Experiences of user involvement in mental health research: exploring reflections from a service user researcher using autoethnography

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Experiences of user involvement in mental health research: exploring reflections from a service user researcher using autoethnography

Purpose: User involvement in research is entering the mainstream of traditional mental health research. In practice, there are diverse ways in which the process of involvement is experienced by mental health service user researchers. This paper aims to explore two diverse experiences of involvement by the researcher.

Approach: Autoethnography is the research methodology employed in this study; it combines a process of reflective writing and critical analysis which enables me to explore my experiences of being both a service user and academic researcher. Two accounts of my involvement in mental health research are presented: one which builds on a consultation model, and the other, based on co-production principles.

Findings: Experiences of power-sharing and collaborative decision-making, alongside disempowerment are discussed; leading to exploration of the theoretical and practical processes for promoting participation of users in research.

Research limitations: The research is limited because it is undertaken by one individual in a local setting, and is therefore is not generalisable; however it provides useful insights into the diverse processes of involvement that many service users experience.

Practical implications: Recommendations are presented to support the involvement of service users in research; with final remarks offered considering the possible future implementation of this still emerging tradition.

Originality: This paper reflects on the experiences of one service user academic involved in research and highlights diverse experiences of both empowering and disempowering involvement, providing recommendations for best practice.
Introduction

The prevalence of service user involvement in mental health research has been increasing over the last 20 years; indeed Rose (2017) notes that it has been acknowledged as entering the mainstream of traditional forms of mental health research. User involvement in research was initiated with developments in the 1990s with user focused monitoring (Rose et al, 1998), and a growing acceptance in mental health service provision in the early 2000s (Simpson and House, 2003) of the desire of service users to become involved with developing and evaluating mental health provision.

Since this early practice, user involvement in mental health research has grown, as service users contribute more widely to the design, delivery and implementation of research (Happel et al, 2018; Mjøsund et al, 2017). Even more widely, the National Institute for Health Research (NIHR) (2018), now requires the involvement of patients, carers and the public to contribute to the planning of research design and implementation proposals. These advances in policy and practice (NIHR, 2018; Rose et al, 2018) reflect a slowly changing discourse in mental health, in which there is recognition of the importance of the expertise of lived experience in influencing mental health research.

I occupy a hybrid identity as both a service user and a social work academic (author, 2016) and am committed to sharing this dual perspective in my teaching, research and practice. This expertise associated with experiential knowledge is often described as expertise-by-experience; in contrast to practice or academic based wisdom (Beresford, 2002). Recently, I have encountered two different forms of involvement as an expert-by-experience participating in mental health research. These incidents lead me to explore the diverse experiences in this article, using autoethnography to reflect on how to effectively involve
service users in research. I discuss the levels of involvement in which service users contribute to research processes and consider the implications of these elements for this autoethnographic study. Recommendations on how to implement best practice in service user involvement in mental health research are presented, derived from both my own autoethnographic reflections and the literature base that has developed my thinking.

Background

User involvement in mental health is based on the experience of the survivor movement (Rose, 2014) that acknowledges the expertise of service users in managing their own conditions and recognises their capacity to contribute to the development of research and services. This stance is eminently political and calls for a different approach to the dominant medical model, supported by the influential power of psyche and pharma (Fabris, 2016; Rose et al, 2018). Accordingly, Staley (2009, 13) defines the meaning of public involvement as ‘doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public’; a similar concept in health research that reflects the definition of user involvement in social care research. User involvement processes are encompassed in the early slogan of the disability movement ‘Nothing about me, without me’ adopted in the survivor research movement (Nelson et al, 1998). There is now an increasing evidence base for the usefulness of service user involvement in contributing to mental health research; moreover it has been shown to improve research outcomes by allowing the topic, design and processes to reflect more closely the needs and experiences of people who use mental health care (Mjøsund et al, 2017).
This new tradition in mental health research, developing in the 1990s (Rose et al, 1998), is one manifestation of a greater activist position of different communities wanting to monitor, develop and contribute to service provision and research (Ledwith, 2011). It was paralleled by the community critique of groups of people who experienced a power differential in research (Ledwith and Springett, 2015), for example, in the feminist movement (Fitch et al, 2016), and for people of colour (Hooks, 1992). Involvement of service users in mental health is positioned within this broader evidence base that acknowledges the need to involve members of different communities in research about and for them; moreover, the phrase “Talk with us, not about us” was used extensively in HIV/AIDS communities in the mid-eighties (Canavan, 2003/4), echoing the mantra of the user movement, ‘Nothing about me, without me’ (Nelson, et al, 1998).

