

Service user involvement in mental health research: a user's perspective

Michel Syrett

SUMMARY

This article focuses on service user involvement in supporting and undertaking mental health research. It is written from the author's perspective as a service user with bipolar disorder who has built on previous experience as an academic researcher in business and management studies by active involvement in a number of mental health research projects in a service user capacity. The article highlights contrasting approaches taken by different projects in how they involve service users and provides learning points based on the author's and other service users' experiences.

DECLARATION OF INTEREST

M.S. is the Editor of *Pendulum*, an Honorary Fellow at The Spectrum Centre for Mental Health Research at Lancaster University and partner at The Cairn for Mental Health. He is a fully paid collaborator of the steering group for improving satisfaction with medicines for bipolar disorder. He has a diagnosis of bipolar disorder.

'Service user research in mental health is now 13 years old: there have been massive achievements in voluntary organisations, by freelance consultants and more recently in academia. It has not always been easy, but I think there are enough of us now that we form a critical mass and can no longer be ignored.' (Dr Diana Rose, Institute of Psychiatry and Co-director of the Service User Research Enterprise; Dolman 2009)

An article published in this journal 6 years ago (Tait 2005) argued that service user involvement in mental health was still a minority activity, acknowledged as a 'good thing' by many, but relatively rarely practised. Since then, a plethora of mental health initiatives has more than confirmed the benefits of service user involvement in shaping both the perspective and practice of mental healthcare.

This is certainly true of mental health research, where service users have been particularly active. The Sainsbury Centre for Mental Health (2008) carried out a review to see how models of service user involvement in health research could be

applied to research on mental healthcare in prisons. It found established examples of service user involvement in prisoner councils and in prison health service development such as self-managed care and expert patient programmes. There were also direct parallels between prison mental healthcare research and service user involvement research that takes place in secure hospitals.

The benefits were threefold. First, service user involvement benefited the research. It gave service providers the opportunity to hear the direct experiences of people using their services:

'It provides services and government with insights into real lives in order to help them develop policies. Most policies ... are made up without speaking to people with life experience; often they have no involvement at all.' (Criminal justice charity; Sainsbury Centre for Mental Health 2008)

In the projects examined by the Sainsbury report, service users provided a different perspective to that of clinicians or non-service-user researchers. They were often in a better position to identify the key priorities for the research and to recruit other service users to participate in the study.

Their experience was critical in developing more relevant research questionnaires and tools and collaboration between service users and professionals in the analysis of the findings also often led to more meaningful outcomes.

Second, service user involvement benefited the service users. Participation in research provided people with an opportunity to have their voices heard and the prospect of learning new skills. These opportunities were a unique experience for prisoners who may not have been consulted in this way before.

Third, service user involvement improved communication between services and prisoners.

'Service developers get a greater level of key issues but also where changes cannot be made immediately it provides an opportunity for communication with service users which I think encourages respect. So even if outcomes are low, lines of communication are opened and conflicts can be brought out in the open.' (Academic; Sainsbury Centre for Mental Health 2008)

Michel Syrett is Editor of *Pendulum*, the journal of MDF The BiPolar Organisation. He is an Honorary Fellow of The Spectrum Centre for Mental Health Research at Lancaster University and a Visiting Fellow at the Roffey Park Institute, Horsham. He is also Director of The Cairn of Mental Health, a training consultancy that provides briefings to mental healthcare professionals and support workers based on service-user accounts. He has bipolar disorder and is carer to his wife, who also has bipolar disorder.
Correspondence Michel Syrett, The Cairn of Mental Health, Brincliffe, West Duhill Drive, Helensburgh G84 9AW, UK. Email: michelsyrett@aol.com

Mental health research: a personal perspective

My own experience of research projects, as an observer or an active participant, confirms existing research that service user involvement occurs along a continuum spanning three levels.

- 1 Consultation: where service users are consulted about a piece of research with no sharing of power. Service users in these circumstances may review or give opinion on a research proposal, research topic, methodology or published paper. The views of service users may influence the researcher or funder but do not have to be adopted (Williamson 2001).
- 2 Collaboration: which involves an active ongoing partnership with service users in the research, with shared decision-making and service users taking part in any or all stages (Hanley 2004).
- 3 Service user controlled research: where service users control all stages of the research process, albeit with some involvement and support by 'professional' researchers (Hanley 2004).

The following three projects offer examples of involvement at these levels.

