practices of involving mental health service users in research.

Background

Involving mental health service users in research is assumed to heighten the quality and relevance of research as they can contribute to research by drawing on their unique lived experiences and perspectives in research processes (Kara 2013; Trivedi & Wykes 2002). User-researchers can, for instance, raise novel research questions and ensure that interventions are user-friendly. When user-researchers experience their contribution to be useful, for example by identifying key priorities, recruiting participants, and by gathering data that may not be available to academic researchers, they can contribute to the lives of
other mental health service users (Mayes 2009; Syrett 2011; Trivedi & Wykes 2002). Moreover, this involvement is an opportunity to have their voices heard and assist them in their own recovery process (Happell et al. 2018; Kara 2013; Syrett 2011).

The involvement of mental health service users in research is typically defined according to the degree of engagement (Beresford 2007; INVOLVE 2012). At one end of a continuum, user involvement is defined in accordance with traditional research approaches where service users are ‘consulted’ and involved as respondents. At the other end of the continuum, ‘user-led research’ is defined by service users leading and controlling the research processes. ‘Collaborative research’ is on the middle of the continuum and this is characterized by all involved parties, academics and users, being active and engaged as partners in the research (Beresford 2007; INVOLVE 2012).

Several challenges related to collaborative research have been identified. Collaborative research processes are often time consuming and expensive (Kara 2013; Trivedi & Wykes 2002). User-researchers often work unpaid or with a nominal rate of payment, which does not match their use of time and effort (Lemonsky 2015). Due to their mental health problems, user-researchers may be treated as service users by academic researchers (Mayes 2009) and excluding professional jargon may make it difficult for user-researchers to contribute to research processes. Such challenges can lead to power imbalances or failure to genuinely share power in the research team (Kara 2013; Trivedi & Wykes 2002). In recent years, several funders have made user involvement an obligatory part of the formal criteria for funding. This can potentially promote user involvement, but there is a risk that user involvement becomes a symbolic and tokenistic appendix to the ‘real’ research processes (Glover 2009).
The active and collaboratively engagement of all involved parties challenges traditional research approaches where the academic community conducts and controls the research. In collaborative research, control is supposed to be shared between members of the partnership and a key ambition is to eliminate some of the inequities that are inherent to traditional research approaches. If users are actively and genuinely involved in research, academics must give up some of their control over the research processes. The goal is to use collaboration to facilitate mutual learning and through this to generate relevant and practice-oriented knowledge of general usability (Berring et al. 2016).

In collaborative research it is essential to have an awareness of whether the collaborative processes are in effect genuine or tokenistic. Several guidelines on how to involve user researchers have been developed to overcome potential tokenism and other challenges to collaborative research, see for instance (National Institute for Health Research 2014). Despite the political emphasis on user participation, there is a paucity of research on the actual practices of involving mental health service users in collaborative research processes, including how these research practices influence the different parties’ positions in the research process.

Aim

The aim of this study was to identify the range and scope of empirical research of how mental health service users are involved in collaborative research processes and to summarize this research in dialogue with mental health user-researchers.
Methods

We chose to conduct a scoping review inspired by Arksey & O'Malley (2005). A scoping review was relevant as it was difficult to identify the literature in this field and because the topic was relatively broad with studies using many different designs (Arksey & O'Malley 2005). The scoping review consisted of six stages: 1) formulating the research question, 2) identifying relevant studies, 3) selecting studies, 4) charting the data, 5) summarizing results, and 6) consultation exercise with service users (Arksey & O'Malley 2005).

Formulating the research question

Based on the issues described in the introduction and gaps in the existing literature, two research questions were identified: 1) What is the scope of empirical research on how users are involved in conducting collaborative research? 2) How are collaborative research processes described in empirical research?

Identifying relevant studies

A systematic literature search was conducted in five databases (CINAHL, Embase, ERIC, Medline, and PsycINFO). The databases were chosen because they cover the field of mental health research. The search strategy consisted of a systematic ‘building block search’ that included variations of search terms that were customized to fit each individual
database, see the general outline of the building block search strategy in table 1. The search was conducted with both free text and controlled headings in the databases depending on the individual databases’ thesaurus. The building block search was supplemented with a ‘citation pearl search’ in the SCOPUS citation database (De Brún & Pearce-Smith 2014), which was conducted in order to increase precision and recall of the search and to enable the identification of studies outside the five databases. The citation pearl search added seven references. In this citation search, we also searched for grey literature, but nothing was identified. The search was concluded in September 2017.

**Selecting studies**

The inclusion criteria were: Empirical studies investigating collaborative user involvement in mental health research and published in Danish, English, Norwegian or Swedish. The term ‘user’ denoted both current and former mental health service users and relatives and ‘mental health’ did not include learning disabilities, alcohol and substance abuse or homelessness. The exclusion criterion was: Studies that were user-led research without collaboration with academic researchers. If there was doubt about inclusion, the titles, abstracts and full texts of papers were screened and discussed by three authors (CS, LH, LB) until a consensual decision was reached. The review included a total of 32 studies. The study selection process is summarized in a PRISMA flowchart in Figure 1. In order to support the reliability of the study selection, ‘Covidence.org’ was used to manage the search process.
Arksey & O'Malley (2005) original framework did not include a quality assessment of studies. However, in line with Pham et al. (2014) we chose to assess the quality of included studies. Therefore, the 32 articles were read systematically using Critical Appraisal Skills Programme (CASP) to assess the studies’ strengths and limitations, but not to exclude studies. However, not all the studies were easily assessed by CASP as they were either written in a genre that was very different from conventional academic papers or because they did not include sufficient details about the research methods used.

