

**An evaluation of service user
involvement
in studies adopted by the
Mental Health Research Network**

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Colin Tysall, Service user director of Coventry AIMHS (Actively Influencing Mental Health Services)

Executive Summary

Background

The Mental Health Research Network (MHRN) is part of England's National Institute for Health Research. Its mission is to promote mental health research in the NHS in England. The MHRN does not fund research, but provides practical support to a wide range of mental health research studies.

In applying for MHRN support, researchers are asked to complete an application form. The form asks questions about whether any service user or carer involvement has taken place in developing the research proposal. It also asks about future plans for involvement in the project delivery and dissemination.

All applications are considered by the MHRN's Adoption, Allocation and Advisory Committee. The Committee often provides advice to help improve the plans for involvement. The MHRN also offers some practical support to researchers to help with service user and carer involvement.

What we did

We selected 45 studies at random from the MHRN portfolio to include projects at different stages of completion. We interviewed the lead researchers on each study to find out what involvement they had carried out, what difference it had made, what challenges they had faced and their views on the support available from the MHRN. Nine studies were selected for further follow up. We then carried out more detailed and in-depth interviews with both the researcher and a service user to develop case studies describing the involvement.

Findings

How are service users being involved? What difference is this making?

The majority of researchers (40%) are involving service users as members of their trial steering committee/ project steering group. There is a great deal of variation in how well this is working. In some projects, service users have had a major impact for example on trial design and recruitment processes. In others their impact has been minimal. Some researchers report finding it difficult to enable service users to contribute to committee meetings.

About 20% of the researchers are involving service users as co-researchers or as members of advisory panels. These types of involvement impact on every aspect of the research, because the service users are co-contributors to all decisions. The main effects are reported to be keeping the research grounded and focused on the issues important to service users, as well as boosting recruitment and retention rates and improving the quality of interview and focus group data.

Just under 20% of researchers consult service users at the design stage and use a variety of approaches to involve them, including focus groups or informal consultations with study participants. The impact is very varied. On a few occasions,

service users have helped to shape the research question and project design. More often they identify practical changes that would make participation in the study more comfortable for example by setting the limits on questionnaire length or time spent in a MRI scanner.

Researchers are considering many different approaches to involving service users in dissemination. Some of these relate to public engagement or communication of the findings to a lay audience, rather than direct involvement in dissemination.

What challenges are researchers facing?

Researchers report the main challenges to service user involvement as:

- **a lack of time and resources** – particularly at the early design stages before funding has been obtained
- **a lack of know-how** – particularly with involvement in steering groups
- **recruiting service users and maintaining involvement** – finding service users with the right skills and experiences as well as managing periods of ill-health
- **managing the employment of service user researchers** – particularly in ensuring sufficient flexibility at work to be responsive to service users' needs and to support their career development after a project has ended
- **the attitudes and awareness of academic colleagues** – in particular managing situations where colleagues are opposed to user involvement

What support would be helpful to researchers?

Researchers said they would like help with finding service users to get involved. Some researchers would also like training in service user involvement, to help improve their practice and to develop the skills they need to effectively involve people, for example skills in chairing a mixed group of professionals and service users. Some suggested the MHRN could also provide general training for service users that would help prepare them for a wide range of involvement roles.

Some researchers expressed a general concern about involvement becoming an essential requirement of funders and other organisations like the MHRN, when there is little reward for doing it well. They suggested that researchers would benefit from greater support at early stages to understand how and why involvement could bring added value to their research. Researchers also need better incentives for following good practice and avoiding approaches that are tokenistic.

Discussion

Reflecting overall on the challenges researchers are facing, it appears that:

- There is not a shared understanding of what constitutes service user involvement in the context of MHRN adopted studies – different researchers expressed very different views.

- Some researchers are choosing certain methods to involve service users without being clear about the purpose of the involvement or how to make the method work well.
- Not all researchers are taking a strategic approach to recruiting service users to be involved and would benefit from advice on more formal processes.
- Few researchers were aware of the support the MHRN provides in relation to service user involvement.

Recommendations

We recognise that the MHRN might not be the most appropriate organisation to act on all of these recommendations, but could pursue them in collaboration with others or through other means.

- 1. Develop a practical definition of service user involvement** – to develop a consensus of what constitutes genuine involvement and where it brings added value to different types of MHRN study.
- 2. Revise the MHRN application form to request more detailed plans for service user and carer involvement** – to help researchers plan involvement more effectively and to help the MHRN carry out more detailed appraisals.
- 3. Introduce more regular follow-up of the implementation of involvement plans at the same time as offering support to overcome any challenges.**
- 4. Develop new MHRN policy and guidance to help researchers overcome some of the most commonly reported challenges to effective involvement** – in particular guidance on involvement in steering groups, managing the employment of service user researchers and the formal recruitment of service users to different involvement roles.
- 5. Develop training and support for researchers** - to meet the diverse needs of researchers with different levels of understanding and experience of involvement.
- 6. Develop training and support for service users** – to provide the generic training that is likely to benefit large numbers of service users involved in different ways.
- 7. Develop MHRN guidance on service user involvement in the dissemination of research.**
- 8. Work with other organisations to promote service user involvement at the early stages of project design and bid development.**
- 9. Raise the profile of the MHRN and increase awareness of the work it does to promote user involvement.**

1. Introduction

1.1 Background

The Mental Health Research Network (MHRN) is part of England's National Institute for Health Research. Its mission is to promote mental health research in the NHS in England. Studies which are adopted by the MHRN are given practical support to make the research happen. This involves working with everyone who needs to be involved in research projects – researchers, mental health professionals, people with experience of mental health problems and their families.

The MHRN does not fund research but supports a wide range of studies including randomised controlled trials, service evaluations, qualitative studies, epidemiological research, genetic research and basic science projects. This encompasses small-scale, pilot studies through to large-scale, multi-centre projects. For further information see www.mhrn.info

In applying for MHRN support, researchers are asked to complete an application form. The form includes questions about any service user¹ or carer² involvement³ that has taken place in the development of the research proposal, as well as any plans for involvement in the project delivery and final dissemination. All applications are considered by the MHRN's Adoption, Allocation and Advisory Committee. In addition to other types of feedback, the Committee often provides advice to help improve the plans for involvement. However since most studies are adopted after the research design has been decided, there may be limited scope for further service user influence.

The MHRN also provides some support to researchers to help with service user and carer involvement. This includes putting researchers in touch with people who are willing to get involved in research – the service users and carers working with local hubs. Researchers can also access two centrally-based organisations supported by the MHRN, Service Users in Research and FACTOR (Families/ Friends and Carers Together in Research). Further guidance on good practice is also available via the MHRN website.

¹ The term '**service user**' is used to refer to people with current or past experience of mental health problems and the use of mental health services. We recognise this term is not universally supported. Other terms used include 'mental health survivor' or a 'person who uses services'. The term 'service user' is used to be consistent with the terminology used by the MHRN.

² The term '**carer**' is used to refer to family members and friends who support people with mental health problems.

³ The term '**involvement**' in research is the term used to describe the active engagement of service users and carers in the design, delivery and dissemination of research – where service users and carers are partners in the research process and can influence what research is done and how it is done. This is the commonly accepted definition of involvement as described by INVOLVE (www.invo.org.uk).

1.2 Aims of the evaluation

This evaluation was commissioned by the MHRN and this report has been produced for the MHRN Executive Committee. The MHRN defined the scope and approach of the evaluation. They asked that it focus solely on **service user** involvement. This is because the work they have undertaken to promote carer involvement is relatively new and may not have yet had an impact.

The MHRN asked that the evaluation address the following questions:

- Have researchers implemented their plans for service user involvement as described in their MHRN application form?
- How have service users been involved in MHRN adopted studies? What difference has this involvement made to the research?
- What challenges have researchers faced in carrying out service user involvement?
- What support have researchers received from the MHRN relating to service user involvement? What kind of support would researchers find useful?

The main audience for this report is the MHRN (and the other clinical research networks). The main aim has been to identify what more the MHRN (and others) could do to promote successful service user involvement in adopted studies (see Section 5). Lessons relating to good practice have also been drawn out in a series of case studies (see Section 8) with the aim of helping researchers, service users and the wider involvement community.

1.3 About the author of this report

This evaluation was carried out by Kristina Staley from TwoCan Associates. TwoCan Associates carry out research and evaluations and provide training and support to help voluntary and statutory organisations involve people who use services in their work. Almost all of our work is undertaken in partnership with service users or carers. For further information see www.twocanassociates.co.uk

1.4 About the structure of this report

The report is structured as follows:

Section 2: Methods

Section 3: Findings from Part 1

Section 4: Discussion

Section 5: Recommendations

Section 6: Case studies from Part 2

Section 7: Lessons for researchers and service users

Direct quotes from interviewees are included *in italic font*.

2. Methods

There were two parts to this evaluation which will be described in turn.

2.1 Part 1

The MHRN selected 45 studies at random from its portfolio. These included studies that had started recruiting participants at various times before the selection was made: 6-18 months, 18-32 months or 32-40 months. 15 studies were selected from each category.

A senior researcher from each study was invited to take part in a short telephone interview. 41 researchers agreed to take part or were available for interview. The interviews were semi-structured and lasted 15-30 minutes. They included questions about the involvement that had taken place, its impact on the research, the challenges involved and the support received from the MHRN.

With permission from the interviewee, the interviews were recorded for note-taking purposes and to obtain accurate quotes. Anonymity has been assured since neither the names of the interviewees nor the projects have been identified in this report. Some details have been removed to prevent interviewees from being identified, but as far as possible all the quotes have been included in the interviewee's own words. The interviewees were able to check early drafts of this report to confirm they were happy with the way they had been quoted. All the interview recordings were deleted at the end of the project.

The findings were analysed both quantitatively and qualitatively to address the aims of the evaluation (see 1.6). The quantitative analysis involved simple descriptive statistics. The qualitative analysis involved framework analysis⁴. The themes for the framework were derived from:

- the author's previous knowledge of good practice in involvement and the kinds of impacts involvement has on research
- the aims of the evaluation
- issues raised by the interviewees

2.2 Part 2

Nine projects from Part 1 were selected for follow-up. These included projects which followed good practice or offered valuable lessons for others. The same researcher was interviewed again, this time asking for their views on the factors that had contributed to the success of the involvement, what they could have done differently and the lessons for other researchers. A service user (or representative) who had been involved in each project was also interviewed. They were asked for their views

⁴ Framework analysis involves developing and applying a framework to organise and classify qualitative data according to key themes, concepts and categories. The framework is used to identify a series of main themes which are then sub-divided by a number of related sub-topics. When all the data has been analysed using the framework, it is then examined for any further patterns and connections.

on the impact of the involvement, the factors that had influenced their success and the lessons for other researchers.

These semi-structured telephone interviews lasted 30-45 minutes and were conducted in the same way as in Part 1 (see 2.1).

2.3 Working with the advisory group

The methods used in this evaluation were specified in the original brief from the MHRN. Before the work began, an advisory group with three service user members and the project commissioners was established. The group met four times during the course of the project and provided valuable advice and guidance throughout. In particular they helped with developing the interview schedules, selecting the projects for follow-up in Part 2, analysing the findings and drafting the final report.

3. Findings from Part 1

This section first provides an overview of the service user involvement across all 41 projects (Section 3.1). It then considers the main questions addressed through the evaluation (Sections 3.2 – 3.6).

3.1 Overview of the service user involvement across all the projects

3.1.1 Types of research

The majority of the projects were randomised controlled trials or observational studies (Table 1).

Table 1:

Type of research project	% (number) of projects
RCT (including pilot RCTs)	44% (18)
Observational study	37% (15)
Measurement development	10 % (4)
Basic science (e.g. neuroimaging studies)	7 % (3)
Non-randomised intervention study	2% (1)

3.1.2 Methods of involvement

The majority of the studies involved service users as members of a trial steering committee or project steering group (Table 2).

Table 2:

Method of involvement	% (number) of projects *
Steering committee/ group member	41% (17)
Consultation during early stage of project design	17% (7)
More than one method used at different stages	10% (4)
Service user as grantholder	10% (4)
Service user researcher	10% (4)
Service user reference group / advisory group	10% (4)
Member of management group/ research team	7% (3)
Service user interviewers	5% (2)
A service user adviser – consulted throughout	2% (1)
No involvement	2% (1)

* The total adds up to more than 100% because some projects used more than one method.

3.1.3 Implementation of involvement plans

The vast majority (85%) of projects had implemented their plans for service user involvement as described in their MHRN application form. However, as discussed in section 3.2, most of the plans contained very limited detail. Even though researchers

proceeded as planned, this was not linked in any way to the quality or the impact of the involvement.

Where there was a difference between the plans for involvement and what was implemented in practice, there were no dramatic changes in terms of the extent of involvement or the stage of involvement. For example, one rather than two service users were recruited to a steering group or there was less involvement in the dissemination than originally intended.

3.1.4 The impact of involvement

The majority of the researchers reported that service user involvement had had an impact on their research design (Table 3). This included an impact on the:

- conceptual elements (e.g. outcome measures, the nature of the intervention)
- practical arrangements for participants (e.g. times of appointments)
- patient information sheet and recruitment processes

About a fifth of the researchers reported that the involvement had influenced every aspect of their study because service users had been involved throughout (Table 3). In these cases the researchers found it more difficult to describe the unique contribution of service users, because they had been co-contributors to all decisions.

About a fifth of the researchers reported that involvement had had little or no impact on the research (Table 3). This was largely because of the nature of the study (for example with involvement in a basic science study) or the level of engagement (for example where a single service user had attended only one meeting of a steering group).

Table 3:

Nature of the impact of involvement	% (number) of projects reporting this impact*
Impact on the design of the study	61% (25)
Impact on conceptual elements	22% (9)
Impact on practicalities	27% (11)
Impact on recruitment material and processes	12% (5)
Extensive influence throughout a study	20% (8)
Limited or no impact	20% (8)
Provided a service user perspective on the findings	7% (3)
Made interviews better for the interviewees	5% (2)
Better retention of participants	5% (2)
Confirmed the topic was important to service users	5% (2)
Motivated the research team	2% (1)

* The total adds up to more than 100% because some researchers reported more than one kind of impact.

3.2 Did the researchers implement their involvement plans as described in their application forms?

Although a large proportion of the 41 projects had implemented their involvement plans, these plans often lacked detail. For example they simply stated:

Users will be involved.

A service user/carer on the trial steering committee.

Some plans included processes that do not fit with the widely accepted definition of involvement used in this evaluation. For example they described 'talking to one or two patients in the clinic', or reacting to feedback from trial participants rather than actively seeking their views. About a fifth of the studies in this sample reported involving service users, but were not in fact genuinely involving them. This suggests there is not a universally shared understanding of service user involvement amongst MHRN researchers.

One of the researchers had included detailed plans for involvement but expressed some deep concerns about involving service users during the interview. They were the only person to express this very negative view:

"We did what we had to do, but it was not successful. It's hypocritical and dishonest and a waste of time. We have to write nonsense [on the application form] – to be politically correct – but it's demeaning to people with mental health problems. We have to do it for the money. So these poor people come to meetings where they are not contributing. All user involvement should be scrapped..."

However other researchers did express some general concerns that the research community are being forced to take forward involvement without understanding why or how it could be of benefit:

"The PI's are being battered into doing it [user involvement]. If you force them to do it, they'll just do something to tick the box – there's no motivation. If you want to them to do it well – they've got to really see the benefit of it. The message has become 'You will do this on top of everything else – and you're really bad for not doing it well'. It's become a bit 'them and us' actually..."

"You don't get any credit for it [user involvement] in your own organisation – no matter how hard someone outside is hitting you with a stick, no matter how well you are doing it – no one in your organisation is going to give you a promotion – it's like a hobby of yours on the side. What you've got to do is get the work done, on time and within budget and get the papers out. So there's no incentive in your working day to do all this extra work. There's no place where you're getting credits for that".

