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Mental health researchers' views about service user research: a literature review

Abstract

Services users are becoming actively involved in mental health research. How this is perceived by other researchers is not well known. The aim of this paper is to review the international literature exploring other mental health researchers' views of service users conducting research, between 1996 and 2016. Searches of multiple databases (PubMed, PsychINFO, CINAHL, Google Scholar) was undertaken. Combinations of terms related to service user research and mental health researcher perspectives, views and attitudes were used. Manual inquiry of reference lists was also undertaken. Relevant papers were coded by topic, location, study design, and other dimensions. Five articles met inclusion criteria. Most referred to perceived benefits, such as greater validity of research findings, challenges of collaborating with service users, and the validity of research findings. There was some evidence of more openness to mental health service users providing suggestions, preferably in early stages of the research process. Reluctance to co-research with service users was reported. There is limited research directly addressing other mental health researchers' views about service user research; barriers to inclusion (whether involvement, co-production or user-controlled) and creating incongruence with health policy statements. Further research to more fully understand these attitudes and how they might be influenced is warranted.

Key words:

Consumer researcher

service user research,

researcher attitudes,

mental health

mental health research,

literature review

Introduction

There has been increased focus on the inherent role of service users (also commonly termed consumers) in health policy and health practice models (Canadian Medical Association, 2010; National Health and Medical Research Council, 2016; The Mental Health Foundation, 2003). The role of research in achieving these goals is crucial. In the United Kingdom for example, 'patient and public involvement' in research is viewed as an essential mechanism to ensure health services are relevant and responsive to the needs, values and preferences of people they are designed to support. (Department of Health, 2003; National Institute for Health Research, 2017) More recently, calls have been made for service users to conduct research in recognition of their differing priorities and approaches. (National Health and Medical Research Council, 2015, 2016).

The INVOLVE continuum (Consultation – Collaboration – User Controlled) describes different levels of user involvement in research; reflecting the amount of control users have in the research process (INVOLVE, 2012). At one 'end' is consultation and involvement, providing advice on research study questions and interview questions, as well as conducting part of the research, such as being an interviewer. Towards the 'middle' are forms of research collaboration or co-production, where users partner with other mental health researchers in decision-making and conduct of the research. The other end of the continuum is user-controlled,

where the service user researcher has power over major decisions in the research process. User-controlled research does not necessarily mean other researchers are not involved in conduct of the research study (INVOLVE, 2012).

Alongside this continuum is how user engagement may vary across the phases of the research process (INVOLVE, 2012), from specification of research focal points and questions, (Banfield, Barney, Griffiths, & Christensen, 2014; Rose, Fleischman, & Wykes, 2008) to dissemination and translation into policy and practice reform. (Callard & Rose, 2012) User involvement in research may be brief and specific, such as conducting interviews and assisting with recruitment. Alternatively, it may be conducted across all phases of research (Callard & Rose, 2010). Participatory Action Research, frequently utilised for evaluation of mental health services, is an inclusive format where service user researchers, (e.g. Corrigan, Pickett, Kraus, Burks, & Schmidt, 2015) can centre user needs, values and experiences in knowledge production. The current paper is concerned with mental health service user research across the INVOLVE continuum. For brevity, the phrase 'service user research' will be used to describe research activities undertaken by service users which may be at any point on the INVOLVE continuum.

Government policy frameworks and service users (Callard & Rose, 2010), have argued research by service users makes a valuable contribution to the literature. Such an approach enables research questions and

subsequent policy to be aligned with the needs, values and interests of service users; (Faulkner, 2017; Linhorst & Eckert, 2002; Michalak et al., 2016). In addition, the research process is enhanced by the application of lived experience of mental illness (or “insider’s view”) through more in depth analysis which leads to increased validity and applicability of knowledge than otherwise possible;(Case et al., 2014; Mjosund et al., 2017).