Furthermore, the evidence shows that service users can have a huge impact in contributing to all elements of mental health research: in designing and improving interview schedules to make them more sensitive to the needs of research participants (McCauley et al, 2015); in analysing and synthesising data to reflect new insights into the authentic experiences of service users (Mjøsund et al, 2017); in delivering and evaluating educational initiatives (Terry et al, 2015); in developing new research paradigms and of analysing data (Rose, 2014). Moreover Rose et al (2018, 478) argue that user led research now occupies a ‘distinct and established form of research practice’ based on an international body of knowledge, in which service users have actively contributed to the research process. However, it remains difficult for the processes of user involvement to be consistently applied across research with best practice implemented to support involvement (Sangill et al, 2019).
Sangill et al (2019) conducted a scoping review of the literature comprising service user involvement in research and identified themes derived from their analysis of the research. The overarching theme found was that user researchers often need to negotiate precarious positions in research processes; thus recognising that often their roles and tasks are not clearly delineated and defined. The three underlying themes present in the research were:

i. Recognising the need to clarify expectations of users' involvement in the research processes: Often expectations for users' involvement in the study are not discussed and clarified; this leads to uncertainty about the levels of involvement and the roles of the user researchers.

ii. Understanding the contribution of user researchers to research processes: It is necessary to understand that users contribute to mental health research in many and varied ways, and it is important to recognise the impact of their involvement.

iii. Acknowledging the training needs of user researchers and recognising the skills they develop from participation: User researchers often receive different levels of training in order to participate effectively in research; they often come to the research with varying levels of expertise and subsequently build skills through involvement processes.

These issues are pertinent to this article and will form the basis of later discussion both in the findings and during my analysis of the autoethnographic accounts that detail my experiences of research participation.

Additionally, the central question raised in all user involvement research is what is the nature of user involvement and how does it impact on the research process? INVOLVE, the UK
body charged with responsibility for developing public and patient involvement in health and social care research (Hanley et al, 2012), has tried to quantify the nature of real contribution and proposes three levels of service user participation in research: consultation, collaboration and control. Moreover, Sweeney and Morgan (2009), whilst acknowledging these levels of participation, propose an extra level of involvement between consultation and collaboration on the INVOLVE level which they call contribution. They define it as: ‘...research where service users/survivors make a significant and meaningful contribution to research but with power and decision-making still residing with traditional researchers’. (Sweeny and Morgan, 2009: 9). However, this magnifies the beliefs that many are either service users or researchers, whilst in this article it is argued that researchers can occupy a hybrid identity as both expert researchers and people who use services. These definitions help to describe what we mean and understand by the concept of service user involvement in mental health research.