This suggests that some researchers are feeling obliged to develop plans to involve service users to meet the requirements of funding bodies and research organisations

like the MHRN. However, there are numerous reasons why they may not then follow through with good quality involvement that makes a positive impact. This may promote negative attitudes to involvement and is detrimental to all involved. It is therefore important to provide support early on to help researchers identify a clear purpose for the involvement that will bring benefits to their research. It is also essential to train and support researchers and to equip them with the necessary skills and competencies (See Sections 3.3.1 and Section 5).

These findings also highlight that there are limitations to the MHRN application form. In its current format, it only requires researchers to provide an outline of their plans for involvement. There are no questions about the quality of the involvement process, the budget and resources set aside for involvement, or whether training and support is being offered to service users or researchers. Nor do researchers need to specify the purpose of the involvement, or describe what role they expect service users to play. In the absence of this detail, it is very difficult to assess the quality of the involvement plans. It also means that researchers could take a 'tick-box' approach to involvement and still be said to be implementing their plans in full. The application form could be improved to encourage researchers to consider all aspects of involvement in their plan and to enable the MHRN to carry out a more in-depth assessment (see Section 5).

3.3 How have service users been involved in MHRN adopted studies? What difference has this involvement made?

The most common approaches to involvement used by the 41 projects included:

- membership of steering groups/ committees
- consultation at the design stage
- service users as collaborators/ co-researchers

These will now be discussed in turn, highlighting the different kinds of impact that the involvement made.

3.3.1 Membership of steering groups/ committees

This was the most commonly used method of service user involvement. However, there was great variation in the precise role that services users were asked to play and the extent of their influence on the research. This appeared to depend on:

- the nature of the project, for example there was little room for service user influence on steering groups overseeing basic science projects or studies testing the use of validated measurement scales
- the terms of reference for the steering group/ committee and whether the committee was involved in managing the research or acting as an oversight/ governance committee
- the way in which service users were involved, for example whether they were sufficiently trained and supported in their role

In some projects, service user members of a steering committee influenced the study design. For example, they helped to identify outcome measures, or helped to shape the intervention being tested, or helped with recruitment and follow-up of participants:

“The service user advised on the best quality of life questionnaire to use. We ended up using a questionnaire I had not heard of - rather than phrasing it all negatively – it phrased it all positively. This was more acceptable for service users – it was not too depressing for them to fill it out”.

“They [service users] changed the way the treatment was delivered in the trial – but the information also went into the training programme that we delivered to staff who were implementing the intervention. So that was really helpful”.

“I was being wishy-washy, bending over backwards so that potential participants wouldn’t be put off, but the service user pulled me up – and said that it’s not normal to treat people like that... she said ‘If they don’t play by the rules, then you need to tell them’.”

“The service user we involved was extremely useful. She had a clear cut way of thinking about the study and could relate to the participants and could think about what could help them engage in the study – so when it came to recruitment we could think about what would be most realistic...”

However, more commonly researchers expressed concerns about how well this approach was working. Some of the reported challenges included:

(a) Enabling service users to make a meaningful contribution to group discussions

“The conversations go fast. It is not easy to include lay people in a meaningful way... it’s difficult to make it more than a tick-box exercise...I’m not sure it always works. The meetings are dominated by academics so it’s hard to keep people included at a real level – we need to work at it more”.

“It’s difficult to know if the service users feel comfortable enough to say what they think. It may be difficult for them as they are not fully part of the research team. The team knows each other well as we have been working together for years. And the service users cannot be involved in all the decisions as many are made outside of the meetings... So it’s more difficult for them to make a contribution as they don’t have the full picture”.

“Lay members can feel overwhelmed. The professors are here, there and everywhere – and talking about very complex stuff. The best contributions I got during the lunchbreaks – which was a mistake of ours...”

(b) The service users involved sometimes had a limited understanding of research

“Lay people don’t have the same in-depth understanding of the project - some of the points the service users made were not in line with what our research was aiming to do”.

“The main challenge was trying to get the balance right between the scientific rigours of the trial steering committee and the involvement – most of the researchers probably felt overwhelmed as well...”

(c) Practical difficulties in attending steering group meetings

“We invited a carer to join the steering group, but the meetings were held in London, which was too far for them to travel, so we only corresponded by email”.

“The service user is not able to take part in the way that the rest of the committee likes to work. The other committee members are spread across the country, the only way to hold discussions is through teleconferences – but the service user has problems with teleconferences. Working round all this is really hard”.

In some instances, these barriers to involvement resulted in the service users only attending one or two meetings before resigning from the project.

In summary, it seems that this approach is being used with varying degrees of success (See also Sections 4.1 and 4.2). It seems that researchers would welcome guidance on when this approach is most appropriate and how best to involve service users in this way to ensure a positive outcome.

3.3.2 Consultation at the design stage

Researchers reported using various approaches to consult service users at an early stage in the development of their research project. These included running focus groups or a pilot study, or establishing a service user reference group.

The majority of researchers who had involved service users at this stage had found it useful. The impacts were varied and included:

- (a) improvements to the conceptual and practical elements of project design
- (b) improvements to the patient information sheets and recruitment process
- (c) identifying or shaping the research question

These will now be discussed in turn.

(a) Improvements to the conceptual and practical elements of project design

A number of interviewees commented on the benefits of this early involvement in terms of helping to identify relevant outcome measures and a meaningful focus for the research, for example:

“We organised two focus groups and asked them what outcomes they thought were important for mental health services... we did that before finalising the protocol so that their thinking was integrated into the research methods we used and also some of the outcome measures. They said communication was very important so we added measures about how readily people could communicate with service providers and included questions about what sorts of communication were ideal”.

Some reported that involvement had helped with developing or refining the intervention being tested:

“... the more sensitive you are to what participants want to do and find feasible, the more successful you will be... We are constantly revising the programme and the way we deliver it, so we structure it around what people want and are willing to do... There’s buckets of user involvement in the process itself as it’s a collaborative process”.

“We got the service users views’ on the issues around medication management and the best way of dealing with medication refusal. This informed our approach to this issue in the intervention we are going to test through the research”.

Most often involvement had led to changes in the practical arrangements for participants which had helped to make their participation easier, as one researcher commented:

“We made substantial changes to the way we approached service users and their carers during recruitment [as a result of the involvement]... it gave us confidence that having tuned our approach in this way, it was likely to be acceptable to sufficient numbers of people – so the participants knew that taking part was unlikely to be intrusive or difficult”.

Other examples of this type of practical impact included:

- commenting on a questionnaire to make it more accessible and easier to complete
- advising on the feasibility of assessing service users in different locations and settings
- commenting on what would be a reasonable amount of time to spend for example in an MRI scanner or completing assessments
- offering advice about the best times for appointments and the frequency of appointments
- highlighting travel issues around attending appointments
- commenting on the need to pay participants’ expenses promptly

The extent of service user influence varied greatly. For example in terms of service user involvement in questionnaire design, most of the researchers asked service users whether the questions were easy to understand and whether the questionnaire was an acceptable length. A much smaller number involved service users in deciding what questions needed to be asked and whether all the important issues were being considered.

(b) improvements to the patient information sheets and recruitment process

Some researchers reported that early involvement had helped to improve patient information sheets and the process of obtaining consent:

“The service users were really helpful in ‘dejargonising’ things... they were also good at spotting where someone reading the patient information sheet would be really worried... and how best to explain what’s involved and who’s going to know things... so they made the materials less ‘paranoia-inducing’. Things that I wouldn’t have thought to be troublesome in any way, they spotted them, so then I could eradicate them at that stage”.

“It [user involvement] made us a lot more aware that what we communicate to people needs to be much clearer and user friendly. It also streamlined the process so people knew what they had to do when they got the invitation letter”.

One interviewee described the importance of involving users as early as possible. They had only sought feedback from service users *after* they had already received ethical approval for all the recruitment materials. When they later realised they needed to make substantial changes, they had no choice but to reapply to the ethics committee to get approval for the amendments. The researchers have since changed their practice and now involve service users right from the beginning.

(c) identifying the research question

A small number of researchers reported that the research question had come from service users. Some research departments have established service user research panels which are consulted by all the researchers working in that department and can help identify topics for research.

Other researchers reported that their choice of research question had been influenced by service users via more informal communication channels. These included:

- identifying concerns frequently raised by service users / carers in the clinic
- responding to issues raised by service user participants in previous research studies
- talking to service user and carers at conferences, support group meetings, consultation events
- working in partnership with staff from voluntary organisations who are aware of the concerns of a broad range of service users

As one researcher described, when talking to service users is an integral part of the way researchers work, the views of service users will shape and influence their ideas continually, without it always being clear exactly when and where that influence took place:

“We do many different things to get the patient perspective. We talk to people when we go to conferences, community groups or consultation events on health policy and strategy. It can be very influential. It’s part of how you work as a research unit - rather than thinking we’ve got a new research project – how do we staple service user involvement to the bid”.

3.3.3 Service users as collaborators/ co-researchers

The studies that involved service users at all stages of the research used different approaches including: setting up a service user advisory group that was consulted at every stage; or employing service user researchers as members of the research team.

The impact of this kind of involvement was often distinct in being all-pervasive (rather than limited to discrete elements or stages of the research). It ensured that the research was practical and realistic, reflected service users' concerns and was more relevant and meaningful to the people it was seeking to help:

"It had an impact in lots of ways – the way we did the interviews, some of the questions that we had – I'm struggling to think of bits that weren't influenced".

"The main effect is that it is keeping us grounded... making sure we don't have too high an expectation of things, so we know the problems before we start".

"The service user holds us to account. When we are talking, he brings us back to reality and the care of people by asking 'what impact would this have on me as a patient?'... which is very useful because we as scientists can go off on the technical discussions. He makes sure we don't stray".

"It's all about the direction of the research and the relevance and translational utility".

However, there were sometimes limits to the influence of service user researchers, linked to the nature of the project. For example one researcher who is also a service user commented:

"My role is 80% researcher 20% service user. Because of the nature of the project it's not so focussed on the service user perspective".

Some researchers did identify particular stages where this type of involvement had more of an impact. For example, they attributed high recruitment and retention rates to the influence of service user colleagues:

"Service users helped us develop the materials. They shaped a lot of the things in the study so that out of all the people who took part, only one person dropped out. 80-90% of participants completed all the sessions which doesn't happen very often. Some of the participants even sent us thank-you letters to show their appreciation of the process".

"We have recruited an enormous amount of people. We recruit 50% of people in the wards we go in to. That is in part because of our approach...we demonstrate that we value their participation and the involvement has given credibility to the project..."

"It has helped us to access a wider range of service users who may not want to speak to a more traditional researcher – but are willing to open up to a service user researcher. It has given us a greater depth in terms of recruiting a whole range of people".

"That initial contact and first five minutes and perhaps the whole conduct of interview feels a bit less like you're being studied if the interviewer is a service

user. I think it's a better experience. In the context of declining rates of participation, it's a good thing to try and make sure that experience is as positive as possible – so people will take part again”.

Service users researchers also helped to overcome some of the barriers to recruitment to research, in particular some professionals' attitudes to recruiting their patients:

“If a service user approaches a professional... then it's difficult for a professional to say 'My service users won't want to take part – they don't like research', if there's a service user standing there saying 'I think this is really, really valuable and that services users will want to take part in this research'. The professional can say 'I know better than you' to a junior researcher but they can't say that to a service user”.

“It was useful to have that service user involvement... to reflect on research and what they experienced – to feedback that a lot of service users got a lot out of taking part in the research – and it's not necessarily a negative experience”.

Service user researchers have also helped to improve data collection by encouraging participants to be more open:

“When service user researchers disclose their status, it changes the quality of the information we receive back and the engagement levels in focus groups”.

They have also have helped with the interpretation of data, in particular helping with analysing the implications for practice:

“The involvement helped to refine some of the conclusions and to get an alternative perspective to our own views. This added an extra dimension because we didn't collect data from service users at this stage”.

“The involvement seemed to enhance the data collection and interpretation by bringing in a service user perspective that was different from ours...”

One researcher reported that the involvement of service users had been crucial to keeping the research team motivated:

“We had a roughish ride with this project, particularly from psychiatry colleagues about why develop this intervention – but the service users said it was absolutely essential and asked why someone hadn't done this before and how much it would help them deal with their condition. This helped to keep us going...”

3.4 How have service users made a difference to the dissemination of results?

The majority of studies in this evaluation were still ongoing at the time of the interviews and had not yet reached the stage of dissemination. Therefore this section first describes what user involvement had taken place in the small number of completed studies. It then describes what user involvement was planned in the ongoing studies.

3.4.1 Service user involvement in completed studies

These studies involved service users in the dissemination stage by asking them to:

- comment on a lay summary of the results for the participants
- comment on draft journal articles
- co-author journal articles
- participate in short films to describe their experience of the intervention that had been tested. These were developed for a website providing a more accessible summary of the results aimed at clinicians and service users.

The researcher who had involved service users in filmed interviews commented:

“This was important because the research report is lengthy and written in a research style, so it isn’t easy reading for most people. The filmed interviews are critical, not just for getting the service users to get their point of view understood – but also for GPs and clinicians to understand the research conclusions”.

3.4.2 Plans for service user involvement in ongoing studies

The researchers’ plans for service user involvement in dissemination covered a broad spectrum of activities. These included activities that might be best described as ‘public engagement’ activities such as giving talks at schools, science festivals, and local user groups. Some researchers discussed plans to provide the *participants* in their research a lay summary of the results. Others discussed how they planned to publish or present their results in a way that would better reach a service user audience for example by:

- publishing their findings in publications suitable for service users
- using different media – not just journals
- presenting at workshops/ conferences targeted at service users
- working with patient organisations or user groups to disseminate findings
- participation in MHRN events

Only a small number of researchers planned to involve service users in the process of dissemination for example by:

- seeking advice from service users on dissemination
- involving service users in dissemination activities
- involving service users as co-authors of the study publication
- testing the conclusions out with service users to ensure that any recommendations for practice would meet the needs of service users as well as professionals

Overall it seems there are many different views as to what constitutes service user involvement in dissemination. This is an area where researchers would benefit from clearer guidance about where service user involvement can bring added value.

3.5 What challenges have researchers faced in carrying out service user involvement?

The main challenges reported by researchers were:

- a lack of time and resources
- a lack of know-how
- recruiting service users and maintaining involvement
- managing the employment of service user researchers
- the attitudes and awareness of academic colleagues
- handling people's emotions
- responding to criticism

These will now be discussed in turn.

3.5.1 Lack of time and resources

Service user involvement can have the greatest impact at the early stages of designing a research project. However this is also the time when researchers find it most difficult to involve service users. This is partly due to the deadlines set by funders and ethics committees, which do not allow sufficient time for proper involvement. A lack of time can compromise the quality of the involvement:

“What happens is - it's a mad rush to get things done. The fast pace of early stages is a problem. Funders need to acknowledge it [user involvement] takes a long time”.

“Ethically it was a very difficult study to design. We sent a draft protocol to lots of lay people to check it was ethically acceptable... It would take too much time to get meaningful involvement... at a time when we just don't have any time. So [service users] were limited to agreeing to what we'd written rather than developing it with us”.

“If the MHRN want a report or ethics want something – you've got a certain window to do it in – but service users aren't employed fulltime, so it may be difficult to get everyone together for a meeting, even if that's the best way to do it. You have to find ways to overcome it for example email discussions...”

This involvement also has to take place *before* researchers have received any grant money which may set limits on what can be done:

“It's [user involvement] not cheap. It's a lot of resources to invest upfront before you've got a grant – before knowing even if you have a grant. We need to be provided with funds to do involvement during grant development – so at least we can pay people for their time”.

“It's hard/ impossible to get funding to involve people at the conceptual stage – people can't do it for free – there are no structures to fund that involvement. If you have spare money – you can do it. We need more structures and external systems to enable that to happen...”

