Mental Health Research Network

NHS
National Institute for Health Research

■ **Mental health researchers'**
T O O L K I T

for involving service users in the research process

produced by the Mental Health Research Network North London Hub Service User Representative Group

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June 2011

Advantages of service user involvement in research

■ Subjective experience of mental health problems can inform research questions. These experiences include, for example, side effects of treatments, relapse triggers, relapse prevention and stigma.

■ An alternative perspective from the professionals' 'illness' model.

■ Diversity of views on what constitutes a 'good outcome'.

■ Better recruitment.

■ Instruments are more 'user friendly' and need less piloting.

■ More 'honest' responses from participants, especially regarding satisfaction with services.

■ More clinically relevant output.

■ Cross-fertilisation of ideas.

■ More likely to get funding.

■ Recovery-based practice.

Message to researchers

Oiling the wheels: how to involve service users in the research process

What should we be doing to involve service users in our research? How can we find the people who can help to carry out this task sensitively and well? What is the procedure for involving service users? What forms need to be completed? How do we advertise for the right people to do this work?

This Toolkit aims to answer these questions and offer practical guidance to mental health researchers to help them involve service users in their studies and develop opportunities for involvement. We have also created templates of documents that can be used by researchers when involving service users in their studies. These include role descriptions, agreements and adverts. A full list of the templates is on page 12.

They are all also available as separate Word documents, downloadable from the Mental Health Research Network website, www.mhrn.info/toolkit. The Toolkit has been created as an open source document which means anyone can customise, adapt and use the templates and do not need to credit the authors or the MHRN.

Much of the information and advice within this Toolkit can also be applied to the involvement of families, friends and carers of people with mental health problems.

'... service users have the experience and skills to complement those of current researchers ... they know what it feels like to undergo treatments and their various side effects ... they will have a good idea about what research questions should be asked ... and how questions might be asked differently.'

Goodare and Lockward,
BMJ, 1999, 319: 724-725.

About the Mental Health Research Network

The National Institute for Health Research Mental Health Research Network (NIHR MHRN) helps make research about mental health happen in the NHS in England.

We work through eight regional offices (called hubs) and currently support more than 300 multi-centre studies and clinical trials. We offer very practical support to research teams, helping them set up and recruit research participants through services run by more than 60 mental health trusts.

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

Our hub teams support, and can introduce researchers to, service users who are willing to act as consultants, advisors, steering group members or researchers.

Our centrally-based Service Users in Research supports involvement activities throughout the MHRN and commissions people with experience of mental health problems to produce guidance and resources for researchers – such as this Toolkit. Service Users in Research has also produced guidance for good practice for both research teams and people with experience of mental health problems who plan to work together on studies and trials. There is more information about the guidance on page 6 and you can download a copy on the MHRN website at www.mhrn.info/publications

Contact details for Service Users in Research and the MHRN's eight regional offices are on page 9.

Contents

Why involve service users (and others) in research?

The NHS has adopted the concept of 'Patient and Public Involvement' (PPI) since the Health and Social Care Act 2001 placed a duty on it to involve and consult patients and the public about NHS plans, services and resources. This resulted in many patient forums being developed. PPI in mental health research is now a requirement for gaining ethical permission and is becoming a requirement of funding support.

It is really important that PPI within mental health research be effective, meaningful and sustainable and not a tick box exercise. Making people who are involved feel part of the process and ensuring that their views are listened to and acted upon, is all part of effective and sustainable PPI.

Researchers and clinicians have developed their expertise through study and clinical practice: their knowledge is not through their own experience of living with a particular condition and what is involved on a personal level.

Involving service users and others, therefore, is crucial in order to understand other aspects that may not have been thought about, and to embrace the knowledge that service users have about their condition from an experiential point of view. PPI is concerned with creating a forum where the experience, knowledge and expertise of both health care professionals and the public can come together in an equal partnership to benefit health care research.

The levels of PPI in research have increased following the establishment of INVOLVE, a national organisation funded by the Department of Health to facilitate public and patient involvement in health and social care research, the National Institute for Health Research (NIHR) and its Clinical Research Network (CRN).

The MHRN is one of six topic-specific research networks that are part of the NIHR's CRN in England and all of them have been championing involvement since their formation. INVOLVE has been doing the same for more than a decade, and a change is now occurring. Some research charities are employing a PPI lead to encourage patient representation to influence campaigns for service provision and to bring a patient view to discussions on funding of research studies. The pharmaceutical industry is also exploring methods of involving patient advocates in their discussions about future research. These are huge steps forward that may finally break down some of the long-standing barriers to effective involvement.

Terminology

How do you refer to people who use (or have had) used) mental health services?

This is a very difficult area and there is no general agreement. Perhaps the most widely used term is 'service user', and this is the term which is used throughout this document. Other commonly used terms are 'patient' and 'survivor'. All these terms have proven to be problematic in one way or another.