In this article, I reflect on my experiences as both an academic researcher and service user expert and explore two critical incidents of involvement that occurred in two different projects: one large scale multi-site project that committed itself to the integration of service user involvement into its processes, and one small scale project, that, through both actions and rhetoric, supported effective participation. Reflection is undeniably at the very centre of social work practice and theory-making (D’Cruz et al, 2007); thus it is important to understand the reflection in the role of generating theory and developing recommendations for practice that emanate from this article. Moreover it is intended that this discussion can contribute in a small way to evidence suggesting how users can participate more effectively in research.
Methodology

Winter et al (1999) in the field of education and social care, explored the art of reflective writing, using creative methods such as stories, patchwork texts and critical incidents to generate theory. Furthermore, D’Cruz et al (2007) explored how the concept of reflection was understood in social work, identifying that there is only a vague consensus about its meaning. They noted three elements that contribute to understanding this idea: reflection, critical reflection, and reflexivity. Firstly, they state, that reflection is associated with applying theory to a practice experience in order to achieve a more objective stance to the development of knowledge. Secondly, critical reflection is an approach to the generation of knowledge which values the practitioner’s wisdom and seeks to generate theory from practice experience. Thirdly, reflexivity involves a critical awareness of the role of the emotional and physical self in influencing knowledge creation.

The concepts of critical reflection and reflexivity are central to understanding the process of writing this paper (D’Cruz et al 2007) because the methods used to generate theory are underpinned by recognition of the value of practice wisdom and of the place of the self in this procedure; moreover engagement with creative writing is used as a medium to enable this reflection (Winter et al, 1999). Accordingly, the two accounts were chosen as they provide contrasting experiences of user involvement in mental health research. The reflections take place in two research contexts that have different settings and employ different methodologies; moreover, there are different objectives for involvement and different levels of involvement in the two projects. This diversity enables a rich discussion to take place about the nature and extent of user involvement in research; thus building on the principles of
reflection and the medium of creative writing, I use autoethnography as a method to explore user involvement in mental health research.

Autoethnography has been used widely in health and social care (Author’s own, 2017); it is a research methodology that enables people or groups of people to reflect on their situations through the process of writing and reflexivity (Fook, 2014). Thus, autoethnography provides a framework in which I recount two reflections about my experiences of user involvement in mental health research, which I then analyse in order to understand and position them in the wider political context (Adams et al, 2015). Autoethnography builds on the epistemology of critical social theory that emphasises the importance of knowledge in changing and improving situations (Denzin, 2017). Adams et al (2015) note that the autoethographic study has a dual focus: autoethnographers must consider carefully both the epistemic (claims to knowledge) and the aesthetic (practices of imaginative, creative, and artistic craft) characteristics of autoethnographic texts.

Autoethnography is political (Denzin, 2017) and strives for social justice (Adams et al, 2015) it promotes moral and ethical debate through the process of reflexivity (Denzin, 2017). It is therefore a useful method to support the processes of my reflection in this paper, indeed, as Rose (2014 p. 155) notes ‘To survive, marginalised groups need to comprehend the language of the dominant but in the process to not lose their own’. Accordingly, my accounts are written in the language of the dominant, drawing on professional reflection and theory, but through my writing, I also explore incidents of marginalisation as I consider the encounters presented in the narratives from the perspective of an expert-by-experience.
Thus, I have drawn on the work of Winter *et al* (1999) and D'Cruz *et al* (2007) in my methodological approach to autoethnography: by recognising the art of creative writing and by using practice-oriented knowledge and the personal experience of the self to develop theory. These short accounts were analysed using thematic data analysis (Braun and Clarke, 2006), and themes commensurate with the literature were identified and integrated into the article discussion. Braun and Clarke (2006: 87) highlight that thematic analysis involves a six-phase process which includes familiarisation with the data, followed by a procedure of searching for and defining themes, which are then confirmed through further iterative analysis of the data. Braun and Clarke (2006: 83) acknowledge that thematic analysis is often flexible, encompassing an approach that can be both ‘inductive’ and ‘data-driven’.

