Good Practice Guidance for Involving People with Experience of Mental Health Problems in Research

The Mental Health Research Network is part of the National Institute for Health Research Clinical Research Network which supports research to make patients, and the NHS, better
INTRODUCTION

The NIHR Mental Health Research Network (NIHR MHRN) supports hundreds of mental health research projects across England. The NIHR MHRN supports mental health research in many different ways. One of the major roles of the NIHR MHRN is to help recruit people to research studies as participants. The NIHR MHRN has a Coordinating Centre based in London and Preston with regional offices (or ‘hubs’) based across England. For further details about the NIHR MHRN and its regional offices please visit its website at: www.mhrn.info. Throughout this document hyperlinks are given wherever possible. All links were accessible as of April 2013.

Service user involvement in the NIHR MHRN

The NIHR MHRN has long had a major commitment to involving mental health services users in its work and the research it supports. The majority of service user involvement in the NIHR MHRN is carried out at a local level through each of its eight local offices or ‘hubs’. Service Users in Research is the national, service user involvement arm of the NIHR MHRN.

For more information about Service Users in Research and the work that it carries out please visit: http://www.mhrn.info/pages/people-with-experience-of-mental-health-problems.html.

Carer involvement in the NIHR MHRN

As well as involving people with personal experience of mental health problems the NIHR MHRN also has a commitment to involving those that care for them. In 2008 the NIHR MHRN established FACTOR (Families/Friends And Carers Together in Research) to support its carer involvement activities.

For more information about FACTOR and the work that it carries out please visit: www.mhrn.info/pages/family-members-friends-or-carers.html.

The NIHR MHRN has produced a companion to this document on involving carers in research. The NIHR MHRN ‘Good Practice Guidelines for Involving Carers, Family Members, and Close Friends of Service Users in Research’ can be downloaded here or from www.mhrn.info. An executive summary is available here.

About this document and how to use it

In 2005 MHRN-associated service users produced a document ‘Guidance for Good Practice: Service User Involvement in the UK Mental Health Research Network’. The current document is a revised version of this guidance. Since 2005, there have been significant changes in the world of public and patient involvement. For example, the welfare benefits system has changed significantly (and continues to do so) and so the ways that people who get involved in research should be paid has changed. There has also been a pleasing rise in the number of people with experience of mental health problems becoming researchers in their own right, working alongside existing research teams. Two major texts have been published focusing exclusively on involving service users in mental health research (Handbook of Service User Involvement in Mental Health Research (Wiley, 2009) and This is Survivor Research (PCC Books, 2009)). This document has been revised to broadly take into account these developments.

This document has been produced by the NIHR MHRN to support researchers and others to actively involve people with experience of mental health problems in research.
This document is divided into four main sections:

1. **The introduction**, defining involvement, and summary sections on p3-9 constitute a concise introduction to involving people with experience of mental health problems. Many links to useful documents produced by the NIHR MHRN and other organisations are also given.

2. **Part 1**: Practical aspects of involving mental health service users in research on p10-20 provides guidance on some of the more practical aspects of involving people with experience of mental health problems in research such as payments and training.

3. **Part 2**: Broader issues to consider when involving mental health service users in research on p21-37 provides detailed guidance and information on service user involvement in different stages of the research process (i.e. section 4.5.1 Planning and starting a project). Guidance is also given on service user involvement as it relates to broad issues in research such as identifying priorities for research (section 4.2).

4. **Part 3**: Glossary of terms, references, acknowledgements, and useful contacts on p38-47 contains a glossary of some commonly used research terms together with a comprehensive list of references and useful contacts.

**Note about the terminology used in this guide**

For the sake of consistency, throughout this guide the term ‘service user’ is used to refer to people with experience of mental health problems. Other terms are commonly used such as ‘patient’ and ‘consumer’.

**Other useful documents**

There are accompanying documents that the NIHR MHRN has produced to support researchers in involving people with experience of mental health problems in research. They focus on the more practical aspects of involvement.

These include:

- **NIHR MHRN Service Users and Carers Payments Policy**
  
  This is a two part comprehensive guide to making payments to people for involvement work. These documents can be accessed here or at www.mhrn.info.

- **NIHR MHRN Payments Logbook for Involvement Work**
  
  Service users and carers that get involved research often carry out involvement work for more than one organisation. Keeping track of payments for involvement work, and knowing how to respond to enquiries from organisations such as HM Revenue and Customs can become difficult. The NIHR MHRN Payments Logbook for Involvement Work Part A explains what records for involvement work need to be kept for people in different circumstances, and gives advice for people on tax and welfare benefits. Parts B and C of the Logbook contain charts that can be adapted as needed so that people can keep records of all payments that they receive for involvement work. The Logbook can be accessed at www.mhrn.info.

- **Mental Health Researchers Toolkit for involving service users in the research process**
  
  The Toolkit contains generic (or ‘pro-forma’) role descriptions, advertisements, job descriptions for service user researchers and other documents that can freely and easily be adapted for use. The toolkit can be accessed here or at www.mhrn.info/toolkit.
This guidance document is extensively cross-referenced with this toolkit and with any associated web-links.

**Toolkit Template Documents:**

- Sample role description and person specifications for service user representative/project advisor on a study/trial steering group, or on a group (informal or formal) developing a research proposal. [Download here](#).
- Sample generic advertisement to recruit a service user representative/project advisor to mental health research activities. [Download here](#).
- Sample application form for service user representative/project advisor. [Download here](#).
- Sample guidance notes for filling out an application form for service user representative/project advisor. [Download here](#).
- Sample involvement agreement. [Download here](#).
- Sample contact sheet for service user representative/project advisor.

One major but very preventable way that service user involvement in a project goes wrong is simply that people do not have each other’s contact details. It is very worthwhile when someone begins to get involved in any research project to give them a contact list of all the people who would be involved in the group/project, or at least the details of a few suitable contacts. [Download here](#).

- Sample training needs analysis form for service user representative/project advisor. [Download here](#).
- Sample involvement evaluation form for service user representative/project advisor. [Download here](#).
- Sample involvement evaluation form for researchers or other staff. [Download here](#).
- Sample confidential evaluation form for service user representative/project advisor involved in a study or trial. [Download here](#).
- Sample confidential evaluation form for researcher about service user involvement in a study or trial. [Download here](#).
- Sample role description and person specification for a service user researcher. [Download here](#).
• Sample application form for a service user researcher
  Download here

• Sample interview questions for a service user researcher
  Download here

INVOLVE (www.invo.org.uk) is an organisation funded by the Department of Health ‘to support active public involvement in NHS, public health and social care research’. Many documents and resources that have been produced by INVOLVE are referenced in this document. The following is particularly useful:

INVOLVE Briefing Notes for Researchers

This resource contains “ten briefing notes for researchers on how to involve members of the public in research”, supplemented by detailed information on public involvement in specific types of research and on specific involvement activities. Many case studies are included. This document can be accessed here or from www.invo.org.uk.
2 DEFINING INVOLVEMENT

Whilst opinions on what constitutes ‘involvement’ differ there is a consensus that taking part in research as a study participant does not constitute involvement.

When considering the involvement of service users and others in research it is important to define what ‘involvement’ means. The NIHR MHRN has adopted the following definition of ‘involvement’:

‘Involvement’ in research is when research is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants. ‘Involvement’ does not mean participation in a research study, such as taking part in a clinical trial.

Taken from the INVOLVE briefing notes for researchers (2012).

Summary – Key Principles of the Involvement Process

Where to find people to get involved in your research:

- Try advertising locally. Remember that people who use mental health services are as individual as anyone else. It should not be assumed that any one service user can necessarily represent the views of other service users on any given topic. It is therefore good to involve a number of service users in any given research study so as to get a range of different opinions. It is often a good idea to try to find someone with direct experience of the condition or service to which your research relates. Try to avoid involvement by ‘proxy’ (for example, involving a professional who works with people who experience a given health condition instead of involving someone who actually has the condition itself or an unpaid carer)

- Many charities such as Mind (www.mind.org.uk) and Rethink (www.rethink.org) have local branches that can be approached. There are also a number of regionally based service user and carer groups based up and down the country that can be consulted

- If you are a health professional there is no reason why you can’t approach suitable patients of your own for involvement in research

- INVOLVE has an excellent website called People in Research (www.peopleinresearch.org) which can be used to freely advertise for people

- MHRN Service Users in Research produces a monthly Bulletin in which you can advertise freely. To advertise please email mhrnppi@kcl.ac.uk

How many people should be involved in a research study?

- This depends on the nature and scale of the study. The NIHR MHRN recommends that you always involve at least two service users in any given study so they can provide each other with support. This will also help mitigate against the effects of illness
Payments and expenses:

• The NIHR MHRN recommends that payment for involvement work is made wherever possible

• As a minimum, always offer to pay travel and other expenses

Before you actually involve people:

• Involve service users as early as possible. In general, the later you involve people, the harder it is to establish meaningful levels of involvement. The NIHR MHRN recommends that you involve service users from the point of the formulation of the basic research question(s)

• Involving people in research does usually cost money. Try building in an ‘involvement budget’ when you make an application for funding or, if possible, seek funds elsewhere

• Think about the skills and experiences of the people who would help your research and offer appropriate training whenever possible

• Decide what you want service users to actually do before you involve them in your research (for example, to sit on a committee overseeing a research study, carry out interviews, analyse interview transcripts, etc)

• Contact the finance department of your organisation as early as possible to work out the best way (if applicable) of paying people for their involvement and reimbursing expenses. Delays in making such payments may cause ill-feeling

When you involve people:

• Give people a plain English (‘lay’) introduction to the area of research in question. Service users (or anybody else) will only be able to contribute meaningfully to research if they have a reasonable understanding of the area of research in question

• “Service user”, “patient”, “consumer”? Identity is a personal thing, so why not ask what term is preferred by those you involve?