Identity is a very personal thing and we feel that it is important that researchers give people who use mental health services the chance to self identify (within reason) and to use a term that they feel most comfortable with. This may be a neutral term – such as 'project advisor' – that does not betray someone's use, or previous use, of services.

There are advantages to using a neutral term such as 'project advisor' – people are able to list any involvement work on a CV and use it as work experience without disclosing their use of mental health services, for example.

Opportunities for involvement throughout the research process

Identifying a research topic
- **People who use services are consulted about research topics.**
- **People who use services collaborate with researchers to identify research topics.**
- **People who use services help to identify topics for research themselves.**

This is one of the most powerful ways to involve people who use services in research. The task of identifying a research topic should be a dialogue. We have found that the best way to involve people in identifying topics for research is to talk with them face to face. You will need to check whether your priorities match those of the people who use services related to your topic. Talk about what you each want from research. Be clear about what research can and can't achieve. Research alone very rarely leads to change – but sometimes the involvement of people who use services can influence the uptake of research. If you have already identified a research topic, it would still be useful to consult with people who use services about how appropriate the topic is to them.

Prioritising
- **People who use services prioritise topics for R&D.**
- **People who use services collaborate with researchers to prioritise topics for R&D.**
- **People who use services are consulted about prioritising R&D topics.**

If you consult people who use services about their priorities for R&D, ensure you consult a wide range of organisations and individuals, and that you use accessible language. It would be better to arrange to meet people who use services face to face, on their own ground, rather than sending out letters. This will enable you to hear about their views and to explain your reasons for contacting them. Expect to hear some strong views: service users tend to prioritise issues related to social welfare and daily living, abuse and discrimination, self-management and alternatives to mainstream treatments and services.

Commissioning
- **People who use services are consulted about which research to commission.**
- **People who use services collaborate with research funders to commission research.**
- **People who use services commission research themselves.**

A number of funding organisations have involved people who use services in reviewing proposals for research. They have found that people who use services bring a different perspective to the review process. If you plan to involve people who use services as reviewers, think about the following:
- don't underestimate the abilities of people who use services to review proposals – some people already have expertise in this area;
- ask people who use services to review the elements of a research proposal that focus on the research design and dissemination of results.

People who use services can be consulted about which research to commission in a number of ways:
- by sending surveys to people to ask for their views;
- by carrying out interviews or focus groups with people;
- by going to meetings of service user groups and discussing research proposals with them.

Information should be provided to people in user-friendly language, their views should be taken into consideration and the results of the commissioning process should be fed back to them.

Designing research
- **People who use services are consulted about the design of a research project.**
- **People who use services collaborate with researchers to design a research project.**
- **People who use services design the research project.**

If you are involving people who use services in your research, it is helpful to plan this involvement before submitting a proposal for funding. Increasingly, research commissioners are asking for information about how you are involving people who use services in your research on the application form. It is important that you think through how you are going to involve people and the implications of asking people to become involved. When designing the research you will need to budget for the additional cost of involving people.

Identifying a research topic

- **People who use services collaborate with researchers to manage the research: commissioning, evaluating, analysing and interpreting.**
- **People who use services are consulted about the management of research.**
- **People who use services manage the research themselves.**

This kind of involvement is usually undertaken through a committee or steering group. You will need to think about issues of confidentiality before you ask people who use services to take part in steering groups or committees to oversee a research project. For example, if your committee will be looking at patient notes, does the organisation's confidentiality policy allow a 'non-professional' to be involved in this? Some people who use services have been asked to leave the room when discussions like this take place in steering groups for research. If this is likely to be the case, advise the people concerned when you first invite them to participate. Alternatively, prepare a confidentiality statement for everyone to sign.

You can also collaborate with people who use services to recruit researchers for your project. People who use services can bring useful perspectives to the selection process, particularly if you are recruiting researchers who will need to build relationships with research participants to access data for the research. We believe that it is not usually appropriate for those being researched to also become actively involved in the management of the research. People can find it compromising to be both the participant and the researcher, particularly if the research is concerned with relationships.

Undertaking research

- **People who use services are consulted about the research process.**
- **People who use services collaborate with researchers to carry out research.**
- **People who use services carry out the research themselves.**

Meetings may be held during the research process to let people who use services know that the research is being undertaken and what it is about. This is particularly important if the topic is a sensitive one. As well as informing people who use services about the research, meetings can also help with response rates to questionnaires. Researchers involved in clinical trials may use meetings with patients or voluntary organisations during the research to keep the community up to date about progress.

Members of the public and their organisations have access to a range of networks. They should therefore be able to help you access particular communities, help you gain consent from potential study participants, gather data and so on. People who use services may take a variety of roles in undertaking research. They may design the research instruments (that is, the questionnaire or the interview schedules). They may also carry out the research themselves. This may take the form of surveys, interviews, focus groups, the gathering or reviewing of documentary evidence, or undertaking library-based research. If people who use services carry out the research themselves it is important to make sure they have the right skills and that training is provided for those who need it.

