



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

Journal:	<i>Mental Health Review Journal</i>
Manuscript ID	MHRJ-11-2019-0040.R2
Manuscript Type:	Discussion Piece Review
Keywords:	mental health, service user involvement, expertise-by-experience, autoethnography

SCHOLARONE™
Manuscripts

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

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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).

1
2
3 This new tradition in mental health research, developing in the 1990s (Rose *et al*, 1998), is
4 one manifestation of a greater activist position of different communities wanting to monitor,
5 develop and contribute to service provision and research (Ledwith, 2011). It was paralleled
6 by the community critique of groups of people who experienced a power differential in
7 research (Ledwith and Springett, 2015), for example, in the feminist movement (Fitch *et al*,
8 2016), and for people of colour (Hooks, 1992). Involvement of service users in mental
9 health is positioned within this broader evidence base that acknowledges the need to involve
10 members of different communities in research about and for them; moreover, the phrase
11 “Talk with us, not about us” was used extensively in HIV/AIDS communities in the mid-
12 eighties (Canavan, 2003/4), echoing the mantra of the user movement, ‘Nothing about me,
13 without me’ (Nelson, *et al*, 1998).
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31

32 Furthermore, the evidence shows that service users can have a huge impact in contributing to
33 all elements of mental health research: in designing and improving interview schedules to
34 make them more sensitive to the needs of research participants (McCauley *et al*, 2015); in
35 analysing and synthesising data to reflect new insights into the authentic experiences of
36 service users (Mjøsund *et al*, 2017); in delivering and evaluating educational initiatives
37 (Terry *et al*, 2015); in developing new research paradigms and of analysing data (Rose,
38 2014). Moreover Rose *et al* (2018, 478) argue that user led research now occupies a ‘distinct
39 and established form of research practice’ based on an international body of knowledge, in
40 which service users have actively contributed to the research process. However, it remains
41 difficult for the processes of user involvement to be consistently applied across research with
42 best practice implemented to support involvement (Sangill *et al*, 2019).
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 reflection and the medium of creative writing, I use autoethnography as a method to explore
4
5 user involvement in mental health research.
6
7
8
9

10
11 Autoethnography has been used widely in health and social care (Author's own, 2017); it is a
12
13 research methodology that enables people or groups of people to reflect on their situations
14
15 through the process of writing and reflexivity (Fook, 2014). Thus, autoethnography provides
16
17 a framework in which I recount two reflections about my experiences of user involvement in
18
19 mental health research, which I then analyse in order to understand and position them in the
20
21 wider political context (Adams *et al*, 2015). Autoethnography builds on the epistemology of
22
23 critical social theory that emphasises the importance of knowledge in changing and
24
25 improving situations (Denzin, 2017). Adams *et al* (2015) note that the autoethnographic study
26
27 has a dual focus: autoethnographers must consider carefully both the *epistemic* (claims to
28
29 knowledge) and the *aesthetic* (practices of imaginative, creative, and artistic craft)
30
31 characteristics of autoethnographic texts.
32
33
34
35
36
37
38
39

40 Autoethnography is political (Denzin, 2017) and strives for social justice (Adams *et al*, 2015)
41
42 it promotes moral and ethical debate through the process of reflexivity (Denzin, 2017). It is
43
44 therefore a useful method to support the processes of my reflection in this paper, indeed, as
45
46 Rose (2014 p. 155) notes 'To survive, marginalised groups need to comprehend the language
47
48 of the dominant but in the process to not lose their own'. Accordingly, my accounts are
49
50 written in the language of the dominant, drawing on professional reflection and theory, but
51
52 through my writing, I also explore incidents of marginalisation as I consider the encounters
53
54 presented in the narratives from the perspective of an expert-by-experience.
55
56
57
58
59
60

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, A~~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 2 ½ 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.