• Consider creating an ‘involvement’ agreement form. The form gives details of the role to be performed by the service users, contact details of the research group, rates of payment (if applicable) etc

  You can download a pro-forma involvement agreement to adapt for your own needs here

• Give people the opportunity to meet with a member of the research team before or after any meetings they might be asked to take part in. This gives service users an opportunity to ask questions they might otherwise feel uncomfortable asking

• The involvement of service users and others on committees, such as on a trial steering committee, can be challenging. INVOLVE has produced a document entitled ‘Public involvement in clinical trials: supplement to the briefing notes for researchers’ which is particularly helpful in such cases. This document can be accessed here or at www.invo.org.uk.
Disseminating Research Findings:

- The NIHR MHRN recommends that a plain English ‘lay’ summary of the findings of a research study be sent to all those who were participants. Service users can be very helpful in producing (or helping to produce) such a summary.

- Service users can help to disseminate the findings of research to local and national user groups and organisations. The same groups and organisations can be invaluable in lobbying for the findings of research to be implemented.

- There is a strong move in the UK towards an ‘open access’ model of publishing. Consider publishing the findings of your research in an ‘open access’ format so that they can be read by the widest possible audience. Very often service users that have taken part in research as participants cannot read the findings of the research when they are finally published as they do not have access to a university library. By publishing the results of your research in an open access format it makes it possible for everyone (including people that took part in the research as participants) to access the findings of the research.

Other Considerations

Jargon - Most areas of medical research are full of technical terms and jargon. The meanings of such terms are not obvious and it is worth trying to use ‘lay’ language wherever possible. It is useful to provide people you involve with a glossary of any technical terms and their meanings. INVOLVE has produced a useful jargon buster, which is available online at: www.invo.org.uk/resource-centre/jargon-buster/

Hard to involve? - The NIHR MHRN suggests that no matter what the subject of the research might be, there is almost always a way to actively involve people. For studies relating to people with very severe forms of a condition it may be difficult in practice to involve them in research. However, it might be possible to involve someone with a less severe form of the condition being studied. For studies relating to very young children or infants, it is still possible to involve their parents or other caregivers.
3 PART 1: PRACTICAL ASPECTS OF INVOLVING MENTAL HEALTH SERVICE USERS IN RESEARCH

3.1 Benefits of involvement

As well as the overall potential benefits for the research, user involvement may also be beneficial to both service users and researchers.

Szmukler, Staley and Kabir (2011) give three ‘main’ reasons for the involvement of service users in research:

1. It makes for better research - for example, research that is more relevant, more likely to lead to meaningful results, and more likely to recruit to target
2. There is a strong moral case based on social justice for doing so
3. It is increasingly being demanded by funding bodies

The moral case for the involvement of people with experience of mental health problems in research is well described elsewhere (Kitcher, 2001 and Szmukler, 2009).

Several papers suggest that the user perspective itself brings benefits: by offering insight into the experience of mental health problems, the use of mental health services, or of receiving certain treatments, service users can help ensure that the content of the research is relevant to clinical practice and relevant to the needs of service users.

A few examples are presented below. For further discussion please see, for example, Hanley et al (2003), Trivedi and Wykes (2002), Allam et al (2004), Rose (2003a), and more recently Staley (2012).

Rose points to the particular value of taking up a research position within an academic institution:

‘I think it can complement and sometimes challenge mainstream mental health research. This perspective should not compromise research rigour, and there may be a danger of being over-involved. But I do not see this in our team any more than I see it in other professionals who are committed to their discipline.’ Rose (2003a)

Service users can make positive contributions to the design of research questions, methods, questionnaires and the use of appropriate outcome measures. Indeed, Crawford et al (2011) studied the acceptability from a service user perspective of many of the commonly used outcome measures in psychosis research. The study found that ‘concerns were raised about some widely used measures such as the Global Assessment of Functioning and the European Quality of Life measure ‘Euro-QoL’. Crawford et al concluded: “we consider it essential that service users' views are taken into account when selecting measures to evaluate treatment outcomes.”

Allam et al (2004) discuss the value of involving service users and carers in the framing of relevant questions. For example, Trivedi and Wykes (2002) have detailed the considerable negotiation that may be needed to determine the best outcome measures to be used, in this case in a study of the effects of medication education sessions for inpatients. Two originally chosen measures related to ‘insight’ and ‘compliance’, both of which the service user researchers argued were of less value
than measures of patient empowerment. A decision was eventually made to use both types of measure.

Wykes (2003) has taken her argument a stage further. She examined three areas where user involvement might change clinical research for the better:

1. Improving scientific quality (the research questions may change for the better)
2. Changing the outcome measures (outcome measures are more in line with those important to service users)
3. Amending the method of research (perhaps augmenting the randomised control trial approach to include the views of service users)

Ramon (2000) contends that user involvement in the conduct of research leads to the ‘generation of new and more in-depth knowledge in the field of mental health’. She comments on some potential benefits to researchers (such as a better understanding of the lives of service users and lay perceptions of research) as well as those of service users, and mentions one of the findings of evaluation research was that it resulted in: ‘more truthful information from the research participants than would otherwise have been possible’.

This last issue is mentioned by Allam et al (2004) for whom it was one of the main reasons for adopting a collaborative approach to the research:

> ‘People who have been interviewed by service users have said that they feel able to speak more freely to others who are using services rather than those providing it; they have less fear of being judged, and therefore response rates have been found to be higher in user led research.’

Both Rose (2001) and Faulkner & Layzell (2000) refer to this phenomenon, and Rose examines it in relation to previous authors (Clark et al, 1999; Polowycz et al, 1993) both of whom found a positive difference in the responses made to service users as opposed to professional interviewers.

Allam et al (2004) have detailed the collaborative process throughout, exploring the involvement of users and carers, not only in the development of questions and interview schedules, but right through to analysis, interpretation, and dissemination. The section on analysis and interpretation is of particular interest, since it highlights the systematic differences in the interpretation of responses between the service users and carers (and potentially professionals). The authors suggest that this provides strong justification for involving service users and carers in the later stages of the research process:

> ‘The validity of the findings must be improved by working together and coming to a joint agreement about the meaning of the data.’

Another potential contribution mentioned by some researchers is that of facilitating access to a broader range of service user participants in research, particularly people who belong to marginalised groups (Hanley et al, 2003; Fleischmann and Wigmore, 2000).

Others have discussed the value of service user involvement in the dissemination of research (e.g. Telford et al, 2002). This, it seems is one area where service users come especially into their own. Often they are more familiar with accessible routes to reaching service users and user groups as
well as local stakeholders, than the academic researchers whose preferred medium tends to be peer-reviewed journals.

Hanley et al (2003) reported that voluntary organisations may assist in dissemination by carrying summaries of research in user-friendly language in their newsletters and magazines. This has certainly been the route for such projects as the Mental Health Foundation’s Strategies for Living project and the Sainsbury Centre’s User Focused Monitoring projects (now known as the Centre for Mental Health)

3.2 Early involvement

Several researchers (Faulkner and Morris, 2003; Thorne et al, 2001; Faulkner, 2004) point to the value and importance of involving service users at an early stage in the research process for two reasons. Firstly, so that service users involved in research gain a full understanding of the project from the outset and secondly, so that the benefits of service user involvement can be realised from an early stage.

In practice, this may be difficult to implement, as the need for proposals to be developed quickly in response to research tenders means that there is limited time in which to organise such early involvement. Despite these constraints, however, early involvement has considerable value and should be aimed for where possible. This point has recently been reinforced by an audit of levels of service user involvement in a randomly selected sample of studies supported by the NIHR Mental Health Research Network (Staley, 2012):

The majority of researchers who had involved service users at this stage [the design stage of a research study] 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

The value of involving service users in early discussions about the research has been particularly well stated by Thorne et al (2001):

Everyone should be involved as early as possible in the research process so that the direction of the research is clear, everyone knows what they are doing and there is commitment to the project.

A major initiative in this area has been the free service, known as FAST-R

(www.mhrn.info/FAST-R), established by the NIHR MHRN. The FAST-R service provides researchers from across England access to a group of trained service users who can comment on research protocols, patient information sheets, and consent forms. It is hoped that this service (and others like it) can provide one way that researchers can obtain service user input into their studies at an early stage.

This issue points to the importance of building up relationships over time with service users, so that some groundwork can be established in preparation for such time-limited funding rounds. In their key principles for user involvement in research, Faulkner and Morris (2003) advocate building up ‘relationships of trust and respect over time between researchers and local service users’. Telford
et al (2002) similarly suggest, in their recommendations for NHS Trusts, that Trusts identify local expertise through the registration of past or current initiatives involving users and staff/researchers with experience in this area. Rose (2003) emphasises the importance of building capacity for the future; offering training and opportunities to enable service users to achieve relevant qualifications if they want to, or to be trained as interviewers and facilitators of focus groups. All of these proposals seek to avoid the tokenism of inviting one or two service users onto a research advisory group at the last minute, when a research project has already been established, designed and funded.

3.3 Clarity and transparency

Several researchers have referred to the importance of the principles of clarity and transparency in relation to a willingness to share power with service users through the process of negotiation (Trivedi and Wykes, 2002; Carrick, 2002; Thorne et al, 2001; Faulkner, 2004). The general principle of this is to advocate clarity from the start; about why service users are to be involved in a project, and about their roles and responsibilities.