Analysing Results

- **People who use services collaborate with researchers to analyse and interpret the results of research.**
- **People who use services are consulted about the analysis and interpretation of research results.**
- **People who use services analyse and interpret the results of research themselves.**

Consultation with people who use services about the analysis of research results may take the form of meetings with those who are interested in the research area. People can also be consulted by providing them with draft copies of the analysis for comment. They may be able to advise on which areas of the findings are of most interest to them, and which they would like to be analysed further, or featured in reports.

You can involve people who use services in analysing results of research. This can result in feedback or comments that aid analysis and interpretation. You can also hold a participative conference to check your initial findings. People who use services may be experienced in analysing and interpreting the results of research, or they may benefit from some guidance from a researcher.

Evaluating results
- **People who use services are consulted about evaluating the research process.**
- **People who use services collaborate with researchers to evaluate the research process.**
- **People who use services evaluate the research process.**

Whether people who use services do the research themselves, collaborate with researchers or are consulted about research, it is important that the research process is evaluated. People who use services who have been involved in research should be involved in this evaluation and reflection process. This is the time when both researchers and people who use services can consider and reflect on what went well during the research, what did not work so well and what they would do differently if they were to do the research again. It is important that people who use services feel able to share their experience of the research process and their involvement in it openly and honestly. Through an open exchange between researchers and people who use services, both parties can learn from each other. Sometimes an external facilitator can be helpful. Evaluating the role that members of the public played in the research process provides useful information and encouragement for other researchers wishing to involve people in their work. It can also help you to involve the public more effectively next time.

Disseminating results
- **People who use services are consulted about disseminating the results of research.**
- **People who use services collaborate with researchers to disseminate the results of research.**
- **People who use services disseminate the results of research.**

People who use services are most likely to want to see research implemented to change practice for the better and they can be instrumental in making this happen. They will be able to raise the research in different forums, often those to which researchers do not traditionally have access. People who use services are much more likely to disseminate the results of research to their peers if they have been involved in the research from an early stage. You can involve people who use services in reviewing draft research reports. This is particularly helpful if you want to produce a report that is accessible – people who use services are very good at identifying jargon.

MHRN guidance for good practice

The MHRN has produced guidance for researchers and service users who wish to develop collaborative research projects and programmes involving service users. These guidelines are currently being reviewed but can be accessed via our website, www.mhrn.info/publications

Guidance for Good Practice: Service user involvement in the Mental Health Research Network (2006) is in two main parts:

Literature review
This provides much of the evidence for the guidance, covering a range of issues including the benefits of involving service users in research; the use of accessible language; training and support; payments and resources. This section is particularly useful if you need to gather evidence for supporting the involvement of service users in research. Many of the papers referenced are based on the experience of conducting real projects and are practical in nature.

Guidance for good practice
The guidance contains practical pointers and suggestions about how service users can be involved in research. It includes information about the underlying principles of involvement; capacity building; identifying priorities; commissioning research; ethical approval and ethics committees; undertaking research; dissemination and implementation; and user-controlled research.

Examples are given throughout of ways in which some organisations have addressed the issues. Three case studies are included.

We expect these guidelines to be used in different ways by different people, depending on the level of experience and knowledge of this approach to research.

Trusts and research organisations that are just beginning to think about involving service users in their research might find it useful to start by considering the *Underlying principles* and *Capacity building* sections (2.1 and 2.2).

Service users wishing to work with a trust or research organisation might find the *Underlying principles* section (2.1) and *Undertaking research* section (2.6) useful in identifying good practice and issues that they need to think about before embarking on a research project. People who are already engaged in collaborative research (both service users and researchers) might find the *Undertaking research* section (2.6) and *Dissemination and implementation* section (2.7) useful in reviewing and revising any policies or practical issues they have found difficult, as well as in planning for future projects.

The *Undertaking research* section (2.6) covers the range of service user involvement from consultation through to employment, with advice and information on such areas as payment, budgeting, support and training.

The *Commissioning research* section (2.4) is aimed primarily at commissioning bodies and funders of research.

The *Ethical approval and research ethics committees* section (2.5) is aimed at research ethics committees.

However both sections may prove useful to researchers and service users who are wishing to communicate their needs to either of these bodies.

Service users and researchers who are interested in creating opportunities for user-controlled research should find the *User-controlled research* section (2.8) useful in identifying some of the supporting evidence and helpful contacts. Section 2.8 is also valuable for those wishing to support the further development of user-controlled research.

Making payments to service users for involvement work

The MHRN strongly recommends that wherever possible, service users and carers are adequately paid for any involvement work they carry out. At the very least, out of pocket expenses such as travel costs should always be reimbursed.

However, making payments to people in receipt of welfare benefits is challenging because of the complex rules regarding the amount people on benefits can earn. Most (but not all) people can only earn around £20 a week before their benefits are affected.