Involvement has positive implications on participant recruitment and data collection. There is a greater willingness of service users to participate when they know the team includes a service user researcher (Happell et al., 2016). Furthermore, service user researchers are able to foster a stronger rapport with research participants which encourages frank opinions and richer data .(Wallcraft, Schrank, & Amering, 2009). Offering service users opportunity to become involved in research processes can be empowering through, for example, the growth of research skills and as a potential form of employment and income.(Patterson, Trite, & Weaver, 2016). On a more conceptual level, mental health service user involvement in research maintains a commitment to protect human rights. Such research and knowledge development is congruent with principles of autonomy and democracy,(Patterson et al., 2016) often summed up as – “nothing about us without us”,(Phillips, 2006) and similarly, “no decision about me, without me”. Overall, service user research represents a promising strategy for reform of mental health services to be guided by the views and perspectives of service

users to facilitate more relevant and responsive mental health services, and enhanced health outcomes.

There is a focus in the literature on the experiences and views of service user researchers, illuminating the nature and level of progress, and observed benefits and barriers. Successful research projects have been identified in terms of new knowledge for health care reform, and what service users see as authentic participation in research (Ennis & Wykes, 2013; Mjosund et al., 2017). However, sustaining service user research activity has been described as very challenging from the perspective of service user and nurse researchers working collaboratively (Fothergill, Mitchell, Lipp, & Nortway, 2012). Amongst the most common barriers raised were: other researchers having difficulties adopting a different social dynamic (at the heart of user research models), and sharing of power; resistance, ambivalence and often condescending or patronising stances to mental health user(s) ranging from the subtle to explicit – and often seen as a manifestation of broader stigma of mental illness; tokenistic participation which has little capacity to change the formal agenda (Borg, Karlsson, & Kim, 2009; Clark, Glasby, & Lester, 2004; Patterson, Trite, & Weaver, 2014; Wallcraft et al., 2009). Examples of strong commitment to research partnerships with service users, where identified, were generally hampered by shortages in resources and organisational infrastructures that are inhibitive, such as lack of training opportunities for users and other researchers (Rose, 2011; Wallcraft et al., 2009). The most

complex and seemingly insurmountable obstacle was that other researchers were culturally not open to users having an active research role.

The future success, reach and sustainability of service user research are partially dependant on the readiness and commitment of other researchers to adopt different relationships and research practices. By 'other researchers', we refer to what might commonly be thought of as conventional mental health researchers; including academic researchers and practitioner-researchers in psychiatry, psychology, mental health nursing, occupational therapy and social work. While there are several studies exploring service user views on involvement in mental health research, (Patterson et al., 2014; Rose et al., 2016) and some studies where other researchers recount their experiences of working with service users as part of the research team, (Case et al., 2014; Patterson et al., 2016) there are few research studies addressing other researchers' views of service user involvement in research more generally. This information is crucial to minimising the barriers to service user research activity (including co-production, user-led research).

Literature reviews have described the level of service user participation, the views of service user researchers (Ashcroft, Wykes, Taylor, Crowther, & Szmukler, 2016; Boote, Baird, & Sutton, 2011; Domecq et al., 2014; Shippee et al., 2015; Thompson et al., 2009), and other researcher views about service user participation in the health care system, (e.g. Ward et al.,

2009). However, these reviews do not attend specifically to *mental* health service users and have not brought together and consolidated knowledge on the views of other mental health researchers on service user involvement and co-production of mental health research.

Therefore, a literature review is needed to understand other mental health researchers' views of mental health service user involvement in research processes. This source will assist in addressing key questions pertaining to facilitating mental health service user research involvement, such as:

- What are the benefits of mental health service user involvement/co-production? (perceived, anticipated, as found in practice)?
- What are the views, attitudes, knowledge and experience of mental health service user involvement/co-production of research by/with other mental health researchers that have been investigated?
- How do other mental health researchers describe ways of involving/co-producing with users in research?
- What are the barriers to service user involvement/co-production, in general, and pertaining to certain stages, such as recruitment?
- What do other researchers see as the desired scope and depth of mental health service user involvement/co-production, policy directions, and what is the vision for the future?

