

## 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](http://www.mhrn.info/serviceusers)

# Investigation of the impact of introducing Individual Placement and Support in a mental health catchment area (WISE)

■ This case study was compiled in 2010 by David Hindle, a service user researcher on the WISE study. It was commissioned by the MHRN via North East Hub and produced in this format in June 2011.

It is based on an interview with the study researcher, questionnaire responses from seven service user researchers working on the project (including training leads), informal discussion, observation and personal participation.

## Information about the WISE study

Employment rates of people with severe mental health problems are very low and have fallen over the past few decades. Individual Placement and Support (IPS) helps people find and keep jobs. Studies in the USA have shown that IPS is successful in increasing employment, but UK studies suggest possible difficulties in finding people willing to make use of the scheme.

The aim of the WISE study is to find out how much difference IPS makes when it is introduced to a mental health catchment area, and how to maximise its uptake and success. It is being carried out within Camden, an inner London borough.

The study includes interviewing 80 service users, 15 employers, 4 IPS workers and 18 community mental health team workers. An accompanying service evaluation based on 1,400 service users will provide information to compare employment experiences of those in Camden's community mental health teams (CMHTs) which offer the employment and support services and those that do not.

Data collection is due to be complete in November 2011.

The study's chief investigator is Professor Sonia Johnson at University College London. WISE is funded by the National Institute for Health Research *Research for Patient Benefit* funding stream.

WISE stands for 'Workplace Impact of Supported Employment'.

## Involvement of service users and how they were recruited

Service user involvement has been seen as a central part of WISE from the beginning. £25,000 (approximately 10 per cent of the total budget) was set aside for that purpose. So far, involvement has been within four distinctive areas.

### Steering committee

A member of Camden and Islington Service Users Research Forum (SURF)<sup>(1)</sup>, who was already known to the study team, agreed to join the study's steering committee from the early days (SURF is a local group of service users interested in research). This entailed attending meetings, email and phone communication before the funding bid and afterwards. The person acted as a joint applicant in the funding bid and also had the opportunity to contribute to study documentation, interview schedules, training and interviewing. The person was an experienced service user, so support in this role was not an issue. It should be noted that the MHRN publication, *Mental health researchers' Toolkit for involving service users in the research process*<sup>(2)</sup>, advises that more than one service user should normally be involved in a study steering committee.

### Service Users Research Forum consultation

Two consultations were undertaken with SURF prior to the bid being submitted. A fee of £300 was paid to SURF for each consultation.

### Service user interviewers

The study team had a clear objective to establish a team of trained service user interviewers who could work on this study, and on future studies. For WISE, service users are undertaking 80 structured qualitative interviews with service users who have agreed to participate in the research.

Known contacts and local sources were used for recruitment, but notably the MHRN (including Service Users in Research) was not. Interviewers came from three main sources:

- South East Essex Service User Research Group (SE-SURG)<sup>(3)</sup>
- Camden and Islington Service Users Research Forum (SURF)<sup>(1)</sup>
- Local IPS service (the one to which WISE refers).

In addition, people were recruited on an ad hoc basis, including two people made known to the study after they had enquired about another project.

27 service users originally expressed interest in being interviewers, 18 undertook the training (see below) and 12 (possibly rising to 14) became interviewers. Reduction over time seems to have been mainly a product of the change in individual circumstances, rather than for reasons of health. As the time from initial enquiry to first interview was nine months, it is not surprising that circumstances changed.

#### **Training service users as interviewers and facilitating supervision sessions**

An academic from the study steering committee, plus the service user administrator from SE-SURG (this group comprises experienced researchers) initially led the training. Following the initial training, the service user administrator took the lead in training, supported by the service user who is on the steering committee, and the study researcher. Sessions, content and session feedback were a collaborative effort. Subsequent supervision sessions (currently every six weeks) have been led by the service user administrator from SE-SURG and the study researcher.

### **Future service user involvement opportunities**

There are no fixed plans, but there are two further areas where service users may be involved. Firstly, in developing a coding frame (a way of analysing results from interviews) and secondly, at the dissemination stage. This could possibly include attending a stakeholder conference and journal article preparation.

### **Issues arising and support provided**

A number of challenges have arisen in relation to involving service users in WISE, necessitating appropriate support and time.

#### **Training and supervision of interviewers**

Being responsible for carrying out qualitative interviews of 45 minutes to one hour is not easy. Potential interviewers had a mixture of experience – from none at all to a lot. Support offered includes:

- initial explanation of role – two hours;
- interview training – two sessions, each five hours, including explanation, interview practice, lone working guidance and work details;
- refresher and supplementary training – one session, two-and-a-half hours;
- two-hour group supervision sessions every six weeks;
- individual practice with the study researcher, if needed;
- observing a full interview if needed, by being paired up with an experienced interviewer;
- meeting with the study researcher prior to and after each interview;
- individual advice/feedback after listening to recordings;
- easy access to the study researcher by internet and phone;
- planning and feedback sessions with service user trainer/group supervision.

As well as being necessary for the success of the project, having appropriately trained interviewers was also needed by the Trust Research and Development (R&D) department. Trying to build interviewing skills from scratch has, in some cases, been a challenge. It is possible that there may be shortcomings on some of the early interviews due to inexperience. This is being minimised by feedback; individual training/supervision; individual practice and doubling-up. This does have time consequences.