This issue is a particular concern for researchers working with seldom heard (hard to reach) groups. While mental health trusts and the MHRN have established service user groups who can be consulted to help with the design of projects, these groups may not include people with the kinds of experience that researchers wish to tap into. For example one of the interviewees works with people with a dual diagnosis of learning difficulties and mental health problems. In order to genuinely involve service users, the research team had to establish their own advisory group as there were no other suitable groups available. This took a lot of time and resources, first to establish good working relationships with the group, then to improve the service users' understanding of research so that they could comment in a meaningful way. The researchers also had to pay people for their expenses and provided support to facilitate their involvement at every stage:

“Proper involvement needs to be with an ongoing group. You can’t just pluck people out of the clinic and give them a research-related task. The people we worked with had no training in research. So we had to start with discussions around ‘What is research?’... You need an infrastructure – people who are supported, trained ready to participate – and be able to pay them... When people say they’ve done a consultation – I’d like to see what kind of consultation they’ve done”.

3.5.2 Lack of know-how

Some researchers reported problems with managing involvement, particularly with members of steering committees:

“We’re not very good at it – to do it in a more meaningful way is hard. The group of academics are very experienced people and their discussions are very very valuable. The lay people are operating at a different level”.

“It’s difficult setting boundaries when patients are participants and advisers. How do you manage relationships when people’s roles change?”

“The circulation of documents and deciding what to send people. What’s reasonable to expect them to read? That’s been difficult to manage”.

Others reported that they had experienced problems but had learnt valuable lessons as to how to improve their planning for subsequent studies. For example, one group had carried out all their involvement without budgeting for the work, but then subsequently ensured there was a separate budget line for involvement in their next grant proposal. Another researcher reported that they planned to involve service users much earlier in their next project, to ensure there was still time to make changes to the design in response to service user input.

3.5.3 Recruiting service users and maintaining involvement

Some researchers reported difficulties with finding service users with the relevant experience, knowledge and skills suited to different involvement roles (see also Section 3.6 below).

One researcher also commented on the challenges of working with service users over a long period of time, because of problems with ill-health (see also section 3.5.4):

“Both of the service users involved at the beginning are now not working because of ill-health. Service users often become unwell and disappear for lengthy periods of times when they don’t have the psychological or physical resources to remain involved. This has been an issue”.

3.5.4 Managing the employment of service user researchers

Researchers who have employed service users as researchers report that it is important to be prepared to be flexible and responsive to employees’ needs. Employing people who have recent experience of mental health problems can mean that they are more likely to need time-off. The challenges lie in planning for this likelihood and ensuring there is capacity within the team to ‘take up any slack’. While researchers may be prepared for this eventuality, other stakeholders may not be willing to be as flexible, for example, funders and HR departments:

“There needs to be more ‘give’ in the system to meaningfully employ service users - none of the funders acknowledge the need for funding when people are off work for extended periods...”

“There’s an issue around the usual HR procedures that come into play when people take time off work... When you employ service users you expect that they will need to take time off for ill-health – that’s normal... That needs to be built into the job, so that if they take three days off not all the heavy-handed procedures automatically come into place... you have to help people adhere to policies – while being sensitive to their mental health needs - you need to be flexible about working hours and time spent in the job...”

Some service users may also experience difficulties in their role that are linked to their mental health problems. It can be a challenge for researchers to manage this sensitively:

“You need to have reasonable expectations of a service user researcher – to have an appropriate job description that takes account of their issues. We worked with a service user who found it difficult to be involved in the way we planned, but was reluctant to talk about it. It took a while to work out what the problem was, but then we were able to re-jig things without traumatising the person”.

“We employ people who are researchers who also happen to have a diagnosis [of a mental health problem]. There are issues there that we need to work through. What’s the difference between those people and service user researchers - it is important to get a sense of what those two things mean – they are different... There are initiatives for service user researchers but not for researchers who happen to be a service user...”

At the end of a project, there are challenges around helping a service user researcher to find additional work or to further develop their skills and experience. There is no formal career structure for service user researchers and no obvious path

for them to follow. Some service users may want to continue in research, others may want to use their experience as a means to get back into other forms of employment. As one researcher commented it is important to find ways to support service users to make the next step:

“We need to be careful not to assume that a person in a service user role needs to stay stuck in it ... Some may want to stay in that role, some may want to develop more of a researcher role – we’ve had some service users who have moved into clinical psychology training... You don’t want to put anyone under undue pressure, but it may be important to provide support to move on...”

3.5.5 Attitudes and awareness of academic colleagues

One researcher commented on the problems they had experienced with one of their colleagues who is opposed to user involvement:

“If somebody is like that then I feel really worried at putting a service user into a situation where they might meet with ill-feeling...you have to be able to give the service user some support and make sure you choose the right kind of person”.

3.5.6 Handling people’s emotions

One of the interviewees reported experiencing difficulties in working with people with a lot of anger and frustration:

“People who start working on research on discrimination often have a reason for it which is linked to a lot of anger...so we face a lot of anger and frustration – they project a lot of stuff on us because we are professionals... they can perceive you as the enemy, not as a co-worker who can do research with them. I have found it very challenging, also emotionally challenging. It’s pretty tough sometimes”.

3.5.7 Responding to criticism

It can be difficult for researchers to respond to negative feedback from service users even when that feedback is constructive:

“We generate an environment in which people can express their own opinions which is what you want – but after you have spent a long time preparing something and then find it’s heavily criticised – when you’ve got tight deadlines, you don’t always think ‘That’s great’, because it slows you down... but in the long term it is very useful”.

3.6 What support have researchers received from the MHRN relating to service user involvement? What kind of support would researchers find useful?

Very few researchers reported having accessed the service user involvement support offered by the MHRN (Section 3.6.1). The remainder were therefore asked what support would be useful (Section 3.6.2).

3.6.1 What support have researchers received from the MHRN?

Many of the studies in this evaluation were up and running before MHRN support for service user involvement became available. A number of researchers commented that had the current resources (e.g. support from MHRN local offices/ hubs) been available when they were starting their project, they would have certainly found them useful.

A small number of interviewees had received help with involvement from the MHRN. One researcher had involved a service user from an MHRN hub in developing their grant application and reported that the service user had provided sensible advice and helpful feedback.

Another researcher commented that they had found the service user involvement guidance from the MHRN useful and had given the guidance to colleagues when they were writing grant proposals. They suggested that the MHRN do more to publicise the resource.

3.6.2 What kind of support would researchers find useful?

The interviewees identified various ways in which the MHRN could support them in involving service users. These included:

- (a) helping with recruitment of service users for involvement roles
- (b) training and support for researchers
- (c) training and support for service users
- (d) relationship-building between service users and researchers

These will now be discussed in turn.

(a) Helping with recruitment of service users

A number of the interviewees said they would welcome help with finding service users to get involved:

“I’m desperate - I cannot find people to participate. I’m not in a clinical job so am not in direct contact with service users. I’d be very willing to involve service users – even so it’s extremely difficult. I can’t find anybody that gives you a pool of people who are able to be active”.

Some researchers wanted help with recruiting service users to their trial committees. Others wanted help with finding service users to work on developing projects. The service users currently involved in MHRN hubs may not always be eligible or appropriate for all types of involvement:

“I had to find my own service users from my own connections with great difficulty. The trial is two years in and I’m still trying to find a service user for the data monitoring and ethics committee. My local MHRN has service users working with them, but they are ineligible because they are perceived to be too close to me and not independent enough - we work in the same building...”

Some researchers said they preferred to work with local service users because this reduces travel costs, makes it easier to meet people regularly and because local people have more awareness of the issues that might be relevant for example to

recruitment strategies. The MHRN hubs were sometimes felt to be too far away to be of value:

“We need more guidance about how to identify where there are service users and how to contact different kinds of service users. I need some local people because I can’t afford to ask people to travel miles and miles for monthly meetings”.

“[Working with local people] is preferable, rather than sending off my proposal to someone I don’t know to review it... it’s better to actually have someone there all the time – who knows the local service well – someone who is the sort of person we want to recruit. I want more of an ongoing dialogue with them... you need a local structure that does that”.

“People who become representatives of service users won’t necessarily be representative of the patients we want to reach”.

Some researchers also wanted the MHRN to help with finding specific groups of service users, people who are not always represented in the user advisory groups set up by Trusts or universities:

“Local user groups mostly have members with experience of serious mental illness. You may need different types of service user – people experiencing depression and anxiety for example. So I would like help finding those people”.

This is also a serious challenge for researchers working with ‘seldom-heard’ groups, for example people with dementia or people with learning difficulties. Such groups are not often represented in the current infrastructure set up to support involvement, requiring researchers to establish groups themselves. This places considerable extra demand on their time and resources which needs to be recognised in funding involvement.

Specific suggestions as to what the MHRN could do to help with recruitment included:

- setting up a panel of service users who could get involved in trial steering committees or data monitoring committees
- working with Trusts and universities to develop well-functioning user groups at a local level
- setting up panels with specific groups of service users, for example a central group of people with learning difficulties that can be accessed by all researchers working in this field

It was also suggested that the MHRN could help with accessing funds to pay for service users’ time, especially during the early stages of research design (see Section 3.5.1).

(b) Training and support for researchers

Some researchers thought it would be valuable if the MHRN could provide training to help motivate them and to develop their skills and competencies for involvement:

“They could teach researchers how to do it, to explain to researchers who may be naïve about user involvement... nobody really explained the concept to me... I read a book in the library – so you need some kind of training... with more expert encouragement then more people will do it”.

“Look at how we can do it better. Train us in how we do it better – so we are more effective. Offer training for researchers in how to get the most out of the lay people”.

One area where researchers could improve their skills is in chairing meetings of mixed groups of academics and service users. One researcher commented on how meetings with service users need to be chaired in a slightly different way:

“When I’m chairing I explain why we’re discussing different items – because people may not let on that they haven’t understood what’s going on – I do this out of courtesy to ensure everyone can engage”.

Training in good practice around chairing would be of benefit to those researchers who have reported difficulties with integrating and meaningfully involving service users in committee meetings (see section 3.3.1).

Another researcher wanted help with involving young people. They raised concerns dealing with the specific issues that may arise for example, disclosure that a child is at risk. They wanted the MHRN to provide explicit guidance on what is expected from young people’s involvement and how best to do it. An enormous amount of guidance is already available on these kinds of issues. For example, advice on involving children and young people would be readily available from the Medicines for Children Network. There are also other sources of specialist advice that the MHRN could usefully signpost to researchers.

One researcher suggested it would be helpful if the MHRN provided input right at the beginning of a project to help with developing plans for involvement and to offer more detailed advice about how these could be improved:

“Is there an opportunity to for someone to take a more detailed look at the plans – after winning the bid? Maybe you could have a meeting or phone call with someone from the MHRN, to explain about how you’re going about user involvement to get some feedback. We don’t know what other research teams are doing and whether have they got a particularly good way of going about things that could be useful. Or maybe we’re doing something that would be useful to others. Could they build that into the timetable?”.

In this context one of the researchers also suggested that the MHRN work more closely with funding bodies to promote service user involvement in research and to send a clear message to researchers:

“We need to raise awareness of the advantages of involvement and keep raising these. There needs to be a clear message from funding bodies about the inclusion of service users in the design of studies – there is now a requirement to involve and there is a support available from the MHRN...”.

(c) Training and support for service users

Some of the interviewees thought the MHRN could help with training service users to become involved:

“Some academics can be a bit pompous - and if you’re not confident and used to speaking your mind then you’re not going to operate effectively... If you’re a person with experience of a mental health problem then these are the very things that are knocked to bits – your self-confidence and your self-worth... so it might be useful to address this through the MHRN... it would also provide a useful way for service users involved in different projects to meet with each other and compare notes”.

It was thought this training could usefully address general topics including:

- an introduction to research and clinical trials
- the value of the service user expertise in research
- assertiveness and confidence building
- contributing to meetings
- how to communicate ideas effectively

One researcher offered to help with this training:

“I’d be prepared to do that kind of thing – the service users give you their time – so we ought to be obliged to contribute to that training and support for service users to build up a body of people who are skilled and able”.

Training a group of service users who are willing to be involved, would help with problems researchers reported in finding service users who are suitable for certain involvement roles:

“Find good people and train them. Provide people who are easy to access at short notice and have a thorough knowledge of research...”

Some researchers commented that they are not always able to provide the support that service users need during involvement and that they might not always be the best person to provide that support. They suggested that the MHRN develop the infrastructure to offer this centrally:

“One of the problems is that we [researchers] don’t give them [service users] enough time and support. It would help if service users could link in with a wider network – so that the PI doesn’t do it all. For example, negative results in research can be demoralising for service users and they may benefit from support from people experiencing same thing. It could be central or departmental and specialised in mental health”.

“Service users might benefit from having an independent place to go and check things out if they need to - somewhere to go for support, someone who’s not in the research team”.

(d) Relationship building between service users and researchers

Some researchers had given presentations at MHRN events and found this useful. They suggested that the MHRN run more of these kinds of events as well as local ones to help researchers establish better relationships with service users:

“Could they have a regular forum to better broker the relationships between researchers and service users? By bringing together user groups and researchers to exchange information, the links would be in place, so that when you’re designing a new study, perhaps you’ll remember someone that you spoke to last year, so you’re not always having to search for the links from scratch”.

“Maybe the MHRN could help with identifying potential service user audiences for dissemination and provide input on how best to reach the right audiences. It would be helpful if our communications officer could establish relationships with user networks – to get the messages out”.

4. Discussion

This section considers some of the common themes that have emerged from across all of the 41 studies included in this evaluation. It focuses on the challenges and uncertainties that researchers have faced, with the aim of identifying what more the MHRN could do to maximise the positive impact of involvement. The key themes are:

- definitions of service user involvement
- matching individual service users to specific roles
- choosing methods that are fit for purpose
- changing perceptions of the MHRN

4.1 Definitions of service user involvement

In response to questions about the service user involvement, some interviewees discussed the participation of service users as research subjects or referred to activities that would not fit with the widely-accepted definitions of service user involvement (see Section 1.1).

There does not seem to be a shared understanding of what constitutes service user involvement in research amongst MHRN researchers. Even some of the researchers who were involving users did not seem familiar with this term.

Other researchers responded with common misconceptions about involvement:

“Researchers have had years of training to do research which is highly technical. It’s unreasonable to expect service users to contribute to the technical discussions – they have nothing useful to contribute – so it’s hypocritical and dishonest to imply that they do have something to offer”.

“As psychiatrists we know what patients think – we listen to patients’ views all the time”.

It therefore might be useful for the MHRN to develop its own definition of user involvement that clearly explains what involvement looks like in the context of adopted studies. This would help researchers to better understand the rationale and purpose of involvement and to know what kinds of activity constitute good quality involvement.

4.2 Choosing methods that are fit for purpose

In a number of the projects included in this evaluation, the service user involvement was quite limited in scope, for example service users only contributed to discussions about the practical arrangements for the participants. The methods used to involve service users were then quite limited, often only seeking informal feedback from study participants.

It also seems that some researchers have adopted a particular method of involvement without being clear about its purpose or the range of potential benefits. For example a number of studies had recruited service users to steering committees

when the nature of the project or the terms of reference for the group meant there was very limited room for service users to have an influence.

Some researchers seemed to believe that involving service users on a steering committee is a requirement for studies to be approved by the MHRN:

“It gives you brownie points on the form if you say you are having a committee of service users”.

Some researchers took this approach based on the advice of the MHRN. In one case it was questionable whether this approach was the most effective way of involving service users, because the project was a basic science project involving a seldom heard group of service users. The researcher went to considerable lengths to try and establish a committee, but none of the service users they approached were willing to get involved. Another mechanism of involvement might have suited this group better. The researcher concluded that user involvement was *‘a big waste of time and money’*.

In some cases the impact of the involvement has been limited by the way the involvement is managed. For example in one study, service users were involved as interviewers but did not reveal their service user status, thus limiting the potential for this involvement to make a difference:

“Our service users don’t disclose when they carry out their interviews, so I don’t think it has made a difference... the end product is that the people being interviewed don’t know they are being interviewed by a service user – so the main purpose gets lost. I’ve been really frustrated. The way it’s planned it is not logical. We shouldn’t just do it to say we are involving people, but do it in a way that takes advantage of the fact that we have service users helping us”.