1
2
3 *For the first time in a long time, I understood how many service users feel when contributing*
4 *to a group meeting. At the start there should have been instructions that if we felt we needed*
5 *to, anyone could leave the room. If we wanted a drink, we could help ourselves. With plenty*
6 *of breaks built in to support the lack of concentration – I am a senior lecturer but felt*
7 *drained, tired and with the beginnings of a pounding headache. It is really hard as a service*
8 *user to concentrate for that long. I build in breaks to all my lectures as I get tired and my*
9 *concentration reduces. I encourage people to talk – and give space and time to ask*
10 *questions.*
11
12
13
14
15
16
17
18
19
20
21
22
23
24

25 *In this situation I felt very small asking questions... There were too many things I didn't*
26 *know and felt too embarrassed to ask. How much is this replicated for many service users*
27 *who are initiated into groups of people who already know each other, but don't deliberately*
28 *isolate the person they don't know? I felt embarrassed, excluded from the club, with little*
29 *effort made to involve me in the breaks or lunchtime when I didn't know anybody. A long*
30 *time since I have felt that. But how often is it experienced by those who are asked to share*
31 *the service user perspective?*
32
33
34
35
36
37
38
39
40
41
42
43
44

45 *Afterwards I was told they really valued the service user input and wanted the real*
46 *involvement at all levels. But in this meeting I couldn't participate – there were too many*
47 *barriers to participation; too many barriers to effective involvement. The commitment was*
48 *there but it had to be operationalised. And I am not afraid to speak up, but I felt*
49 *disempowered, disabled, small, and excluded.*
50
51
52
53
54
55
56
57
58
59
60

Reflection 2

1
2
3 My second experience is presented in the reflection of a meeting which occurred in a
4
5 different project. It was a meeting in which I was invited to help develop a conference for
6
7 which one post graduate student and a junior fellow had secured funding. I attended as an
8
9 expert-by-experience. In this meeting, two of the conference organisers attended, together
10
11 with ten experts-by-experience from a variety of backgrounds; many of the experts-by-
12
13 experience were studying in higher education but had needed to intermit or extend their
14
15 studies due to mental health needs. The account of this meeting, which took place at a
16
17 university, was recorded in writing on 07.06.19 shortly after the meeting.
18
19
20
21
22
23
24

25 *The meeting had no agenda. How do you see the conference should go? There was an*
26
27 *unbounded discussion as to what we wanted the conference to include. There was*
28
29 *recognition that mental health diagnoses also cross with other traits. The representation in*
30
31 *the room did not include the intersection of people from a non-White British background, it*
32
33 *included a lot of people with academic qualifications who had experienced difficulties whilst*
34
35 *studying. This lack of representation was clearly recognised. The group facilitators*
36
37 *committed to going out to recruit increased representation. We all acknowledged the*
38
39 *intersectionality of mental health; that processes of poverty, social exclusion, socio-economic*
40
41 *disadvantage, educational status all impacted on the processes in the room. We all had other*
42
43 *experiences beside mental ill health that impacted on our opinions, experiences and*
44
45 *commitments to change. We shared a passion: to open up the world to greater understanding*
46
47 *of mental ill health, that even though some people work in mental health related faculties,*
48
49 *their distress wasn't managed appropriately. Their exclusion was underlined by their mental*
50
51 *ill health. The process was open to change, the agenda not already generated. Involvement*
52
53 *was located at the top end of Arnstein's (1969) ladder of involvement. We had the power.*
54
55 *There were certain funding constraints but the process was based on partnership work.*
56
57
58
59
60

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.

1
2
3 The second account relates an experience of power sharing and collaborative decision-
4 making. Limitations linked to funding were clearly set out and clearly defined. Changes were
5 agreed in partnership with the conference organisers, taking direction from the advisory
6 group. It was an experience of co-production at the top of Arnstein's ladder of involvement
7 (Arnstein, 1969).
8
9
10
11
12
13
14
15
16
17

18 *Developing capacity and skills*

19
20 Finally, Sangill *et al* (2019) consider that the goal of user research is to use collaboration to
21 facilitate mutual learning and develop capacity and skills. The first reflection reveals the
22 disempowerment that I felt from participation in this meeting, whilst the second shows how a
23 much simpler and clearer process governed the meeting, allowing the expertise of the user
24 researchers to influence decisions.
25
26
27
28
29
30
31
32
33
34
35