‘It is very important that people’s roles and responsibilities and the aims of the project are clear right from the beginning.’ (Thorne et al, 2001)

For some authors, the notion of clarity and transparency incorporates values of honesty and trust in a collaborative partnership (Allam et al, 2004; Ramon 2000, Carrick 2001; Thorne et al. 2001). However, clarity and transparency are more tangible and easier to establish at the outset. Trust takes time to develop and is dependent on building up relationships.

Practical examples of explicit agreements have been developed by Trivedi and Wykes. Another example is the ‘sample involvement agreement’, which is part of the MHRN PPI Toolkit for Researchers and can be downloaded from www.mhrn.info/toolkit

Certainly the absence of such clarity early on can lead to a breakdown of trust, as described by Faulkner (2004). One recommendation to emerge from this experience was as follows:

‘That arrangements for the management and supervision of a project are made clear to all from the start, particularly in the case of a collaborative project and with particular reference to the support needed for service users and project co-ordinator(s)’

The issue of support is taken up later. The process of negotiation itself can establish and develop trust (Allam et al, 2004; Ramon, 2000; Trivedi and Wykes, 2002), which can be built on subsequently in future projects. For Ramon, this process was a way of working out a shared perspective on the research, as noted above. Allam et al (2004) note, from the service users’ and carers’ perspective, trust and confidence in the researchers built up over time alongside an understanding of their roles and approach. Trivedi and Wykes (2002) noted the ‘often challenging and not always comfortable’ meetings between researchers and service users but concluded that they served an important purpose:

‘In allowing a mutually respectful relationship to build up between clinical researcher and user, which eventually enabled them to agree to look again at the project and consider working on it together in partnership research.’
3.4 Flexibility

A flexible approach towards research involving service users and carers is advocated by a number of authors (Allam et al, 2004; Trivedi and Wykes, 2002; Carrick, 2001; Ramon, 2000).

This flexibility may need to extend beyond the individual research team. For example, some flexibility might need to be shown on the part of funders and commissioners of research regarding deadlines and the resources needed to support effective involvement in research.

Practical guidelines advocate the need for flexibility in relation to time and resources, as well as the need for an approach that can accommodate variations in availability or attendance, which may reflect peoples’ fluctuating mental health needs. (See Faulkner, 2004; Thorne et al, 2001; Ramon, 2000).

Frequently research is obliged to follow the pathway laid down in an agreed proposal, particularly after approval has been granted by a research ethics committee (REC). This is where the importance of a reasonably flexible approach from research funders, commissioners of research, and research ethics committees comes into play.

3.5 Accessible language

All authors stress the importance of the use of accessible language, and note the resentment felt by service users who feel excluded by the use of research or academic jargon. Ramon (2000) for example, has recorded the alienation felt by some of the service user researchers in response to inaccessible language.

Faulkner & Morris (2003) and Thorne et al (2001) also emphasise the importance of jargon-free language, as well as accessible formats for those with visual impairments or learning difficulties:

‘If research is easy to understand, relevant people are more likely to be motivated to become involved’.

Training may be a way of bridging the gap and enabling service user researchers to understand the formal language of research, in addition to providing them with a glossary or referring them to the INVOLVE jargon buster, available online at: www.invo.org.uk/resource-centre/jargon-buster/

3.6 Support

Everybody involved in research (service users, carers, and indeed the researchers themselves) need effective support for the involvement to be successful. The level of the support needed will of course depend on a variety of factors, including the nature of the research and the specific characteristics of the people involved in the research.

Allam et al (2004) conclude that support should be available at every step of the research process. Examples include: where service user interviewers are employed, it is important to ensure that systems within the research environment do not place undue stress on them and that proactive support (or de-briefing) is made available.

Staley (2012) suggests that researchers themselves need support and training to involve service users in their studies:

‘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’
Other challenges identified by Staley included, ‘a lack of time and resources’, ‘a lack of know-how’ and ‘the attitudes and awareness of academic colleagues’.

Telford et al (2002) reported that training and support emerged from their study as important factors to consider when involving service users. They cite one researcher’s observation that ‘she needed to spend a great deal of time boosting consumers' confidence, as well as providing practical support’. Macran et al (1999) suggest that service users need training and support in order to ‘feel confident and able to express their views’.

Two significant sets of guidance have produced very similar recommendations on support (Faulkner, 2004; Thorne et al, 2001). The latter suggests that, in addition to financial support, both practical support (in terms of transport, accessible meeting places etc.) and emotional support are necessary. Faulkner (2004) proposes three elements to support: alongside emotional and practical support is research-related support (or supervision). It is important for researchers to understand that a lack of confidence amongst service users might not simply result from either their health issues or from dealing with difficult issues, but from the very fact that they have not had formal training in research skills and may worry about how well they are carrying out their responsibilities.

Both reports suggest that it is valuable to break down the notion of support into these separate elements in order to clarify and provide what is needed both for projects and for individuals. Ramon (2000) also suggests that personal continuity of such support is important and that the key person providing support needs to be trusted by the service users concerned.

The success of projects and the continued involvement of individuals can be placed at risk if the need for support is not properly thought through. Some of the difficulties encountered by the TRUE Project (Faulkner, 2004) could be attributed to the fact that one person was expected to provide all forms of support to a team of seven people and ensure that the project progressed.

Whilst the issue of payments is dealt with under a separate heading, it is worth noting here that money is a vital aspect of the support needed to secure user involvement in research. In particular, within the bureaucracies of the larger institutions and universities, the practical function of providing payments and ensuring that people receive money before being expected to pay for travel or other expenses, can create insurmountable barriers and be very time-consuming to resolve.

3.7 Training

There is near universal agreement about the importance of providing adequate training to people seeking to get involved in research. The NIHR MHRN recommend that an assessment of the training needs of every involved person be carried out prior to their being involved in a research study. The MHRN PPI Toolkit for Researchers contains a sample training needs analysis that can be used for this purpose. This form can be accessed at www.mhrn.info/toolkit.

INVOLVE have recently developed an online resource which offers “advice and guidance to help you develop your own training and support packages suited to different situations and contexts”. The resource also “provides an overview of training and support for both researchers and members of the public as well as information on how to carry out a needs assessment”. A number of case studies are also provided. The resource can be accessed at: www.invo.org.uk/resource-centre/training-resource/
Townend and Braithwaite (2002) propose that training programmes need to be accessible for service users to develop research skills and should include aspects such as developing proposals, methodologies, data analysis, report writing and dissemination. Elsewhere training is discussed as a valuable incentive, providing service users with skills and confidence for the future as well as for the immediate project. Ramon (2000), for example, regards gaining new skills as one of the personal rewards to be gained from involvement. Faulkner and Morris (2003) also mention training in new skills as one of the non-financial incentives for the involvement of service users.

However, it is clear that training in research skills is not the whole story. Several authors talk of the role of training in providing people with the confidence to participate (e.g. Lockey et al, 2004; Macran et al, 1999) or with the opportunity for mutual support (Nicholls et al, 2003; Lockey et al, 2004). Allam et al (2004) recommend that training for interviewing should include a number of additional issues: active listening, reflection & exploring skills; managing one’s own emotions, managing interviewees’ emotions; responding to ‘inappropriate’ behaviour or unexpected responses from respondents.

Both the Strategies for Living project and the User Focused Monitoring project (Sainsbury Centre for Mental Health) emphasise that training needs to be adequate and thorough if it is to maintain high standards of research. This is supported by Townend & Braithwaite (2002) who envisage a future where service users will be seen as capable of undertaking research that is at least as rigorous as that undertaken without them.

Faulkner (2004) addresses some of the ethical issues surrounding the provision of training and emphasises the need for flexible and accessible training, as well as the importance of ensuring that the timing of training is appropriate to the needs of the project and the trainees. Many people consulted for this report favoured a step-by-step approach.

Several papers have addressed the need to provide complementary training for the researchers and clinical academics involved in carrying out the research. This implies that, although the training needs of service users might be more obvious, clinicians and researchers also require specialised training in order to function more effectively within this specific research context.

For example, Townend & Braithwaite (2002) suggest that training be provided in ‘how to work effectively in collaboration with service user researchers’, while Trivedi and Wykes (2002) suggest that training involving both service users and clinical academics will ‘help to break down the barriers on either side’. In a similar vein, Macran et al (1999) suggest that researchers and therapists will need training in the skills to conduct co-operative inquiry and Rose (2003a) suggests that the capacity of the academics needs to be built alongside that of service users learning to be researchers: ‘They need to learn what user involvement in research can and should amount to and be persuaded that collaborative research will increase quality and provide a necessary complement to mainstream research.’
From: Training for service user involvement in health and social care research: a study of training provision and participant’s experiences (The TRUE Project) Lockey et al, 2004.