**Charting the data**

The key items of information obtained from the included studies were entered to a data charting form with the following headings: title, author, year, country, aim, methodology, study population, context and key findings (Arksey & O'Malley 2005). See an abbreviated data charting form in Table 2.

**Summarizing the results**

After charting the data, a collating and summarizing process began. All authors contributed to collating and summarizing the results thematically, which strengthen the analysis’ internal validity. The included studies were coded (Miles et al. 2014) and three themes were identified across the studies: *Expectations to research processes*, *Contribution to research processes* and *Training and learning from research processes*. This led to the description of a main theme, “Negotiating precarious positions in research processes”,
which accounted for a central thematic plot running through the full dataset. The main theme, the three subordinated themes and the codes are presented in Figure 2. A narrative account of the existing literature is reported in the result section. Throughout the process, memos (Miles et al. 2014) were written to capture creative thoughts at all stages.

**Consultation exercise with service users**

The scoping review process also included dialogues with service users. Several of the service users consulted had formal research education and were actively involved in mental health research. The consultation exercise was divided into two parts because of a gradual development of the key arguments. In the first part, preliminary results were presented to an already established service user panel (n=12) in a Danish mental health trust. After an oral presentation, the user panel was asked to discuss to which extent they could recognize and/or agree on the preliminary findings. The session was audiotaped, and a written summary was agreed upon by the participants. In general, these service users recognized the preliminary findings, however, the findings raised a discussion about whether service users should be involved in all kinds of research, for instance pharmacological research. In the second part, four Australian service users with formal research education were invited to reflect on a full draft of the introduction, methods and findings of this paper. This included reflections of the relevancy of the paper and its findings and an invitation to question or edit sections that did not seem clear to them. They acknowledged the preliminary findings and emphasized that user-researchers can take very different positions depending on user-researchers’ level of insight into research processes.
and that different positions most probably will encounter different challenges to their participation. This second part of the consultation exercise led to a re-organization of the findings with a stronger emphasis on user-researchers’ precarious position in collaborative research.

Results

In this section, we first describe the study characteristics followed by the three themes: 1. Expectations to research processes, which illustrated expectations to user-researchers as well as user-researchers’ unmet expectations. 2. Contribution to research processes, which identified which parts of the research process user-researchers were involved in. 3. Training and learning from research processes, which was concerned with what user-researchers needed to train and learn as they took up their role. Then we describe the main theme: Negotiating precarious positions in research processes, which was identified as a central thematic plot running through the full dataset.

Characterizing the reviewed studies

Apart from a study from 1994, the reviewed studies were all published between 2000 and 2017 (see Table 2), which probably indicated that collaborative research is a relatively recent practice and a young area of research (of such practice). The majority of the studies were from the UK (18) and the remaining from Canada (5), Norway (3), Australia (2), Ireland (1), Korea (1), Sweden (1), and USA (1). The methodologies of the
studies ranged from five quantitative studies, out of which one had a randomized design, 24 qualitative studies, and three mixed methods studies. There were 17 studies with a clear participatory/collaborative design.

**Theme 1: Expectations to research processes**

This theme encompassed descriptions of the expectations to user-researchers when they were involved in collaborative research. User-researchers were expected to be ready to collaborate across organizations. Most notably, no studies investigated expectations of or to academic researchers.

Expectations to user-researchers were often linked to specific tasks in the research process, such as becoming a research interviewer (Bengtsson-Tops & Svensson 2010). In these situations, user-researchers needed self-knowledge and an ability to interact socially, because they were expected to add to the development of valid data (Bengtsson-Tops & Svensson 2010). One study developed a guideline describing the expectations to user-researchers’ contribution to ‘their’ research. The guideline, in particular, focused on user-researchers contributing with their lived experiences of mental health problems (Hutchinson & Lovell 2013).

Some user-researchers experienced their expectations to the partnership as unresolved (Morrell-Bellai & Boydell 1994; Pellicano et al. 2014). For example, an experienced lack of interest from the academic researcher and less feedback than anticipated led to frustration (Pellicano et al. 2014). Some user-researchers were reported to experience a lack of reciprocity in their interaction with academic researchers and they did
not feel valued and listened to (Pellicano et al. 2014). However, Tischler et al. (2010) found that user-researchers felt valued by academic researchers and experienced that their opinions were respected.

Unclear expectations to user-researchers could give rise to uncertainty. This could be related to the academic researchers being unclear about how user-researchers could contribute (Moltu et al. 2012; Moule & Davies 2016) and some user-researchers negotiated their own positions as user-researchers by sharing experiences with peers they met in an educational program (Moltu et al. 2012; Moltu et al. 2013). Training and regular meetings was reported to promote user-researchers’ understanding of what was expected of them. This helped them defining different research positions and added to create opportunities for taking decisions about their level of involvement in different parts of the research process (MacInnes et al. 2011). MacInnes et al. (2011) involved service users from a forensic setting in all part of the research process, which systematically clarified expectations. They concluded that such clarification and sharing of power helped developing a good collaborative relationship, which supported a genuine and involving process. The theme suggested that clear mutual expectations supported and enabled service-users contributing in research.

**Theme 2: Contribution to research processes**

This theme illustrated how user-researchers contributed to research in terms of making decisions about the research topics and managing particular tasks in the project, such as interviewing, recruiting informants, data collection and analyzing data. User-
researchers’ contributions were assumed to improve all stages of the research process and were, in general, regarded as fundamental for creating new knowledge through an authentic partnership. The articles primarily focused on the user-researchers’ contribution and secondarily on the possible synergy of the collaboration (or the academic researchers’ contribution).

