



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

Understanding and evaluating recovery in individuals with experience of bipolar disorder (part of the NIHR-funded RECOVERY programme)

■ This case study was written 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

Understanding and evaluating recovery in individuals with experience of bipolar disorder is actually three inter-related research studies under one heading. It forms part of the wider National Institute for Health Research-funded RECOVERY programme of research, which looks at 'psychological approaches to understanding and promoting recovery from psychosis'.

Outline of the research

The study seeks to explore individuals' experiences of recovery from bipolar disorder and to develop an intervention that is focused around their own individual goals.

In the first phase of the study, qualitative interviews were carried out with individuals with a diagnosis of bipolar disorder to identify the key themes associated with recovery in individuals who have a diagnosis of bipolar disorder. The purpose of this was to:

- 1) explore the subjective experience of recovery;
- 2) elicit service user definitions of recovery; and
- 3) identify themes for the recovery process.

Recruitment for this phase was completed in July 2009.

On the basis of the information collected in phase 1, a self-report questionnaire was developed to provide a quantitative measure of recovery from bipolar disorder (the Bipolar Recovery Questionnaire – BRQ). Each of the items in the BRQ reflected the themes elicited in phase 1.

Recruitment for this phase was carried out between November 2009 and April 2010.

In the third phase, an exploratory randomised control trial for an individual cognitive behaviour therapy-based recovery intervention for individuals with a first diagnosis of bipolar disorder will be conducted. In particular, the elements of the intervention will be adapted in accordance with findings from the evaluation of recovery themes from the initial phase of the study. Recovery will constitute a primary outcome for the intervention. Phase 3 was expected to begin recruiting in August 2010.

The chief investigator of *Understanding and evaluating recovery in individuals with experience of bipolar disorder* is Professor Steve Jones at Lancaster University.

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 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 key themes emerged:

- 1) different levels/degrees of service user involvement;
- 2) identifying individuals to become involved;
- 3) problems/issues arising;
- 4) support mechanisms;
- 5) reported benefits of service user involvement.

Different levels/degrees of service user involvement

The principal investigator was forthright as to the motivation for involving service users throughout the study. It was considered self-evident to develop an intervention that had its basis in the direct lived experiences of individuals' own journeys of 'recovery'. As with the RECOVERY programme as a whole, the influence had in no small part been the earlier work of two local service users' qualitative research into individuals' narratives of recovery from psychosis (Pitt and Kilbride, 2007)¹. Their input was sought at the outset and the draft proposal circulated to local service users who had an interest in research for comments.

The service user co-applicant was previously employed as a service user researcher within the Greater Manchester West Mental Health NHS Foundation Trust and is now contracted for the duration of the research programme. In addition to leading on one of the other studies on the programme, they have responsibility for 'service user involvement' on the programme as a whole, and to take the recommendations of a service user reference group (see *below*) to the RECOVERY programme meetings.

After the application was successful in securing funding, five per cent of the total grant application had been explicitly allocated to 'service user involvement'. This was to cover costs such as payment for consultancy fees to individuals. A 'service user reference group' (SURG) was established to comment and advise on the research programme as a whole. Service user consultants were identified for each of the studies and a named representative from each of the component studies also attended the SURG meetings (members receiving £10 an hour and travel expenses for each meeting).

Whilst the research in this instance was not directly carried out by a 'service user researcher' (although this had been suggested), the research assistant employed on the project enjoyed a close working relationship with the SURG and consulted the group regularly for advice on interviewing individuals on their experiences of 'recovery from bipolar disorder' (phase 1); the development of a 'recovery measure' (phase 2); and in hosting focus groups for the development of a recovery-focused psychological intervention for individuals early in their course of bipolar disorder (phase 3).

In addition, the MHRN North West Hub's service user development officer chairs the SURG, and has assisted in various ways across the programme. This has included meeting with the principal investigator and service user co-applicant to discuss potential involvement opportunities; attending consultation meetings to comment on the measures employed, the content of the questionnaire and the development of the intervention.

Identifying individuals to be involved

There had been the early input into the study prior to securing funding and the RECOVERY programme as a whole was launched in March 2008 in central Manchester. At the launch, all the principal investigators were required to provide a plain English summary of their respective studies to an invited audience of service users and clinical staff from across the region, and to highlight the opportunities that would be available for individuals to become involved. At the close of the event, individuals were able to sign up to become involved in any of the studies on the programme and, following further promotion of the research, an advisory group of five service users was established for the current study.