The aim of this article is to review and analyse the literature regarding experiences and views of other mental health researchers about service user research and produce a synthesised analysis. The findings will assist to bridge the mental health (research) policy implementation gap and provide insight as to how to cultivate more receptive attitudes to service user research activity.

Methods

Selection criteria

Literature was reviewed for the period 1996 and 2017. This time period was selected given the increasing visibility of service user participation in government policy from the mid-1990s (Rose, 2015). Articles were selected if: i) peer-reviewed; ii) written in English; iii) explicitly focused on identifying the views of researchers in the mental health area (i.e. this did not include non-researcher mental health clinicians, practitioners or service providers) on service users as researchers in mental health. The review was open to any type of study design and to all potential topical areas. Studies did not have to be exclusively about mental health, so long as at least one mental health researcher was within the sample. For example, a study would be included in the final pool if it included at least one mental health researcher, even if the topic was not on mental health.

Search strategy and identification of relevant papers

The literature search was conducted in April and May, 2017. The electronic databases searched were CINAHL, PubMed, and PsychINFO. The search was of title, abstract and key words or subject. The general combination of search terms applied were: ('ex-patient research*' OR 'consumer research*' OR 'mental health consumer research*' OR 'survivor research*' OR 'service user research*' OR 'user research*' OR 'mental health service user' OR 'lay research*' OR 'participat* research' OR 'consumer inclus*' OR 'co-product*', OR 'action research' OR 'user-led' OR 'consumer-led') AND ('health professional*' OR psychiatrist* OR nurse* OR 'social worker*' OR psychologist* OR 'mental health research*') AND (view* OR attitude* OR perspective* OR experience*). To identify peer-reviewed papers that may have been missed through these key searches, we also conducted a search in Google Scholar and a manual search of the grey literature on service user research participation, of the reference lists of articles at the interface of mental health and participative research, and the International Association of Service User Academia database.

Data extraction and analysis

Each article was coded according to location of research, participant researcher group (psychiatry, nursing, psychology, social work, occupational therapy), area and issue of research involvement, topic of mental health

research, aim of the study, year, study design (e.g. method of recruitment, sample size, type of method of data collection and analysis), type of researcher/author (other or service user researcher), and source of funding. Key findings of identified articles were recorded in detail.

Results

The initial pool of literature from the key data base searches was 1,327 articles, with 1003 remaining after duplicates were removed. In the screening of article titles of the initial pool, combined with the search of Google Scholar and manual searches, twenty-four articles were identified as potentially meeting criteria. Nineteen were excluded after examining the full text document. The remaining five studies met the inclusion criteria.(Boaz, Biri, & McKeivitt, 2016; Bromley, Mikesell, Jones, & Khodyakov, 2015; Bryant et al., 2012; Lawn, 2016; Staley, Kabir, & Szmukler, 2013) The domains of 'other researcher' perspectives included attitudes,(Boaz et al., 2016) type and extent of mental health service user involvement,(Lawn, 2016; Staley et al., 2013) experiences of projects where there was mental health service user research,(Bryant et al., 2012) and ethics.(Bromley et al., 2015)

Three articles were from the UK, (Boaz et al., 2016; Bryant et al., 2012; Staley et al., 2013) one from the USA (Bromley et al., 2015), and one from Australia.(Lawn, 2016) All studies had a qualitative component. Three involved interviews(Boaz et al., 2016; Bromley et al., 2015; Staley et al., 2013)

and two, semi-structured surveys.(Bryant et al., 2012; Lawn, 2016) Given the small number of studies and the diversity of contexts and designs, it was not possible to conduct a direct analysis of article-specific findings (e.g. comparison of ratings of attitudes towards consumer research). Instead, a narrative synthesis of the identified literature is provided.