Decision-making in research was frequently investigated in the studies, but there was no consensus about what types of decisions user-researchers should be involved in and how it should take place. Simpson et al. (2014), found that user-researchers contributed with research topics based on their lived experiences, which included ideas that the academic researchers may not have thought about. Some user-researchers asked for more involvement in decision making (Simpson et al. 2014), which was highlighted by Callander et al. (2011) who found that decisions about methodology were made without involvement of user-researchers. van Draanen et al. (2013) exemplified how user-researchers, after decision-making was discussed in a training session, were involved in deciding on the methodological approach in a narrative study. These user-researchers noted the richness that their perspective brought into the research (van Draanen et al. 2013).

Studies investigating user-researchers’ contribution to recruitment of study participants indicated mixed findings. Some studies reported that higher levels of user involvement were more likely to achieve recruitment success (Bengtsson-Tops & Svensson 2010; Ennis & Wykes 2013). User-researchers reported having access to potential study participants as they already had well-established relationships with them. Study participants stated that they were more willing to participate in a survey because of their trust in a user-researcher (Kim 2005). User-researchers were described as contributing to research by
making interviewees more comfortable compared to academic research interviewer (Croft et al. 2016). User-researchers influenced the research as they promoted the informants’ understanding of the interview questions and helped academic researchers to understand what the interviewees tried to express (Moltu et al. 2013). They also contributed by changing the academic researchers wording in reporting research findings (Simpson et al. 2014). Contrary to this, Hamilton et al. (2011) found that there was a significantly lower acceptance of an invitation to participate in a quantitative interview when it was revealed that the interviewer would be a user-researcher and some user-researchers have felt disrespected by interviewees when they disclosed their user identity (Morrell-Bellai & Boydell 1994).

User-researchers were reported to contribute to data collection by conducting self-report measures (Hancock et al. 2012), conducting survey tools (Croft et al. 2016; Kim 2005; O'Donoghue et al. 2013), and by preparing interviews with support provided individually or in groups (Gillard et al. 2010a; Gillard et al. 2010b; Gillard et al. 2012a; Gillard et al. 2012b; Hutchinson & Lovell 2013; Morrell-Bellai & Boydell 1994). Data from self-report measures gathered by user researchers trained in conducting self-report measures met the high standards expected (Hancock et al. 2012) and questionnaires and surveys were conducted by a user-researcher with low risk of response bias (O'Donoghue et al. 2013). This exemplified that user-researchers were sometimes expected to contribute by taking up the same research tasks as the academic researchers rather than ‘just’ drawing actively on their particular lived experience.

User-researchers have taken part in analysis of qualitative interview data in a number of studies (Gillard et al. 2010a; Gillard et al. 2010b; Gillard et al. 2012a; Gillard et
al. 2012b; Hutchinson & Lovell 2013; Mjøsund et al. 2017). Some studies found that user-researchers analyzed data from a different perspective than academic researchers (Gillard et al. 2010a; Gillard et al. 2012a; Tischler et al. 2010). For example, user-researchers coded interviews in terms of experiences and feelings of the interviewees, while academic researchers coded in terms of processes and procedures (Gillard et al. 2010a). User-researchers’ experiences influenced their analysis of data (Sweeney et al. 2013) and some user-researchers were reported to contribute to qualitative data analysis by expanding the horizon of data analysts, adding insight, depth and complexity to the analysis. User-researchers contributed to the quality of the study by slowing down the pace of the research, which also made it possible to scrutinize how the phenomenon was perceived from the user-researchers’ perspective (Hutchinson & Lovell 2013; Mjøsund et al. 2017; Moltu et al. 2013; Pellicano et al. 2014).

The theme emphasized the importance of clear mutual expectations between academic researchers and user-researcher. User-researchers were engaged in different tasks, however, their contribution to collaborative research seemed precarious and depending on circumstances beyond the individual user-researchers’ control.

**Theme 3: Training and learning from research processes**

This theme included accounts of user-researchers’ training programs and the personal benefits from being part of collaborative research. In several studies, user-researchers or potential user-researchers had participated in research training (Callander et al. 2011; Croft et al. 2016; Gillard et al. 2010b; Hancock et al. 2012; Hutchinson & Lovell
Some studies reported that collaborative research required training and both individual and group support had a valuable role (Callander et al. 2011; Palmer et al. 2009). Patterson et al. (2014) found that user-researchers were concerned about their ability to obtain training and Morrell-Bellai & Boydell (1994) found that several user-researchers would have liked more training. Training programs were performed in a range of different ways; from 5-20 minutes learning tasks, over five hours training sessions, to workshops with practical introductions to interviewing and role-play interviews (Hancock et al. 2012; Hutchinson & Lovell 2013; Palmer et al. 2009). User-researchers considered it important that training contained both formal and informal networking (Moltu et al. 2012). Training programs were reported to give user-researchers the opportunity to establish trust in and respect of other user-researchers and to learn by sharing experiences and recognizing different experiences (Callander et al. 2011; Simpson et al. 2014). Besides enhancing relationships, user-researchers could support each other in other ways than academic researchers were able to. By supporting each other, user-researchers adapted and learned research strategies and by doing so they developed their own understanding of research (Callander et al. 2011; Cook & Inglis 2012).