Thus, initially, themes were identified inductively and drawn out of the narratives as I read and re-read the reflections; this led to the generation of emergent themes that described the experiences expressed in the accounts. Thematic analysis can be flexible in approach (Braun and Clarke, 2006) and was adapted to support me to simultaneously both actively engage with the literature and identify important themes presented in the accounts. Following this preliminary task, an iterative process of analysis was undertaken by re-reading the moving between the narrative *narratives* accounts and identifying themes that were commensurate the with the published literature. This analytical method enabled a more critical understanding of the data to be developed. This process led me to use allowed me to connect themes from both sources a framework developed by Sangill *et al* (2019) to structure the evolving ideas and organise them into a comprehensive whole and to develop the recommendations. Thus, thematic analysis was found to be a particularly useful tool because it is flexible in approach (Braun and Clarke, 2006); moreover it was adapted to enable me to draw out emerging themes presented in the accounts and to confirm their significance by grounding them in the
literature. This procedure led to the generation of the recommendations. Furthermore, this iterative process of analysis is commensurate with built on the tradition of autoethnography which seeks to facilitate the connection of “the autobiographical and personal to the cultural, social, and political” (Ellis, 2004, xix).

**Ethical issues**

Ethical approval was not sought for the writing of this paper because the study only drew on my own personal reflections and did not incorporate the perspectives of other participants. However, there are ethical challenges that may arise when a social work academic uses such a personally revealing research methodology such as autoethnography. It could be argued that autoethnography opens up the writer’s actions and ideas to scrutiny; this could be perceived as putting the writer at risk of overstepping the boundaries that delineate personal and professional values in social work (Beckett *et al*, 2017). Accordingly, Beckett *et al* (2017) note the need to preserve the separation of personal and professional boundaries for social workers; however increasingly it is beginning to be acknowledged that emotional content suffuses social work practice, education and research (Howe, 2009), and that is important to acknowledge its influence. This suggests the potential of methodologies such as autoethnography in exploring social work theory and practice (Fook, 2014).

**Findings**

I present two experiences of involvement. The first one is an empirical research project that sits within a very inflexible set of structures and processes with historically rigid roles and relationships. The second is an event planning exercise that is inherently more flexible, collaborative and gives greater opportunity for reflection and discussion. The challenges in
the first (for both researchers and service users) are much greater than in the second. This begs the question that while there may be the same level of goodwill and commitment, are the structures and processes the primary barriers to service user inclusion? This perhaps suggests that although service user involvement in mental health is entering the mainstream (Rose, 2017), perhaps, paradoxically, in its inclusion in traditional forms of research, it is losing its innovation and potential for actively representing the user voice.

Reflection 1

The first reflection is an account of my experiences as a service user expert and researcher invited to contribute to a multi-site project developing the use of innovative psychological therapies. The narrative below was recorded in writing on 03.02.2018 shortly after the first meeting of the project. The meeting objective was to set out the forthcoming goals for the project and develop it accordingly.

It was a meeting very much outside my expertise. The meeting had many eminent and very knowledgeable people in the room. For the first time in many years, I felt nervous, anxious and out-gunned. The first part of the meeting was drawing information from a systematic review. Unfortunately I am not versed in systematic reviews – I was overwhelmed by the information and prompted to respond – but had very little to put forward in response. I muttered something which was met with respect – but clearly missed the point. The morning session lasted for 2½ hours with no break with a subject I was attempting to concentrate on, but couldn’t follow. The afternoon session another two hours. My head was hurting not only through concentrating, but through feeling disempowered and out of my depth.
For the first time in a long time, I understood how many service users feel when contributing to a group meeting. At the start there should have been instructions that if we felt we needed to, anyone could leave the room. If we wanted a drink, we could help ourselves. With plenty of breaks built in to support the lack of concentration – I am a senior lecturer but felt drained, tired and with the beginnings of a pounding headache. It is really hard as a service user to concentrate for that long. I build in breaks to all my lectures as I get tired and my concentration reduces. I encourage people to talk – and give space and time to ask questions.