In summary, it seems that some researchers are choosing certain methods to involve service users without being clear about the purpose of the involvement or how to make the method work well. Offering training for researchers might help overcome some of these challenges.

4.3 Matching individual service users to specific roles

Some of the researchers recognised the importance of matching individual service users’ skills and capabilities to their involvement role:

“You need a broad range of service users, a variety of people to be involved in different roles... putting the wrong person in the wrong role can make them feel like a fish out of water. It would be bad for anyone”.

Other researchers did not appear to have considered these issues. For example, a small number of the studies had recruited service users to their steering committees who did not have direct experience of the topic being investigated. Depending on the tasks they were given, this may have limited the relevance of their input.

Some researchers expressed concerns that the service users they were able to access via organisations like the MHRN were not necessarily the 'right' people to involve. For example, one researcher commented:

"[Service user groups] tend to involve people who are now well, who are very articulate and get involved – but it's some time since they have been the type of person who we are trying to recruit. I want people who can tell me things I haven't thought of... people who can say something about what it's like being recruited... It made me wonder whether we have been going about it [service user involvement] the wrong way?"

It seems that not all researchers are taking a strategic or considered approach to recruiting the 'right' service user for the job. For example one researcher reported that they had recruited a service user on the basis a verbal recommendation from another researcher. They were given the phone number of a service user who had worked on a similar project, and simply called them up to recruit them to the team. It later became apparent that this person did not have the necessary skills for their involvement role:

"The person wasn't very sensitive to people and really lacked certain social skills which in their case was related to their mental health problems. In a very sad way it made them less competent to do the job... Listening to their interviews was really painful because they ignored people's disclosure of very sensitive issues. So it would have been better for a psychologist to have done the interviews. It has to be the right person for the job..."

This researcher also commented that it was very difficult to manage the situation and to find a way to give constructive critical feedback:

"I had to give this person some feedback that wasn't uncritical, and I could tell they took it personally... I could tell that for them it is even harder to hear criticism than for anyone else... but I still need to get my point across but I don't want to upset the service users that help us... if I was doing a bad job, I'd expect to get feedback... but it's really hard to criticise service users because it sounds like I'm not sensitive to their problems. But to get good results we need to do good interviews".

In summary, it seems that some researchers would benefit from advice on more formal processes of recruiting service users to involvement roles. They might also welcome guidance on the kinds of skills and experience that are relevant to different tasks and responsibilities.

4.4 Changing perceptions of the MHRN

Most of the interviewees associated the MHRN more strongly with support for recruitment rather than service user involvement:

"The MHRN is helpful generally, but least helpful with respect to user involvement".

“All of the contact from MHRN is about recruitment. User involvement does not seem to be a major part of the process. Prompting from the MHRN would be important – it would signal that the MHRN see it as important”.

“Contacting us to get data about people being recruited is the sole point of reference for the MHRN. They’ve not proposed any other involvement or services”.

A number commented that they were uncertain about what support they could expect from the MHRN in relation to involvement as well as other areas:

“They need to flag up to research teams as to what support is available – many of us are not quite sure what adoption means. There’s some confusion as to what it means practically – what are the benefits to the project. Is there something in addition to screens and procedures?”.

“It’s not clear what’s reasonable to expect they will deliver. It’s supposed to be a bonus to get MHRN support – but it hasn’t been so far”.

A small number of researchers expressed concerns about the quality of the support they had received from the MHRN. Some commented that there seemed to be inconsistency across the hubs and suggested that the MHRN adopt a common set of standards for support so that researchers would know what they could expect.

One researcher suggested that the MHRN ask for follow-up reports to see whether involvement plans are being put into practice:

“We’re forever sending them reports [the MHRN] – a monthly statement on recruitment - if I don’t I do that then I’m harassed until I do. Maybe there is something that they could do around that [with involvement]”.

5. Recommendations

This section includes a series of recommendations based solely on the findings from this evaluation. The aim is to highlight how some of the challenges faced by the research community might be overcome. We have not considered what the MHRN is already doing to further these goals. Nor have we considered the existing constraints on the work of the MHRN for example, the fact that the MHRN does not have a training budget. We recognise that the MHRN might not be the most appropriate organisation to act on all of these recommendations, but could pursue them in collaboration with others or through other means.

Recommendation 1: Develop a practical definition of service user involvement.

This could usefully describe what involvement looks like in the context of different kinds of MHRN study and describe more clearly where and when service user involvement brings added value. This would help to develop consensus on what types of activity constitute genuine involvement. It would also help clarify how, for example, involvement can benefit basic science studies in a way that is distinct from the added value it brings to clinical studies. This would enable researchers to think about the purpose of involving service users within the specific context of their research.

Recommendation 2: Revise the MHRN application form to request more detailed plans for service user and carer involvement.

There are a number of advantages to developing the application form including:

- It would help researchers to be clear about the purpose of the involvement and to think about methods that are fit for purpose
- It would remind researchers about elements of good practice for example if specific questions were asked about budget, training and support
- It would enable the MHRN to make a more informed assessment of the quality of user involvement plans and to offer advice earlier on. This could help improve the plans and their implementation.
- It would enable the MHRN to tailor their advice to the needs of the project and the individuals involved.
- It would help with future evaluations of this kind

However, given the workload of researchers and the current concerns around 'being forced' to do user involvement', it is essential that this development work is informed by researchers' views as well as other stakeholders. The changes need to be perceived as supportive and facilitative of applicants, rather than more 'enforcement' or 'stricter checks'.

Recommendation 3: Introduce more regular follow-up of the implementation of involvement plans at the same time as offering support to overcome any challenges.

This would help the MHRN to identify where researchers are experiencing difficulties in implementing involvement plans and to develop more effective support mechanisms. This would also encourage researchers and service users to evaluate where involvement worked well or didn't work well and how it could be improved in future projects.

Recommendation 4: Develop new MHRN policy and guidance to help researchers overcome some of the most commonly reported challenges to effective involvement.

Based on the findings from this evaluation there are four main areas where this would be welcome:

(a) Involving service users as members of steering committees.

This could usefully include advice on:

- When to use this method and when not to use this method
- How to support and promote effective steering group membership for example through training and support for chairs and academic group members as well as training and support for service users
- The desirable and essential skills and experiences needed by service users in this role

(b) Managing the employment of service user researchers.

This could usefully include advice on:

- Planning for the eventuality that some service user researchers may need time off for ill-health
- Developing 'crisis-plans' – agreeing with service users how any relapses should be managed at work
- Working with HR departments, funders and other relevant stakeholders to build in flexibility at work that allows service users to take time-off when they need it - 'mental health days'.
- Ensuring that service users can access any support they may need to manage any mental health issues that arise through their work
- Supporting service user researchers in finding opportunities to develop their involvement career

(c) Formal mechanisms for recruiting service users to involvement roles.

This could usefully include advice on:

- The skills and experiences which are desirable or essential for different type of involvement to help match individuals to different roles

- Best practice in formal recruitment processes

The MHRN could also provide guidance on where and when working with the service users linked to local offices/ hubs brings the most added value to research projects and where it may be more appropriate to work with service users who are 'closer to the ground' and have more direct, relevant experience.

Recommendation 5: Develop training and support for researchers.

Researchers working on MHRN adopted studies appear to have greatly varying levels of skills and experience in carrying out service user involvement. Many are keen to learn how to make involvement work well. However, different researchers will want different types of training and support depending on their existing skills and current practice.

Based on the findings from this evaluation it seems that the key areas where additional advice/ training would be useful include:

(a) Different methods of involvement – where and when different approaches work well and what can be achieved. This would help encourage researchers to:

- be clearer about what they want to achieve and to choose the best method
- be more innovative and expand their service user involvement beyond membership of steering groups
- think about involving service users in a number of different ways within a single project – expanding involvement to different stages of research and extending their sphere of influence

(b) Developing and improving researchers' practical skills – so they are better able to support effective involvement. These skills include chairing skills, facilitation skills and communication skills.

(c) Motivating and encouraging researchers – to help them see involvement as a means of solving the problems they face in their research, rather than as an obligatory extra. This would involve raising awareness of the benefits of service user involvement in ways that connect with the concerns of researchers – better quality research design, better recruitment and retention rates and better quality data. There needs to be a focus on motivating and encouraging researchers so that involvement becomes something they want to do gladly and want to do well, rather than resenting the additional workload.

Recommendation 6: Develop training and support for service users.

Much of the training for involvement is specific to the role service users are asked to play and the research context for example, training for service user interviewers. This context-specific training is best provided by a research team and tailored to the needs of a particular project. However, there are some forms of general training that may be useful to many service users involved in different ways. These include:

- an introduction to research methods and the terms used
- confidence building and assertiveness
- IT and communication skills

This type of training could be usefully provided to large numbers of service users at a regional or even national level. The MHRN could offer this general training to all service users working with local offices/ hubs who are willing to get involved in research projects. This would provide researchers with a pool of service users who are better equipped to take on various involvement roles.

Service users may also benefit from informal and formal mechanisms of peer support, where they can talk to other service users about their experiences of involvement. The MHRN could promote the development of service user networks for example through conferences, use of social media and newsletters that would enable service users to share the learning and obtain support from their peers.

Recommendation 7: Develop MHRN guidance on service user involvement in the dissemination of research.

This could help to develop a shared understanding of what is meant by service user involvement at this stage, in particular to clarify:

- The distinction between public engagement activity, communicating findings to a service user audience and service user involvement in dissemination activities.
- The benefits of involving service users at this stage and what is considered good practice.
- How the MHRN can help at this stage for example through participation in MHRN events.

Recommendation 8: Work with other organisations to promote service user involvement at the early stages of project design and bid development.

The MHRN could usefully work with funding agencies and other research organisations (for example research design services and research ethics committees) to promote early involvement and ensure a consistent message and approach across the system. This could involve identifying funding and other resources to support this involvement as well as developing new policy and practice.

Recommendation 9: Raise the profile of the MHRN and increase awareness of the work it does to promote user involvement.

The MHRN should provide researchers with more information about the user involvement resources available and the different kinds of support it can offer.



*Mental Health
Research Network*

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Health Research***

Case Studies

Part 2

Case Study 1: Service user member of trial steering committee

Background

This randomised controlled trial involved service users in the early stages of project design and also recruited a service user to the trial steering committee. We spoke to the lead researcher and the service user member of the steering committee. The practicalities of the committee meetings have proved a barrier to involvement, and the service user has therefore finally resigned. The researcher and the service user describe what the challenges were and how these barriers might have been overcome.

The researcher's experience

How well has the involvement worked?

The service user involvement on the trial steering committee hasn't been successful because of practical reasons. The committee meets face-to-face once a year and in between we have teleconferences. The service user attended the first meeting – but hasn't been able to attend at all after that. There are various reasons for this - she's been ill, she's had family problems which have obviously been a priority and she has registered for a degree course and the times have clashed with the meetings. She doesn't like teleconferences and doesn't want to do them – so her participation has fizzled out. So her impact has been low for the last 10 months. There's only so much you can do to accommodate people – and now she's decided to resign.

The challenge has been that the service user is not able to take part in the way that the rest of the committee likes to work. The other committee members are doing this as an extra to their day jobs on a voluntary basis and I have to accommodate all the members. As they are spread across the country, the only way to hold discussions is through teleconferences – but the service user has problems with teleconferences. Working round all this is really hard.

It's been frustrating not to have the service user involvement when we've needed it. But when you've got a volunteer who's agreed to participate, but is not delivering the goods, it's not like with a professional where you can say 'we're going to have to let you go' – you've got to be patient and supportive.

How have you tried to overcome these difficulties?

We had lots of informal discussions with the service user in between the teleconferences – keeping her up to date and asking for her views and opinions. I think service users need more informal communication between formal meetings – to keep the pot boiling – to keep them going.

We also invited the service user to join the trial management group which does all the day to day business. We hoped this would support her involvement at a greater

level. If people land in a meeting once a year, they may not know what's going on and you want to avoid that.

But you need to be clear about boundaries. It's not really appropriate for the same person to be on the trial steering committee and the trial management group – because the steering committee is supposed to be independent. So this may not be the right way to go.

What difference has the involvement made to your research?

Her involvement in the management group worked much better because this is where you're talking about the nitty-gritty – it's much more regular business and there are more the issues that impact on the service users. It seemed to be an easier mechanism for involvement and the service user had more of an influence.

She was really good at drawing things back to the question 'Is this good for the service users?'. She was bright and capable and right for the job as she wasn't afraid to speak her mind. At one point, I was being a bit wishy-washy in my approach to recruitment. I was bending over backwards so the potential participant wasn't put off. The service user pulled me up on that and reminded me that it's not normal to treat people like that. She was saying 'if they don't play by the rules – you need to get rid of them'.

Based on your experience, what would you advise others about service user involvement?

Think about involving different kinds of people for different kinds of job. You need certain kinds of people to be on a trial steering committee – people who are able to make a commitment over the long period of a trial, who are able to travel to meetings and take part in teleconferences. They need to be bright, well-informed and confident people – willing to shove their weight around if they need to.

Write an accurate job description and a person spec – something more formal that includes specific criteria. Then service users know what's expected of them, you can be sure they are able to participate and this can all be agreed earlier on.

If you involve people with mental health problems, they might become ill. Some may have physical health problems as well that you can't predict. So involve more than one service user - so if one can't attend, you can rely on the other person. Two people are better than one – they can give each other moral support.

The service user's experience

What aspects of your involvement have worked well?

I was very well briefed initially. The researchers were very thorough in explaining what the project was about and what my involvement could be. I spoke by email with one of the research team members and then met with her and talked through the roles. Then I met with the chief investigator and the researcher – for one and a half hours - to talk about the aims of the project and what my role might be. They gave

me all the information that had been written up already and gave me the websites to look at the research behind what they were doing.

The trial management group meetings also worked very well. They met often enough for me to keep up with it. I got loads of minutes from all the meetings and all the information given to everybody else before the meetings. At the meetings themselves, I was unquestionably treated as an equal person by most people. If I asked a question what I wanted was a proper answer – a full answer – not something that was vaguely put in English that I might understand.

In between the meetings, if I had a question then the researchers were always straight back with an answer for me – on the phone or through email. So I never felt left out of the group at that level.

They also supported me very well. They always met with me before and after a meeting. The lead researcher met with me afterwards to check I was personally alright – and if I wasn't we'd talk through what my issues were - and also professionally - whether there was anything I needed an explanation for or wanted to say.

It was very, very thorough. It was just the practical issues that were a problem – the researchers couldn't have done it any better.

What hasn't worked as well?

The steering committee was more difficult. We met so infrequently – months and months apart. They did a lot of the work through emails and I found that quite difficult to keep up with – because I didn't know the people very well – I didn't know quite where they were coming from.

I met with them once and then the second meeting was down in Oxford and I live in Nottingham. For me to travel, it means I need a friend or my husband to come with me – for what was essentially an hour's meeting, to go there and back was just too much. This was a change from what we agreed when I met with the steering group at the beginning. They had said that all meetings would be in Nottingham.

Then they started doing teleconferencing which we didn't agree to at the start either – I explained I can't cope with that. I have enough voices in my head, I don't need to listen to four more. So I said I can't do this. I can't concentrate well enough. I understand why teleconferencing was good for them – but I then felt I had to resign from the group, because I really can't contribute anything.

The researchers tried to overcome that by filling me in on what was going on and they emailed me and came and met with me and talked it through. But in the end I didn't feel like I was part of the group. And if I can't fully get involved, and am just paying lip service, then I'm not doing it. That's just me. If I can do something properly and really have an impact then I think something is worth doing. But I was having a really low impact on the steering committee.

I did have a lot of other commitments at the time – but I have participated in other projects successfully which were much more demanding of my time...if I had felt I was being valued by the steering group I would have continued.