Several studies indicated that support from academic researchers and other user-researchers was a crucial part of user researchers being part of collaborative research (Patterson et al. 2014). Simpson et al. (2014) found that this was a key aspect for user-researchers’ experience of being valued and accepted. Studies found that user-researchers needed more support and guidance than what they received and that they were frustrated because they received little or no feedback from the academic researchers (Kim 2005;
Morrell-Bellai & Boydell 1994; Pellicano et al. 2014; van Draanen et al. 2013). Morrell-Bellai & Boydell (1994) and Palmer et al. (2009) found a need for strategies to reduce or manage user-researchers’ level of anxiety. They needed emotional support to be able to handle personal difficulties. Also, some user-researchers found it challenging to learn while managing their own serious mental health problems (Simpson et al. 2014).

Studies described that some user-researchers may have gained personal learning when they were involved in collaborative research (Moule & Davies 2016; Paul & Holt 2017; Robinson 2007). This included personal learning and some user-researchers found it important to learn as much as possible about their own illness. This made them able to make a difference in the lives of other people (Bryant et al. 2012; Moltu et al. 2012; Townsend et al. 2000). van Draanen et al. (2013) found that user-researchers felt valued and proud instead of shameful when being involved in research. User-researchers related their involvement in research to a sense of purpose, pride and empowerment and the collaboration with other user-researchers gave rise to a feeling of strength (Simpson et al. 2014).

Being an active part of research contributed to user-researchers’ personal development and they felt empowered to take on other work commitments (Simpson et al. 2014). Robinson (2007) found that user-researchers experienced “positive changes in the personal, social, and political aspects of their lives” (p. 140). However, Pellicano et al. (2014) stated that user-researchers’ experiences of involvement in research varied widely. Nevertheless, the theme suggested that user-researchers’ involvement in a well-established partnership give them the possibility to undergo significant learning processes as a result of receiving research training and support.
Main theme: Negotiating precarious positions in research processes

The main theme, ‘Negotiating precarious positions in research processes’, accounted for a complex set of negotiation practices taking place during collaborative research processes. Academic researchers and user-researchers were positioned and positioned themselves and each other in novel, but precarious ways, which impacted on user-researchers’ opportunities for participation. Research positions depended on circumstances beyond individual (user-)researchers’ control, such as how academic researchers understood user researcher’s dual role. Collaborative research processes was challenged by tokenism, the academic language-use and power inequalities (Cook & Inglis 2012; Moltu et al. 2012; Moltu et al. 2013; Palmer et al. 2009; Patterson et al. 2014; Paul & Holt 2017; Pellicano et al. 2014; Tischler et al. 2010).

User-researchers experienced tokenism when they were positioned as someone who were involved due to requirements in research grant applications and not because of their potential contribution (Paul & Holt 2017). Tokenism was reported to be linked to user-researchers’ lack of research training and uncertainty about how they were supposed to contribute (Patterson et al. 2014). This positioned the academic researcher as the research authority, as someone who always knows what was right, and positioned the user-researchers as someone not in complete control, in need of a legitimate voice, expertise and of self-confidence. Tokenism could be avoided by involving several user-researchers in a genuinely collaborative partnership, which could promote a feeling of representing a ‘we’
due to shared experiences and perspectives (Moltu et al. 2012; Ochocka et al. 2002; Palmer et al. 2009).

Academic language use was a barrier for establishing equality, e.g. when researchers had not sufficiently explained their clinical language use and the research terminology. The academic language could be incomprehensible for some user researchers (Cook & Inglis 2012; Moltu et al. 2013; Pellicano et al. 2014; Tischler et al. 2010) and using language, which was already known or comprehensible for all parties, was reported to promote collaboration (Ochocka et al. 2002).

Moltu et al. (2012) illustrated how power inequalities influenced collaborative research. They reported how user-researchers felt dependent on the academic researchers’ continuing interests in involving and supporting them in the research process. When user-researchers did not get feedback or experienced a lack of interest from academic researchers, it could obstruct more extensive involvement in the research processes (Pellicano et al. 2014). This emphasized that user-researchers often positioned themselves as somebody in need of the academic researcher’s attention and support, which created a sense of inequality and inferiority.

The studies depicted how the relationship between user-researchers and academic researchers was important for the possibilities of creating a genuine collaboration. Moltu et al. (2012) suggested that collaboration could be enhanced by engaging in each other’s perspective such as sharing experiences, stories, knowledge and skills. The willingness to move towards each other would make it possible to reach a mutual understanding. When a research group succeeded in establishing a partnership, user-researchers were able to
contribute to many parts of the research (MacInnes et al. 2011), e.g. decision making, recruitment of informants, data collection and data analysis.

In order to collaborate in research, it seemed necessary to develop mutual trust and respect for each other (Bryant et al. 2012; Callander et al. 2011). However, Townsend et al. (2000) concluded that it could be difficult to radically shift the traditionally embedded power inequalities. They argued that such inequalities must be discussed openly, if research should be truly participatory, such as in collaborative research.

Discussion

This scoping review indicated that actual involvement of user-researchers was based on a complex set of precarious negotiation practices taking place during collaborative research processes, where academics and user-researchers were positioned and positioned themselves in novel ways. Our study identified the range and scope of empirical research of how mental health service users was involved in collaborative research processes and extracted themes concerned with: Expectations to research processes, Contribution to research processes, and Training and learning from research processes. Finally, the review indicated that there is a notable lack of research on academic researchers’ practices in collaborative research practices.