In this situation I felt very small asking questions... There were too many things I didn’t know and felt too embarrassed to ask. How much is this replicated for many service users who are initiated into groups of people who already know each other, but don’t deliberately isolate the person they don’t know? I felt embarrassed, excluded from the club, with little effort made to involve me in the breaks or lunchtime when I didn’t know anybody. A long time since I have felt that. But how often is it experienced by those who are asked to share the service user perspective?

Afterwards I was told they really valued the service user input and wanted the real involvement at all levels. But in this meeting I couldn’t participate – there were too many barriers to participation; too many barriers to effective involvement. The commitment was there but it had to be operationalised. And I am not afraid to speak up, but I felt disempowered, disabled, small, and excluded.

Reflection 2
My second experience is presented in the reflection of a meeting which occurred in a
different project. It was a meeting in which I was invited to help develop a conference for
which one post graduate student and a junior fellow had secured funding. I attended as an
expert-by-experience. In this meeting, two of the conference organisers attended, together
with ten experts-by-experience from a variety of backgrounds; many of the experts-by-
experience were studying in higher education but had needed to intermit or extend their
studies due to mental health needs. The account of this meeting, which took place at a
university, was recorded in writing on 07.06.19 shortly after the meeting.

The meeting had no agenda. How do you see the conference should go? There was an
unbounded discussion as to what we wanted the conference to include. There was
recognition that mental health diagnoses also cross with other traits. The representation in
the room did not include the intersection of people from a non-White British background, it
included a lot of people with academic qualifications who had experienced difficulties whilst
studying. This lack of representation was clearly recognised. The group facilitators
committed to going out to recruit increased representation. We all acknowledged the
intersectionality of mental health; that processes of poverty, social exclusion, socio-economic
disadvantage, educational status all impacted on the processes in the room. We all had other
experiences beside mental ill health that impacted on our opinions, experiences and
commitments to change. We shared a passion: to open up the world to greater understanding
of mental ill health, that even though some people work in mental health related faculties,
their distress wasn’t managed appropriately. Their exclusion was underlined by their mental
ill health. The process was open to change, the agenda not already generated. Involvement
was located at the top end of Arnstein’s (1969) ladder of involvement. We had the power.
There were certain funding constraints but the process was based on partnership work.
The themes from the reflections

The themes developed by Sangill et al (2019) from their scoping review of the literature comprising user involvement, as described in the background, provide a framework to analyse the reflections. Hence, discussion in the next section centres on identifying the themes pertaining to: the importance of clarification of expectations in research, the contribution of user researchers to a study, and the role that involvement in research plays in capacity building for users who participate in such studies.

Clarification of expectations

Firstly, Sangill et al (2019) identify that the expectations about the role of user involvement in a project should be clearly set out and communicated. The first account shows that the academic researchers believed the meeting to be clear with theory being well-explained, whereas I felt out of my depth. The reflection reveals how the project team themselves misunderstood some of the requirements for user involvement, and therefore participation was less effective than it might have been.

The first meeting focused on the technical aspects of the research, there was no clear strategy to explain this clearly to user experts and to involve them meaningfully in decision-making. Furthermore, later in the study, as stakeholders continued to be under-involved in the processes of decision-making, this resulted in some members feeling let down by the research team as their influence in the research process was diminished; not only were expectations and roles not clearly explained, they changed throughout the duration of the project.
Unfortunately, commitments made to sharing power were overwhelmed by the need to make decisions quickly and to address real research issues in a prompt way, hence expectations were unmet.

In contrast, discussion in the second project, a much smaller scale study, was wide-ranging (as discussed later in the article); time and space were allowed to respond to stakeholders' concerns, enabling issues to be clearly addressed, valuing the views of user researchers. Expectations about the role we could play in defining and developing the conference were transparent, with a clear description of our contribution; this ensured that each member had a well-developed understanding of their role.

### Contribution to the research process

Secondly, Sangill et al (2019) note the many diverse ways in which service user experts can contribute to the research process and the different levels at which they can and do participate. The two reflections, recounted in this article, comprise contrasting experiences of participation in the research process and of levels of power to influence decision-making.