- Training was perceived as being most useful when it had a clear aim and purpose, and was centred around specific research tasks and real research problems that drew upon the participants experiences.
- Participants wanted to be involved in creating and developing ideas in which they could become absorbed and take ownership. Service users wanted their input to be creative and not just reacting to others’ ideas, and wanted to be involved in both training and research from the start.
- A key aspect of successful training was exchange and sharing between people, both trainers and participants. This was mutually supportive, sometimes using ice-breaking exercises, small group work and role-play.
- Training helped affirm the strength and value of service users’ experiences and understanding of health conditions and services.
- Confidence to contribute developed in a ‘safe’ environment. This is one where others show that they value what a participant is saying and that if they wish to challenge it, then that is done in a constructive and helpful way.
- Considerable time and space was needed to allow all participants to make a full contribution. Project timescales and funding should reflect this.
- Training had enormous value to participants’ personal development and confidence. Almost without exception, training led to actual involvement in research and a desire to do more.
- Language was a significant challenge for those providing training. Effective training ‘demystified’ research, providing a base from which stakeholders can understand one another’s language and purpose.
- Payment was a sensitive issue. Although training commonly was seen as a mutual ‘exchange’ of skills and knowledge, typically participants were not paid for attending training, whilst trainers and employed researchers were paid.

A further finding from this study was that ‘training for service user involvement in research was not readily available. Only a handful of organisations provided open access training on a regular basis. Training was diverse in style and content, and often was developed for a particular service user group or project.
3.8 Language and terminology

‘The language used to describe service users is perhaps more varied in mental health than in any other sector of health and social care’ (Dickens and Picchioni, 2011).

‘Service user’, ‘patient’, ‘survivor’, ‘consumer’, ‘client’ etc? There is no agreement amongst service users (or anyone else) over the preferred terms used to refer to people who use mental health services. The Mental Health Foundation has compiled a list of the various terms that are frequently used and this can be accessed here.

Dickens and Picchioni (2011) recently carried out a systematic review of empirical studies relating to the terms used to refer to people that use mental health services. They state that:

‘Despite a stream of debate in editorial columns and letters pages, it is unclear whether terminological use is important to the people who use mental health services.’

Dickens and Picchioni conclude that:

‘At present it seems that the preferred terms of those who use mental health services to describe themselves are, dependent on geography, and are either ‘patient’ or ‘client.’

The terminology used to refer to people with mental health problems may be an emotive subject. Therefore consider:

- Within reason, giving the chance to choose a term with which they feel comfortable
- Being offered the chance to identify themselves using a ‘neutral’ term such as ‘project advisor’. An advantage to using such a term is that someone’s involvement experience can be listed on documents such as CV’s without it betraying their use of mental health services

3.9 Payments

The NIHR MHRN recommends that service users are offered payment for any involvement work that they carry out. However, making such payments often pose real difficulties for a number of reasons. For example, many service users (but not all) will be in receipt of welfare benefits, almost all of which carry strict limitations on the amount of income that can be received in any given week. At present this figure is around £20 per week, although this does vary.

The issues relating to making payments for involvement work are very complicated (especially so when regarding people on welfare benefits). A full treatment of all of the relevant issues is not possible here. However, the following documents will cover the issues that commonly arise.
1. MHRN Service Users and Carers Payment Policy

The NIHR MHRN has produced a two part comprehensive guide to making payments to service users and carers for involvement work, which can be accessed here or at www.mhrn.info. The titles of these two documents are:

- **MHRN Service Users and Carers Payments Policy: Benefits Systems and Conditions around Paid and Voluntary Involvement (January 2012).**
- **MHRN Service Users and Carers Payments Policy: Service user and carer participation: helpful benefit rules and benefit pitfalls to avoid (January 2012).**

2. Payment for involvement: a guide to making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE, 2011).

**Making payments for involvement work: frequently asked questions**

**How to make payments**

In practice, the way that you make payments for involvement work will depend on local circumstances. Some organisations will issue petty cash for making payments, whilst others will not. You should establish what means of payment may be available to you to pay people for involvement work as soon as possible (petty cash, invoice etc).

**Rates of payment**

The rate of payment that you make is entirely up to you. There are no nationally recommended rates of payment. The amounts that service users are paid for involvement work varies widely.

**Employment status**

The employment status (employed, self-employed or volunteer) of people carrying out involvement work is something that the finance and/or human resources departments of universities and NHS trusts sometimes query. This point is important because if someone is seen as ‘employed’ then they are entitled to a number of benefits including sick pay etc. There is no single definition in law of what it means for someone to be employed or self-employed. The HMRC have a useful online tool, which you can use to check whether someone might be considered as employed or self-employed in law. This can be accessed at http://www.hmrc.gov.uk/calcs/esi.htm

The Advisory, Conciliation, and Arbitration Service (ACAS, www.acas.org.uk) operate a useful telephone helpline that can be freely consulted on any employment matter. Once you have a determination of someone’s likely employment status this information should help you decide whether someone needs to be registered as a casual employee or if they can be paid on an ad hoc basis.

**Tax**

Payments for involvement are subject to tax in just the same way as any other income. In practice, the payments that are made to service users for involvement work are so small that they can often be disregarded for tax purposes. This is due to the fact that tax is only due on a person’s income once it rises over the given personal tax allowance. There are two ways to deal with any tax issues that may arise from making payments for involvement work.

1. Deduct tax at source from the payment being made
2. Make a payment to someone on the basis that they are self-employed and state that it is the payees responsibility for paying any tax that may be due

It may also be possible for your organisation to obtain a ‘dispensation’ from the HMRC. A dispensation is a formal agreement from the HMRC that payments need not be taxed at source.
This often resolves a number of concerns that are raised by university or NHS finance department when paying people for involvement work.

**Key recommendations**

- Offer payment to service users for involvement work wherever possible
- Remember that there are strict limits on the amounts of money that people in receipt of welfare benefits can receive each week.
- Working out a way of paying people for involvement work with university or finance departments often takes a long time. If at all possible begin making enquiries as to how your institution might require you to make payments as early as possible, so as to avoid delays later on.
- Use the quickest means of payment available to you to pay service users (this may or may not mean making payments using petty cash)

**When you first involve people …**

- Inform service users how to claim payment (petty cash, invoice etc) and provide them with a claim form if needed.
- Inform service users how long they are likely to have to wait until they receive payment.

Always be clear with service users from the outset what the rate of payment that is being offered actually is.

### 3.10 Resources

Resources (financial and otherwise) are needed in order to successfully involve service users in research. Whilst this may often entail extra financial resources, and therefore careful consideration of the budgetary implications of involving service users, it is important to note that the most precious resource may be time. Although time itself invariably has financial implications, this is not always the case; flexibility in the approach to deadlines can also be helpful.

‘If user-researchers are to be closely involved then a time commitment needs to be given to this process in the research proposal and this must be costed into the project’s finances.’

Trivedi and Wykes (2002)

Guidelines, such as Faulkner & Morris (2003); Thorne et al (2001); Hanley et al (2003), all advocate the need for adequate time and money to enable the successful involvement of service users in research to take place. Research papers too reflect on their experience of needing more of both:

‘We all found that working collaboratively was much more time-consuming than expected: the training took longer than anticipated; organising interviews was a very lengthy and frustrating process; interviews took at least half a day each including travelling in a rural area, preparation and winding down with the interviewee; analysis and coding took up several days of researchers’ own time. We had budgeted for a payment per hour long interview, in reality this only represented a small fraction of the time that service users and carers invested in the research.’ Allam et al (2004)

Physical resources associated with access to computer and office equipment, stationery and administration were also mentioned by some as inadequate or ill-prepared for (Faulkner, 2004).
4 PART 2: BROADER ISSUES TO CONSIDER WHEN INVOLVING MENTAL HEALTH SERVICE USERS IN RESEARCH

4.1 Underlying principles

Clarity and transparency

- Reasons for involvement: researchers need to be clear about why they are seeking user involvement and service users about why they wish to become involved in a project. It would be useful for both to put their reasons down in writing and/or to discuss them at the start of a project.

- Roles/responsibilities: clarity is needed from the start about the nature and aims of a project, and about the roles and responsibilities of all parties.

- Limits of involvement: in particular, it is essential that it is made clear to service users if there are any limits to their involvement – for example, limits to what aspects of a project they can influence or participate in.

- Incentives: researchers need to be clear about the incentives to involvement they are making available (e.g. payment, training) and the support and supervision to be provided.

- Expectations: both researchers and service users would benefit from a frank discussion about their expectations of the research project, what they hope they will gain from it and so on.

- Contract: it may be helpful to establish a contract outlining rights and responsibilities on each side (for example, Trivedi and Wykes, 2002).

Diversity

- It is important that the diversity of service users to be involved in a research project should reflect the nature of the research project itself.

- When looking at capacity building, researchers need to ensure that they take into account the diversity of the population which they serve and include people from minority ethnic communities, as well as people with different mental illness diagnoses, taking into account issues relating to gender, sexuality and physical disabilities.

- Like their professional counterparts, service users have a diversity of views and will not all feel the same way about an issue or research project. This diversity of views needs to be taken into account when considering involvement in a project or group.

INVOLVE has recently published a document entitled ‘Strategies for diversity and inclusion in public involvement’ which “provides ideas and information to support the involvement of a wide range of people in research and to identify ways to reach out to members of the public who do not often get involved in research”. The document can be downloaded here or from www.invo.org.uk.
Respect

- It is important that all those participating in a research project respect each other and, in particular, respect each other’s right to express their views.

Flexibility

- Flexibility needs to be built into research projects involving service users from the start; this has implications for funders and commissioners of research to allow greater flexibility in timescales and resources.

- Researchers need to be aware of the need for flexibility in relation to time and resources also; as well as in relation to the level of involvement, since some service users may experience ongoing distress and be unable to attend at all times.

- Flexibility in relation to the nature of the project itself is also needed if genuine involvement - and hence negotiation about the project - is to be enabled.