The review identified that there were unmet and unclear expectations to user-researchers’ positions in research and despite unclear expectations, user-researchers were expected to be ready to work together across organizations. Unresolved and unclear expectations could give rise to uncertainty and have an impact on user-researchers’
involvement. Our study indicated that clear mutual expectations enabled service users with severe and enduring mental health problems to contribute in research. Mjøsund et al. (2018) explored the process of involving mental healthcare service users in a case study. They highlighted how expectations towards each other must be clarified throughout the research process. They developed a list of guiding principles for ‘salutogenic’ involvement of service users in research, including six features; 1) “Leadership”, where meetings are chaired and facilitated by the researcher; 2) “Meeting structure”, which included time and place for the meetings; 3) “Role clarification”, which explicated and clarified expectations towards each other in the research process; 4) “To be members of a team”, which included sharing the responsibilities to contribute in discussions; 5) “Focus on what is possible”, which created opportunities instead of limitations and finally; 6) “Holistic individuals”, which included the self-awareness among participants and the way their life-stories influenced the research. These guiding principles were designed to make members of collaborative research groups feel safe and comfortable and support user-researchers in actively contributing. Mjøsund et al. (2018) guidelines are clear, but some issues, such as ‘who decides what is possible?’ in principle five, are still open for discussion. This is because the ways in which the question about ‘possibility’ is revolved in a research team could be based on skewed power relations. Guidelines on how to involve user-researchers can be regarded as useful contributions in order to create a positive research atmosphere that appreciates user-researchers’ experiences.

Rose (2014) pointed out that user-researchers must be involved in all stages of a research process if a genuine collaboration process is to be established, and, further, that the research atmosphere surrounding the collaborative work is probably underestimated in
research. Banfield et al. (2018) emphasized that involving user-researchers was challenging because they predominantly were regarded as passive participants and that the conventional previous top-down researcher-driven model had generated distrust. Creating a positive research atmosphere, where research groups establish a safe working relationship, as forwarded in Mjøsund et al.'s (2018) six guiding principles, is time-consuming. However, it is of utmost importance for user-researchers that they feel valued by academic researchers and that they experience that their contributions are respected.

In the participatory turn, collaboration and involvement are regarded as fundamental for creating new knowledge through authentic partnerships. The findings included the observation that user-researchers and academic researchers sometimes contributed markedly differently to the research process. User-researchers took different positions depending on their research training and such experience-based knowledge could potentially add insight, depth and complexity to an analysis. Collaboration in research can potentially re-shape spaces of concern and research interests. The knowledge co-produced by marginalized groups can ultimately, as forwarded by Rose (2014), change knowledge itself because of the changing relationships between the knowledge-producers. Rose argued that user-focused positions in research generate different findings compared to conventional research positions. Rose’s argument took its outset in how electroconvulsive therapy treatment was changed on the basis of user-led research. The review highlighted challenging and precarious research positions as the participatory turn shifts the power relationships between mental health care service users and academic scientific experts (Groves 2017). Arguably, there are still significant challenges in academic research culture about how to create the changes that collaborative research requires.
Involving user-researchers in collaborative research can be beneficial as it can assist users in their own recovery process (Syrett 2011). It can be an opportunity to have their voices heard and have the awareness that marginalized groups can co-produce knowledge that might influence future mental health. Aligning expectations towards each other is important as user-researchers can feel isolated on teams. Banfield et al. (2018) described how they had experienced exclusionary behavior from academic researchers, such as devaluing or compartmentalizing their contribution, e.g. by commenting that user-researchers “could not know the real consumer experience” (p. 1228). This could indicate that user-researchers were not positioned as ‘real’ service users, but as privileged outsiders, which in effect positioned the user-researchers in an illegitimate position betwixted and between the legitimate services-users and the legitimate researchers. This anecdote corroborated the findings of the review that indicated that the user-researchers’ position was precarious. However, such blatant devaluation and resistance was not a general finding and the studies indicated that academic researchers also emphasized the important contribution consumer researchers can make to mental health research by bringing unique perspectives and enhancing an environment of mutual learning.

The research terminology related to participatory research has yet to be developed. Rose (2014) described how user-researchers dual-role lead to challenges where they must operate within the mainstream discourse of research and their own discourse related to their lived experience.

The studies of user-researchers’ actual involvement collaborative research was occasionally published in non-conventional genre and this research was difficult to evaluate by means of mainstream checklists for reporting research. Staniszewska et al. (2017) have
recently co-developed GRIPP2, a checklist for collaborative research, together with service users. Still, the core conceptualization was founded in the language of conventional research, such as asking for the aim, methods and results. Staniszewska et al. (2017) argued that we currently do not have the knowledge needed to develop the concepts for evaluating the quality of collaborative research and collaborative research processes and GRIPP2 should be interpreted as a step towards developing such knowledge.

**Strengths and limitations**

The original description of a scoping review (Arksey & O'Malley 2005) did not include quality assessments of included papers, as all relevant studies, regardless of methodological quality, should be included (Pham et al. 2014). To strengthen the reliability of our reading, the evaluation and the data extraction, we decided to systematically use the CASP checklist and to compare at least two independent evaluations. However, some highly collaborative studies were difficult to evaluate using CASP, whose items did not ‘match’ the analyses very well. This could indicate that there is a need for a quality assessment tool for studies using collaborative methodology, such as GRIPP2. Finally, during the consultation exercise, several of the consulted user-researcher objected that we should have included user-researchers in the review process right from the beginning of the review process. Even though we consulted users in the early analysis, we believe this a valid criticism and that we could have included user-researchers in our review team and thus creating some of the advantages described in the review.
Conclusion

This review highlighted the precarious positions of user-researchers involved in collaborative research. The area of research was young and was focused almost exclusively on the expectations, contributions, and training and learning of the user-researchers, who as the latest newcomers in the field had to legitimize their position and justify their worth. More research in the area is needed, in particular with a stronger focus on the academic researcher’s positions and contribution in collaborative research.