Maybe I should have voiced my disquiet at the changes in how they ran the meetings directly to the steering group and more forcefully - I didn't do that. I only told the researchers and they weren't in a position to really change things.

What difference do you think you made to the research?

I think I made more of a difference on the trial management group. It was much easier to pick up on the issues there. It was face-to-face meetings which gives you the opportunity to listen to what everyone has to say and to discuss the issues. Because the majority of people answered my questions properly, I felt right I can actually now join in – I can make my own points.

There was a discussion about the assessments of patients prior to joining the project. They were talking about the length of time it was taking and whether they should shorten it. My view was that you shouldn't shorten it – you need to be absolutely certain that any patient joining the project has a full assessment so they get the best out of it. The group was pretty divided on that one. In the end they decided the assessments would go ahead in full.

What would you advise other researchers about service user involvement?

Thoroughly brief everyone so that everybody has a clear understanding of what the role is. Be clear about what you are going to ask a service user to do before getting them involved. After that be as considerate to the needs of the service users as you are to the other professionals.

Genuine communication between steering group members is important and this needs to be a clearly identified as an essential requirement for all steering group members - including the chair. It takes more time and effort, but it is worth it when this facilitates genuine service user involvement

Make sure to challenge service users and allow them to challenge appropriately. That's quite crucial. The service user involved has got to understand that they're not right just because they're a service user. They should be listened to - but may not have their point taken up. Professionals also need to understand that they have treat us as genuine equals – it's no good placating us, if we wobble on about something that's got nothing to do with the meeting.

You have to get the right people to do the right jobs. You can't put someone on a steering committee just to tick your boxes if they get lost after 3 minutes. That's unfair. But you can't just rely on service users who have been in management positions to get involved. I felt I was being overused by other research groups I've worked with in the past – because of my experience and professional background. But just because I can cope with meetings and speak the language – that doesn't make me representative. That began to worry me.

There are service users who need to be involved who are as not as well-educated – their ability to follow a meeting may be limited - but they're the majority of the population – and therefore there has to be other ways of involving them. It may not be reasonable to expect them to take part in a normal meeting where they can't possibly understand what's going on – but somebody from the committee could meet with a group of service users. It could be managed differently.

Service users have got so much to offer – they do know far more than anybody gives them credit for – so someone needs to work with them who is able to work with them and then take it up with the steering committee. Someone needs to work with that group and really listen to what they've got to say and then feedback what the committee says in response - so that they are genuinely involved. There are ways of doing that. If steering groups need service user involvement, then they are going to have to have a rethink.

I think it's important to use service users who are in the services now - as their experiences are current. However, if researchers involve service users who are using services, then relapses are likely to occur. This needs to be taken into consideration when setting up involvement.

There is also a view that finance and statistics are two areas that are too difficult, if not impossible, to involve service users in. It must be remembered that service users come from a wide variety of working backgrounds. Professionals should remember that there will be service users who can be truly involved at an equal level.

Case Study 2: Service user reference group member

Background

A service user group was set up to enable ongoing involvement in all of the projects within a five-year programme grant. We talked to one of the researchers and one of the service users who worked together on an early study within the overall programme.

The researcher's experience

How did you work with the service user group on your study?

The service user group was set up at the same time as our study – so there wasn't time for them to input into the design. The involvement was later on, during a discussion of the results.

We did more than just present them with the results and say 'What do you think of that?'. We made sure we structured the discussion - so we put the findings from this study together with other research findings, largely from our group, and talked about the issues more broadly. For example we talked about special observation, which is when a nurse keeps someone within their reach, if they're at risk of suicide or self harm. Our findings made us think about this as being more like surveillance than a therapeutic intervention. So we ran a workshop with the group and asked them about their views on the use of the word of surveillance. Did their experiences of observation chime with the idea of surveillance? Had it been therapeutic in any way? What could nurses do to make observation a more bearable experience? How is it be done well or badly...

How did their involvement make a difference?

The group helped to refine some of the conclusions and provided an alternative perspective to our own views. People with a personal experience of mental health problems view things differently to ourselves. The group also added an extra dimension, because we hadn't collected data from service users at that stage. So it helped us explore the implications for practice.

Working with the group also helped with developing the intervention we are testing in the rest of the research. For example we got the views of the service users on the best way of dealing with medication refusal. This informed our approach to medication management within the intervention.

How have you continued to work with the group?

Now we meet with the group about once a month. Other researchers use it as well. So it's usually a packed agenda. We don't do formal presentations, but we give people opportunities to contribute their own ideas. We try to generate discussion that will give us feedback - that we can take away and make use of – we don't just want it to be a talking shop.

Since our initial study we've been thinking it would be good to interview service users about special observation to find out whether they would welcome being consulted about its use - and we've been discussing this with the group. We've asked them about how we should approach this kind of research and how it could work in practice. Sounding out these kinds of ideas can be very helpful, particularly to fine tune developing projects, and to develop future funding bids.

What makes the group work well?

The service users themselves. The group hasn't changed much over the past 12-18 months. The same people have stuck with it - which has really helped because you get to know people and you don't have to explain the background to your research all the time.

There's also a strong training component. In the morning we have research discussions and in the afternoon the group gets research training. This is good because as time goes on the service users have a better understanding of some of the problems researchers face in doing research - then you can then talk to them about the practicalities. There's a growing understanding of the mechanics which is very helpful when discussing potential future projects.

Have there been any challenges?

It can be difficult to explain the research and the findings in a way that's accessible to the group – although really that's a useful exercise, to get us to explain our work in a more accessible way.

If you could do your study again, would you do anything differently?

It would have been interesting to involve service users from outset. They have since been involved in planning a related trial which has been helpful. It might not have made much difference to what we went on to do – but there were probably one or two things that would have cropped up that we hadn't thought of. That tends to happen. It's that dreadful feeling once you start looking at the data, when you realise that it would have been nice to have asked one or two more questions. If we had discussed the study with service users beforehand they might have spotted that. They have definitely made a difference in some of the other studies we've asked them about.

What would you advise other researchers thinking about setting up a service user group?

Make a medium to long term commitment. We've been lucky that we've been able to do that. It's largely because we have long term funding for this programme. It's made perfect sense to set up a group like this and now they are being consulted by other researchers – so it seems to have taken off.

The fact that the group has been going on for sometime also means there's an accumulation of knowledge and interest and awareness amongst the members – that does make a difference. Long term commitment is also needed from the service users as they are acquiring skills and competencies.

Working with a group like this is not just about presenting results – it's more like an ongoing conversation. You can say 'Remember when we were talking about this – this is where we are now with it' and it's very helpful to be able to have that kind of conversation.

The service user's experience

What has made your involvement on the group work well?

Having a space where you get to meet other service users and professionals and where you're really valued. We have so many professors coming to present their research proposals – it makes us feel valued - we are actually able to make a difference. We went to a conference and presented our work - that was a massive opportunity for us. It makes you feel really valued and makes you feel you want to be involved.

And there's the fact that we have been given honorary lecturer positions. We're remunerated for our time. We are able to access training and all the resources that university students can access.

It's also been beneficial that the group includes service users AND carers from across a wide area. It has to be varied – so we can contribute to a variety of topics. We have had stuff that people have found really hard to understand – like self-harm – there's members of the group that self harm – so it has been enlightening to hear someone talk retrospectively about self harm.

What kind of training have you been offered?

We've had training around research because as a group we decided we wanted an element of critiquing research proposals. That hasn't made a great deal of difference to me personally because I already had those research skills – but there were other members in the group who had no skills in understanding research. So for the group as a whole, it helped to get everyone to the same place. It's made the individuals become a group which is very, very good.

It's also enabled us to say 'We understand this from the training - but now you're telling us that'. It has helped us to challenge a bit more.

What support have you had from the researchers you work with?

There are obviously good researchers and there are obviously bad researchers. When we talk about bad and good – it's not about their academic ability or the research project – it's about whether they take the time to explain their research. Do they value service users? Do people feel they are listened to? This is the most fundamental part of any successful service user involvement. You can have a fantastic research project but not be so good at communicating with service users.

Our involvement has been successful because of the work of the junior researchers a lot of the time – but even the professor we work with is not your normal professor - because you can call him up and have a chat.

How has your involvement made a difference?

I think some of the points that have been come from the group have never, ever, ever, ever been thought of by the researchers themselves – because they haven't been patients. You may work for the system but not fully understand that system.

We've demonstrated that the power dynamics of the mental health system impact greatly on service users' experiences and I don't think the researchers take that into account sometimes. We've made sure we have challenged assumptions - there's quite a few assumptions!

For example looking at one of the projects and how they were going to have the two different groups in the trial, I was really interested in how they were going about that. I wanted them to be mindful that you often get the same kinds of people who take part in research – and you have to think outside the box to involve those people who wouldn't naturally be involved. That's about time, being present on the ward and building rapport with people.

We've also challenged the necessity of some of the research. We've said we don't see the value in this – or we're worried it might be used in negative ways. So I feel we've been able to influence what sort of research takes place.

So the fundamental point that we've demonstrated is that if you work in a certain way with service users you'll maximise any research undertaking. When research proposals go in now it's pretty standard for a service user to be a co-applicant. None of us would be a co-applicant without really knowing, understanding and questioning the research.

What would you advise other researchers thinking about setting up a service user group?

Develop close relationships with service users – even if you're just emailing 'What do you think about this?' or 'Can we meet and talk about this?' or asking 'How do you think this would be seen by service users?'

Keep talking to people for that process to make it feel really shared. Involve the service user in the whole process, in the submission for any research grants and working alongside the researcher, to support the researcher if they're doing research on a ward – to be central to the research.

The biggest key to working with service users is not about the disability but about the access. If you minimise those barriers and change what you're doing – then you'll have such a wonderful experience. Any work you do, it's going to be collaborative and meaningful. You'll see how good research with involvement can be.

Case Study 3: Service user member of trial management group

Background

This randomised controlled trial involved service users in developing the bid and as members of the trial steering committee and the trial management group. We spoke to the lead researcher and to a service user who was involved from the beginning and is a member of the trial management group.

The researcher's experience

What has helped the involvement to work well?

The service user himself. He comes to all our meetings and gives feedback on any documents. He reminds us of the current implementation context. He's got a very sophisticated understanding of that - he's been engaged in policy and education to try and change things so that health services are more responsive to people's needs. He makes us think about that.

So the lesson there for me is that it's important *who* you have as your service user. Some service users are only able to represent their own experience. While of course this is valid, if it doesn't generalise, then you could go down tracks that are only relevant to a small subset of individuals.

You can't just choose anybody because they happen to have been depressed. You have to think very carefully about who you involve in the same way one thinks about a statistician or a health economist. As a chief executive or principal investigator for the research, you need to select the right people for the needs of the project. This level of sophistication isn't always understood in the mental health research field – thinking about who this service user is and what they might bring. It shouldn't be a box-ticking exercise.

I think it's also important to always include the person in the discussions – to treat the service user just the same as any one else on the team. When I chair the meetings I make sure he is able to say what he wants to say. Sometimes other professionals find involvement to be a very new experience – particularly the technical bods. But the clinicians are well-used to that agenda.

Also when I'm chairing the meetings I want experts from different areas to contribute. I wouldn't expect the service user to know what the statistician knows and I don't want them to do that. When an expert is telling us something, we have to recognise that this is someone speaking with authority – the same goes for the service user input. It's my role to distil all those views – like a chief executive managing the different parts of an organisation.

The other key factor is that the service user was involved from the beginning - so he has a big buy into this and he knows where the project has come from.

What difference has the involvement made to your research?

The service user holds us to account. When we are talking, he brings us back to the implementation issues and the care of people with depression – what impact would this have on me as a patient? This is very useful when we as scientists can go off on the technical discussions. He makes sure we don't stray.

It's about the direction of the research and the relevance and translational utility.

Is there anything you would have done differently?

We could have involved a couple of service users not just one. I think this would avoid the danger of drifting into anecdotal experience and they could boost each other's confidence. Also then if someone gets ill – you have a back up.

Based on your experience, what advice would you give to other researchers about service user involvement?

Have a really good think about what you need from the service user – then think about what they need to make their involvement really effective. It's probably worthwhile thinking about interviewing the service user for the role and having a person spec - so it's not just about having a service user experience. But you also need to avoid always going to the same person.

Be aware that assertive academics may make the service user feel overawed. Make sure everyone is able to contribute – good chairing skills are important.

Treat the service user like anyone else – an equal member of the team. Enable people to feel comfortable to speak. Invite people to speak without putting them on the spot – and shut people up when they butt in and make them wait their turn – including the service users!

The service user's experience

What has helped your involvement to work well?

A sense of respect around the table. There's a good atmosphere. All the meetings have been extremely interesting and I hope I've been helpful – I've learnt a lot. My relationship with all the members of the group, I'd like to think is a very good one, and the researcher has involved me right from the beginning.

I've attended 3 or 4 meetings a year for the past couple of years. All email discussions outside the meeting are shared and I'm asked for comment and involved with all the developments - so I have been totally involved throughout. The conversations have been good and the researcher has always been very, very helpful. He's answered any questions I've had and reassured me that my questions are perfectly appropriate.

Sometimes when you're working in such a refined environment – the conversations can be amazing and the levels of expertise really high. I found myself completely and utterly struggling with some of the conversations – but I trusted the people round the table – which is very important. They took an enormous amount of trouble – that's one of the most impressive things. If everyone delivering care was taking as much trouble as the people designing this study, then things would be very different...

Have there been any challenges?

It can be intimidating to sit round the table with the people who have written the national care guidelines on the topic – you can be a bit mute. It's all about competencies and confidence. Because I'm a qualified doctor some assumptions may have been made about my level of competence in terms of being able to interpret statistics and figures and all the rest of it.

Being involved in such a study can be extremely daunting. Nobody should make any assumptions around competencies around the table.

Also I didn't always understand what some members of the research team were doing in terms of piloting in different areas. I wasn't always clear about what was going on – because they had some conversations about the rolling out which I wasn't always privy too...

How has your involvement made a difference to the research?

I have been quite challenging especially around the design of the study. I'm not interested in dissent for the sake of it, but challenge is important to keep things tuned up.

I've tried to keep things real and asked questions about what this [intervention] is going to look like – we've had huge struggles wondering what it is exactly. The cynic in me as a service user, I've had to say well, what a lot of people get is a mayhem of miscommunication or poor communication – seeing different doctors every time they go to the surgery or up to the hospital... And one of the issues for me about all studies is how do you get a 'usual care arm'? Usual care is not a uniform thing across the country.

The study is a very rigorous one, but the concern for me has been that when it gets rolled out, the people out there will interpret terms like 'usual care' in all sorts of different ways. When an intervention is being rolled out across different contexts where other fundamental things aren't in place – like excellent communication – then it's just not going to happen. I have all those issues rolled up into my rucksack – and I've spilt the beans at regular points over the past couple of years!

I've also challenged the term service user. I challenged that in the first meeting. I can't abide it. I'm a person using a service – I'm a tax payer – service user makes us sound passive and comes with a load of baggage. We need to break down some of this language.

Is there anyway you think your involvement in the study could have been improved?

It may be a good idea for the service user to have their own advisory group – as a sounding board. Some way of garnering the views of 8 -10 diverse people. So you could go to that group after a meeting and see what they think about the things that were discussed. It would be a way of checking that I'm in touch with reality. I'm prone to bias just like everybody else. From my work in the third sector, I'm very mindful of the issues around people speaking up for others...

I would have also liked to have gone to some of the pilot sites – to meet the people they were working with. If I had had more hands-on contact with the study at the front, it would have given me a greater sense of connectedness. I'd have heard it from the horse's mouth, so might have had more to contribute about how the work was being done...for example, around the recruitment and the approach to training...There may not have been a budget for that, but it need only be 3 or 4 days a year to visit some of the sites.