Example: Shaping Our Lives (SOL)

Shaping Our Lives is a national independent user controlled organisation (www.shapingourlives.org.uk). In a ground-breaking project exploring user-defined outcomes and outcome measures, Shaping Our Lives engaged with nine groups of service users:

- Three generic groups for users of social services
- Two groups of disabled people
- Two groups of people with learning difficulties
- One group of survivors/people with mental health problems
- One centre for integrated living

The findings of the research included that service users believed outcomes should be approached from a qualitative standpoint that fully recognises the individual and subjective nature of outcomes for people. Many of the issues raised were related to the actual process of service provision, which the authors relate to the fact that in many cases services are not delivering a discernible outcome for people.

The way in which Shaping Our Lives works is to bring together a range of different service users in all their work. The degree of commonality ‘makes working together in this way extremely valuable’. A follow-up project looked at the application in practice of on-going work about what service users meant by ‘user defined outcomes’. This piece of work included older people, mental health service users, Black groups and disabled people.
Accessibility

- It is important for researchers to use plain language and avoid unnecessary jargon (or explain it clearly where it is necessary to use it)

- Accessible formats for the presentation of research materials may be necessary for research collaborators as well as participants; it would be good practice to establish any particular access needs at the start of a project

Summary of key guidance: underlying principles

It is important for all researchers and service users participating in a research project to consider the principles underlying their work. The NIHR MHRN recommends the following principles as essential to good collaboration:

- Clarity and transparency
- Diversity
- Respect
- Flexibility
- Accessibility

4.2 Identifying priorities for research

Service users and user groups have different priorities for research to those identified by researchers, Trusts or Government policy. The most successful involvement of service users in research is likely to take place where there is some convergence and agreement on priorities: in short, where a research project or tender is also an issue of concern to service users. It is significant that where consultations have taken place, service users and user groups tend to paint a rather different picture of the topics in need of research.

The James Lind Alliance (JLA, www.lindalliance.org/) is an organisation that “aims to identify the most important gaps in knowledge about the effects of treatments, and has been established to bring patients and clinicians together in 'Priority Setting Partnerships' to identify and prioritise the unanswered questions that they agree are most important. This information will help ensure that those who fund health research are aware of what matters to patients and clinicians”. The approach used by the James Lind Alliance is quite democratic giving patients and clinicians an equal say in the way that research questions are identified and prioritised.

A number of Priority Setting Partnerships relating to a very wide range of health conditions (everything from pressure ulcers to schizophrenia) have been established. A significant number of research questions that have been identified by Priority Setting Partnerships have lead to successfully funded research studies. A comprehensive guide to establishing Priority Setting Partnerships is available online: www.jlaquidebook.org.
Key recommendations

- Consult with local service users and user groups about their priorities for research and seek to find areas of common interest with the current research priorities of your organisation
- Inform service users of your priorities in terms of research currently being carried out in your organisation

4.3 Commissioning research

Where a funding body is asking for service user involvement in research proposals, it is vital that the funding body itself is able to demonstrate good practice; how otherwise is it to judge the value or strength of the user involvement claimed in the proposals? INVOLVE held a workshop on commissioning in 2003, to which service users, researchers and commissioners were invited. The workshop addressed three key themes: how to involve members of the public on commissioning boards or advisory groups, as peer reviewers and in grant applications. The common themes to emerge across the groups were: the need to reduce jargon, define terms and make language more accessible; payment and the financial implications of involving members of the public in research; the need for support for everyone involved in the process and the value of building relationships; and finally the need to ‘close the loop’ by informing members of the public of the outcomes of the research.

In 2012 INVOLVE produced an extensive tips sheet entitled ‘recruiting members of the public to get involved in research funding and commissioning processes’, which gives a more comprehensive treatment of this topic than is possible here. The tips’ sheet can be downloaded from here or from www.invo.org.uk.
We would additionally recommend:

- At least two service users to sit on the decision making forums of research funders
- That research funders offer advice and guidance on user involvement to researchers and service users planning to put a proposal to the funding body
- Service users to act as (paid) reviewers on all research proposals where user involvement is a requirement
- Funders meet with short-listed applicants and their proposed service user partners to ensure that the proposed collaboration is genuine
- Some flexibility in the management of resources. The Joseph Rowntree Foundation, for example, has a separate and significant budget, which they use to disseminate the findings of work supported by the Foundation to relevant audiences.

Key recommendations

- Commissioners need to ensure that all literature regarding research funding is accessible to the involvement of people not familiar with research jargon
- Commissioners need to take account of the financial implications of involving service users in commissioning processes
- Any decision-making commissioning body should involve at least two service users
- Where funding is to be given on the understanding that user involvement in the research is to take place, funders should meet with shortlisted applicants and their proposed service user partners to ensure that the proposed collaboration is genuine
- Flexibility in the funding and commissioning procedures should be introduced in order that researchers can respond appropriately to the needs of the service users involved

4.4 Ethical approval and research ethics committees

Service user involvement and the ethical acceptability of research

A recent INVOLVE report entitled ‘Public involvement in research: impact on ethical aspects of research’ (2012) highlights the positive impact that the involvement of service users and others can have on research ethics. The report can be accessed here or from www.invo.org.uk.

These impacts are stated as being:

- Making research more relevant:
  - so that research is a valuable and respectful use of people’s time and the results are more likely to be useful to patients and the public

- Helping to define what is ethically acceptable;
  - particularly in controversial or ‘risky’ research

- Improving the process of informed consent;
  - making it easier for prospective participants to understand the research and potential risks
• Improving the experience of participating in research;
  o checking that the practical arrangements for participants are appropriate

• Dissemination of research to both the participants and the wider public;
  o providing information on the progress of the research as well as the final results

A number of examples are given throughout the report of how the involvement of service users and others improved the ethical acceptability of specific research studies.

The role of research ethics committees

The role of research ethics committees operated by the Health Research Authority is to ‘safeguard the rights, safety, dignity and well-being of people participating in research in the National Health Service. They review applications for research and give an opinion about the proposed participant involvement and whether the research is ethical’ (Health Research Authority, www.hra.nhs.uk).

When is ethical approval needed?

The majority of research involving people with experience of mental health problems requires the approval of a research ethics committee before it can take place. Exceptions to this are service evaluation and audit projects, which do not require the approval of a research ethics committee.

The Health Research Authority (HRA, formerly NRES)

The vast majority of ethics committees that are legally empowered to give ethical approval to a research project are run and administered by the Health Research Authority (www.hra.nhs.uk, formerly NRES). A number of universities and other institutions have their own ethics committees but these bodies are not recognised in law as being empowered to give ethical approval for research projects.

The way that HRA operates has changed significantly over recent years. The number of committees in England has been reduced dramatically. There are also now ethics committees whose role it is to consider social care research.

Gaining ethical approval

Gaining approval from ethics committees is widely seen as challenging. The majority of research projects do not receive outright approval after being presented to ethics committees. It is common for ethics committees to ask for revisions and other changes to a study protocol and patient information sheet and/or consent form before full ethical approval is given.

“A research project looking at NRES REC’s decisions showed the most common concerns to be: informed consent; care, protection and recruitment of research participants; and the provision of information such as patient information materials and lay summaries of the research” (Angell et al, 2007).

There are no hard and fast ways of ensuring that a study is approved quickly by a research ethics committee. However, one way in which service users can help is to review patient information sheets, consent forms, and advertisements to ensure that they make sense to potential research participants. This exercise can reduce the number of amendments ethics committees ask to be made to such materials as well as dramatically improving their readability.
The FAST-R Service

The NIHR MHRN provides a free and confidential service known as FAST-R (Feasibility And Support to Timely recruitment for Research service) to mental health researchers in England. The FAST-R service offers fast and easy access to people with experience of mental health problems and their carers who have been specially trained and can offer expert advice about patient information sheets, consent forms and recruitment strategies. The FAST-R team can advise on potential recruitment barriers to a mental health research project and make sure information for potential participants (such as patient information sheets and consent forms) is clear and easily understood.

By using the FAST-R service it may make it more likely that a research study will gain ethical approval faster than would otherwise have been the case. To access the service please click here: http://www.mhrn.info/pages/fast-r-service.html.

Ethical approval for projects that involve the active involvement of service users

Research ethics committees do raise various issues when considering research that actively involves service users as research collaborators (i.e. carrying out interviews, analysing study data, etc). In 2009, INVOLVE published a statement in conjunction with NRES (now the HRA) to ‘provide clarity and guidance on patient and public involvement in research and the requirements of research ethics review’.

The statement broadly considers two scenarios:

a) Where there is no direct contact with study participants

‘The ethics committee will not need to consider within its review the active involvement of patients and members of the public in carrying out research that involves no direct contact with study participants e.g. helping to analyse survey data, postal surveys etc’.

b) Where there is direct contact with study participants

‘Where people’s involvement results in direct contact with study participants the ethics committee will need to give specific consideration to the involvement as an element of the ethical consideration and approval. A research ethics committee (REC) will need to check that the person carrying out the research has adequate training, support and supervision appropriate to the circumstances in the usual way’.

In such cases (for example, studies where service user researchers carry out interviews with study participants), researchers should make clear plans for supporting and training such people. It should also be made clear (if applicable) whether service user researchers have been assessed by occupational health departments as able to carry out the work at hand. Also, a CRB check should be carried out. This will show the ethics committee that the user researchers have been treated in just the same way as any other member of the research team.
4.5 Undertaking research

It may be useful for service users and researchers alike if an individual research project is classified by the degree of service user involvement proposed. INVOLVE (www.invo.org.uk) subdivides service user involvement in research into the following categories:

- Consultation, where service users are consulted with no sharing of power in the decision-making
- Collaboration, which involves an active on-going partnership of service users in the research process
- Control, where service users design, undertake, and disseminate the results of a research project

4.5.1 Planning and starting a project

There are many things to think about at the planning stage, including the success of the proposal in obtaining funding and ethics committee approval, as well as adoption onto the NIHR portfolio. In addition, we would suggest that the following issues are thought through at an early stage in order to maximise the potential success of user involvement.