36 The second reflection acknowledged the diverse expertise of the user researchers, not placing
37 their wisdom into that of the 'user researcher' silo, but recognising their academic and practice
38 wisdom (Rose, 2014). Although this was a small project, which enabled greater flexibility in
39 the research process, compared to a large multi-site research study, time was set aside to
40 allow the group to participate effectively in this process, and acknowledge the diverse ideas
41 and skills the members brought to the group. There was also a focus on the need for diversity
42 within the members of the group to influence decision-making, and a recognition of the
43 intersectionality of disadvantage in the acknowledgement that the original advisory group had
44 no representation from people from ethnic minorities, or of a different sexual orientation, or
45 from different socio-economic and educational backgrounds. This discussion led to a real
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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.

1
2
3
4
5
6 Clear terms of reference can help to clarify expectations and highlight the scope of
7
8 involvement. They can be used to hold the research team to account about the agreements
9
10 made, and if necessary, can be revised and revisited during the research process to ensure
11
12 transparency about the expectations of involvement. Moreover, if decisions need to be taken
13
14 quickly without recourse to the whole stakeholder team, user researchers should be kept
15
16 informed of study developments, by regular, clear, and simple updates detailing important
17
18 milestones in the project. This is clearly linked to the need for expectations and roles to be
19
20 transparent in order for user involvement to make a real and radical difference to research
21
22 studies (Rose, 2014) from project inception to implementation and write up.
23
24
25
26
27
28
29

30
31 Secondly, service users contribute in many different ways to research and their impact can be
32
33 significant (Sangill *et al*, 2019). The first account models a framework of consultation
34
35 (Sweeney and Morgan, 2009), although initially user involvement was promoted as
36
37 comprising partnership and collaborative working. The model of consultation, which was
38
39 actually utilised, is defined as the sharing of power that underpins decision-making in the
40
41 research process (Rose, 2009); it echoes the level of contribution suggested by Sweeney and
42
43 Morgan (2009). In the level of consultation employed in the first study, service user
44
45 perspectives may still influence the research design and still strongly impact on research
46
47 outcomes and findings, but decisions in the process are very much based on power being
48
49 retained by the research team (Minogue, 2009). Although academic researchers may want to
50
51 implement high levels of user involvement, structural barriers in a research project may
52
53 impede effective user participation. Moreover this dichotomy between the *desire* to involve
54
55 users in research, and the *actuality* of their participation, may be partly determined by *when*
56
57
58
59
60

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

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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, 20121).

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 be 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

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Author 2011

Author 2016

Adams, T., Holman Jones, S., and Ellis, C. (2015), *Autoethnography: Understanding Qualitative Research*. Oxford University Press, New York.

Arnstein, S (1969) “A Ladder of Citizen Participation,” *Journal of the American Planning Association*, 35 (4): 216-224

Banfield, M., Randall, R., O’Brien, M., Hope, S., Gulliver, A., Forbes, O., Morse, A., and Griffiths. K., (2018), “Lived Experience Researchers Partnering with Consumers and Carers to Improve Mental Health Research: Reflections from an Australian Initiative”. *International Journal of Mental Health Nursing*, 27: 1219–1229. doi: 10.1111/inm.12482

Beckett, C., Maynard, A., and Jordan, P. (2017), *Values and Ethics in Social Work*. Sage, London.

Beresford, P. (2002), “Thinking about Mental Health: Towards a Social Model”. *Journal of Mental Health* 11 (6): 581 – 584.

Beresford, P. (2019), Austerity is Denying Patients and Care Service Users a Voice.
Available online at <https://www.theguardian.com/society/2019/jan/14/austerity-denying-patients-care-service-users-voice> Accessed 18.06.19

Braun, V., and Clarke.V, (2006), "Using Thematic Analysis in Psychology". *Qualitative Research in Psychology* 3: 77–101.