Better preparation of the group may have been helpful. Something a bit more than the standard introductions of what people do. It might be valuable for all studies to have a one hour session like this at the beginning. When you come into a room with a lot of different people who all have their own psychologies – it's important to understand each other before you start work. Otherwise it can be a bit of a surprise and a shock. It could also help you find your allies. The person who might help you most in a group, may be someone you've not met before...maybe people could say something about why they think the study's important – so it's more personal – so you understand where everyone is coming from...and what their expectations are.

What advice would you give other researchers about service user involvement?

Good preparation.

A real sense of joined-upness during the project – for example through site visits.

Some sort of sounding board for the service user – so they can be more confident they are presenting a balanced view. This would also give them more of a mandate and some support. A lot of the people round the table, they come from organisations so they have their own mechanisms for support. They come from a background of academia – so confidence is not usually an issue. There needs to be a balance so that the person coming in from the outside has as good a support mechanism. I've not had a big problem doing that – because I'm familiar with the language and the methods – but other service users might not be...

Case Study 4: Service user researcher

Background

This project involved developing a measure as part of a bigger programme of work. Two service user researchers were grantholders on the programme and were involved throughout. Another service user researcher was employed to help deliver this project and was involved in recruitment, data collection and analysis and dissemination. We talked to the lead researcher and the service user involved in the delivery of the project.

The researcher's experience

What factors contributed to the success of the involvement?

Involving some service users right back at the inception of this project and then in writing the protocol helped to make this a success... because we incorporated the service user perspective into the entire fabric of the application. Without that we would have been writing it from our perspective and then having to change it on the basis of later input.

That's something I've adopted as routine now – to get a collaborative team from the beginning, which includes a service user researcher. They are then part of the team in the same way as the health economist or the statistician. So that's their job – they are a co-applicant, who contributes to the whole of the project, specifying the research question, the methodology, where we're going to run it...doing all that helps me to feel confident that all those perspectives are being included and I hope makes the service users feel like they are equal members of the team.

How did the involvement of the service user researcher make a difference?

It's made a huge difference – particularly in terms of the focus of our questions and the measure we were developing. It's also made a difference to the recruitment. It has helped us to access the service users who may not have wanted to speak to a more traditional researcher, but were willing to open up to a service user researcher. This has given the project a greater depth by recruiting a wider range of people.

It also made a difference when we tried to recruit participants via health professionals. If a service user approaches a professional, this presents a different dynamic than when a junior researcher is trying to recruit service users. Then it's more difficult for a professional to say 'My service users won't want to take part – they don't like research' when a service user is there saying 'I think this is really, really valuable and that service users will want to take part in this project'. Senior professionals can say 'I know better than you' to a junior researcher, but they can't say that to a service user.

Having a service user researcher involved also seemed to enhance the data collection and the interpretation of the findings – different points were emphasised

with the service user perspective. But they have had an influence on all aspects of the project really - because they were an integral part of the team.

The service user perspective was also helpful in the dissemination. The service user researcher was able to reflect on the research and what they experienced and fed that back. They were able to tell the professionals that a lot of service users get a lot out of taking part in research and that it's not necessarily a negative experience.

How did you recruit the service user researcher?

We advertised for a service user who had experience in research methods from a health discipline. We recruited in the same way that we do for our research assistants, but of course they had to have the additional qualification of having experience of mental health problems.

How did you train and support them in their role?

We identified what their training needs were, and they did receive some additional training. We have a separate support and supervision mechanism for our service user researchers because we bear in mind the fact that different issues may arise because of the interaction between the job and their mental health.

So the service user researcher was part of the project management meetings for the whole team, but they also had a separate, regular meeting with a senior clinical psychologist to help them look at their role and reflect on it. The psychologist also helped them plan what they would do if their mental health problems arose during their job.

You can't always give enough support to the service users during project management meetings. Often service users need extra support, and extra time to do the job, particularly if they are going through a slight relapse. They may need more time off and more flexible working arrangements. For example service users may feel well enough to be at work and do some data analysis but not to go and visit a patient in their own home for an interview. So managing their work load is useful to do separately from project managing the team.

Is there anything you would have done differently?

We could have had much more pre-project consultation. This project started four years ago and we've learnt a lot from doing this work. Now what we're trying to do within our department is to integrate service users much more into the culture so that they are also involved in coming up with the ideas for research projects.

I also think I wasn't realistic enough about the time that might be needed for service users. We assumed they would be there as much as our other staff – but mental health problems get in the way and people may need more time off. So you need to factor that into the equation when planning what you want to do - that's part and parcel of having service users involved. I think that would have helped them to be able to take time off when they needed it and to not feel pressured.

What advice would you give to your peers about service user involvement?

Get people involved early on before you've developed the research question.

Get a discussion going with service users about their priorities for research and match your priorities to theirs.

Get service users involved at all levels.

Be realistic about what they are going to do – factor in their need for time-off.

Provide extra support and supervision that's separate to the main project team.

The service user's experience

What helped your involvement to work well?

I've got quite a bit of research history. I had eight years experience before I went off ill, so I've got a basic grounding in research. So I felt confident I could do the job - but that was tempered by the fact that I hadn't worked for seven years. So it was just getting my confidence back and that's been one of the best things about the job really...I remember on one of the first days I was here another service user researcher asked me 'What do you think you'll be doing in five years?'. I think that was the first time since I'd been in hospital that anyone had assumed that I would have moved forward. That's stuck with me ever since...it was a sea change for me – being with people who have sense of purpose and direction.

The project was really well led and the research assistant was brilliant. I couldn't have done anything without the encouragement and support of everybody here. I had a couple of episodes of ill-health and they've even managed to work round that. I've had quite lengthy periods of being off and they've accommodated me through that. Though they always say it's not a problem, you always have that sense that you are letting people down...there's a little bit of guilt.

It really helped that there were two service user researchers working on the project – so there was someone who could give me support and act as a mentor for me. I am very lucky working here aren't I? It's been fantastic they've been really good with me.

How do you think your involvement made a difference?

A lot of research is carried out, especially in psychology, by psychology graduates. I'm older and have more shared experience with the participants. It was easier for me to strike up conversations. I put a different angle on it – it's hard to explain – but I've been through the system...

I think it encouraged people to take part in the research. I work in this environment but I'm also in the mental health field. There is still a 'them and us' culture and I think although sometimes uncomfortably – service user researchers can bridge that.

As a service user you come across some types of researcher that don't relate in anyway to your life – so you feel like someone who's being prodded. When I was on the ward someone like that came to do a study on me and it was absolutely dreadful – and I think I'm not like that.

Some researchers seem not to have a lot of empathy at all. It's about getting these questionnaires done. In this department everyone's really good. Research isn't the most important thing is it? It's the person who's getting something from the research that's most important. If that means not pushing people into doing it then that's fine with me. I'm not as ambitious – I'm happy where I am – targets aren't that important to me.

There's a whole body that sits over the programme and I'm part of that. We monitor exactly how many instruments are being used in the assessment. We've been good at making sure people aren't overwhelmed. Unfortunately we have to do a certain amount to get validity for publication – so we've made sure there are time limits – it shouldn't exceed one hour unless the person is happy for it to do so. There's a tendency for add-ons, for people to think 'Oh that might be interesting to look at – while we're doing it'. But there were some questionnaires that we thought were far too difficult for people to go through, given what we were already expecting them to do.

I'm also quite good at presentations. I try not to be at all academic – I like to try and communicate the ideas clearly if I can and I'm generally well received – you wouldn't get any jargon from me. I do enjoy being a service user and addressing professionals. I'm a little bit polemic - when you get a chance to stand up in front of people – you can slip in little bits of where you think things are wrong and where you think they could be improved.

I think part of reason I was employed was because the head of department is very keen on a recovery model and the idea of service user researchers being a walking-talking example of that - showing that you can get back into society and make a difference again.

What support have you received to help you in your role?

I've had supervision with the lead researcher. We have a clinical supervisor as well. I see her once a week. That's important as I've found it quite difficult on occasions because you see quite a lot of yourself...occasionally you'll see people who have recovered to some extent, to an extent where you were quite a while ago. So sometimes it's like you're looking into your past. There's a tranche of people who live in similar social housing, with similar social problems and economic problems and there's a lot of me in that - it can be difficult. But saying that, at other times it can be a real joy - you meet some absolutely fantastic people.

So it's good to have that support because you can just talk about it, and once you've spoken about it, you can get rid of it...you can generally walk away a bit better.

Is there anything you think could have been done differently?

Not for this project, but more generally – there's no clear entry or exit point to being a service user researcher. It's pretty much the same as being a researcher - you're always tied to the next project or the next bid coming in. But there's even less of a career structure with a service user researcher. Hopefully that will change with time...

Somehow you need to gain some level of qualification – that's awarded from the body that does the research - so that the skills you gain through involvement are accredited. You get a lot from feeling you've professionally attained something.

What advice would you give to other researchers about service user involvement?

Just drop the term service user and regard them the same as anyone else – when their views are needed they'll speak up.

Push the service users – that's one thing that's really missing in how service user researchers get treated – they get wrapped up in cotton wool. Although I think there's a fine line between pushing people and knocking them over – but the more you give people to do, the more they will do and the better they'll come up...

Case Study 5: Service user interviewer

Background

This project involved research into the organisation of mental health services. A community representative joined the steering group and service users and carers were involved as interviewers. We talked to the lead researcher and one of the service user interviewers.

The researcher's experience

What helped the involvement of service user interviewers to work well?

We were careful about the recruitment of the interviewers to include people with different experiences – experience of research and/ or working with older people - as well as users of mental health services. We developed a call for expressions of interest and we were careful with the selection criteria. We made it clear that we were not just interested in people with research qualifications, since we were providing any necessary training. We asked for experience of working with or spending time with older people with mental health problems for example people who regularly participate in older people's community groups.

We sent the person spec around as many groups as possible and asked for it to be forwarded on. I did telephone interviews with the people who sent in their CV and asked them questions to gauge how well they met the criteria. One of the main things was whether they would be comfortable calling people and talking to them about the research project – so they also had to have an interest in the research.

The interviewers were based all around the country as it was a national project, but the management side was based here. We held two training events for the interviewers because not everyone could come on the same day – which meant it was a bit smaller and a bit more informal. We gave out a lot of information on the day and covered data protection and safety at work as lone workers.

Importantly we followed this up with one-to-one conversations. I spoke to the interviewers on the phone the night before their first interview. We went through the questionnaire just to check whether they had any questions. Remembering everything from a training day can be difficult so I think that was a helpful reminder. – I then called them for a debrief afterwards. I kept a log about what issues had come up in the interview or what questions the participants had asked and circulated this to all the interviewers.

After the first or second interview I also rang the participant. It was just a courtesy call to see how it all went and whether there was anything we could have done better. So I could give that feedback to the interviewers as well. I think all this preparation and support was really key to making the involvement successful.

How did their involvement make a difference?

When it came to the training event, the interviewers gave a lot back in terms of contributing their perspective on services – so it was an extra ad-hoc feedback group.

But the main thing was that we got glowing reports back from the participants. I think there's a subtle difference between a service user interviewer and an academic researcher. In the end, we probably got the same quality of data back because we were using a structured questionnaire – but the experience for the participants may have been a bit different.

I suspect that the participants feel a natural sense of comfort when engaging with other people who use the same sort of services. I think service user interviewers may have a different sort of antenna to the other researchers – which probably makes an interview feel like a more natural experience. We want participants to feel as comfortable as they can be, and not subjects of an experiment. It's as authentic as it can be.

And maybe when you're setting up the interview in the first place – a service user ringing up another service user – then maybe they are more likely to take part... in the context of declining rates of participation in a research, I think it's a good thing to try and make sure that the experience is as positive as possible – so people will agree to take part again.

Is there anything you would have done differently to increase the impact of the involvement?

Some of the interviewers didn't get involved as early as we wanted them to. The university needed to carry out background checks which slowed down the whole process. What we should have done is started the recruitment of the service user interviewers earlier than we did. In some cases the interviewers didn't do nearly as many interviews as we hoped - because they got involved too late.

This wasn't just linked to our university. The local trusts also have to scrutinise everything and issue research passports. This is difficult enough for researchers who have been working here for a long time. For someone who is new and with the added dimension of having a background as a service user – there are other questions which can take even more time to address.

It was all handled professionally and sensitively but it takes a lot of time. It also meant there was a delay between some people receiving the training and starting their interviews – which made the briefing calls all the more valuable.

What advice would you give to researchers to maximise the impact of service user involvement?

Involve people early in the process and have a continuous thread of involvement throughout your project – so that you have input from service users at all stages.

Think about involving different groups of service users and carers in different ways. For example in my next project, one of things I'm planning is to talk to an MHRN

group. I'm expecting them to be very experienced in research and so I'm going to seek their input at a strategic level. But I expect a formal research group like that won't have representatives of older people with mental health problems. They can't be representative of everyone. So I also going to talk to people who have greater awareness of the condition we're studying. I think it's valuable to have a greater mix of people involved.

Do more reading on research on service user involvement. There's a lot that's been published, including material from INVOLVE, which I think would be very useful.

The service user's experience

What helped your involvement to work well?

I had a lot of relevant experience. I have been involved as a volunteer research interviewer with my local trust, interviewing adult patients on acute wards. I have studied to postgraduate diploma level. So I've looked into research which made me feel more confident as a person who's qualified to do interviews. I also used to volunteer on an older people's ward. So I'm used to working with older people in a friendly way. That helped.

I thought the research was important as well. I have just been under mental health services for the last 13 years and chances are I will end up under them again. So I have a vested interest in making sure services run well when I'm older, and hopefully they will run better for my mum, who has a severe and enduring mental health problem. That helps in your enthusiasm for getting the research done. I also feel strongly about getting people's views across... getting across exactly what they want to say.

The researcher I worked with was very pleasant and understanding all the way through, putting me at ease. He was good at keeping me updated and open to talking about issues coming up in the interviews. So even though I was miles away I felt like there was support there if I needed it. The university was helpful as well when I had to go there for an occupational health interview. The occupational health doctor said they would also be there for support if I needed it.

We did get some training, which was a bit rushed – but I thought they told us what we needed to know. There was a lot of background information, maybe more background than we needed but it was good to put it in context. Quite often when I went to do interviews there were carers present. The carers had a lot of questions and I would probably have been less confident answering their questions if I hadn't had all the background information.

This the first piece of work that I've done where I've been paid at a level that is equal to my level of qualifications. I'm mostly asked to do stuff for free – but just because you are service user doesn't mean you receive benefits. I have been involved in projects where everyone else was being paid to be there except me. Sometimes they give you £20 and expect you to pay your travel out of that as well. When it costs you £18 to get there – that's taking the mick!

Working on this project was a positive experience and I would like to do it again. I used to have really bad anxiety problems. Now when I do stuff I'm always really surprised that I felt confident doing it – and it's done my CV good as well.

How do you think your involvement made a difference?

I had empathy with the people I was interviewing. I understand and know what it's like. I used to take medication that made it quite hard to organise my thoughts. So I understand what that's like and I know you have to give people time. Someone who hasn't experienced that kind of confusion might not understand.

As well as that I was able to disclose - to say I've suffered from mental health problems in the past and that seemed to help people feel more comfortable with me. It does seem to make a massive difference to people. I was also able to say that my mum's in an older person's service when the carers were talking to me. They seemed to appreciate that. That was helpful when I phoned people up to make the initial appointments. They were saying they were worried in case the person they cared for wasn't good on the day. I was able to say I know what that's like because my mum can be very variable. I think that it helped that they could relate to me. And we found a way round that, so I was able to say I would ring them before I left home and that we could re-arrange if it wasn't a good day.

I suppose people are suspicious of who this person is who wants to talk to them about the care their loved one receives. A lot of people have had good and bad experiences with professionals – so it helps if they feel they have something in common with you and you might understand how they are feeling. In other projects I've worked on, people have said to me 'I wouldn't have said this to the ward staff'. They feel like they can be honest with you – they feel they can open up to you.