Problems and issues arising

It was regarded as a novel venture to have such a high degree of service user involvement embedded within the research, and help and guidance was sought by the principal investigator from other colleagues, including the director of the MHRN, and through an ongoing process of negotiation with the service user collaborators. The presence of the service user researcher and co-applicant, with responsibility for 'user involvement' on the programme steering committee, was considered particularly invaluable. They did suggest that awareness of other models of involving service users would have been valuable, for two principal reasons – to 'normalise' the problematic issues that were encountered, and to provide possible solutions to some of the difficulties that might arise.

The service user co-applicant has a strong commitment to the principle that individuals' involvement be meaningful, and reported an early naivety and lack of self-confidence in asserting concerns about involvement opportunities, but their confidence has grown through employment on the programme.

The programme is administered by a research programme coordinator who has only been in post since April 2010, replacing the previous job-holder. They were unaware of any significant administrative difficulties, possibly attributable to the host Trust's (Greater Manchester West Mental Health NHS Foundation Trust) good track record of employing and involving individuals with mental health difficulties. They remembered being asked of their experiences of service user involvement at their interview, and encouragingly added that they did not think of the 'service user researchers' on the programme as service users but as colleagues, and attributed that in part to the culture fostered within both the research team and the host Trust.

One problem that had been encountered was the reimbursement of travel expenses to individuals attending meetings conducted as part of the study that appeared 'unusual' – for example, taxi fares from hospital outpatient clinics – that required some negotiation with the Trust's payroll to resolve.

Although budgeting for 'service user involvement' had been included in the initial grant application, (five per cent of the total grant application), it demanded a constant process of flexibility in the funding allocation. One example of this was the decision to host a 'RECOVERY programme research update and service support' event to provide feedback on the progress of the programme, and the additional costs of reimbursing travel expenses to service users who attended.

Support mechanisms

The 'service user researcher' emphasised the importance of support in their role, which they stressed was provided on two distinct levels – formally within the research team, through weekly supervision with the programme lead and the lead therapist; and informally through peer support from the other employed 'service user researchers' and the SURG.

Reported benefits of service user involvement

The principal investigator emphasised the valuable feedback that had been received on the qualitative research and the development of the recovery measure.

The service user co-applicant believed their involvement to represent a partial reversal of the 'passive subject' role of someone with mental health problems to being offered the opportunity to allow their often negative past experiences to be of benefit to the research process.

Two particular recommendations that were accepted by the research team were that 'the ability to work collaboratively with service users' should be an essential criteria for all of the RECOVERY programme posts, and the proposal that all trial participants be provided with a follow-up telephone call after any assessment to check on their well-being. This structure of feeding back the SURG's concerns did, however, inadvertently highlight the lack of representation of research assistants at the project steering committee, who at times reported exclusion from some of the decision-making.

One SURG member had had some initial concerns as to the extent of user involvement on the study, but acknowledged that they had become involved with high expectations that could not possibly be met within the constraints of a programme of research of this scale. Throughout the course of the study, the SURG member did report that they felt they were playing a more active role in the research

One issue that was reported, but that does not fall neatly into the major themes, was that of the concept of 'service user researcher', which the individual reported some ambivalence about. On the one hand, they valued their personal experiences and it had been a criterion for the post, but simultaneously they felt that it marked them somehow as the 'other'.

References

(1) Pitt L, Kilbride M, Nothard S, Welford M, Morrison AP (2007). Researching recovery from psychosis: a user-led project. *Psychiatric Bulletin*, 31, DOI: 10.1192/105.008532

Conclusions and recommended good practice

- The study had been a learning experience for all concerned and the study highlighted the value of early involvement and the continued presence of a service user co-applicant.
- The value of the launch event cannot be underestimated, allowing for promoting the research and highlighting opportunities to become involved.
- As part of a wider programme of research, the benefits of the Service User Reference Group, assisting in both the research and as a supportive mechanism, must be emphasised.
- The importance of a supportive research culture within the Trust has arguably been a major benefit to the involvement of service users in the research.
- The principal investigator emphasised the potential benefit of shared experiences, largely to offer possible solutions to issues that arose through the employment and involvement of service users in research.



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