Canavan, P., (2003/4), "Because it's personal: what good advocacy can achieve, and how" [online]. *Australian Health Consumer*, 1, (No. 2003-2004 Winter): 17-20. Availability: <https://search.informit.com.au/documentSummary;dn=489718418412167;res=IELHEA> ISSN: 1441-5151

D'Cruz, H., Gillingham, P., and Melendez, S., (2007). Reflexivity, its Meanings and Relevance for Social Work: A Critical Review of the Literature. *The British Journal of Social Work*, 37 (1): 73 - 90 <https://doi.org/10.1093/bjsw/bcl001>

Denzin, N. (2017), *Interpretive Autoethnography*. Sage, Thousand Oaks.

Ellis, C. (2004), *The Ethnographic I: A Methodological Novel about Autoethnography*. AltaMira press, Walnut Creek.

Fabris. E. (2016), "Community Treatment Orders: Once a Rosy Deinstitutional Notion", in *Searching for a rose garden: Challenging psychiatry, fostering mad studies*, Russo J and Sweeney,A (Eds) , PCCS, Monmouth, pp. 97-104.

Fitch, K., James, M., Motion, J. (2016), 'Talking back: Reflecting on feminism, public relations and research'. *Public Relations Review*, 42 (2): .279-287

Fook, J. (2014). "Learning From and Researching (My Own) Experience: A Critical Reflection on the Experience of Social Difference", in *Narrating Social Work through Autoethnography*, Witkin, S. (Ed). Columbia University Press, New York, pp 120-140.

Freire, P. (1998), "The Adult Literacy Process as Cultural Action for Freedom". *Harvard Educational Review* 68 (4): 480 – 498

Freire, P. (1970), *Pedagogy of the oppressed*. Seabury Press, New York.

Hanley, B., Bradburn, J., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S. Thomas, S., and Wallcraft, J. (2012), *Involving the Public in NHS, Public Health, and Social Care Research: Briefing Notes for Researchers*. INVOLVE Support Unit, London.

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Platania-Phung, C., and Scholz, B. (2018), "How Did I Not See That? Perspectives of Nonconsumer Mental Health Researchers on the Benefits of Collaborative Research with Consumers". *International Journal of Mental Health Nursing*, 27: 1230–1239. doi: 10.1111/inm.12453

Hooks B. (1992), *Black Looks: Race and Representation*. Turnaround, New York.

1
2
3 Howe, D. (2009), *A Brief Introduction to Social Work Theory*, .Palgrave, Basingstoke.
4
5
6
7

8 Lambert, N. and Carr. S., (2018), “‘Outside the Original Remit’: Co-production in UK
9 Mental Health Research, Lessons from the Field”. *International Journal of Mental Health*
10 *Nursing*. 27: 1273–1281. doi: 10.1111/inm.12499
11
12
13
14

15
16
17 Ledwith, M. (2011), *Community Development: A Critical Approach*. Policy Press, Bristol.
18
19
20
21

22 Ledwith, M.and Springett, J. (2015), *Participatory Practice: Community-based Action for*
23 *Transformative Change*. Policy Press, Bristol.
24
25
26
27

28
29 McCauley, C, McKenn, H., Keeney, S., and McLaughlin, D. (2017), “Service User
30 Engagement: A Co-created Interview Schedule Exploring Mental Health Recovery in Young
31 Adults”. *Journal of Advanced Nursing* 17 (73): 2361–2372. DOI: 10.1111/jan.13314
32
33
34
35
36

37
38 McGowan P., Mac Gabhann, L., Stevenson, C, , and Walsh, J.. (2009), “Power”, in
39 *Handbook of Service User Involvement in Mental Health Research*, Wallcraft, J., Schrank,
40 B, and Amering, M., (Eds). Wiley and Blackwell. Chichester, pp. 199 – 211
41
42
43
44
45
46

47
48 Minogue, V (2009), “Consultation”. In *Handbook of Service User Involvement in Mental*
49 *Health Research*, in *Handbook of Service User Involvement in Mental Health Research*,
50 Wallcraft, J., Schrank, B, and Amering, M., (Eds). Wiley and Blackwell. Chichester, pp.,
51 153 – 167.
52
53
54
55
56
57
58
59
60