I enjoyed meeting the older people and discussing things with them. They went off track quite a bit – but I'm time-rich so I didn't mind as long as they didn't mind. I let them talk about what they wanted to talk about. Quite a few of them said they enjoyed meeting me as well.

Do you think anything could have been done better?

I was going to interview ten people, but I only did five in the end. My paperwork got held up by the healthcare trust – it was sitting around for months. It was a research passport - to say that the trust would accept me to interview their patients. The researchers needed this form signing – so without it they had to give my interviews to someone else who already worked in their department.

That was really frustrating because I got made redundant in March – and because I was expecting to start working on this project, I didn't sign on. But I didn't do any work til August. I thought it would start at any moment – so I didn't sign on all that time.

The researcher kept saying he was sorry and asking whether I wanted to continue and I did. He tried to get me more work even though I had to travel a bit further. He had to put in quite a lot of effort. He said he wanted to make sure I got something on my CV after all the effort I'd put in – which I thought was a really lovely attitude.

He sent the same paperwork to another trust in another area and they signed the paperwork straightway and then I got five interviews – so I did five in the end.

What advice would you give to other researchers about service user involvement?

Give service users the support when they need it. They might need it even more than other researchers because their emotions can be quite high and close to the surface.

Discuss whether the service user can disclose and are happy to do that.

Pay service users properly for their expenses and time. Pay for all the travel - for the training as well – because service users can often be a bit skint!

Case Study 6: Service user member of a trial steering group

Background

This randomised controlled trial involved a service user researcher as a co-applicant on the study and as a member of the project advisory group. Other service users were consulted about the design of the intervention and the study via focus groups and one-to-one interviews. We spoke to a senior researcher and the service user researcher.

The researcher's experience

What helped the involvement to work well?

The service user researcher who was involved is a senior researcher who is very well known and respected - so we knew we were going to get good results. Because they were so experienced, we didn't need to offer any training and they didn't need to be brought up to speed with the research process...

They were one of the more active members of the advisory group. They were always at all the meetings, whereas other people might give their apologies and then just read the minutes. So they did have a lot of input. They are an outspoken person, and if they had something to say they would say it.

What difference did the involvement make?

They did what they were there to do – to let us know how service users might see the study – and whether what we were doing was appropriate or not.

It kept us grounded. We may have gone off on tangents without their advice – that might have been irrelevant or laborious and unproductive – but they kept guiding us the right way. So it didn't become a purely academic venture, where a bunch of researchers think they know best and set out to do a project...

Quite often they would raise points where things could be more appropriate or suitable or even less offensive. They pointed out if something was deemed old language, something that we hadn't even considered – they were very on the ball and up to date with that. They were a constant, guiding influence.

They recommended we use a different quality of life questionnaire to the one we were planning to use. The one they suggested was phrased positively rather than negatively, for example, it asked people if they felt happy and had energy, rather than whether they felt sad and depressed. The service user researcher thought this was more acceptable to service users and not depressing for them to fill it out.

That was very helpful. I was doing the interviews myself and I know it can feel quite depressing to sit down in a room and talk about all the negatives – there's a different vibe in the room when you do an interview using this other questionnaire. I hadn't

even heard of it before – so that was 100% down to the service user researchers' influence.

Did you have any concerns about the service user researchers' 'representativeness'?

We purposively set out to recruit the best person we could think of. There were other very senior people on the advisory group, so we needed someone who could be effective in that environment.

Also very importantly this wasn't the only way that we brought the service user perspective into the project. We also carried out focus groups with people who are currently receiving treatment – people who are in the exactly the same situation as the people we are trying to recruit to the study. And they made a huge difference to the design of the intervention and the way we described the study... we relied on them as experts in their own treatment, to help us design the best study and the best intervention – rather than just swooping in, taking what we wanted and then leaving – we went back to them with their specific changes, to see what they thought of the new version... so they could see there was a direct link with what they suggested and what we went and did...

So we were also talking to the very population we wanted to recruit to the study. Obviously you can't expect to pick one service user to represent all the other service users...

There might also be a danger of always involving the same person – who then becomes a professional service user on every advisory group. In an ideal world it would be good to involve different people on each study – to avoid saturation. But this has to be balanced with making the most of people's skills and choosing the best person for the job.

It's no good bringing in a service user just to have a service user. The selection process needs to be transparent and it mustn't be about doing things for the sake of being seen to doing it – or just to have someone's name on all the papers. But of course that's also true for researchers.

What advice would you give to your peers about service user involvement?

In advisory group roles, aim to involve someone with a lot of experience - they might be more help than someone less experienced.

Don't involve a service user on your committee just to be seen to have one – when you recruit a health economist or health population researcher, you want someone who's good, so by the same token you want someone who's a good service user. It's not enough just to look good. Go for the right person.

Try and involve service users at every stage - from day one - to help with the design the study... because it adds to the real world validity – it keeps you from running away with thinking you know best.

Involve service users from the population you're wanting to study – that's the best real world validity. Involve them as often as possible and don't make it a box-ticking exercise.

You need to recognise the value of the service user perspective. I've now recognised that service users know much better than me about the experience of being unwell and the experience of receiving treatment – being a researcher does not make you any better qualified to comment on these issues.

The service user's experience

How well did the involvement work?

I was involved from the start as a co-applicant and so I was involved in the design of the project. I was lucky in that, because some projects find that difficult because it costs money.

But overall, I found it personally very difficult. The project involved a group of people with a particular diagnosis which in the long and distant past I once had. There were psychiatrists on the team who talked about this group in what I found to be very negative ways – that made me feel very uncomfortable and I didn't really feel that I could pull them up on it without exposing myself.

I found it hard to contribute as I felt they were talking about me in the past, being burdensome, difficult...

This was unlike any of the other projects I've been involved in. It's just because it was about this particular group of service users and the way the clinicians talked about this group and the language they used.

It seemed to me that they had bought into a stereotype. They talked about difficult doctor-patient relationships without seeming to recognise that those relationships are two way and doctors might be part of the problem... Every time something didn't go to plan, it was because the participants were difficult people – not that there might be something wrong with the research.

When I had that diagnosis, I was very young and the psychiatrists were horrible to me. These people weren't horrible at all – but they still had this stereotype of this diagnosis that I found difficult to handle because I had experienced treatment from people like them... They were all very nice well-meaning people and their attitude towards this group of service users is commonplace within psychiatry. It's how everybody thinks about them – so it's not as if they were different...

In spite of these difficulties, do you think your involvement made a difference?

There was sometimes an issue because the steering group often wasn't quorate. However I feel I still had some impact for example I suggested they use a quality of life measure that service users had said they really liked in another project.

How could it have been different?

The problems were probably partly due to me and maybe I should have said something to the chief investigator – but somehow it didn't seem appropriate or I didn't want to expose myself. It's the only project where I've come out of a meeting feeling upset. Normally I feel there are good and bad things – but this was a negative experience for me as a person.

Did you receive any support in your role?

I do have a line manager – but I don't think I ever said anything to that person. It did feel like if I said anything it was going to look unprofessional. I talked to one of my colleagues about it – and she agreed the attitudes left a lot to be desired.

But I don't think it occurred to my collaborators that something like this might be going on – they're nice people. I didn't say to the team that I had this diagnosis – maybe they would have behaved differently if they had known...

What do you think the lessons are for others?

If you are a service user researcher working with psychiatrists and psychologists and you find something upsetting and offensive – then speak up.

Understanding that service users bring a perspective that professionals cannot possibly have is important. It can be difficult for clinicians to see this – they can treat people in a stereotyped way. In this particular field it can be more difficult for clinicians and researchers to revise their perspective and see that service users provide a critical part of the research jigsaw.

Case Study 7: Service user researcher

Background

In this study of acute psychiatric services, a service user was involved as a researcher running focus groups with service users and conducting interviews and assessments of in-patients and ward staff. We spoke to the lead researcher and the service user researcher.

The researcher's experience

How did the involvement of the service user researcher make a difference?

The main effect has been to keep us grounded. It ensures we don't have too high an expectation of things and that we know the problems before we start.

We have also recruited an enormous amount of people. We recruit 50% of the people in the wards we go in to. This is in part because of the involvement. With the input of our nurse researcher and service user researcher we have developed a good approach to recruitment and established good working relationships with the staff on wards. The service user involvement has also given credibility to the project.

Our researchers have influenced the details of our recruitment and engagement. We treat both staff and service users with respect. We keep people in touch with the study by sending newsletters to wards and the service users who took part in the study. We take boxes of sweets in at Christmas and when going to collect to data. These details have had the effect of demonstrating that we value people's participation.

What factors contributed to the success of the involvement?

I employ a number of researchers – so if a service user researcher is ill the others can take up the slack, but we also make sure that no one is overloaded. There's a clear understanding that this is how it will work – that they will help each other out if someone is experiencing difficulties. So if we are working on a difficult ward we may send 3 or 4 people to go in and help. We work as a team and that makes it successful.

Being committed to service user involvement is also important for the people who are running the whole programme. We work as a team at every level. We all think the service user involvement is important – so it's not an issue – there are no arguments about it.

How did you recruit the service user researchers?

I recruit people who already have research experience. They fulfil the same criteria as the other researchers but they also have service user status. To appoint to a Band 5 position in the university, they need to have a degree. But because I'm also concerned about putting people into a research position without any experience of working with mental health service users, we also ask that they have some relevant

research experience, or have been in jobs where they have acquired the relevant skills.

How did you train and support them in their role?

Everyone gets the same training to ensure reliability in the use of measures between researchers – whether they are service users or not.

We've found that because we have a number of service user researchers they can give informal support to each other.

Service user researchers always have a slight tension in their role – are they a service user or are they a researcher – what is this thing called a service user researcher? Some feel more akin to researchers. Others feel that their service user status is really vital and they need to talk about it.

If someone is specifically recruited as a service user researcher, based on previous learning, we now make sure to ask them how they might feel about other people knowing that they are a service user researcher at the interview. We have had one person who decided they weren't ready for that.

Is there anything you would have done differently?

One service user researcher was unwell and so was off work a great deal. Another person came in and was uncomfortable working on the wards. They found it very difficult to be on an in-patient ward because it brought back their own experiences. They also found it difficult to interview the staff. So that didn't work so well.

The other researchers also probably had problems going on to the ward – and it was difficult for all of them. So the issue was that some people were more sensitive to it – but the stress was there for everyone. Since then we have always asked people how they feel about working on a ward before they join us on a project.

So part of helping involvement to work well is choosing the right people and giving them the right information so they can be prepared for the challenges. We now talk to people at interview about the fact that the work might be tougher than they expect. If you get people to reflect on the fact that there might be problem then, if there is a problem, they're prepared for that and realise it's normal. If they've not thought about it and something happens, they sometimes feel it's about them and their inability to cope, rather than it being a difficult situation. Warning people helps.

What advice would you give to your peers about service user involvement?

Involve service users from the beginning – so that they can influence the design of the whole project.

Have someone who can provide support to the service users who get involved.

Have a 'crisis plan' about how periods of ill-health will be managed at work. Usually people don't want to think about it, but it's wise to think about beforehand. Then it's not catastrophic if it happens. You can plan for it and manage it. You will then know how to recognise if someone is becoming ill and who to contact if this happens – the

person/ people who provide their care. You also need clear boundaries. Sometimes if service users are working in a mental health institution they think their mental health needs will be taken care of. But as an employer there are limits to what you can and should do.

The service users' experience

What difference did your involvement make?

There's a huge amount of benefit to employing service user researchers. It's very valuable to be able to say to service users this is who I am. When you're running a group or an interview, it breaks down those traditional barriers. Imagine if you had a psychiatrist running a focus group asking people about issues on the ward – how open are they going to be about that? There is something about a shared experience that makes people feel more comfortable and more open and honest in what they say. I remember when I was talking to one participant she said 'I feel like I can tell you everything, you understand me and I can really talk to you'. So I think it makes a massive difference.

There is also a utility in having that shared experience. I've not been in hospital though this project is about being in hospital. When I ran focus groups my supervisor was my second facilitator and she has been in hospital. So she was able to interject at times and ask questions that were incredibly relevant that hadn't occurred to me. Service users have got that knowledge to ask those kinds of questions - which other people don't have.

It also improves recruitment and people come back. We ask them to come back to repeated group sessions and they do. I've recruited people where their care co-ordinator has said 'He won't engage – you won't get him on board', and yet he's come back to five of my groups. So I think people choose what they want to be involved in and what we do is so much more inclusive. We are really interested in hearing what they have to say and giving them a voice. And I think that means a lot to people.

I've think because of my experience, I've got more of an understanding and commitment to informed consent. I can put myself in people's shoes a lot more and think about how I would feel in that situation. When people are on a ward they're there to get better – not to be research guinea-pigs – so there's always this inherent thing in me that feels uncomfortable asking them to do research. So I don't push it or force them, which you think might impact on recruitment...but I still always hit my targets.

Being a service user you also assume that service users have more capacity than others do. There are stereotypes that people don't know their own minds – but I assume people are capable – especially in my research when I'm only talking to people about how they think and feel – I think most people can do that.

People get disregarded in the system. We've got that ethos that these people are just as valid as anyone else and they have an opinion and we must listen to them if we want to improve services. Because if you don't – if you just talk to professionals to

find out about the service users experience, you're never going to get the true story. So how are you going to improve the evidence base? The people using the services are the ones that know.

What helped your involvement to go well?

I had a very strong, supportive line manager who is also a service user researcher and had supervision with her once a week. It was very good to be able to discuss the project with her. She was very good at developing us and getting us to think about how we were doing things and pushing us forward. It was incredibly helpful. That was the main driver in making it easier.

She helped with the technicalities of doing the research, how to manage the process of working with people with serious mental illness – who to get in touch with and where to start looking with recruitment. And also to sort out the sticky issues. It was very good to be able to talk to someone who had previous experience, who knew where you were coming from and cared. She has her own passion about doing this and doing it the right way – so she was a strong leader.

She helped with setting boundaries and managing sometimes difficult relationships with the participants. They can expect more of you than they would any other researcher - because you are a *service user* researcher, you're setting it up as a blurred boundary. It's difficult to find the right balance and she helped me through that.

What were the challenges?

When I first got here I'd not heard the term service user, even though I had used mental health services for five years – I didn't know what the term meant. So coming here and being open about that was quite difficult for me and I've seen other people struggle with that. I just wanted a research job and I've been lucky to land here. I've come to realise that my history is an absolute strength and a bonus for the role – but it was a hard one to get my head around. Having always kept that part of my life secret professionally because there is that stigma out there and people judge you –to move to being very open about it - I found quite difficult.

I see myself as a researcher first and a service user second. But when you introduce yourself as a service user researcher, people see it the other way round. They assume you've been employed just because you're a service user and that you don't necessarily have the skills and knowledge to do research. You can come across some negative attitudes amongst colleagues and healthcare staff. You have to remind yourself you are a professional and to keep working as a professional and eventually people will see you as a professional rather than just as a service user.

I disclose my status to other service users but rarely to ward staff because I don't think I would be taken as seriously. I have overheard staff saying things about how they couldn't trust what service users tell them – and it's frustrating because I can't say anything about it. You've always got to remember your role is to go in there and collect data. You don't want to upset the apple cart if you're going to ask people to do things for you. It can be difficult. It's a hard job to do if you haven't got your own head around the issues.

I think I'm successful at my job because of my research and communication skills – which doesn't have much to do with my being a service user. Having that lived experience is a bonus – it gives you some extra knowledge and understanding of how people might be feeling – so they feel less judged.

What advice would you give to researchers so as to maximise the benefits of involvement?

Involve people as much as possible. Often people think involvement is about participants and upping recruitment rates and ticking the box on the ethics application form – but it's about involving people at every stage of the process. That's an incredibly hard thing to do especially in medical research as there's such a power structure. It takes an open mind.

Find out what genuine involvement means and how to do it properly. Sometimes there are processes that are dressed up as service user involvement and they are not at all. We need to spread the word a bit more.