The MHRN commissioned a comprehensive policy/guide to cover payments for those involved in the work of the MHRN and research in general.

There are two documents, both of which are available to download at www.mhrn.info/publications. They are:

MHRN Service Users and Carers Payments Policy: Benefits Systems and Conditions around Paid and Voluntary Involvement (April 2010) and

MHRN Service Users and Carers Payments Policy: Service user and carer participation: helpful benefit rules and benefit pitfalls to avoid (February 2010).

People who cannot receive payment
For various reasons (often benefits or pension-related) there are some people who cannot receive any payment for the work that they do. In such cases it is often possible to compensate people somewhat by making a one-off 'gift' during any given financial year. This gift must not exceed £200 in worth and full details of how to make such a gift is included in our payment policy/guide.

Problems making payments via institutions
There can often be problems making payments to an individual via institutions such as NHS trusts and universities. Here are two common problems:

● **uncertainty regarding the tax and NI that might be due on payments to individuals who are not employees.**

Often, simply indicating in writing that someone is solely responsible themselves for making payment of any tax and NI that is due on payments that they receive is sufficient.

If not, any institution can apply for a 'dispensation' to HMRC for making payments to individuals for carrying out involvement work. A dispensation is a formal agreement by the HMRC that any payments that are to be made of such a nature are unlikely to be taxable.

The full procedure (including a model letter to give to the HMRC) is included in section 6.3 of Part B of *MHRN Service Users and Carers Payments Policy: Benefits Systems and Conditions around Paid and Voluntary Involvement* (April 2010) on pages 18 to 20.

● **employment law issues: whether or not people who carry out involvement work would be classified as employees (with access to employment rights) or self-employed.**

(The following information is reproduced by kind permission of INVOLVE (www.invo.org.uk) from their *Payment for Involvement, A guide for making payments to members of the public actively involved in NHS, public health and social care research* document.)

Advice from the Advisory, Conciliation and Arbitration Service (ACAS) indicates that where payment for involvement is one-off or casual and there is no expectation that further involvement will be offered or accepted, employment law is unlikely to apply (www.acas.org.uk).

When paid involvement is expected to be ongoing or planned into the future, whether this can be deemed paid employment rests on a number of factors.

These include:

1. Mutuality of obligation – the extent to which an organisation is required to offer ongoing involvement and whether the involved person is obliged to accept it;
2. Control – the extent to which an organisation or the involved person decides what tasks are to be carried out, whether by specific people and how and when the tasks are carried out.

Deciding if or when an employment relationship exists can be complex and is usually approached on a case-by-case basis. ACAS can provide general advice on their national helpline 08457 47 47 47.

Staff in the human resources department should also be able to advise you. If there is any doubt, it is advisable to seek independent legal advice. Where there is ongoing paid involvement, with mutual obligation and control resting with the organisation, an individual may be classed as a 'worker' and as such they may gain rights to some core employment rights and protections.

One approach to managing this is by using flexible arrangements, such as a bank registration agreement. This approach is explained more fully and an example provided in the Department of Health's *Reward and recognition: the principles and practice of service user payment and reimbursement in health and social care* (second edition) (2006) (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138523).

More information about employment status can be found on the HM Revenues and Customs website (www.hmrc.gov.uk/employment-status/index.htm).

There may be times when a formal employment relationship will be the most suitable arrangement – if, for example, you want regular weekly involvement over a number of months or you are employing someone as a user researcher.

Most organisations can provide part-time contracts and these can be for as little as two to five hours per week. If children or young people are involved in paid activity, there are legal restrictions on the times and amount of hours they can undertake activities.

Contacts and places to promote service user involvement opportunities

All 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

Mental Health Research Network
PO77 Institute of Psychiatry
De Crespigny Park
London SE5 8AF
email: mhrnppi@kcl.ac.uk
phone: 020 7848 0644
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: geraldine.mason@kcl.ac.uk
phone: 020 7848 0643
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

MHRN East Anglia Hub

Hub manager: Angela Browne
email: angela.browne@cpft.nhs.uk
phone: 01223 746 135
MHRN East Anglia Hub
Douglas House
Trumpington Road
Cambridge CB2 8AH

MHRN East Midlands Hub plus South Yorkshire

Hub manager: Ann Priddey
email:
ann.priddey@nottingham.ac.uk
phone: 0115 823 1302
MHRN East Midlands Hub
plus South Yorkshire
Institute of Mental Health
Sir Colin Campbell Building
University of Nottingham
Innovation Park
Triumph Road
Nottingham NG7 2TU

MHRN Heart of England Hub

Hub manager: Carly Cooper
email: carly.cooper@bsmhft.nhs.uk
or heartofenglandhub@bsmhft.nhs.uk
phone: 0121 678 4326
MHRN Heart of England Hub
Research and Innovation
Birmingham and Solihull Mental
Health NHS Foundation Trust
Radclyffe House
66-68 Hagley Road
Birmingham B16 8PF