Relevance for clinical practice

Collaborative research in the mental health field necessitates changes of traditional research practices. It is important to be aware of user-researchers’ and academic researchers’ position in the research process to ensure a genuine collaborative partnership and thereby avoid tokenism and power inequalities.

This review illustrated the importance of clarifying mutual expectations between user-researchers and academic researchers to promote genuine collaboration in research practice. In addition, creating new knowledge through an authentic partnership requires that user-researchers contribute to all stages of the research process. Furthermore, avoiding the use of academic language is important to build an authentic partnership. Some of the challenges faced in research practice when involving users in the research process can be met by research training and support for both academic researchers and the user.
researchers. This gives the opportunity for both groups of stakeholders to undergo learning processes when being involved in research collaboration.
References


INVOLVE. (2012). *Briefing notes for researchers: involving the public in NHS, public health and social care research*. Eastleigh, UK: INVOLVE.


Table 1: General outline of the building block search strategy

<table>
<thead>
<tr>
<th>Context</th>
<th>and</th>
<th>Research</th>
<th>and</th>
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<td>Psychiatry</td>
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<td>Mental health</td>
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<td>Mental disorders</td>
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<td>Collaboration</td>
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<td>Author, year, title</td>
<td>Aim</td>
<td>Study context and participants</td>
<td>Design and methods</td>
<td>Key findings</td>
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<td>Bengtsson-Tops and Svensson. 2010. “Mental health users’ experiences of being interviewed by another user in a research project. A qualitative study”.</td>
<td>To describe how users experience participation in research interviews performed by other users.</td>
<td>Seventeen mental health users, interviewed by another user in Sweden.</td>
<td>Qualitative content analysis of interview data.</td>
<td>Being interviewed by another user was both a positive and negative experience.</td>
</tr>
<tr>
<td>Bryant et al. 2011. “Meeting in the mist: Key considerations in a collaborative research partnership with people with mental health issues”.</td>
<td>To gain insight into experiences of collaborative work within the group, identifying the barriers and facilitators to successful joint work.</td>
<td>Eight members of collaborative research team (five mental health users and three occupational therapy staff) in UK.</td>
<td>Participatory action research with semi-structured questionnaire and group discussions.</td>
<td>The members engaged with each other’s perspective. It was important to create time and space within the collaborative cycle to gain a shared vision for the future.</td>
</tr>
<tr>
<td>Callander et al. 2011. “Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia”</td>
<td>To enable the consumer and carer research teams to reflect on their experiences of working together.</td>
<td>An unknown number of mental health users involved in research from a consumer team and carer project team in Australia.</td>
<td>Qualitative analysis of group discussions.</td>
<td>It was important to have support and have the possibility to build relationships, establish mutual trust and respect, and define a shared vision. The group experienced both barriers and encouraging factors.</td>
</tr>
<tr>
<td>Cook and Inglis. 2012. “Participatory research with men with learning disability: informed consent”.</td>
<td>To examine how people with learning disability make informed choices in relation to participation in research; and to highlight both the competencies of people with learning disability and the impact of their understanding.</td>
<td>Seven participant researchers with learning disabilities detained in relation to mental health Act in UK.</td>
<td>A collaborative approach with qualitative analysis of data generated from workshops, interviews and field notes.</td>
<td>Participant researchers had an illusory understanding of research, and poorly understood the complexities of research. Their understanding was developed through collaborative approaches.</td>
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<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Objective</td>
<td>Method</td>
<td>Findings</td>
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<td>Croft et al. 2016.</td>
<td>“Peer interviewers in mental health services research”</td>
<td>To describe an approach to involve persons with lived experiences of mental health in research as interviewers.</td>
<td>Case study based on a collaborative research project.</td>
<td>A number of benefits and challenges of the peer-interviewer approach was identified.</td>
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<tr>
<td>Ennis and Wykes. 2013.</td>
<td>“Impact of patient involvement in mental health research: longitudinal study”</td>
<td>To identify whether patient involvement is associated with study success.</td>
<td>Quantitative, statistical analysis.</td>
<td>Patient involvement was associated with, but not necessarily a cause of, study success.</td>
</tr>
<tr>
<td>Gillard et al. 2010.</td>
<td>“Staying native”: Coproduction in mental health services research”</td>
<td>To consider whether user researchers are able to contribute to the research process as experts by experience, or if their experiential knowledge is “colonized” within the academic research team.</td>
<td>Qualitative comparative case study based on observations and interviews.</td>
<td>Expert by experience researchers had powerful effects at all stages in the research. Expert by experience researchers retained their experiential identity.</td>
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<tr>
<td>Gillard et al. 2010.</td>
<td>“What difference does it make?” Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients”</td>
<td>To investigate the potential to provide empirical evidence of the impact of service user researchers on the research process.</td>
<td>A qualitative collaborative study with secondary analysis of interviews.</td>
<td>User researchers and university researchers conducted and coded interviews differently.</td>
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<tr>
<td>Gillard et al. 2012.</td>
<td>“Patient and public involvement in the coproduction of knowledge: Reflection on the analysis of qualitative data analysis”</td>
<td>To describe a mental health research team consisting of 17 individuals out of which seven were user researchers in UK.</td>
<td>Case study based on description and reflection of the process of analyzing data with a high degree of user involvement.</td>
<td>User researchers took part in several stages in the research. The coproduction influenced the findings of the study. A systematic reflection on the process of knowledge co-production had the potential to...</td>