The first account takes place at the inception of this project. Communication was lacking, and as a user expert, I felt under-utilised, reflecting a sense of powerlessness and of disillusion. The barriers to participation were evidenced in the lack of breaks and of appropriate support to explain and clarify technical points, both of which led to a process of disempowerment and disadvantage.
The second account relates an experience of power sharing and collaborative decision-making. Limitations linked to funding were clearly set out and clearly defined. Changes were agreed in partnership with the conference organisers, taking direction from the advisory group. It was an experience of co-production at the top of Arnstein’s ladder of involvement (Arnstein, 1969).

Developing capacity and skills

Finally, Sangill et al (2019) consider that the goal of user research is to use collaboration to facilitate mutual learning and develop capacity and skills. The first reflection reveals the disempowerment that I felt from participation in this meeting, whilst the second shows how a much simpler and clearer process governed the meeting, allowing the expertise of the user researchers to influence decisions.

The second reflection acknowledged the diverse expertise of the user researchers, not placing their wisdom into that of the ‘user researcher’ silo, but recognising their academic and practice wisdom (Rose, 2014). Although this was a small project, which enabled greater flexibility in the research process, compared to a large multi-site research study, time was set aside to allow the group to participate effectively in this process, and acknowledge the diverse ideas and skills the members brought to the group. There was also a focus on the need for diversity within the members of the group to influence decision-making, and a recognition of the intersectionality of disadvantage in the acknowledgement that the original advisory group had no representation from people from ethnic minorities, or of a different sexual orientation, or from different socio-economic and educational backgrounds. This discussion led to a real
effort by the conference organisers to seek input from these under-represented groups, leading to a process of co-production.

**Discussion**

In this section, the themes from the autoethnographic reflections are now framed within the wider body of research that supports user involvement in mental health research, allowing personal experiences to be contextualised in the cultural, social and political environment (Ellis, 2004). Each of the three elements considered by Sangill *et al* (2019) are now discussed, which leads to the generation of suggested recommendations to support user involvement in mental health research.

Firstly expectations about the levels of participation in the research must be transparent and roles in the study must be clarified at all stages of the process for both user and academic researchers to understand their position in the project (Sangill *et al*, 2019). The two accounts evidence the need for stakeholders to share the same expectations about their participation, alongside acknowledgment of the expertise of the different members of the research team.

Moreover, in order to utilise the many opportunities to bring about service innovation through involving user researchers in mental health research, there must be a commitment to making the participation of user researchers real and meaningful (Happel *et al*, 2018; Rose *et al*, 2018). However, as previously emphasised, central to this process is ensuring that roles and expectations are clarified to ensure all members of the research team can use their experience and wisdom clearly, be valued for their expertise, and contribute appropriately.
Clear terms of reference can help to clarify expectations and highlight the scope of involvement. They can be used to hold the research team to account about the agreements made, and if necessary, can be revised and revisited during the research process to ensure transparency about the expectations of involvement. Moreover, if decisions need to be taken quickly without recourse to the whole stakeholder team, user researchers should be kept informed of study developments, by regular, clear, and simple updates detailing important milestones in the project. This is clearly linked to the need for expectations and roles to be transparent in order for user involvement to make a real and radical difference to research studies (Rose, 2014) from project inception to implementation and write up.

Secondly, service users contribute in many different ways to research and their impact can be significant (Sangill et al, 2019). The first account models a framework of consultation (Sweeney and Morgan, 2009), although initially user involvement was promoted as comprising partnership and collaborative working. The model of consultation, which was actually utilised, is defined as the sharing of power that underpins decision-making in the research process (Rose, 2009); it echoes the level of contribution suggested by Sweeney and Morgan (2009). In the level of consultation employed in the first study, service user perspectives may still influence the research design and still strongly impact on research outcomes and findings, but decisions in the process are very much based on power being retained by the research team (Minogue, 2009). Although academic researchers may want to implement high levels of user involvement, structural barriers in a research project may impede effective user participation. Moreover this dichotomy between the desire to involve users in research, and the actuality of their participation, may be partly determined by when
users become involved; if their perspective is only sought after the funding has been secured, and hence after the key decisions on the aims and milestones of the project have been made, their involvement will become tokenistic.