- Ideally service users should be involved from the very start of a project if they are to have real influence over the direction of the project and the way in which it is to be carried out
- At the design stage, ensure that a full assessment is made of the required resources in terms of both time and money (see suggested checklist for funding/budget planning). This is a strong message from many people who have undertaken or are undertaking collaborative research
- Flexibility should be built in from the beginning if it is to be given due consideration. Issues such as additional support, the capacity to re-schedule the timetable or scope of the research and anticipating the need for extra time at the end of the project may need to be considered
- Ensure that the provision of support for service users is included in the plans; if service users are involved from the start then discussions about this can take place early on. If not, then some resources need to be set aside for external and/or peer support and supervision
- Researchers and service users need to find ways of dealing with distress if and when it arises; it may be helpful to set this up at the start of the project. For example, service users may nominate a mentor or person to contact should they become unwell at work, or suggest other strategies that enable them to retain control of the process
- Good communication with your finance department needs to take place at an early stage. Financial systems need to be established from the start in order to ensure that the project can pay people for involvement work promptly
- Similarly, communications with the Human Resources and/or Occupational Health departments need to take place in order to ensure that the involvement or employment of people with a history of mental health problems can take place without any unnecessary barriers or bureaucracy
- It is advisable to be well informed about the various ways of paying service users and the barriers to paying them at an early stage. Payment should be offered to service users alongside access to advice regarding any potential effects on their receipt of benefits
• Researchers/research managers need to assess whether service users will need to have an honorary contract and establish this if it is required

**Suggested checklist for funding/budget planning:**

- Payment of fees and travel/care expenses to user-researchers, including advice on how to combine with receipt of benefits.
- Fees for research participants.
- Enough funding to include more service user interviewers, consultants or researchers than the project needs, to cover for periods of absence.
- Support for service users (may be an additional support worker or alternative).
- External supervision.
- Physical resources, such as space and communication technology to enable service users to take an equal part in the project.
- Training for service users and for staff (as appropriate).
- Time/venue/refreshments to meet with each other for mutual support.
- Dissemination and feedback to participants in different formats relevant to your project (e.g. language, accessible written and oral presentations).
- Insurance – liability.


### 4.5.2 Consulting with service users

It is common for researchers to consult with service users and to subsequently decide how and whether to use their views. This is not an ideal route to user involvement in research but it may be an important starting point for some researchers and organisations, particularly where research priorities are being established. Consequently it is useful for us to consider some issues of good practice in relation to consultation. Consultations may be a one-off with a group of service users, or may involve regular meetings or an invitation to service users to join an existing professional research group or meeting.

- Always involve more than one service user in any advisory group, consultation or meeting – whether it is a one-off meeting or a group meeting regularly over a period of time
- Where two or more service users are invited to join a meeting or advisory group, ideally they should have access to (or be members of) a larger group to provide them with support and accountability
- Provide refreshments and allow regular breaks in any meeting
- Ensure that service users receive adequate information about the nature of the consultation well in advance
- Any such information should be provided in accessible language and/or appropriate formats
• Payment should involve at least the provision of travel expenses and money should be available on the day of a meeting if at all possible

• Where service users are in the minority in a group or meeting, ensure that the Chair is well-briefed to enable the group to hear from the service user members

Example: Cost of Stigma Inventory (COSI)

The aim of the COSI study was to develop a Cost of Stigma Inventory (COSI) questionnaire to be used to determine the economic costs arising from the stigma borne by people who have mental health problems. The researchers considered that the best way to formally involve service users in the COSI study would be through participation in a focus group. The remit of this group was to examine a draft of the COSI questionnaire and to supply feedback, so that the questionnaire could be amended in the light of the participants’ experience and knowledge of stigma and discrimination. Service users were recruited through the MHRN and the group met at the Institute of Psychiatry, a school of King’s College London. The chief investigator chaired the meeting, which was attended by seven service users and one carer, and which lasted for approximately two hours. Participants were paid for their time.

The chief investigator has reported that the focus group was a very useful component of the COSI study, and, following the meeting, significant changes were made to the questionnaire.

In summary:

• Consultation with service users concerning the COSI questionnaire was a central component of the COSI study
• This consultation took the form of a focus group, which service user participants report was a positive and useful exercise
• The chief investigator considered consultation with the members of the focus group to have been of significant assistance in developing the COSI questionnaire
• The COSI questionnaire was substantially revised following the focus group, so as to better capture the costs of stigma and discrimination experienced by people with mental health problems.

Adapted from the Cost of Stigma Inventory (COSI) Case Study by Harminder Kaur. The full case study is accessible [here](#) or from [www.mhrn.info/publications](http://www.mhrn.info/publications).

4.5.3 Supporting and maintaining a project

The process of working on a project is often of more importance to service users than it is to researchers, in the sense that they may not have the same outcome-related incentives as researchers for whom the report and publications may have greater significance. Whether or not this is the case, it is vital that the process is inherently ‘pleasant’ to sustain people’s interest and enthusiasm, or service users may withdraw from a project before the end.

Adequate support is vital. In common with other guidelines, we would recommend that support be subdivided into the following elements, in order to ensure that the issue is considered comprehensively.
• Practical support (e.g. administration, finance/expenses and travel arrangements, communications)

• Research related support (e.g. regular supervision, de-briefing)

• Emotional support (e.g. peer support, external supervision, time to talk through difficulties and issues arising)

Providing support does not mean acting as a clinician: it is vital to establish boundaries, so that researchers or research supervisors do not act as clinicians to their service user researchers, unless this is agreed between both parties.

Training in relevant knowledge and/or skills is also a vital part of the process. Training may be necessary in order for service users to be able to make an equal or appropriate contribution to the research project, but it can also act as an incentive in its own right, providing skills for people that may be useful in other contexts. Training for staff, as is mentioned in the literature review, may also help in assisting research staff to understand about user involvement in research, and some of the issues facing service users coming into the workplace.

Resolving difficulties constructively is another vital part of sustaining the process. There are issues of power and disempowerment to be considered and acknowledged. The way in which differences of opinion are dealt with and resolved is a major part of how this will be played out. It is essential that respect is built up on both sides and that the views of service users are taken into account in these situations.

Flexibility needs to be an on-going consideration. If someone is unwell during the project, there need to be strategies in place to deal with this both personally and from the perspective of the project (see above), but perhaps also there may be ways of retaining someone’s involvement at a lower level than was originally planned.

4.5.4 Employment of service user researchers

‘Service users working in academic and other institutional settings can be a major asset to both the team and the research itself, with the potential to improve research relevance, quality, and dissemination’.

Delman and Lincoln in the Handbook of Service User Involvement in Mental Health Research (Wiley, 2009)

The employment of service users as researchers is a particular version of ‘user involvement’. Employment is a key element of social inclusion; having a job may have enormously beneficial consequences for a service user or survivor. There are a couple of particular challenges, however, which merit consideration. The academic environment is hierarchical and can be highly competitive. For someone entering or re-entering employment after a period of unemployment, there may be a conflict between the culture of an academic institution and the less structured nature of, for example, user groups and other related activities that service users might be more familiar with.

The hierarchical nature of an organisation and the pressure to treat employees equally within it may mean that the ‘user perspective’ brought to the organisation by a service user researcher becomes marginalised. If the individual is employed as a research assistant, does this mean that
their views are no longer respected as those of a service user? If they are treated as an equal with other research assistants then this may mean that their views are of low status within the academic hierarchy – yet they were employed because of their experience as a service user implying that their views or perspective are uniquely valuable. In addition, employment brings with it responsibilities as well as rights. These issues together point to the particular importance of ensuring that the individual has adequate support and supervision in their role.

- Support for a service user researcher is just as important for someone who is formally employed as it is for someone who is ‘involved’ in a project on a less formal basis. The provision of both personal support and research supervision should be addressed

- Researchers looking to employ people as service user researchers need to take responsibility for communicating with Personnel or Human Resources departments regarding their intentions and the nature of these posts. Significant delays in recruiting service user researchers have been reported due to these issues in a number of different studies.

- Managers and supervisors in clinical posts should avoid any temptation to act in the role of a clinician to the service user researcher, as this is inappropriate and can be undermining. Professional and personal boundaries should be observed.

- Serious consideration needs to be given to the role of the employed service user in the project and the organisation, and to the ways in which their views are able to be expressed and taken account of.

There have been an increasing number of mental health research studies in recent years with service users as paid or unpaid members of the research team. Two studies have specifically attempted to evaluate the quality of data collected by service user researchers as compared to researchers who did not disclose their mental health status (Gillard et al, 2011, and Rose et al, 2010). To date the findings are inconclusive and further research is needed “to determine the conditions under which service user researchers obtain information that differs from that obtained by nonuser researchers” (Rose et al, 2010).

The NIHR MHRN has produced a number of case studies of research projects that have involved service user researchers. These are available here or at www.mhrn.info/publications.

These case studies include practical examples of the benefits of utilising user researchers, the challenges that researchers faced when employing user researchers, and solutions that researchers found to these challenges. A sample role description, interview questions, and advertisement can be found in the MHRN PPI Toolkit for Researchers and can be downloaded from www.mhrn.info/toolkit.