Research champions at the Bipolar Disorders Research Network (BDRN)

I was not an active participant of this initiative but as Editor of *Pendulum*, the quarterly journal of MDF The BiPolar Organisation, which champions service user involvement in mental health research, I have had the opportunity to interview and publish accounts with many service users who took part in the initiative.

The Bipolar Disorder Research Network (BDRN; <http://bdrn.org>) is a group of researchers, clinicians and research participants in the UK undertaking a major study aimed at investigating the underlying causes of bipolar disorder. The BDRN is led by Professor Nick Craddock's Mood Disorders Research Team based jointly at Cardiff University and the University of Birmingham.

The BDRN study is funded by two of the world's leading medical research charities, the Wellcome Trust and the Stanley Medical Research Institute. Working with collaborators in the UK, continental Europe and the USA, it is by far the largest study of bipolar disorder in the world.

To support their research, the team is aiming to find a further 4000 people with bipolar disorder from across the UK to help with the research.

'Because everyone's personal experience of illness is different, it is important for us to see many more people in order that we can get the best possible understanding of how illness affects the broadest cross-section of those experiencing bipolar disorder.

This help from those with direct knowledge of the illness is the crucial foundation on which scientific advances are being made.' (Forty 2009)

To help recruit volunteers for the study and to actively inform the thinking of the research team, BDRN have developed the role of 'research champion' from members of MDF The BiPolar Organisation who are keen to spread the word.

'We very much appreciate the help of these "research champions" in helping us to make as many people as possible aware of our research study. We feel that everyone with bipolar disorder should have the opportunity to participate in our research if they would like to. We very much appreciate the help of our research champions in helping us to reach as many individuals with bipolar disorder as possible.' (Forty 2009)

To support the work undertaken by research champions, BDRN holds regular training/research days at the team's offices at the University of Cardiff. The aim of these events is to enable research champions to be as informed about the research as possible and for researchers to gain insights into any important issues that the research champions feel BDRN should be aware of.

The initiative is therefore part-consultation, part-collaboration. Research champions actively promote the research undertaken by the research team and recruit new participants. But they also inform the thinking of the team, adding their perspective of what issues and new ground the research undertaken by BDRN should uncover.

According to one research champion, the advantages of this approach include the following (Dolman 2009).

- Service users can offer different perspectives, helping to make sure research projects are asking the questions important to them and therefore to the healthcare services generally.
- This in turn can help to ensure that money and resources are not wasted on research that has little or no relevance.
- If service users are thoroughly engaged by the research process and feel their contribution has been worthwhile, this not only enhances their own self-esteem but may also help with the recruitment of their peers, including those who are often marginalised.
- From an individual's point of view, to have a real influence on research which could be of tremendous value to future generations is very empowering and rewarding.

Improving Satisfaction about Medicines Prescribed for Bipolar Disorder

My active participation in this project neatly shows service user involvement at the collaboration level.

Improving Satisfaction about Medicines Prescribed for Bipolar Disorder is (at the time of writing) an ongoing study investigating how to identify service users' needs regarding information about medicine and how to develop interventions by healthcare practitioners to help meet these needs. The study was prompted by a survey conducted by the School of Pharmacy at the University of London and MDF The BiPolar Organisation earlier this decade, which uncovered widespread dissatisfaction with medicine information available to people with bipolar disorder. The Improving Satisfaction study will examine both the prejudices and the legitimate concerns that service users have about psychiatric medicine, the way service users source and interpret the information about medication that informs their choices, the opportunities and pitfalls of using the internet and how healthcare practitioners can best advise and reassure service users about the medication choices available to them.

The Steering Group is led by Rob Horne, Professor of Behavioural Medicine, Head of the Department of Practice and Policy, and Director of the Centre for Behavioural Medicine at the University of London. Professor Horne is an expert on behavioural medicine, patient beliefs about illness and treatment, adherence to medication, self-management of illness, health psychology, communication in healthcare and development of theory-based interventions to effect behaviour change in chronic illness.

In my capacity as Editor of *Pendulum*, I was recruited to the Steering Group from the outset. I am a fully paid collaborator and have played an active role in all meetings of the Group to date in shaping not only the aims of the project but its methodology as well.

One example of where my input proved critical was in helping the Steering Group draw up the protocol for the study. The initial protocol proposed that feedback from participants be captured through a series of discussion groups. I suggested that, in the light of the fact that people with bipolar disorder vary from taking a dominant role in discussions (during episodes of mania) to passive or apathetic participation (during episodes of depression), it would be a more effective way of capturing all feedback to use structured one-to-one interviews with participants. This suggestion was taken up and the protocol changed accordingly.