A further area of support was to provide service users with reassurance through the application process, including giving role specification, personal specification and interview questions prior to interview.

### Method of 'employment'

The Research and Development (R&D) department at Camden and Islington NHS Foundation Trust is managing the study. The Trust has no protocol for involving service users as interviewers in this way. Therefore, role specification, payment levels, method of employment etc, had to be designed from scratch. This entailed a lot of time-consuming liaison between the study team, the R&D department, Human Resources and Finance. The end result was an agreement that interviewers would be considered as non-permanent contract style workers, but with no guarantee of work.

### Occupational health

The Trust R&D manager talked a lot to Occupational Health. It was agreed that given the status of the interviewers, occupational health clearance would not be needed. Instead, a one-off 'employment' type interview – by a Trust clinician and the study researcher – took place. An opportunity was given at the interview to identify health issues or support that the individual wanted. In addition, a form could be filled in by the service user giving personal health details, but filling in the form was not mandatory. As an additional 'safeguard' on health, the study researcher sees each person prior to them doing an interview, as part of the routine process of handing over the recorder for the interview. There is also no pressure to do a particular interview – on average, each person only does one a month.

### Payments

Pay levels for the interviewers (and doing training/supervision) had to be decided, ending up at around £100 a day (£60 per interview and £30 for group supervision). The Trust wanted an audit trail (payments via bank accounts), although the study team had wanted to pay on the day. Eventually, it was agreed that travel would be paid on the day, and the payment for the activity would be via an individual's bank account, following an invoice. Unfortunately the payments system for invoices has been problematic: up to two to three months delay has been encountered. This has been a massive frustration to both the service users and the study researcher. The main problem seems to be that the Finance department of the Trust is not geared up for a series of what to them are small payments.

### Benefits

The issue of impact of paid involvement activities on benefits is a well-known concern of service users.

Three options were given:

- pay at the agreed rate;
- no pay, with offer of a letter confirming work was being done voluntarily;
- support in doing the interviews/supervision under Permitted Work, including the higher limit.

Having a range of options gives a degree of reassurance and takes into account individual circumstances. The study researcher also offered to speak to each person about their own circumstances.

### Criminal Records Bureau check (CRB)

Each service user needed an enhanced CRB. In view of the potential delays, the Trust R&D staff processed CRB application forms as part of the initial study training. There was a lot of delay, but because of the time taken to get to the first interviews, this did not in reality delay the study.

## Benefits to service users

Service users have identified a number of personal benefits of being involved, including:

- the opportunity to use the skills they already possessed;
- involvement in meaningful activity;
- the opportunity for training, either reinforcing existing skills, or learning new ones. The feedback from the study researcher following interviewing was seen as particularly valuable;
- something to add to a CV that may help in getting similar work;
- improved self-esteem, benefit from meeting others and 'feeling better about myself';
- feeling listened to;
- the opportunity to improve facilitation skills and learn a lot about skills needed to be a good interviewer, as well as the difficulties of designing, developing and organising such a piece of work;
- the opportunity to earn some additional income.

## Benefits of service user involvement to the study

A common comment is that it is a bit too early to say. A key aim of the researchers was to develop a team of trained service user interviewers for WISE and for the future. This aim has partly been met, although it does not perhaps have as much of a local composition as originally intended. There is also a need for some of the interviewers to do their first interview. Another key hope/expectation is that using service users to interview service users will provide for a more frank view. Service users may also show more empathy. The problem here is that the study is not able to test this.

Having service users involved at varying stages has enabled things to be looked at more from the viewpoint of service users, helping to ensure

things are included that are important to service users. Using experienced service user researcher(s) in training/group supervision helps to provide a connection through experience and increase confidence about raising issues. It also acts as a check on the use of too much jargon. Having an experienced service user on the study steering committee is also helping as the issue of variability in interviewing styles and experience levels are looked at – an important issue to overall quality.

Discussion and development of interview schedules have been influenced, as have the arrangements for the interviews themselves. For example, it was originally intended for service users to make appointments with the interviewees. This responsibility was swapped to the study researcher following initial training. The interview schedules were also changed through service user input prior to and following training. It is probable that some further refinement will also take place.

### References

- (1) SURF (Dr Helen Killaspy, h.killaspy@medsch.ucl.ac.uk, telephone 0207 794 0500 x 33950, [www.ucl.ac.uk/mentalhealthsciences/researchthemesandinterests/psychosisrelatedprojects/surf](http://www.ucl.ac.uk/mentalhealthsciences/researchthemesandinterests/psychosisrelatedprojects/surf))
- (2) Mental health researchers' Toolkit for involving service users in the research process, MHRN, [www.mhrn.info/publications](http://www.mhrn.info/publications)
- (3) SE-SURG (Lyn Kent, lyn.kent@anglia.ac.uk, 07976827534)



**KING'S**  
*College*  
**LONDON**

**Institute of  
Psychiatry**

**MANCHESTER**  
1824  
The University of Manchester



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Mental Health Research Network

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NIHR MHRN Coordinating Centre Institute of Psychiatry, P077  
De Crespigny Park, London SE5 8AF  
[www.mhrn.info](http://www.mhrn.info)