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<td>Reference</td>
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<td>Gillard et al. 2012.</td>
<td>“Producing different analytical narratives, coproducing integrated analytical narrative: a qualitative study of UK detained mental health patient experience involving service user researchers”.</td>
<td>To explore the extent to which mental health service user-researchers produced different interpretive narratives compared to conventional university researchers and the potential to co-produce an integrated analytical narrative.</td>
<td>A research team including four professionals and three mental health user-researchers in UK. Qualitative analysis of interviews. Involving user-researchers contributed to co-production of new knowledge.</td>
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<tr>
<td>Hamilton et al. 2011.</td>
<td>“The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: A randomized study”.</td>
<td>To examine the impact of user interviewer status (former/current user or non-user of psychiatric services) on the findings of a quantitative study.</td>
<td>19 interviewers with mental health problems and 12 without mental health problems in UK. A randomized quantitative study. Interviewer’s experiences of mental health problems did generally not impact quantitative interviews about discrimination. However, there was a significant lower accept of the invitation to the quantitative interviews, when it was stated that the interviewer was a service user.</td>
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<tr>
<td>Hancock et al. 2012.</td>
<td>“Participation of mental health consumers in research: Training addressed and reliability assessed”.</td>
<td>To develop and use research training modules to enable consumers to contribute in a meaningful way and examine interviewer reliability of self-report data collected by trained consumers.</td>
<td>Five trained consumers with the diagnosis of schizophrenia or bipolar in Australia. A collaborative study with analysis of self-reported data collected by the consumers. Consumer researchers took part in training modules and were engaged in all steps of the research. Data involving self-report measures could be gathered by trained consumer researchers and met the standard for research.</td>
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<tr>
<td>Hutchinson and Lovell. 2013.</td>
<td>“Participatory action research: moving beyond the mental health ‘service user’ identity”.</td>
<td>To discuss the process of a three-year participatory action research study.</td>
<td>Six user-researchers using community mental health services in UK. Participatory action research study. The co-researchers were allowed to come forward with their perspectives in this study and their identities were transformed over the three years period.</td>
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<td>Authors (Year)</td>
<td>Topic of Research</td>
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<td>Kim. 2005.</td>
<td>To describe the experiences of researchers with a psychiatric disability participating in a project evaluating services and to identify strategies for researchers with a psychiatric disability.</td>
<td>Qualitative interview study, analyzed with a constant comparative method.</td>
<td>Both factors that facilitated and impeded research involving the researchers with psychiatric disabilities were identified.</td>
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<tr>
<td>MacInnes et al. 2011.</td>
<td>To identify factors perceived by professionals and service-users as important for developing a collaborative research study in forensic mental health settings.</td>
<td>Case study following a collaborative research project.</td>
<td>Three themes were found: Administration, formal collaboration and informal collaboration. The themes helped developing a good collaborative relationship.</td>
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<tr>
<td>Mjøsund et al. 2017.</td>
<td>To examine how service user involvement enhanced the research quality in a study using an interpretative phenomenological analysis – the power of multiple perspectives.</td>
<td>Case study based on development of an interpretative phenomenological analysis.</td>
<td>Service users were involved in all stages of the project. Involvement of service users in the research process increased breadth and depth in findings.</td>
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<tr>
<td>Moltu et al. 2012.</td>
<td>To explore what it was like to be a co-researcher in mental health collaborative studies and how co-researchers negotiate their roles and mandate?</td>
<td>Qualitative hermeneutical-phenomenological approach to analyze focus groups.</td>
<td>Some social processes were identified when user researchers attended a research school and became a co-researcher: self-definition, constructive differentiation and negotiations.</td>
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<td>Authors</td>
<td>Research Question</td>
<td>Sample Size</td>
<td>Methodology</td>
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<tr>
<td>Moltu, Stefansen and Svisdahl. 2013.</td>
<td>To investigate how service users experienced their participation as co-researchers and attending a training program in Norway.</td>
<td>12 people with experiences of affective disorders attending a training program in Norway.</td>
<td>Qualitative hermeneutical-phenomenological approach to analyze focus groups.</td>
<td>Service user-researchers experiences of being user-researchers and of having taken part in a research training course were summarized in three themes: the advocate for usefulness, the brakeman, and the interpreter.</td>
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<tr>
<td>Morell-Bellai and Boydell. 1994.</td>
<td>To examine the experiences of six mental health consumers employed as researchers in different research projects in Canada.</td>
<td>6 mental health consumers who were involved in paid employment as researchers.</td>
<td>Qualitative interview study.</td>
<td>Consumers benefitted from being involved in research. However, several unfulfilled needs of consumers were identified.</td>
</tr>
<tr>
<td>Moule and Davies. 2015.</td>
<td>To understand the processes and impact of public involvement in a devolved model of working with user-led organizations in mental health research: Case study learnings.</td>
<td>3 service user researchers and 1 principal investigators in the UK.</td>
<td>Case study based on interviews, observation and review of key case study documents.</td>
<td>Involvement of user-led organizations could be supported by a devolved model. There were some challenges in implementing the devolved model.</td>
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<tr>
<td>Ochocka, Janzen and Nelson. 2002.</td>
<td>To document and reflect on the process and outcomes of consumer researchers’ involvement in a mental health consumer/survivor research project working together in a participatory action research project.</td>