Accordingly, Russo and Stastny (2009) argue that when service users are less involved than they would like, and user involvement seems to be tokenistic, this undermines and reduces any potential opportunities for systems change. Moreover, it undermines the commitment to changing the discourse in mental health research (author, 2011) and makes user involvement meaningless.

Additionally, in the implementation phase of research, if decisions need to be made, then regular communication can keep the research team informed, and ensure they feel involved in the process; meetings should not be used to rubber stamp and validate decisions that have already been made. It is however sometimes necessary to make decisions quickly in research studies, but the process of user involvement is also important; and indeed, required by many research funders (NIHR, 2018). As acknowledged above, the structural constraints of empirical research studies, as in the first project, may also be a barrier to the amount of user involvement that is possible within the research, and the day-to-day decision-making processes.

In contrast, the second account related an experience of involvement that focuses on collaborative and partnership focused work. The framework of co-production and shared power underpins this experience. McGowan et al, (2009) note that the sense of power and
value felt through participation in the research process is directly related to the opportunity to
influence the research process.

However, despite apparent commitment to user involvement by funding organisations
(NIHR, 2018), its reality needs to be understood and effective processes need to be translated
into practical and systematic methods that support co-production (Lambert and Carr, 2018)
and share power with service users. This links back to a structural management of the two
research projects: the former project which requires actions to be undertaken in a systematic
and often procedural way, which may constrain user involvement; whilst the second project is
an event planning meeting which has more scope for creative service user involvement.
Moreover Lambert and Carr (2018, p. 1275) note that:

‘Transformative co-production in mental health research both demands and is
dependent on a more fundamental paradigm shift in research, knowledge, and
knowing towards valuing and legitimizing experiential and first-hand knowledge
within the full spectrum of mental health research’.

This reinforces the need to develop and consider effective user involvement at the planning
stages of the research, not after the research milestones have already been set.

Finally, Sangill et al (2019) consider that the goal of user research is to use collaboration to
facilitate mutual learning and develop capacity and skills. The experiences of contributing to
a research project as an advisor, or participating in service change, can be empowering and
contribute towards recovery, building skills for future personal and professional development
(Rose, 2009). As acknowledged throughout this article, user researchers have diverse and
differential levels of expertise which can enable them to contribute effectively to the research process, beyond their knowledge and expertise of using services (author, 2016); this expertise needs to be recognised at all stages in the study.

Moreover, it is important to offer support and information when this is required, but user expertise should not be siloed merely into the compartment of 'service user experience' and no more. In much research, there is the implicit assumption that ‘service users’ come into the research field from the outside and therefore need to be supported and developed; however this presumption doesn’t allow for the possibility of researchers either having a history of service use, becoming service users while researchers, or recognising their own experiential overlap with the service use community (Rose, 2009; 2014).

Much of the rhetoric around community engagement in research assumes an outsider status for ‘community’ members and fails to recognise the co-positionality of many people in research and community. Countering this is the strength of writers and researchers with a hybrid identity of mental health service use and research expertise (Beresford, 2002; 2019; authors own, 2021).