MHRN North East Hub

Hub manager (acting): Saffra Knox
email:saffra.knox@durham.ac.uk
phone: 0191 256 3290
MHRN North East Hub
Academic Psychiatry
Newcastle General Hospital
Westgate Road
Newcastle-upon-Tyne NE4 6BE

MHRN North London Hub

Hub manager: Sandra O'Sullivan
email: s.osullivan@imperial.ac.uk
phone: 020 7386 1237
MHRN North London Hub
Claybrook Centre
(Imperial College London,
Charing Cross Campus)
St Dunstan's Road
London W6 8RP

MHRN North West Hub

Hub manager: Moira Winters
email:
moira.winters@lancashirecare.nhs.uk
phone: 01772 773 515
MHRN North West Hub
The LANTERN Centre
Vicarage Lane
Preston PR2 8DY

MHRN South London and South East Hub

Hub manager (acting): Sheri Oduola
email: sherifat.oduola@kcl.ac.uk
phone: 020 7848 5015
MHRN South London and
South East Hub
Institute of Psychiatry PO39
De Crespigny Park
London SE5 8AF

MHRN West Hub

Hub manager: Chantal Sunter
email: chantal.sunter@bristol.ac.uk
phone: 0117 331 0921
MHRN West Hub
Academic Unit of Psychiatry
School of Social and Community
Medicine
University of Bristol
Oakfield House
Oakfield Grove
Clifton, Bristol BS8 2BN

INVOLVE
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 have been referenced in this document.
www.invo.org.uk
phone: 02380 651088
textphone: 02380 626239
fax: 02380 652 885
email: admin@invo.org.uk

INVOLVE
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD

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 (RD 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 10 RD Services has staff whose role is specifically to help get service users and carers involved in research studies at the proposal stage. Many RD 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 recently produced a report *Research Design Services and Public Involvement: a National Map* (www.invo.org.uk/pdfs/RDS public involvment map 1904 10.pdf).

This document gives quite a comprehensive overview of each of the RD Services and the support that they can offer researchers looking to establish user and carer involvement in their research proposal.

East of England Research Design Service
www.rds-eoe.nihr.ac.uk
phone: 01206 874144
email: gillgr@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: carol.porteous@kcl.ac.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.org
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

Bibliography of useful literature

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www.mhrn.info/publications
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Template documents

The following template forms, agreements and related documents have been created as part of this Toolkit. They can be adapted and customised by research teams. They are part of an open access publication and you may reproduce, change and adapt the sample documents without acknowledgment. They are all also available as separate downloads in Word format (for ease of adaption) on the Mental Health Research Network website, www.mhrn.info/toolkit

These are the template documents included in the Toolkit:

■ Sample role description and person specification for service user representative/project advisor on a study/ trial steering group, or on a group (informal or formal) developing a research proposal.

■ Sample generic advertisement to recruit a service user representative/project advisor to mental health research activities.

■ Sample application form for service user representative/project advisor.

■ Sample guidance notes for filling out an application form for service user representative/project advisor.

■ Sample involvement agreement.

■ 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).

■ Sample training needs analysis form for service user representative/project advisor.

■ Sample involvement evaluation form for service user representative/project advisor.

■ Sample involvement evaluation form for researchers or other staff.

■ Sample confidential evaluation form for service user representatives/project advisors involved in a study or trial.

■ Sample confidential evaluation form for researchers about service user involvement in a study or trial.

■ Sample role description and person specification for service user researcher.

■ Sample application form for service user researcher.

■ Sample interview questions for service user researcher.

	Sample role description and person specification for service user representative/project advisor on a study/trial steering group, or on a group (informal or formal) developing a research proposal (delete this title when you have customised the form)
Insert logo here	

Name of study/trial steering group or name of informal/formal group

Service user representative/project advisor role description and person specification

Role description

Duration:
Start date   dd/mm/yy   end date   dd/mm/yy

Background to the research study/trial or background to the group and proposed research:
add information about the study/trial
or (name of group) has been established in order to develop a research proposal/research proposals (add specific details).

Involvement of service users:
The name of study/trial steering group or name of group   wants to actively involve a broad spectrum of people who have used mental health services into its research advisory bodies and other activities. The importance of involvement at the early stages is a key part of this. Being a service user representative/project advisor on a is one of the ways that this can be achieved. Service user representatives/project advisors will participate in   study/trial steering group or name of informal group meetings, providing firsthand experience of living with severe mental distress and knowledge about using mental health services. It is not intended that a service user representative/project advisor should represent any group of users of services or organisation. They should lend their perspective as someone affected by mental ill health.

Remit:
The (name of study/trial steering group or name of group) has been established in order to (insert details)
(eg oversee the name of study/trial. The steering group is responsible for:
• providing co-ordination to the study;
• acting as an advisory group to the research team;
• enabling exchange of ideas in order to ensure issues are resolved;
• other responsibilities.