Staley, Kabir and Szmukler (2013) reported on results of interviews with the chief investigators from 45 non-completed research projects, based on a random sampling of the body of studies under the Mental Health Research Network in the UK. The purpose was to estimate the extent of mental health service user involvement in research, as detailed in research plans to obtain support from the Mental Health Research Network. Findings highlighted diverse forms of research involvement by mental health service users and a range of contexts and purposes of the mental health research. The two most common types of involvement were membership of a steering committee (41%) and consultation during the design phase (17%). At least 20% had responded to each of the following impacts: 'on the design of the study', 'on conceptual elements', 'on practicalities', 'extensive influence throughout the study' and 'limited or no impact' (p. 1112).

The level of perceived impact of mental health user involvement was conditional on other researchers' perspectives on what such involvement could offer to the particular project. Expectations ranged from other researchers regarding it as helpful for checking 'lay friendliness' of research

design (e.g. interview questions) to recognising mental health services users as shaping and improving all aspects of a research project. Participants outlined other researchers' views in relation to three broad contexts – mental health service users shaping research design (i.e. early stages of research projects), involvement in steering groups or participation in an advisory group).

Different barriers were highlighted for each of these areas. For instance, for projects that included mental health users as co-researchers, the organisational demands for tight deadlines worked against the need for more flexibility in collaboration to mitigate the difficulties in sustaining full-time workloads by users who may need, at least occasionally, to take time off work to maintain wellbeing.

Staley et al.(Staley et al., 2013) concluded there has been a great diversification in modalities of service user participation in research and the mental health sector more broadly from 2006 to 2012. However, there was a significant lack of organisational support for other researchers to involve mental health service users in research. For example, guidance and training for other mental health researchers on inclusion of mental health users as researchers was “rarely received” (p. 1124).(Staley et al., 2013) Some other researchers did not involve service users as they considered this activity to be ‘ticking the box’ to satisfy requirements of an organisation or to secure funding, rather than as inherently desirable. In these cases, it appeared that

other researchers needed more detail on the funding organisation's expectations and outcomes in relation to user participation.

Bromley et al.(Bromley et al., 2015) investigated the ethics of research which “involves community members with lived experience of the health problem under study – or with responsibility for populations with this lived experience... to participate in planning, designing, conducting, interpreting, or disseminating research” (p. 900). While the researchers (other, and service user or community-based) were from “community-engaged studies” (p. 900) that included mental health research, the details of the topics were unclear from the report. Perspectives on the meaning of ethical research in practice and ethical concerns that arose from involving community members in the research process experiences were gained through interviews. The interviews were with 15 other researchers connected to a clinically-based mental health research centre and 14 community members of the research team. It was found there was inadequate attention to research ethics for projects involving community participation in research teams. The ethical issues raised were diverse, and often reflected lack of support structures for user researchers.

The common theme was “shift from subject to participant” (p. 901) where established ethics protocols were for the traditional “ethical object” (p. 905), the research subject, and so were not well transferable to the “participant”, who “provide data, but also advise, share expertise, advocate

the study, or analyse data" (p. 906). In short, formal ethics procedures are premised on "subjects", but community-based research is more about "participants", and so ethics protocols need to be developed for the latter. It was also argued, upon analysis of the data, that ethical principles such as respect and beneficence are a good basis for working collectively towards establishing procedures for embedding ethical practice in community-engaged research. Furthermore, the authors asserted that consensus building will require challenging conventional procedures of research ethics on matters of choice, autonomy, on expectations and obligations of stakeholders and key assumptions regarding the epistemology of health research.