A consistent theme that emerges from studies with service user researchers is the need for flexibility (see section 3.4). “Researchers who have employed service users as researchers report that it is important to be prepared to be flexible and responsive to employees’ needs” (Staley, 2012).

At the time of writing the NIHR MHRN North West and North East hubs are producing a comprehensive guide to recruiting and supporting service user and carer researchers. This guide will be available via the MHRN website in 2013.
4.6 Dissemination and ‘open access’ publishing of research findings

There has recently been a very strong move, both in the UK and elsewhere, towards an ‘open access’ model of publishing. In the ‘open access’ model of publishing, journals make research papers freely accessible to all. Often (but not always) journals require that authors make a payment for articles to be made open access. Some journals, such as the British Medical Journal, make the vast majority of its contents freely available to all after a certain period of time.

Many public funders (and some charities such as the Wellcome Trust) now require that the findings from research they fund be made publicly available. For a partial list of funders that require findings to be made publicly available please see: http://ukpmc.ac.uk/funders/. It is worth considering, as a matter of course, publishing articles in an ‘open access’ format so that service users and the public can have direct access to the findings of research studies.

Alongside publishing the findings of research in an open access format it is useful for service users and the public to have an understanding of how to find and read a research paper. The NIHR
MHRN has recently published a document entitled ‘Mental Health Research Network Guide to finding and reading a research paper’. The guide explains how research is published as research papers, what the different sort of papers are, how they are structured, how to identify a particular research paper and, finally, how to get hold of it.

The guide can be downloaded here or from www.mhrn.info/publications.

Some general points regarding the dissemination of the findings of research are:

• Dissemination needs to take into account the service user audiences as well as research and other stakeholder audiences

• Resources, both time and money, are needed to manage the dissemination stage effectively – hence it is advisable to build these in from the start of the project

• Accessible reports or a summary of findings can be produced to reach a wider audience of local stakeholders, service users and carers who may be interested or affected by the research findings. A good example of such an accessible report is ‘Outcome measurement in mental health: the views of service users’. This report can be downloaded here or from www.mhrn.info/publications

• Service users may assist with ensuring that research findings reach a service user audience; for example, through newsletters, voluntary sector magazines and relevant email forums

• In situations where there is a delay in disseminating research findings, it is good practice to stay in touch with service users who have been involved and ensure that they know what is happening

• Other formats that may be useful in reaching different audiences are: internet publication, local meetings of service user groups and the use of other media such as radio

Implementation

For many service users, there is little point in carrying out research without the intention of implementing important findings. Some people’s main motivation for becoming involved in research may well be a commitment to changing and improving mental health services. This may well present a challenge in circumstances where researchers do not have the power to implement the results of their own research. However, it is good practice to address this issue in some ways.

• Involving local stakeholders from the start of a project is one way in which research can be connected with and informed by local services

• It may be possible to identify small or intermediate elements that could be implemented

Ending a project

Endings can be difficult for many people. There have been a number of projects where service users have been involved in, or leading on, research where difficulties in finding a way to finish have been recorded (e.g. Nicholls 2000).

This may be a positive sign of the way in which the project team have worked together or an unwillingness to let go of the support, activity, or people involved. If there are no possibilities for continuing in some form (e.g. as an on-going research interest group), then we would recommend that a formal ending event or day is arranged.
• Find a way to mark the ending of a project
• Ensure people hear about the project publications if they happen after the end of a project; and ensure people are informed about any further developments
• Enable service users to reflect on their learning and skills development, and compile a CV if appropriate
• Enable researchers to reflect honestly and openly on the experience and to disseminate their learning to other researchers in the same organisation

4.7 User-controlled research

Over recent years there has been an increase in the number of people with experience of mental health problems carrying out research themselves. In the majority of cases such people work within and alongside existing research teams. Most commonly such people identify themselves as ‘service user researchers’. Well-known research groups that include service user researchers are the Spectrum Centre at Lancaster University and the Service User Research Enterprise (SURE) at the Institute of Psychiatry.

There has also been a rise in the number of groups of people who openly identify as using health services (not just mental health services) who develop and carry out research studies themselves. Such studies can loosely be referred to as user-controlled (or user-led) research. As the name suggests a key characteristic of such research is that service users are in positions of overall (but not necessarily absolute) power and control.

A key introduction to user-controlled research was produced in 2005 by Turner and Beresford (User Controlled Research: Its meanings and Potential: Shaping our Lives and Centre for Citizen Participation). This document is available online. In 2012 INVOLVE, produced a publication showcasing seven user-controlled research studies entitled ‘Changing our Worlds: Examples of user-controlled research in action’. This document can be downloaded here or from www.invo.org.uk.

In this report Faulkner identifies three broad reasons why seven user-controlled research projects were conducted:

• To make change happen
• To highlight the needs of marginalised people
• Because ‘No-one else will do it’

The benefits of such user-controlled research projects were identified in the same report as being:

• Making change happen
• Access and trust
• Improved research quality
• Empowerment
• Credibility

However, a number of authors have also identified challenges to user controlled research. There are few sources of funding for such research. Faulkner identifies instances where people carrying out such research felt that they were discriminated against and their work unfairly discredited. Other challenges relate to the support needs of people carrying out such research and issues relating to their identity (researcher or service-user) and their relationship to other researchers.
4.8 Assessing the impact of involvement

Assessing the impact of involvement on research is a topic that is of great interest to those that fund research, and the wider research community. Whilst various ways of measuring the impact that service user and carer involvement has on research are in development, no single generally accepted way of measuring impact has yet been developed. Reasons for this include the relatively few reports on how service users and carers have been involved in research, and the sheer diversity of the possible impacts that involvement can have at the different stages of a research project.

An established way of recording the impacts that involvement has had on a research project is to write an account of how people were involved, what the involved people actually did, and what specific impacts their involvement had on the research, on a case by case basis. Such accounts are generally known as ‘case studies’.

In 2010 the NIHR MHRN produced five such case studies, which can be accessed here or at www.mhrn.info/publications.


The document is essentially a structured literature review of 89 publicly available articles that contained a ‘substantial amount of critical analysis or reflection on the impact of public involvement in research’. Articles had to have ‘discussed public involvement in NHS, public health and/or social care research.

The main themes identified in the review were that public involvement was of value and helped in the following ways:

- Increasing recruitment to all types of research
- In qualitative research, where participants are asked to share their views and experiences
- Improving trial design and ensuring the use of relevant outcome measures in clinical trials
- Bringing benefit to the researchers and service users involved as well as the research participants

In 2011 an audit of the levels of service user involvement in a randomly selected sample of NIHR MHRN supported studies was carried out (Staley, 2012). Table 1 shows the impacts that service user involvement had on the audited studies as reported by the researchers who were interviewed. By a considerable margin the greatest reported impact of service user involvement was in the design of the study. Nevertheless, it is clear from table 1 that the involvement of service users can make an impact at every stage of the research process.
<table>
<thead>
<tr>
<th>Nature of the impact of involvement</th>
<th>% (number) of projects reporting this impact*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on the design of the study</td>
<td>61% (25)</td>
</tr>
<tr>
<td>Impact on conceptual elements</td>
<td>22% (9)</td>
</tr>
<tr>
<td>Impact on practicalities</td>
<td>27% (11)</td>
</tr>
<tr>
<td>Impact on recruitment material and processes</td>
<td>12% (5)</td>
</tr>
<tr>
<td>Extensive influence throughout a study</td>
<td>20% (8)</td>
</tr>
<tr>
<td>Limited or no impact</td>
<td>20% (8)</td>
</tr>
<tr>
<td>Provided a service user perspective on the findings</td>
<td>7% (3)</td>
</tr>
<tr>
<td>Made interviews better for the interviewee</td>
<td>5% (2)</td>
</tr>
<tr>
<td>Better retention of participants</td>
<td>5% (2)</td>
</tr>
<tr>
<td>Confirmed the topic was important to service users</td>
<td>5% (2)</td>
</tr>
<tr>
<td>Motivated the research team</td>
<td>2% (1)</td>
</tr>
</tbody>
</table>

Table 1. Reported impacts of service user involvement in a randomly selected sample of studies supported by the NIHR MHRN. * The total adds up to more than 100% because some researchers reported more than one kind of impact. This table is reproduced from Staley, 2012.
5. PART 3: GLOSSARY OF TERMS, REFERENCES, ACKNOWLEDGEMENTS AND USEFUL CONTACTS

5.1 Glossary of terms

This section contains a limited glossary of terms that are used in this guide.

For a more comprehensive list of terms used in research please see: www.invo.org.uk/resource-centre/jargon-buster/

Abstract: A brief summary of a research study and its results. It should tell you why the study was done, how the researchers went about it and what they found.

Action Research: Research designed to explore a practical situation or service, with the aim of implementing findings as they are discovered and bringing about positive changes.

Advisory Group: A group of people brought together to offer advice on a project. They will each be chosen on the basis that they have some experience or expertise to bring to the project, and will meet on a regular basis during the life of the project.

Collaborative research: In this case: an active partnership between researchers and service users to carry out a research project. Collaborative research can also refer to any partnership forged in order to carry out research, such as that between researchers and health service practitioners.

Commissioning research: This is the process of selecting someone to undertake a particular research project. It will typically involve advertising the research topic, selecting a shortlist of the best proposals from those submitted, and reaching a decision about which one to fund. The final decision may be informed by peer review, i.e. engaging other independent researchers and experts to read and comment on the short-listed proposals.

