



Mental Health
Research Network



NHS

**National Institute for
Health Research**

INVOLVING SERVICE USERS IN MHRN-SUPPORTED RESEARCH CASE STUDY

The National Institute for Health Research Mental Health Research Network (NIHR MHRN) helps make research about mental health happen in the NHS in England. We work through eight regional offices (called hubs) and currently support more than 300 multi-centre studies and clinical trials. We offer very practical support to research teams, helping them set up and recruit through services run by more than 60 mental health trusts.

The MHRN supports studies that involve people with mental health experience, and, if pertinent, their family members. There are different ways in which research teams can involve the people who ultimately benefit from their studies and trials, and we can offer advice about the best way to do this.

Our hub teams support – and can introduce researchers to – service users who are willing to act as consultants, advisors, steering group members or researchers. Our centrally-based Service Users in Research supports involvement activities throughout the MHRN and commissions people with experience of mental health problems to produce guidance and resources for researchers.

This is one of a series of case studies commissioned by the NIHR MHRN to illustrate and share examples of good practice.

For more information about service user involvement in the Mental Health Research Network and the work of Service Users in Research, visit

www.mhrn.info/serviceusers

Randomised control trial of group psychoeducation versus group support using both expert patients and Trust staff in the management of bipolar disorder

■ This case study was written in 2010 by members of the MHRN North West Hub Service Users Research Panel and Tim Rawcliffe, service user development officer at the hub.

It was commissioned by the MHRN via the North West Hub and produced in this format in June 2011.

Information about the study

This study forms part of the wider National Institute for Health Research-funded 'PARADES' programme of research that looks at the 'development, evaluation and implementation of psychological approaches to bipolar disorder and co-morbid problems'.

Outline of the research

The research is intended to compare two forms of group therapy for individuals with a diagnosis of bipolar disorder. Psychoeducation aims to enhance people's understanding of their disorder, following a set agenda of topics covering issues such as education and management techniques, and is jointly delivered by an 'expert patient' and two health professionals. The peer support allows participants to set their own agenda and discuss issues they feel are the most important to them, and is facilitated by the same three workers but in a much less non-directed way. The chief investigator is Professor Richard Morriss at the University of Nottingham.

Methods for conducting this case study

Members of the Service User Research Panel (SURP) at the MHRN North West Hub designed an interview schedule using the guidelines provided by the MHRN coordinating centre. They then worked together to identify individuals employed and involved with the research study, and subsequently invited them to be interviewed. The interviews were later transcribed and the following themes emerged:

- different levels/degrees of service user involvement;
- identifying individuals to become involved;
- problems/issues arising;
- support mechanisms;
- reported benefits of service user involvement.

Different levels/degrees of service user involvement

The PARADES programme lead has an existing commitment to the benefits of 'user involvement' from previous collaborative projects.

The newly established Spectrum Centre for Mental Health Research at Lancaster University had explicitly appointed two 'service user researchers' when it first opened in 2008 (www.lancs.ac.uk/shm/research/spectrum).

One of these researchers was invited to be a co-applicant on the PARADES programme and has responsibility for overseeing service user involvement on the whole of the programme, in addition to undertaking research as a service user researcher within the Spectrum Centre. They chair the PARADES Service User Reference Group (SURG) and feed back recommendations to the programme steering committee, keeping 'service user involvement' on the agenda. The SURG meets approximately every two months, prior to the programme steering committee.

This researcher also has had responsibility for revising the manual for the therapists to use when running the psychoeducation groups, and invited individual members of the SURG to comment on various chapters of the manual. SURG members were subsequently invited to participate in a pilot run of the psychoeducation therapy groups. Two individuals with personal experience of bipolar disorder were also recruited to help deliver the intervention, as 'service user facilitators'. These positions were advertised through various avenues including the North West Hub's service user database, *Pendulum* (MDF, The Bipolar Organisation's quarterly journal), and through other existing contacts.

In addition, the MHRN North West Hub's service user development officer attends the SURG, is a member of the independent programme trial steering committee, and has assisted in various ways across the programme.

Identifying individuals to become involved

In addition to existing contacts, the launch conference of Lancaster University's Spectrum Centre for Mental Health Research 'Developing better psychological interventions for bipolar disorder' in 2008, afforded the opportunity for individuals to be made aware of the forthcoming opportunities to be involved.