My time is paid for as any independent consultant's might be. I feel a valued member of the group and have never felt patronised or sidelined in the shared decision-making process adapted by the Steering Group.

The Spectrum Centre for Mental Health Research

My role as both an observer and active participant in the work of this centre has been in relation to research projects that have spanned the collaboration/service user controlled end of the service user involvement continuum.

The Centre employs both a service-user researcher with a history of bipolar disorder and a non-service-user researcher. They are involved in projects where they act both as collaborators and/or exert full control.

The service-user researcher is an integral member of the team conducting the PARADES (Psychoeducation, Anxiety, Relapse, Advance Directives, Evaluation and Suicidality) programme and specifically studies bipolar disorder in each of these areas.

PARADES is a 5-year programme funded by a grant from the National Institute for Health Research (NIHR) and it has five streams of research. The programme is being conducted with colleagues from the Universities of Manchester and Nottingham. It is headed up by a multidisciplinary grant-holder team from psychology, psychiatry, service users, clinical psychology, biostatistics, health economics and law. As the non-service-user researcher comments:

'It is a great help to have service users as part of the research team and especially those with bipolar disorder as it ensures the service user voice gets heard.' (Mayes 2009)

The service-user researcher has just completed a study of her own making – Positives in Bipolar Disorder – in which participants with bipolar disorder were asked to explore any positives they associated with their condition. The study is now being analysed before submission for publication in a peer-reviewed journal. She comments,

'During my research posts I sought advice as to whether to disclose my "service user" status in my application to the doctorate programme. Encouragingly, several high-profile researchers and professors said it would improve my application. One even told me it made me "untouchable"!' (Taylor 2009)

My own involvement with The Spectrum Centre for Mental Health Research as an Honorary Fellow of Lancaster University, has been to initiate a study of corporate mental health policies, which I will supervise in collaboration with Professor Cary Cooper, Professor of Organizational Psychology and Health at Lancaster University.

I proposed the study based on my previous work as a researcher in human resources management. I wrote the business plan and if we win funding, I will conduct both the desk and field research.

MCQ answers

1 d 2 b 3 c 4 a 5 b

How institutions can demonstrate a serious commitment to service user involvement

My experience of involvement in mental health research has been largely positive, principally because the institutions that I observed or collaborated with avoided the tokenism that often accompanies the involvement of service users in this field.

Projects that fall into the consultation part of the continuum where the views of service users may influence the researcher or funder but do not have to be adopted, have often been described as ‘lip-service involvement’, as researchers maintain ultimate control of the project (Trivedi 2002). But even in the case of collaboration involving active and ongoing partnership with service users, the nature and amount of this collaboration can differ widely between projects (Hanley 2004).

The initiatives I observed or participated in demonstrated their commitment to service user involvement in a number of ways. The first, in cases of collaboration and service user control (and in contrast to consultation) was to negotiate proper payment for the formal work undertaken by service users.

There is still a tendency for some researchers to see the ‘lived experience’ of service users as a free and easily exploitable resource. Proper payment achieves two things. It validates, in the eyes of the service-user, the contribution they have made and it encourages the researchers to make maximum use of the expertise and insight of the service user in order to gain a proper return on their investment.

In my work for both the School of Pharmacy at the University of London and The Spectrum Centre for Mental Health Research at Lancaster University, a key indicator of the integrity of the relationship in my eyes was the willingness of the project leaders to provide a fair and equitable recompense for the work I undertook.

A second indicator, in all forms of research, was the training and preparation that service users are provided with to carry out their role in the research process.

At the University of Birmingham, which houses the other half of the BRND team, several exciting projects are utilising the experience of service users. For example, five service users, three of them with bipolar disorder, are taking part in a research project on postpartum psychosis. Women came from as far away as Devon and Wales to attend an initial 2-day workshop at the Centre of Excellence in Interdisciplinary Mental Health (CEIMH). With course leader Dr Jess Heron, they learned the principles of qualitative research before

applying those skills to help design a study to find out what practical advice and resources would be most useful to women recovering from postpartum psychosis. Dr Heron says that empowering service users to play a major role in the research process brings many benefits:

‘Developing projects collaboratively ensures not only that the research we are doing is relevant, but that it can be understood, the methodology is acceptable – and that more brains, with all sorts of backgrounds and points of view, have considered the potential benefits and pitfalls.