Involve more than one service user to diffuse the power differential. Pulling one person onto a big group is tricky and maybe meaningless. The user voice is stronger if there is consensus amongst a group of service users. Sometimes the individuals who put themselves forward are not representative – so it is better to include a range of voices.

Help service user researchers to deal with those negative attitudes. It would help if people know it can happen and are clear about what they think about it - so they can deal with it.

Provide support for service user researchers struggling with the issue of their identity. Don't wait for a problem to develop - be more proactive.

Case Study 8: Service user member of trial management group

Background

In this project a service user was involved in the trial management group. We spoke to the lead researcher and the service user involved.

The researcher's experience

What difference did the service user involvement make?

The service user was a very active member of our trial management group and it was good to have her views on a lot of the practicalities as we went along. At the beginning she contributed to a discussion about the measurement scales we were using and how they might be interpreted differently by people with her condition. She also commented on the potential burden of filling out the questionnaires and the format of consent form. But a very important contribution was her validation of the value of the project.

We also did some qualitative interviews and the service user was involved in informing the analysis and interpretation of themes. It helped to have the patient insight – that angle. She's also an author on all the papers that came out.

When the project was finished the company who developed the computer software we'd been piloting carried on working with the service user to implement the recommendations that came out of the research. That was an unexpected bonus and shows how valuable her input was.

What helped the involvement to work well?

It was down to the individual we involved – partly because of the experience she brought and her interpersonal skills. She had experience of the condition we were studying and was familiar with the issues – so she had the exact experience we needed. I think sometimes things don't work because you get someone you've identified as a service user, but their experience is not really relevant to the project or the role.

She was very able to work with the research team. All her comments were totally appropriate and helpful. Sometimes you can work with people and they go off on a tangent or they've got an axe to grind about some terrible health experience that they've had – but she was very professional. There didn't seem to be any difference between working with her and any other member of the team. It wasn't as if you were making some exceptional circumstances or talking to her in a different way – she was just a member of the team – just like anyone else. That's a big help because you can relax.

Obviously there were some issues with her condition. She did get tired and lose train of thought sometimes especially if we were discussing the same thing for quite some

time and it was getting convoluted. But she was very honest so that we could easily take that into account. Someone who was less honest might have hidden things and we wouldn't have known they were struggling. She was very upfront about her limitations – so we could help by making sure the meetings weren't too long for example.

We all got on very well so it made for good working relationship. We respected her, she respected us – it was all quite fun really.

It was a small team which helped - only about five of us and the meetings were informal. The project manager was full-time so had quite a lot of time to work with the service user and develop a good working relationship. So it wasn't one of these things where she didn't hear from us for months and then turned up to a huge room full of professors and faces that she didn't know – which can happen with some user involvement.

Is there anything you would have done differently?

We recruited the service user via one of the clinical psychologists who had been treating her and thought she would be good for the role. That wasn't the ideal way of doing it – although the service user was no longer in treatment. She was also a patient of one of the other clinicians on the advisory board. They didn't ever work together directly on the project, but we made sure they both knew about it and were OK with it.

We should have done more working with the service user on dissemination. But I'm so busy it was almost like 'That study's finished now, let's move on to the next one'. It's always good to have the researcher's and the patient's perspective at the end. It makes it more rounded and interesting for the audience.

Often one of the problems is that we don't give service users enough time and support. If you go along to one meeting with them, and then you often have to run off to another meeting afterwards and the person can be left to deal with whatever came up. It might be helpful if service users could get support from a wider network, other service users who may be working in the same way and sharing the same experiences.

What advice would you give to other researchers as to how to maximise the impact of involvement?

Ideally have somebody whose role it is to work with the service user focusing on them to keep their needs in mind. The trial manager and the PI have got a million things to do and they can forget about the small things – making sure the room's appropriate, making sure the papers are sent out early and in the right font. These things can get forgotten – but are essential. People can feel you haven't made the effort.

Recruiting the right person is really crucial. I would interview someone now in the same way as interviewing a member of staff. You want to make sure they are in it for the right reasons - that they will be capable to take on their role and they will be able to contribute in the way that you want them to. It's also important to have a formal

description of the role, so service users know what they are taking on and what they are going to get out of it.

The service user's experience

How did your involvement make a difference?

I helped with the initial recruitment of participants. I advised them on the wording of the information that was given out as well as how it was given out. I also advised them on the actual mechanics of how people might participate – what was manageable for them. For example I thought that they might need breaks between treatment sessions because of their condition. There were different issues to be taken on board so as to avoid people becoming too fatigued or stressed and anxious. I gave advice on the practical matters – the adaptations people might need.

When the results came in, I was able to help them to understand some of the comments – to interpret them in a slightly different way to the researchers. I think it was useful that I was able to give the perspective of many different people with my condition, because I am involved both locally and nationally with a patient organisation. So I have access to lots of different viewpoints.

What helped your involvement to work well?

They were mindful of my condition because one of their colleagues had been affected by it. So they made sure I was able to contribute. The steering group meetings were manageable and held in the middle of the day - so I could make sure I wasn't tired and could take time afterwards and before hand to rest. That was all taken into consideration.

There were some sessions where I was tired – and when several people were making points, I struggled to follow the conversation. There were a lot of different terms to learn and I haven't got an academic background. It felt like I was getting a look in at another world where I hadn't got a look in before – but it was a nice learning curve. And I felt comfortable enough to say if I had zoned out – because I was tired or I hadn't understood the conversation thread. I could say that.

I felt that my contributions were valued and they recognised that I gave some balance to what was all academic or medical. I helped to add that extra dimension and to keep it grounded.

How were you trained and supported in your role?

The researchers gave me lots of information at beginning so I could make my mind up as to whether this was something I wanted to be involved in. I also met with the study leader for an informal chat before the start of the study and she explained what it was all about.

They paid my expenses and parking but I gave my time voluntarily. If they had had to pay someone it would have cost a lot of money and they were grateful that I could contribute as a volunteer. Also because I wasn't paid – I didn't feel under pressure to

deliver. If I had been paid, it would have pressured me and I wouldn't have felt as comfortable.

I never felt under pressure at any stage. The deadlines, if there were any, were always very comfortable. I never felt bombarded with stuff – it was manageable.

There were times when I had stuff that was difficult to read. But I didn't mind asking if I didn't understand the terms – there was a lot to read at the beginning – I just had to read it several times to work out what it was about.

Being involved also helped me to keep on top of my IT skills. It helped me to get more confident using email. It challenged me to try things that I wouldn't have tried otherwise. It was a step up for me – having to follow and hold my own – surrounded by academics and medics – but it was a nice challenge.

It was a real positive for me to be asked to take part – I was really flattered that researchers thought me articulate and intelligent enough to take part in something like this. I was also motivated by the fact that the outcome might be useful for people like me – so I was very enthusiastic about the project.

What advice would you give other researchers to maximise the benefits of involvement?

Involve service users right from the beginning in the planning stages – so they don't think they are coming into something that is already decided – so they feel part of it right from the start.

Make sure you understand the boundaries that service users are working with – not only the limits because of their health, but because of the other commitments they may have in their life. For example, parents may need to work around picking up children from school. Give people advance warning of meetings so they can make other arrangements if necessary.

At the meetings, let the service user have some time to acclimatise to a new way of working. Make it clear they haven't got to say something about every point. It's sometimes appropriate for them not to say anything in the discussion – if it's about something they are not really there for.

Make sure the minutes are complete as that can remind people what went on in the meeting. At the beginning of a meeting go through the minutes and action points – that can be a useful reminder of what happened the last time.

Case Study 9: Service user representative member of the trial steering group

Background

In this randomised controlled trial a service user representative from a voluntary organisation and a service user were involved as members of the trial steering group. We spoke to the lead researcher and the service user representative.

The researcher's experience

What helped the involvement to work well?

In our field because we are a small field, we all have a sense of having shared values and shared goals – to improve services and treatments. In other parts of psychiatry that's harder because service users may have a model of understanding of their condition that is different to the way researchers are thinking about it. In our field there isn't a problem of service users and researchers coming at it from different angles.

A lot of the research we're doing is about improving psychological therapies and trying to get a better understanding of what underpins the disorder biologically. A lot of patients and carers are interested in that. There isn't a conflict or a basic mistrust - which makes it a lot easier for us.

Our collaboration with the patient organisation has worked well because we got to know the chief executive from working on clinical guidelines together – so we have a well-established, longstanding relationship with a well-established organisation.

It is also important that the organisation has a culture that is like researcher. They are willing to try out new things, to invest in new ideas and are open to new developments. They do not have a preconceived notion of this is how things are and this is how they will carry on. There is a willingness to learn and to be innovative which is very helpful in working with them.

What impact did the involvement of a service user representative have?

It has been really helpful in facilitating recruitment and the dissemination of research findings. That's where having her on board is so valuable.

We've advertised our project via the organisation which has meant we have had additional recruits through them and then people know nationally about what we're doing.

The findings can very readily be disseminated at conferences with carers. It's very good for us that the foremost patient organisation working in this field has a knowledge and appreciation of what we as researchers are trying to do.

How is involvement of a service user representative different from involving service users directly?

They both complement each other. The representative an overview and on a daily basis talks to lots of service users and carers. That perspective frees her up to ask questions of us and inform what we're doing – she isn't tentative about questioning or challenging us. Sometimes the service users we involve look at things from their own perspective and aware of that and may be a bit tentative in their suggestions.

Service users can be anxious and cautious and want to be supportive and nice and respectful to us – there can be a danger that they don't say enough of what they should or could say.

If there is a question for service users, the representative from the service user organisation can call upon people. She can 'feel the temperature' with a whole range of service users.

But it is a complement because it is also extremely valuable to involve people who have first hand experience of the disorder or care for someone with the disorder. It is important to include different perspectives otherwise you might only get the official organisation's version of the issues – so it is helpful to have both.

What advice would you give to other researchers about working with a representative from a patient organisation?

You need to get to know the organisation well – to see what drives them and how they are set up. Take the time to get to know them well.

You need to check the organisation has realistic expectations about what researchers can do for them. Are they a solid, well set-up organisation?

You need to familiarise yourself with key individuals and their key goals and see how you can work with them. Ensure they have are open-minded and have a spirit of enquiry that is supportive of research.

As with all collaborations try to work with people at a human level – that matters too.

The service user representative's experience

How did your involvement make a difference?

Some of the ideas we contributed at the early stage helped to shape the overall structure of the study - just in terms of being able to give examples of the impact this study would have and why it's important to have these questions answered. We identified some of the areas for investigation and the importance of those. We didn't divert the researchers – it was more about helping frame the study in a collaborative way – and to affirm that this was an important area to look at. We were able to prioritise the most useful lines of enquiry.

We have been very successful in helping to recruit people to take part. We've done that mostly through our website which gets two million hits a month. We have a

section which is all about supporting research – people undertaking studies can post requests for participants. And the researchers tell us that they recruit many more people that way than through their own means of contacting people. One attribute that is particularly useful is that we are in contact with people who are not in treatment. That helps to build up a greater range of people who take part – and includes a group of people not often represented in research data.

As a member of the project steering group I've been able to feed in what it is patients and carers are saying about the issue and reinforce the importance of the topic. There hasn't been a need to raise any concerns, but if there had been any, that's where we could have done it.

We're now at the point where we can share some of the findings – to begin to talk about it with our members or share it in appropriate ways. We take it to conferences and workshops with carers. We're really committed to bring as much of the research as we can out to the public. They haven't been told about the latest research findings and we think it's an important part of our role to share that. Even when I am being interviewed in the media or on the news – I talk about the research that is going on right now and how that contributes to our understanding of this condition.

We're also looking forward to implementing the findings in very practical ways - for example working in schools with teachers to help them deal with young people who are affected, as well as parents and carers. There are lots of very practical applications to come out of these studies and we will be best placed to take them forward. The people in the clinical world are limited in the amount of translational work they can do to make changes in the community. There will be come a point when it's going to all be about implementation and we'll be ready to take that work forward.

What helped your involvement to work well?

Having the existing relationship with the clinicians. We know them very well from the work we have done together in other arenas for example working on guideline development or working on various committees together. We have access to people who are leading the research in this field and we have opportunities to build relationships that are an important part of making this all work.

I see it as an essential part of my role in the organisation to build these relationships. I know how important it is to the people we are representing to know more about the research that is going on – so we have deliberately set out to develop those relationships and the researchers have been very open and very generous in giving their time to help cultivate them.

It has also helped that we have been involved right from the beginning of the research and have been able to provide feedback at every stage. We were contacted very early on when the proposal for the project was first being developed - so we had an opportunity to put in ideas at that initial stage. So we helped to scope out some of the research areas even before the funding was secured.

How is your involvement different to the involvement of a service user with direct experience of the condition?

It's important to involve service users directly as well as having representatives like me involved – that's what was done in this study. I don't think you can have either/or – I think you need both. They bring different advantages.

One advantage of involving representatives is that we have direct contact with thousands of people. I'm able to be clear about the basis on which I've drawn my conclusions – I can offer to speak on behalf of a wider group. We bring that overview and we have some distance as we're not directly affected. We stand beside service users and help articulate their concerns. We have the independence to take the messages backwards and forwards. We're able to say to families and carers – this is what researchers are doing – and to say to researchers these are the concerns that people calling our helpline are talking about – this is what they want to know. We can be an honest broker for those messages. We haven't got a vested interest in any one camp.

Our organisation also has the capacity to take forward some of the work after the research findings are produced. I get opportunities to talk in the media and can access large networks for communication.

We can also help with that translational work. The most challenging thing for us is when there's a report in the media about a new treatment based on research and then people ring our helpline to ask where they can get it. It's heartbreaking for us to say that was just a piece of research – it's not yet available. So we are keen to make sure that the research does get implemented and best practice is informed by the research that's out there.

What advice would you give to researchers to get the most impact from involvement?

Involve service user representatives and service users. It's of benefit to have both kinds of involvement.

There's more we can do to make sure that when good ideas do come out that they get implemented quickly and do not get lost in a journal somewhere. Look to publish in the more popular press. Use the more everyday ways to communicate about the research you're doing.

Lessons for researchers and service users

This section contains the key themes from the case studies in terms of the factors that ensure successful involvement and the reported benefits of involvement.

To ensure successful involvement it is important to:

- **Involve service users right from the beginning of a project** when it's easiest to make changes in response to their input. This will maximise their impact.
- **Recruit the 'right' service user for the job** – someone with the experience and skills needed for their role in the research project. Think about how to involve different service users with different kinds of knowledge, experience and skills at different points in the project. This will maximise the benefits.
- **Be clear about what's expected from the service user** – especially in roles where there's a wide range of tasks the service user could be involved in e.g. as a member of a steering group.
- **Treat service users with the same respect and consideration as any other member of the research team** – be careful not to be over protective. At the same time recognise that some service users may need to work in different ways and require different kinds of support to be able to contribute effectively in a research environment.
- **Prepare service users for their involvement role** with appropriate training, briefing and ongoing support. Ensure good communication to keep service users up to date with progress especially if they need to take time off work for ill-health. Build in formal systems to provide emotional support for service users if their involvement in a project could cause distress.
- **Ensure your team members are respectful** in terms of the language they use and their general attitudes to service users – not only those directly involved.
- **Adopt an inclusive and collaborative approach** – ensure service users feel listened to and are aware of how their involvement has made a difference.
- **Think about preparing other stakeholders in your organisation** so that their policy and practice is supportive of service user involvement e.g. HR and finance departments.

The benefits of service user involvement in research include:

- **Bringing ideas and viewpoints that are distinct from academic researchers** – perspectives that the researchers otherwise wouldn't have. This can take the research into unexpected but more relevant directions.
- **Keeping research grounded in the 'real world'** and therefore making the findings more practical and useful.

- **Improving research design** – ensuring the most relevant outcomes are measured, boosting recruitment and providing a more comfortable and positive experience of the research for participants.
- **Breaking down traditional barriers between researchers and participants** – encouraging service users to be more open and honest in sharing their experiences.