Bryant et al.(Bryant et al., 2012) reported on the collaborative research experiences of a research team in the UK, called 'Researching Psychosis Together'. This team was awaiting approval for "participatory action research" (p. 25) on mental health day services, and during that time, as part of the preparatory phase, conducted a systematic inquiry into their own collaborative work in acquiring data collection research skills, to "gain insight into experiences of collaborative work within the group" (p. 25). Besides service user researchers, the research team included an academic researcher and an occupational therapist. Data were derived from open response questionnaires, one interview and a discussion group that took place when themes were proposed after the first round of data analysis. A key theme was that of "meeting in the midst"; where initially there was

difficulty in connecting and sharing expertise, and over time mutual learning would develop and strengthen, leading to more robust knowledge creation.

Lawn (2016) inquired into the perspectives of other researchers from mental health and other health areas, on service user participation in research by conducting a brief survey during a conference by the National Health and Medical Research Council in Australia. Thirty eight completed surveys were obtained. While some mental health researchers were included, the exact number was not reported. Findings suggested researchers saw service user participation as important for ensuring the relevance of early stages of research design and appropriate to later translatability in applied settings. When asked on the level of inclusion of service users in research, the most common response was in consultation roles. There was only one participant who self-reported involving service users as co-researchers (3% of the overall sample). Overall, Lawn argued that there was a discrepancy between positive overtures towards service user participation in research and actual research involving service users (i.e. a gap between voiced favourability and action).

Boaz, Biri and McKeivitt (Boaz et al., 2016) sought to explore the attitudes of health researchers to public involvement in research in the UK. Of the 19 participants in the study, seven were from mental health fields (clinical and health services), including professors, a senior lecturer, post-doctoral researcher, PhD student and research assistant. It was found that researchers

with a biomedical background were less open to service user involvement in research than other health researchers. Also, only one participant of the 19 supported strong research involvement by service users. Overall, Boaz et al. (Boaz et al., 2016) observed reluctance by other researchers to endorse significant public involvement in health research reflecting their desire to retain a neat boundary between 'scientists' and 'patients' in their conception of research.

Discussion

This review has confirmed that the views of other mental health researchers are pivotal in service user involvement, yet there is minimal knowledge available on this topic. Furthermore, there is no indication of a systematic research approach to facilitate policy expectations for this type of research in mental health. The absence of a framework contrasts with an emerging literature base of studies of mental health user researcher experiences and views (Ashcroft et al., 2016; Hutchinson & Lovell, 2013; Rose et al., 2008; Wallcraft et al., 2009). The scarcity of research is perhaps most significant in relation to other mental health researchers who have not included service users in their research team in any capacity. Furthermore, the few studies available did not differentiate between groups of mental health researchers or disciplines, due to the small sample sizes. There were no studies concentrated on a particular research discipline, such as the particular views of psychiatrists or mental health nurses.

it was difficult to locate findings specifically about mental health researchers for two (Bromley et al., 2015; Lawn, 2016) of the three studies that examined mental health researchers as part of a larger group of health researchers from other fields. No direct comparisons were made between mental health researchers in mental health and broader health researchers regarding their views about service user participation in research. It is likely that mental health service users experience greater challenges in instigating service user participation in research due to the stigma attached to mental illness (Gaebel, Roessler, & Sartorius, 2017). It would therefore be helpful for studies examining service user research participation more generally (not mental health specific) to indicate the extent of this; particularly if reporting of results separated the views of those doing mental health research to enable comparative analysis.

A common finding is for other mental health researchers in non-mental health settings to indicate lack of willingness to share control of research (Thompson et al., 2009; Vale, Thompson, Murphy, Forcat, & Hanley, 2012). This reluctance may be more prevalent and/or stronger in the case of mental health service users, due to the widespread deficit-based thinking about people with mental illness diagnoses (Bird et al., 2012) and the general stigma of mental illness (Hamilton et al., 2016). There have been commentaries by other researchers overtly against 'strong' forms of service user participation (van Beinum, 2002). However, the current review suggests we do not know what proportion of other mental health researchers share

such negative views, or conversely views in favour of active mental health service user research participation. Research examining these views would therefore provide a significant contribution to our understanding and provide a basis to advance this agenda.