<td>A research team consisting of three consumer researchers, two professional researchers and two university graduate students.</td>
<td>Case study based on a participatory action research approach.</td>
<td>Four values were central to the research process: Consumer empowerment, supportive relationships, learnings as an ongoing process and social justice.</td>
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<tr>
<td>O’Donoghue et al. 2013.</td>
<td>To determine whether the background of the interviewer (service-user or clinician) affects service users’ perceptions about their admission experience.</td>
<td>6 clinicians and four mental health user researchers in Ireland.</td>
<td>Quantitative analysis of an interview study with a total 161 mental health user. An admission experience</td>
<td>Most interviewees were positive to their admission regardless of the interviewer’s background. No risk.</td>
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<td>Reference</td>
<td>Study Overview</td>
<td>Methods</td>
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<td>Palmer et al. 2009.</td>
<td>To work with, develop, train and support mental health service users as researchers, in order to record the narratives of mental health service users.</td>
<td>Qualitative pilot study.</td>
<td>The research provided opportunities for learning and developing on both individual and group levels and in terms of future research. Difficulties in undertaking research with user involvement were identified and recommendations to overcome these difficulties were suggested.</td>
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<td>Patterson, Trite and Weaver. 2014.</td>
<td>To describe activities, roles and experiences of service users involved in mental health research.</td>
<td>Cross-sectional questionnaire survey with a study population of 166 user researchers.</td>
<td>User-researchers were passionate about improving services. Support of peers was crucial for involvement. Involvement often enhanced user-researchers’ mental health, but challenges in user involvement in research were also identified.</td>
<td></td>
</tr>
<tr>
<td>Paul and Holt. 2017.</td>
<td>To explore the attitude of researchers working in mental health and learning disability research: Can we, should we, do we?”.</td>
<td>Qualitative interview study.</td>
<td>3 themes were identified: Valuing the patient and public involvement perspective, Constraints and Culture.</td>
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<td>Pellicano, Dinsmore and Charman. 2014.</td>
<td>To investigate the views of community members of autism and public involvement in autism research both from the perspectives of autism researchers and of community members.</td>
<td>Mixed Method with a large scale questionnaire and focus groups and individual interviews.</td>
<td>Benefits and challenges to user involvement in research were identified. A lack of a shared approach from user-researchers and academic researchers to community engagement in UK autism research were identified.</td>
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<td>Robinson, 2007.</td>
<td>To explore the views of research participants regarding their experiences as colleagues in the research process.</td>
<td>90 consumer researchers with experiences of currently or previous mental illnesses in Canada.</td>
<td>Participatory action research with both quantitative and qualitative analyses.</td>
<td>In general consumer researchers were positive about the degree to which their experiences were participatory. Consumer researchers experienced changes related to their involvement in research. Social work research was a fertile ground for participatory research.</td>
</tr>
<tr>
<td>Simpson et al. 2014.</td>
<td>To describe the methods and findings from a reflective evaluation of the processes and outcomes of SUGAR from the perspectives of the service user and carer members.</td>
<td>13 user researchers with a range of mental and physical illness and life experiences in England.</td>
<td>Qualitative constant comparative method to analyze written reflective narratives.</td>
<td>Benefits and possible limitations to user involvement in research were identified.</td>
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<tr>
<td>Sweeney et al. 2012.</td>
<td>To demonstrate the value of multiple coding in enabling service users voices to be heard in team-based qualitative data analysis: the case for multiple coding”.</td>
<td>One user researcher, one clinical researcher and one psychology assistant in UK.</td>
<td>Multiple coding used to analyze service users’ discussions of cognitive behavioral therapy.</td>
<td>The user researcher brought unique perspectives and experiences to data interpretation. Multiple coding was an appropriate means to include user-researchers in interpretative work.</td>
</tr>
<tr>
<td>Tischler et al. 2010.</td>
<td>To establish convergent validity for a definition of patient centeredness and to explore the experiences of psychiatrists and service users taking part in research.</td>
<td>14 user-researchers and three senior psychiatrists in UK.</td>
<td>Mixed methods: a categorical rating of patient centeredness in abstracts of schizophrenia research, focus groups and interviews.</td>
<td>Service user-researchers and psychiatrists rated abstracts differently. Both user-researchers and psychiatrists reported benefits to collaborative research.</td>
</tr>
<tr>
<td>Townsend et al. 2002.</td>
<td>To understand people with mental health problems challenges and opportunities for advance their empowerment through participatory research program with observations, interviews and documents.</td>
<td>60 users involved in participatory research and social critique in participatory research was of importance.</td>
<td>An institutional ethnography of a mental health clubhouse in Canada.</td>
<td>Power inequities had to be discussed in participatory research and social critique in participatory research was of importance.</td>
</tr>
</tbody>
</table>
van Draanen et al. 2013. “Meaningful inclusion of consumers in research and service delivery”. To examine lessons learned from the group: “People with Lived Experience”. 23 users with experiences of a range of mental health problems. Many had in addition experiences of being homeless in Canada. Qualitative comparative analysis of focus groups, interviews and documents. Barriers to involvement were identified, however users contributed to research in a meaningful way.
Figure 1: PRISMA flow chart

This flowchart was inspired by PRISMA (2009).
Figure 2: Overview of main theme, themes and codes

Main theme
- Negotiating precarious positions in research processes

Themes
- Expectations to research processes
- Contribution to research processes
- Training and learning from research processes
- Decision making
- Education of user-researchers
- Recruitment
- User-researchers need for support
- Data collection
- Benefits for user-researchers
- Lack of clear expectations
- Data analysis

Codes
- Expectations to user-researchers
- User-researchers’ unmet expectations