Insert logo here	**Sample role description and person specification for service user representative/project advisor on a study/trial steering group, or on a group (informal or formal) developing a research proposal** (delete this title when you have customised the form)

Membership:
The overall membership of the group will fluctuate over the period of the study/trial/development of the proposal as needs change.
The following people are currently members of the group.

Names of member	Role or organisation
Names of member	Role of organisation
Names of member	Role of organisation
Names of member	Role of organisation
Names of member	Role of organisation
Names of member	Role of organisation
Names of member	Role of organisation

As the group may deal with privileged information, confidentiality procedures may be put in place to maintain the integrity of some of the information discussed or circulated for meetings.

Activities:
The group's activities will include:
• activity
• activity
• activity
• activity
• activity
(eg if group developing research proposals: investigating the proposed research study; considering the scope, extent and appropriate methodologies; preparing, consulting on and refining proposals; submitting a bid to funding bodies in collaboration with others, as appropriate)

Insert logo here

Sample role description and person specification for service user representative/project advisor on a study/trial steering group, or on a group (informal or formal) developing a research proposal
(delete this title when you have customised the form)

Responsibilities of service user representative/project advisor:
The service user representative/project advisor will participate in the name of group meetings, bringing their knowledge and experience of living with mental ill health to their input, along with knowledge about mental health services.

Service user representatives/project advisors may also be asked to:
- attend the group meetings. While attending meetings, service user representatives/project advisors will be expected to contribute to the discussions which guide the group's decisions and recommendations. We understand that people may be unable to attend all meetings but regular attendance is encouraged.
- read relevant paperwork in preparation for meetings.
- comment on ideas/exchange ideas informally.
- contribute to and review research proposals.

Service user representatives/project advisors may be asked to:
- attend a session to help to prepare for active engagement within the group.
- occasionally attend other meetings in order to share information concerning the study/trial/research proposals.

Attendance at these other meetings may provide opportunities to meet members of other groups and keep in touch with current developments relevant to the work.

Insert logo here	**Sample role description and person specification for service user representative/project advisor on a study/trial steering group, or on a group (informal or formal) developing a research proposal** (delete this title when you have customised the form)

Support:
Service representatives/project advisors will be supported by the group to feel confident in their role. This will be achieved by ensuring that:

- jargon is kept to a minimum, or explained via a glossary attached to the agenda of each meeting.
- service user representatives/project advisors will be invited to submit their contributions to the agenda before each meeting.
- administrative support is provided. Members of the group can choose to receive papers by email and/or hard copy format.
- papers are circulated in advance of group meetings to provide sufficient time for a response, where appropriate.
- a standing item on the agenda will allow service user representatives/project advisors to raise issues about their participation and involvement.
- pre-meetings between the service user representatives/project advisors and chief investigator/chair of the group   (or other appropriate person – eg an experienced researcher) can be arranged on request.
- appropriate training will be available.

Sufficient representation of service users will be built in to ensure that, should one or more service users become unwell, there will be no loss of service user input.

It is also recommended that the support of an appointed mentor to advise on technical or scientific aspects of the paperwork or meeting is available. This may be someone within the group who is a healthcare professional, an experienced service user or an experienced researcher. Once familiar with the processes, service user representatives/project advisors may be asked to act as a mentor for new members in the future.

Communication:
Communication will normally be via email. However, telephone or written communication will be arranged, where preferred.

Payment and expenses:
Expenses for attendance by service user representatives/project advisors at meetings and for all other pre-aranged work undertaken will be reimbursed at the following rates:
add information about payment and expenses

Service user representatives/project advisors may also choose to waive the payment fee or receive a lower amount following a discussion. Further guidance on payment, along with possible implications for benefits, tax and National Insurance can be found in the MHRN Service Users and Carers Payment Policy: Benefits Systems and Conditions around Paid and Voluntary Involvement (April 2010), which is availble at www.mhrn.info/publications

| Insert logo here | **Sample role description and person specification for service user representative/project advisor on a study/trial steering group, or on a group (informal or formal) developing a research proposal** (delete this title when you have customised the form) |

Time commitment:
It is not possible to be precise over time to be spent in this role, as this will vary. However it is currently envisaged that the group will meet insert anticipated frequency of meetings. The location and dates of meetings will be determined by the group. In addition, time will also need to be spent reading and responding to issues by email or by phone.

Attendance and termination of involvement:
Service user representatives/project advisors may withdraw from the role at any time. The chief investigator/chair of the group   should be notified of this decision as soon as possible. This position is for an initial period of a year, to be reviewed thereafter on a insert renewal period   basis.

Members are asked to give their apologies if they cannot attend a meeting. We understand that you may be unable to attend all meetings, but regular attendance is encouraged.