Inadequate organisational support such as funding and non-familiarity of stakeholders with joint research are cited as significant issues (Hancock, Bundy, Tamsett, & McMahon, 2012). Tokenism is commonly experienced by service users seeking to be actively involved in research (Ennis & Wykes, 2013), and the findings of the reviewed studies, albeit confined to the UK, USA and Australia, broadly suggest organisational research cultures are not assertively committed to mental health service user inclusion in research activities. Enabling policy intentions requires training and education in research skills and competencies for service users (Hancock et al., 2012) and other mental health researchers with respect to collaborative practices. (Parkes, Pyer, Wray, & Taylor, 2014) Other researchers need training in service user inclusion, (Staley et al., 2013) for instance, on the principles of 'community-based participatory research'. (Chene et al., 2005) As the findings of the Bryant et al. Study (Bryant et al., 2012) emphasise, there needs to be commitment and collaboration between researcher groups, in which the journey itself is crucial to the success of joint research. Training of other mental health researchers may therefore need to highlight principles and skills connected to relationship building and sustained engagement, as well as key assumptions underpinning traditional approaches.

The most significant research gap identified in this review is the absence of research on other mental health researcher views on co-production and user-controlled research, that is, modalities of research situated in higher areas of the INVOLVE continuum.^(INVOLVE, 2012) Studies meeting the inclusion criteria indicated other mental health researchers were not asked exclusively about user-led or controlled research. Given the increasingly recognised value and importance of enhanced power in service user research in ensuring improved standards in research and knowledge to inform user-centred health care policy, (and at the very least, to transcend the tokenism often found in consultation-only user involvement) the views of other mental health researchers should be explored in greater detail. Ideally, research would include mental health researchers that have first-hand experience of participation in user-led research as well as those who have not and therefore may not be familiar with the notion of user-controlled research.

Research directly on mental health researchers across areas of specialisation (e.g. nursing, psychiatry, psychology, occupational therapy) on the basis of qualitative in-depth interviews and broad-based surveys is needed to comprehensively examine other mental health researcher viewpoints and opinions in relation to: the significance of mental health service user participation in mental health research; views on the scope and depth of involvement in mental health research (including questions targeted on user-led research); perceived benefits and barriers; and other researchers'

own intentions to incorporate or support mental health service user researchers. Research is needed on mental health researchers' level of knowledge of current policy on inclusiveness of services users in mental health research, (National Health and Medical Research Council, 2016; National Institute for Health Research, 2017) and their views on research ethics in participatory forms of research. (Bromley et al., 2015) Studies are also required on other mental health researchers' level of awareness of the availability of research frameworks and process models that foreground mental health service user research. (Callard, Rose, & Wykes, 2012; Fothergill et al., 2012; Kara, 2012; Schneider, 2012)

Furthermore, research is required on other researchers' interest in, and perceived need for, education and training on how to effectively include mental health service users as research collaborators on projects and how to establish support structures for user-controlled research. More detailed information on these areas would greatly facilitate decision-making on embedding mental health service user research, particularly with respect to long-term planning for sustainability.

Conclusions

Throughout the selected time period, there is limited research reporting directly on other mental health researcher views and attitudes in relation to mental health service user research; especially on co-production and user-

controlled research. The little research available suggests other researchers express favourable views towards the notion of involvement of mental health service users in research, while simultaneously only engaging with this group in minimal or intermittent ways in actual research projects. Enhanced knowledge of other mental health researcher views would inform the preparedness of various research groups to embed and expand mental health service user research. More broadly, this knowledge would contribute to debates on the ethics, relevance and effectiveness of mental health service user research, and its potential to contribute to knowledge that has wide ranging benefits for research, policy and practice. Most importantly, such activity has positive implications for the well-being and human rights of people with experience of mental illness.

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