In summary, the importance of implementing transformational co-production in research design (Lambert and Carr, 2018) is underlined and of acknowledging user researchers’ commitment and passion to service change (Rose, 2009); moreover this requires academic researchers to respect users' investment in the topic. Such experiences of transformative co-production can lead to transformational learning, as suggested by Freire’s (1970; 1998) related notion of conscientization – a process in which learning can produce knowledge and
liberation. Freire (1970), writing in Latin America at the time of a dictatorial government, argued that transformative experiences of learning could build the capacity of uneducated community members to enable them to challenge their disempowered place in society. Moreover, in relating the ideas of liberating educational processes to the field of service user involvement in mental health, such an experience is often replicated for many service users as they become involved in mental health research and service change (author, 2016; Rose, 2014). Thus, this highlights the relevance of the notion of conscientization to user involvement processes in mental health research.

Moreover, conscientization connects to the methodology chosen in this study, as I, myself, have gone through a process of transformative learning through my involvement in research over the last ten years (author, 2011; 2016). The short autoethnographic reflection in this article uses autobiography supported by critical analysis to illuminate my relationship with research and mental health service change (Adams et al, 2015). This practice is associated with the experience of many service users involved in mental health research as they develop new knowledge, skills, and capabilities; similarly it allows user researchers to challenge the current discourse of medical model-dominated mental health research (Rose, 2014). It is therefore essential to value the user involvement process as well as the research outcomes - indeed, the way users are involved is as important as producing and completing the results of the study.

**Recommendations**

In order to make changes to the discourse of user involvement in mental health research there needs to consistent and transparent cooperation between all stakeholders (Rose, 2014; Sangill et al, 2019). The rhetorical commitment to user involvement (NIHR, 2018) must be
translated into reality; accordingly, I suggest some ways in which user involvement can be better supported, derived from the ideas presented in this article, and drawn from the literature.

1. It is important to be realistic and transparent about the nature of involvement by setting out clearly in advance the expectations of the users involved and the expectations of the academic research team. Power is a key concept. The question needs to be posed of who holds the power and is it shared? If co-production is intended, then fulfil that promise; if involvement is at the level of consultation, this expectation must be clearly set out.

2. It is of fundamental importance to co-produce research studies with user researchers right from project inception to development and implementation; only then can service users be truly involved in setting the milestones and aims of the study.

3. It is important to be realistic about the extent and scope of involvement, where this needs to be adjusted, it should be discussed transparently. Despite this caveat, the research process, which promotes involvement, is as important as the outcomes of the study. In order to adhere to agreements, about the nature of involvement, terms of reference can be used to clarify expectations in advance; they can be revisited and revised throughout the research. This highlights that meetings should not be used to merely validate decisions which have already been made, but need realistically to involve user researchers in decision-making, in an appropriate and accessible way.

4. Commitment to user involvement needs to be translated into practical actions such as recognising the expertise of user researchers. It is essential not to compartmentalise user experience into a particular silo. User researchers may have skills and expertise other than those they possess by virtue of being a user / former user of services
Conclusion

There is a commitment by policy makers to user involvement in mental health research, and a claim that this research format has entered the mainstream of mental health research (Rose, 2017). However, I have argued that involvement practice is under-developed and inconsistent (Rose, 2014; Rose et al, 2018). I have explored my own experiences of involvement and addressed the respective experiences of both disempowerment and partnership working experienced through both projects. I have suggested how user involvement can support and facilitate the sharing of power and control in the research process.

Although small changes are important, it is essential to bring about systematic change and commitment to the user involvement field. Moreover, in the political arena, despite espoused commitment to user involvement in research (NIHR, 2018) austerity is causing many user-controlled initiatives to collapse (Beresford, 2019). As funding is reduced, this has the potential to lead to the proud tradition of user involvement, strongly advocated in this country (Rose, 2018), becoming increasingly tokenistic, offering rubberstamping of traditional and medical model research programmes and no longer developing transformative co-production of research (Lambert and Carr, 2018). Moreover, although traction has been made in bringing user involvement into the mainstream of mental health research (Rose, 2017), paradoxically, in remaining in the main stream, it may, lose its unique political and innovative quality and become subsumed into traditional forms of research.

References


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