Mjøsund, N, Eriksson, M, Espnes, G, Haaland-Øverby, M, Jensen, S, Norheim, I, Kjus, S, Portaasen I and Vinje, H. (2017), “Service User Involvement Enhanced the Research Quality in a Study Using Interpretative Phenomenological Analysis – The Power of Multiple Perspectives”. *Journal of Advanced Nursing* 73(1): 265-278. doi: 10.1111/jan.13093

National Institute for Health Research (NIHR). (2018), Public Involvement Standards Accessed https://www.nihr.ac.uk/news-and-events/documents/Public_Involvement_Standards_March%202018_WEB.pdf 25.06.2019

Nelson, G., Ochocka, J, Griffin, K., and Lord, J. (1998), “‘Nothing About Me, Without Me’ Participative Action Research with Self – Help / Mutual Aid for Psychiatric Consumer / Survivors”. *American Journal of Psychology* 26 (6): 881 – 912.

Research Councils UK. (2017), *Widening Cross-Disciplinary Research for Mental Health August 2017*. London: RCUK.

Rose, D. (2009), “Collaboration”. in *Handbook of Service User Involvement in Mental Health Research*, Wallcraft, J., Schrank, B, and Amering, M., (Eds). Wiley and Blackwell. Chichester, pp. 169 – 179.

Rose, D. (2014), “Patient and Public Involvement in Health Research: Ethical Imperative and/or Radical Challenge?” *Journal of Health Psychology* 19(1): 149–158.

DOI: 10.1177/1359105313500249

Rose, D. (2017), "Service User/Survivor-led Research in Mental Health: Epistemological Possibilities". *Disability & Society* 32 (6): 773-789, DOI:10.1080/09687599.2017.1320270

Rose, D, Carr, S., and Beresford, P. (2018), "'Widening Cross-Disciplinary Research for Mental Health': What is Missing from the Research Councils UK Mental Health Agenda?" *Disability & Society* 33 (3) 476-48. DOI: 10.1080/09687599.2018.1423907

Rose D, Ford, R., Lindley, P., Gawith, L., and the KCW Mental health monitoring users' group. (1998), *In Our Experience: User-focused Monitoring of Mental Health Services in Kensington and Chelsea and Westminster Health Authority* The Sainsbury Centre for Mental Health, London.

Russo, J and Stastny, P. (2009), "Beyond Involvement: Looking for a Common Perspective on Roles in Research" in *Handbook of Service User Involvement in Mental Health Research*, Wallcraft, J., Schrank, B, and Amering, M., (Eds). Wiley and Blackwell. Chichester, pp. 61 – 72.

Sangill, C., Buus, N., Hybholt, L., and Berring, L. (2019), "Service User's Actual Involvement in Mental Health Research Practices: A Scoping Review". *International Journal of Mental Health Nursing*.28 (4): 798 - 815 <https://doi.org/10.1111/inm.12594>

Simpson, E., and House, A. (2003), "User and Carer Involvement in Mental Health Services: From Rhetoric to Science. *British Journal of Psychiatry*, 183: 89 - 91

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Staley, K. (2009), *Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research [pdf]*. INVOLVE, Eastleigh. Available through: www.invo.org [Accessed 06.2012].

Sweeney, A., and Morgan, L. (2009), “The Levels and Stages of Service User / Survivor Involvement in Research” in *Handbook of Service User Involvement in Mental Health Research*, Wallcraft, J., Schrank, B, and Amering, M., (Eds). Wiley and Blackwell. Chichester, pp. 25 – 35.

Terry, J., Raithby, M., Cutter, J., and Murphy, F. (2015), “A Menu for Learning: A World Cafe’ Approach for User Involvement and Inter-professional Learning on Mental Health. *Social Work Education* 34 (4): 437–458. <http://dx.doi.org/10.1080/02615479.2015.1031651>

Winter, R., Buck, A., and Sobiechowska, P. (1999) *Professional Experience and The Investigative Imagination: The Art of Reflective Writing*. Routledge: London and New York.