It is important that service users feel skilled and valued. High-quality research training, using university experts, ensures they enter meetings on a level playing field, and feel confident to bring their own skills and experience.’ (J Heron 2008, personal communication)

The care taken to help women at the postpartum psychosis workshop to feel comfortable with the research process was much appreciated by those who took part. Ines Beare, an MDF The BiPolar Organisation member, says:

‘I found it easy to participate. The organisers were extremely helpful and experienced and I gained greater knowledge of the illness. I feel now that I have recovered from postpartum psychosis I want to take part in research so that other women don’t have to face the same difficulties in the early stages of this traumatic illness.’ (Dolman 2009)

Since the workshop, Ines and her colleagues have continued to be involved in the research, with one member transcribing the interviews and the other members contacted to comment on the analyses. Jess Heron has described the process:

‘The study will be written up for an academic journal and we’ll use the information developed to design web advice for recovering women, their partners and families, and also for health professionals involved in caring for recovering women.’ (Dolman 2009)

A third and largely unexplored indicator is whether the training and work experience gained by service users in the course of the research process can be translated into transferable and accredited qualifications.

Professionals in the consultation that supported the Sainsbury Centre’s review of service user involvement in prison mental health research highlighted the valuable skills service users gain from being involved in research (Sainsbury Centre for Mental Health 2008). It was suggested that this type of involvement could be translated into vocational qualifications:

‘I think it is important to develop a range of vocational qualifications that service users could obtain from involvement like work based credits (NVQs [national vocational qualifications]).’ (Independent researcher; Sainsbury Centre for Mental Health 2008)

This last point is important because one of the most valuable by-products of the greater involvement of service users in mental health (and other) research is their capacity to use this experience to increase their employability and/or build a new career as a service-user researcher – both capable of playing a central role in their recovery.

Conclusions

Service user involvement in mental health research is far from being a minority activity. It is now commonplace. However, the institutions pioneering the most creative service user involvement are those that demonstrate commitment to the service users who take part in their projects by negotiating proper payment for their contributions and by providing training in transferable research skills that will help them further their careers as service-user researchers and thus aid their recovery.

References

- Dolman C (2009) Service users in research: how to affect the research that affects you. *Pendulum* 25: 14–6.
- Forty E, Craddock C (2009) Be a research champion. *Pendulum* 25: 14–5.
- Hanley B, Bradburn J, Barnes M, et al (2004) *Involving the Public in NHS, Public Health and Social Care Research: Briefing Notes for Researchers*. INVOLVE Support Unit.
- Mayes D (2009) The Spectrum Centre for Mental Health Research. *Pendulum* 25: 12–3.
- Sainsbury Centre for Mental Health (2008) *A Review of Service User Involvement in Prison Mental Health Research*. Sainsbury Centre for Mental Health.
- Tait L, Lester H (2005) Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment* 11: 168–75.
- Taylor K (2009) My life as a service-user researcher. *Pendulum* 25: 17.
- Trivedi P, Wykes T (2002) From passive subjects to equal partners: qualitative review of user involvement in research. *British Journal of Psychiatry* 181: 468–72.
- Williamson C (2001) What does involving consumers in research mean? *QJM* 94: 661–4.

MCQs

Select the single best option for each question stem

1 What group in mental health was the focus of the report on service user involvement by the Sainsbury Centre for Mental Health in 2008?

- a carers
- b people with bipolar disorder
- c people with schizophrenia
- d prisoners
- e support workers.

2 Which form of service user involvement involves 'an active ongoing partnership with service users in the research, with shared decision-making and service users taking part in any or all stages'?

- a user-controlled
- b collaboration
- c probationary

- d consultation
- e negotiated.

3 What term does the Bipolar Disorder Research Network at the University of Cardiff use to describe service users who actively recruit survey participants on its behalf?

- a research lobbyists
- b research advocates
- c research champions
- d research campaigners
- e research promoters.

4 What group is the focus of the latest research project into medication adherence by the School of Pharmacy at the University of London?

- a people with bipolar disorder
- b people with a personality disorder

- c people with clinical depression
- d people in recovery from a mental disorder
- e people with schizophrenia.

5 In what field of mental health research does the University of Birmingham provide training for service users involved in its studies?

- a clinical depression
- b postpartum psychosis
- c rapid mood cycling
- d cognitive-behavioural therapy
- e medication adherence.