Person specification

Essential:
- Experienced mental health service user.
- Knowledge about mental health treatments/services relevant to the study/work of the group.
- Good communicator.
- Ability to listen to others and express views in a constructive and polite way, including within meetings.
- Ability to work effectively with people form diverse backgrounds.
- Reliable and trustworthy.

Desirable:
- Knowledge of service user organisations.
- Experience or knowledge of research studies, or an understanding of research.
- Ability to review research proposals.

Created by: name of person who originated document
Designation: title of person who originated document
Date: dd/mm/yy
Review date: review date

Insert logo here

Sample generic advertisement to recruit service user representative/project advisor to mental health research activities
(delete this title when you have customised the form)

Call for applications from mental health service users to take part in mental health research activities

Payment negotiable, plus expenses

Insert simple brief introduction to organisation.
eg – the Mental Health Research Network
The Mental Health Research Network (MHRN) is part of the NHS National Institute for Health Research and helps to gather mental health researchers together to coordinate and facilitate the delivery of large-scale research projects that will inform policy and practice; broaden the areas within the scope of mental health research; ensure the full involvement of service users and frontline staff in mental health research; help identify needs for future mental health research; and increase the quality and quantity of researchers, service users, carers, and professional staff who are able to undertake and engage in high quality research with potential to change people's lives.
More information about our work may be found at www.mhrn.info

We are inviting applications from mental health service users to contribute to the work of our (insert details of research activity). Service user representatives/project advisors will participate in the (insert details of research activity) meetings, providing firsthand experience of living with severe mental distress and knowledge about using mental health services. It is not intended for the service user representatives/project advisors to represent any group of users or organisation, but to lend their perspectives as people affected by severe mental distress.

You will (usually*)* need some experience of being involved in research projects as well as experience of using mental health services (insert specific experience needed, if appropriate). We are supportive of our service user representatives/project advisors should they experience periods of feeling less well than usual and we provide mentoring through (add details).

These posts are available from (insert start date) to (insert end date) in the first instance.

For an application form and role description please visit:
(insert website adress)
Alternatively, please write to the (insert postal address) quoting reference number (insert reference number*)*. Please note that an application form must accompany all applications.

Closing date: (insert closing date)

**Sample application form
for service user
representative/project advisor**
(delete this title when you have
customised the form)

Application form for service user representative/project advisor
Insert name of organisation, and/or committee, group

Involving a broad spectrum of people who have used mental health services into research advisory bodies, research and other activities is important. If you are applying to be a service user representative/project advisor on a committee or group, please complete and return this form.

We are committed to protecting your privacy and security. We will only use the information you send to us in the selection process. We will never wilfully disclose personal information about you to any third party without first receiving your permission to do so, or unless we are under legal obligation to do so.

Your details:

Name

Role

Email

Telephone

What role are you applying for?

2. It would be helpful to know if you have any previous experience of:
(please tick all that are relevant)

Working in committees ☐

Voluntary work (including mental health support groups) ☐

Health service user involvement ☐

Research ☐

Please give brief details:

**Sample application form
for service user
representative/project advisor**
(delete this title when you have
customised the form)

3. Please state briefly why you would like to be a service user representative/project advisor:

4. What skills, qualities and relevant experience will you bring that will enable you to take on this role? In answering this question, please refer to the role description and person specification:

Signature:

Date:

Please return this form, along with other relevant documents,

to   insert postal or email address

by   insert closing date

Sample guidance notes for filling out an application form for service user representative/Project advisor
(delete this title when you have customised the form)

Guidance notes for filling out an application form for service user representative/project advisor
Name of organisation

Previous experience
Please do tell us what experience you have had working with different groups, committees, health service user involvement or research. Whatever your involvement, it means you have some experience to share with us. Please give as much detail about this as you can.

Why you would like to be a service user representative/project advisor?
Your interest in mental health and research is important to us. Please do say what areas you have an interest in and if you have a specialist interest and or knowledge in a particular area of mental health research – eg psychosis, personality disorder, depression.   You do not have to be an expert in anything to apply to join us (although it is a bonus!). We are interested in what interests you and we can support you to develop your knowledge and skills further. It may be that you are interested in a certain area of the research process – do say. Whatever grabs you, we would like to hear about it.

Person specification
Go through each point and say on the application form how you meet each area of the person specification. For example, being trustworthy is important in this area as you may be handling sensitive information about people or a project that is confidential.   Describe what situations you have been in that required you to be trustworthy. For example, being on a committee of a local charity or voluntary group, or in paid voluntary work.   If you have done voluntary or paid work, were you always reliable? Explain why. Even if you did part-time work somewhere, turning up each day on time most of the year is an indication of reliability.   Finally … informal phone calls to find out more abut the role of service user representative/project advisor are encouraged. Good luck!