The Centre's agenda places a strong emphasis on the service user perspective, consulting with people who are 'experts by experience' and actively involving service users in the research that will affect them. The Centre has been developing a participant panel (currently numbering approximately 200), and members are kept up to date with the latest research developments via a quarterly newsletter, also detailing involvement opportunities for new studies.

Problems/issues arising

One of the two service user facilitators was interviewed for this case study and the other provided feedback via email. One of the individuals was already employed on another of the PARADES programme studies and is involved two days a week on the current study. Despite taking up the post from another salaried position, they were to encounter initial difficulties with the Trust's occupational health department, who despite never having met with the individual, demanded that they attend a medical three months into the contract. The programme lead reported that this had added an 'extra layer of nightmare' to the recruitment process.

Given the closeness of the issues discussed in the therapy sessions, they did report occasional difficulties in revisiting their own personal experiences, but felt that the support provided through group supervision and individual supervision with the principal investigator for the study, was adequate. They believed that they had a particular empathy with the trial participants through the sharing of experiences, although on occasion this affinity had created some small tension with the other therapists involved. The other service user facilitator reported concerns that her Trust name badge had the role of 'service user facilitator' included as their job title, which, within the confines of the study was not problematic, but caused some embarrassment when they wore it elsewhere in the Trust. This was rectified by a simple title change to 'psychoeducation facilitator'.

Support mechanisms

In addition to the formal support they received within the department, the service user co-applicant emphasised the invaluable support that they received from the other service user researchers employed in the Spectrum Centre and across the region.

They had experienced health problems throughout their employment and thought that this might have diluted the impact of the SURG, as unfortunately there had been no budget available to pay for a deputy. Membership and attendance of the reference group has fluctuated, which has been both disruptive, but conversely afforded the opportunity for others with different perspectives to become involved.

Reported benefits of service user involvement

The benefits of involvement can be divided into benefits to the research itself, and personal benefits.

Given that the study is comparing two forms of group therapy, facilitated by two therapists and a service user facilitator, the programme study lead believed the employment of the service user facilitators had gone some way in helping to break down the 'them and us' of healthcare delivery.

The PARADES research programme manager was similarly emphatic in their view that the involvement of service users on the study was a worthwhile endeavour, bringing their 'insider knowledge' to the research process, and grounding the sometimes esoteric academic thinking and discussions. Although the available evidence is currently limited, it was felt that the use of 'service user facilitators' in the trial had benefited recruitment, and positively impacted upon the conduct of the therapy sessions.

The SURG member interviewed felt that their views had been listened to and appreciated by the study team, and had allowed them make good use of their personal experiences to improve treatments for others. In particular they felt that their contribution to the psychoeducation manual had been meaningful, and also that their assistance in the training of the research assistants would hopefully have had a subsequent benefit to the research.

The service user co-applicant reported that their employment had had a major boost to their self-confidence and, in particular, allowed for what had been often negative past experiences to be transformed into valued positive ones. The service user facilitator considered their involvement had benefited the research in some symbolic, albeit non-quantifiable way.

'I think the benefit of having a service user researcher involved in group therapy is that it does show an openness to valuing a person's personal experience of mental health problems and it sends out a message to the participants that the (research) team is progressive, open-minded and forward thinking.'

'What I tried to do was affirm that I had had similar experiences to the others, and that it was okay to talk about them, and where possible to provide a positive outlook – which is easier said than done. I was able to share my personal experiences as a way of reflecting what the participants were saying and, wherever possible, to normalise them.'

On a personal level, they reported picking up some tips about managing their own depression from delivering the therapy, and from learning from the expertise and knowledge of the lead therapist's experience.

One issue that was reported, but which does not fall neatly into the major themes, was that of 'career progression' for 'service user researchers'. The established career pathway for academic researchers is not readily reconcilable with that for a 'service user researcher' and guidelines for career pathways for 'service user researchers' would be welcomed.

Recommendations to inform good practice

- The study had been a learning experience for all concerned and highlighted the value of early involvement and the continued presence of a service user co-applicant. There should be future consideration of budgeting for a 'deputy'.
- The value of both the launch event and the continued participant panel allowed for promoting the research and highlighting opportunities to become involved.
- The research team emphasised the potential benefit of shared experiences, largely to offer possible solutions to issues that arose through employment and the involvement of service users in research studies.



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Service Users in Research
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