Consumer: The term ‘consumer’ refers to anyone who is a consumer of the service, including patients, carers, long-term users of services, organisations that represent consumers’ interests and members of the public who are the potential recipients of health promotion programmes. The intention is to distinguish between consumers and health or research professionals.

Dissemination: The process of ensuring that the results or findings of a research project reach a wide and relevant audience. This might involve giving talks at conferences, speaking on the radio, writing articles in newsletters or journals and giving talks at events arranged for people for whom the project is relevant.

Empowerment: Empowerment is what happens when someone gains a greater voice in situations where they have little power or say over what happens to them; or when someone gains greater control over their life through learning the skills or finding the opportunities in which to express themselves.

Ethics: In research terms, ethics are the principles underlying the practice of research that will ensure, as a minimum, that no harm or abuse will be done to research participants. Examples include informed consent and maintaining confidentiality. Ethics can also include other values held dear to researchers and service users, such as the importance of respect, clarity and transparency, diversity and accessibility.

Evaluation: An evaluation seeks to assess how well a service or project is doing against its aims and objectives, and against some specified standards or level of quality. It is likely to use both
qualitative and quantitative methods and to gain the views of service users, staff and other ‘stakeholders’ of the service.

**Focus group:** A focus group - or group discussion - is a small group of people brought together to discuss and respond to research questions. It is a good method to use when a researcher needs to gain people’s views about a service or ideas about a new or ideal service.

**Hub:** One of the eight ‘regional offices’ of the Mental Health Research Network. Rather like a hub in the centre of a wheel, the idea is that the hub brings together networks of people and organisations that will undertake research in different partnerships.

**Implementation:** The process of acting on the findings of research to bring about positive change.

**Informed consent:** Ethically, a researcher needs to gain ‘informed consent’ from a research participant before they can proceed to include them in the research. It means that the participant must be fully informed and understand about the research and what involvement will entail before they agree to take part.

**Methodology:** A system of methods or ways of going about undertaking research.

**Outcome/outcome measure:** An outcome may be the result or effect of a treatment on a patient, e.g. a change in the level of depression caused by the use of anti-depressant medication. The outcome measure is what is used to measure the effect of the treatment on the patient. In this case, a questionnaire may be used before and after the use of the medication to assess whether it has brought about any change.

**Pro forma:** In the context of this document ‘pro-forma’ refers to a general document (for example a role description for a service user researcher) that can be adapted as needed for local use.

**Qualitative research:** This is research that endeavors to gain understanding about personal experience and the meanings behind actions or beliefs. It is usually obtained through in-depth interview and seeks themes and issues rather than facts and figures. As it produces rich and detailed information, there will be few participants and analysis may not be applicable to the general population.

‘Service user’ and ‘Survivor’: These terms can be used rather differently by different people. The term ‘service user’ is usually used where the people to be involved in a project are using or have used services, i.e. they are or have been patients or clients. Very often, in the context of research, this means they have used the service being explored within the research project. The term ‘survivor’ is often intended as a more broad term to include people who have experienced mental or emotional distress, whether or not they have used mental health services. However, ‘survivor’ is also used politically to refer to people who have survived mental health services and/or treatments; in this sense it is shorthand for ‘psychiatric system survivor’.

**Stakeholders:** These are people or organisations that have a recognisable ‘stake’ or interest in the service or project in question.

**User controlled / user-led research:** This is research where service users lead or control the research: they design, undertake and disseminate the results of a research project. There may be a distinction between the two: user controlled research may be more comprehensively under the control of service users, whereas user-led research may be funded from within an organisation where some control is retained but the research project is led by service users.
5.2 References

Wherever possible, hyperlinks are provided to the abstract or the full text of every work that has been referred to in this guide. All links were accessed in March 2013. Access to the full text of some of these references may require a subscription to the relevant journal.

The NIHR MHRN has produced a ‘guide to finding and reading a research paper’, which you may find helpful. This guide can be accessed here or at www.mhrn.info/publications.

List of references


Abstract


Abstract


Full text


Full text


Full text


Abstract


Full text

INVOLVE (2011) What you need to know about payment: an introductory guide for members of the public who are considering active involvement in NHS, public health or social care research. INVOLVE, Eastleigh, (www.invo.org.uk).

Full text


Full text
Full text

Full text

Full text

Full text

Full text


Full text


Abstract


Rose, D. (2001) Users’ Voices: The Perspectives of Mental Health Service Users on Community and Hospital Care. Sainsbury Centre for Mental Health (now known as the Centre for Mental Health: www.centreformentalhealth.org.uk).
Full text

Full text
Full text

Full text

Abstract

Full text

Full text

Abstract

Abstract

Full text

Full text

Full text


UFM Network (2003) Doing it for real: a guide to setting up and undertaking a User Focused Monitoring project. Sainsbury Centre for Mental Health (now known as the Centre for Mental Health: www.centreformentalhealth.org.uk).

Wallcraft, J, Schrnak, B, Amering, M (Eds, 2009). Handbook of Service User Involvement in Mental Health Research. Wiley.

Full text
5.3 Acknowledgements

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5.4 Useful contacts

Contacts and places to promote service user involvement opportunities:

All of the contacts listed here can offer advice or support on involvement issues. They will also be able to help research teams advertise involvement opportunities.

**MHRN Service Users in Research**

Service Users in Research is the national service user involvement arm of the MHRN.

MHRN Service Users in Research
Mental Health Research Network
PO77 Institute of Psychiatry
De Crespigny Park
London SE5 8AF
email: mhrnppti@kcl.ac.uk
phone: 020 7848 0644
[www.mhrn.info/serviceusers](http://www.mhrn.info/serviceusers)

**MHRN FACTOR (Families/Friends and Carers Together in Research)**

FACTOR is the MHRN’s network of carers interested in research, and its members are willing to give advice, consult or collaborate with research teams.

FACTOR
Mental Health Research Network
PO77 Institute of Psychiatry
De Crespigny Park
London SE5 8AF
email: mhrnppti@kcl.ac.uk
phone: 020 7848 0644
[www.mhrn.info/FACTOR](http://www.mhrn.info/FACTOR)
MHRN regional offices (hubs)

The MHRN has eight regional offices (or ‘hubs’) based across the country. These hubs should be the first port of call if you need any support with involving users or carers in your research. More details about each of the hubs together with details of the geographical areas they cover can be found at: www.mhrn.info/hubs.

Other useful contacts

INVOLVE (www.invo.org.uk) is a national organisation funded by the Department of Health to facilitate public and patient involvement in health and social care research. INVOLVE also produces many useful documents, many of which are referred to in this document.

INVOLVE
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD
email: admin@invo.org.uk
phone: 02380 651088
textphone: 02380 626239
fax: 02380 652 885

People in Research
www.peopleinresearch.org

National Service User Network (NSUN)
www.nsun.org.uk
phone: 0845 602 0779

Shaping our Lives (hosted by Brunel University)
www.shapingourlives.org.uk
phone: 0845 341 0383

NIHR Research Design Services (RDS)

In 2008-9, the National Institute for Health Research (NIHR) funded 10 Research Design Services: one service for each strategic health authority area. The purpose of the Research Design Services is to help NHS researchers and those working with NHS partners to prepare proposals for submission to national funding competitions for applied health or social care research. They do this by providing expert advice and support on research design and methodology.

Each of the ten Research Design Services has staff whose role is specifically to help get service users and carers involved in research studies at the proposal stage. Many Research Design Services also have small bursary schemes for researchers to cover some of the costs of involving user and carers in their research application.

INVOLVE has assembled a large amount of information about the various Research Design Services and their public and patient involvement activities, which can be accessed online at: http://www.invo.org.uk/find-out-more/information-for-researchers/research-design-services-information/
East of England Research Design Service
www.rds-eoe.nihr.ac.uk
phone: 01206 874144
email: RDSeeoe@essex.ac.uk

East Midlands Research Design Service
www.rds-eastmidlands.nihr.ac.uk
phone: 0116 207 8778
email: rpandya@dmu.ac.uk

Research Design Service London
www.rdslondon.co.uk
phone: 020 7848 6763
email: info@rdslondon.co.uk

North East Research Design Service
www.dur.ac.uk/school.health/rds/
phone: 0191 334 0826
email: rds@durham.ac.uk

North West Research Design Service
www.rds-nw.nihr.ac.uk
email: rds-nw@lancaster.ac.uk

Research Design Service South Central
www.rds-sc.nihr.ac.uk
telephone: 0238 079 4778
email: rds-sc@soton.ac.uk

South East Research Design Service
www.rds-se.nihr.ac.uk/
email: D.Moore@brighton.ac.uk

South West Research Design Service
www.rds-sw.nihr.ac.uk
phone: 08454 225465
email: julie.hapeshi@glos.nhs.uk

West Midlands Research Design Service
www.rds-wm.nihr.ac.uk
phone: 0121 414 7113
email: rdscentre@contacts.bham.ac.uk

The NIHR Research Design Service for Yorkshire & The Humber
www.rds-yh.nihr.ac.uk/
phone: 0114 222 0828
email: rds-yh@sheffield.ac.uk
Charities
MIND  www.mind.org.uk
RETHINK  www.rethink.org
The McPin Foundation  www.mcpin.org
MQ transforming Mental Health  http://joinmq.org
National Service User Network (NSUN)  www.nsun.org.uk
Centre for Mental health  www.centreformentalhealth.org.uk/index.aspx
Mental Health Foundation  www.mentalhealth.org.uk
The Royal College of Psychiatrists  www.rcpsych.ac.uk