Insert logo here

Sample involvement agreement
This is based on an involvement agreement example from the Care Service Improvement Partnership London Development Centre.
(delete this title when you have customised the form)

Involvement agreement

Insert name of organisation:

Name of service user representative/project advisor:

The role of the name of the organisation
Insert details
eg The Care Services Improvement Partnership (CSIP) was created in 2005 to support a number of initiatives developing services to help improve people's lives. Commissioned by the Department of Health and other agencies, CSIP aims to achieve this by supporting the implementation of national policy for local benefit. We work with communities, systems and organisations that are engaged with the health and social care needs of:
• people with mental health problems
• people with learning disabilities
• older people
• children, young people and families
• people in the criminal justice system; and
• the families, carers and supporters of these groups

CSIP works regionally in what are called 'Development Centres'. There are eight regions and London is covered by the London Development Centre (LDC).

Area of work

Insert brief introduction to programme or area of work in which involvement will take place
eg The self-directed support programme is new to London, having started in July 2007. It aims to support local authorities and health trusts to develop self-directed support to ensure that more people in their localities can have more choice and control over the support they need. This includes things like individual budgets, direct payments, and making sure that people get the right help to plan their support. To do this, we are directly supporting organisations and holding events to bring people together and to learn more. We are also engaging with people who have had experience of self-directed support, or who have concerns about how their current support is working and who are positive advocates for the development of self-directed support in their area.

Opportunities for involvement

Insert what and how service user representatives/project advisors will contribute
eg
1. To be involved with an event on 30 June 2008 entitled 'Choice, Self-Directed Support and Mental Health'. This event is for mental health professionals from across London to learn more about self-directed support and is an opportunity for people to come together to share concerns and opportunities for how to move this important development forward in their areas.

To be involved on the day would mean a requirement to:
a) take part in the event alongside other delegates;
b) take an active part in 'round-table' discussions with other delegates, and help facilitate the group discussions;
c) be a positive advocate for self-directed support, such as direct payments and individual budgets.

The event is to be held at Avonmouth House near Elephant & Castle in London. A map is attached for reference. Also attached is the outline programme for the day for your information and the flyer which has been used to make people aware of the event.

2. To become a champion for self-directed support in your area. This would mean that you would agree for your contact details to be held by the self-directed support programme lead, who may call on you/invite you to take part in development activities in your local area. This may or may not lead to specific pieces of work, and no commitment is made in advance by either yourself or the programme lead. However, it is obviously the intention that opportunities will be generated, for which your support would be appreciated. Details of any local involvement would be agreed separately.

Sample involvement agreement
This is based on an involvement agreement
example from the Care Service Improvement
Partnership London Development Centre.
(delete this title when you have
customised the form)

What you can expect from us
Insert details
eg We agreed that I will meet with you for a briefing in advance of the event on 30 June and for a de-briefing session afterwards. In relation to your continuing involvement with the LDC as a local champion for self-directed support, we agreed that we would meet every 3 months to help you to look at progress and review with you how this is working at least every year. We also agreed to support you in an application to attend the next Learning in Partnership course at Surrey University. You will need to be successful in the selection process for this course, but we agreed that you will shadow the LDC Service Improvement Lead for a day to help you to gain a better understanding of service improvement and prepare for interview. If successful, you will receive support and group supervision from us for the duration of the course.

Support required to get involved
Insert details previously agreed
eg When we met, you confirmed that you will not require practical assistance or support to engage with the event or with any other possible involvement, due to being supported by your partner. We also agreed that it was important that you informed the programme lead if you were to find later on that you have support needs which you could not have anticipated.

Travel
Specify any arrangements required for independent or supported travel
eg When we met, you also confirmed that you were happy to travel independently to London and in your local area, again supported by your partner, and that no additional support is required.

Payment and reimbursement
Specify payment and reimbursement arrangements agreed
eg Travel: Your travel costs will be met by a travel ticket to be issued by the LDC in time for the event on 30 June. Payment for the event: The day rate for the event will be £170. This will take into account the time you will spend travelling and any preparation you might do. Payment for any subsequent involvement as a 'Champion' would be negotiated separately according to set rates determined by CSIP within the LDC Payment and Reimbursement guidelines.

Payment method
Insert invoice arrangements and how payment will be made
eg You confirmed that payment for involvement would not cause any problems with reference to benefits and you did not require advice about this. You confirmed that you were registered with the Inland Revenue as self-employed. You informed me that your unique Inland Revenue reference number is: You agreed to invoice SEDC for the agreed amount after the event. The invoice should be sent to: Please mark your invoice 'Self Directed Support Programme' and include the date that the involvement took place.

Insert logo here

Sample involvement agreement
This is based on an involvement agreement
example from the Care Service Improvement
Partnership London Development Centre.
(delete this title when you have
customised the form)

Important contacts
Insert names, email address and phone numbers. eg If you have any queries about your involvement you can contact: Main contact person Administration If you have any concerns or complaints, you should initially contact the main contact person above. Alternatively you can contact *(insert details).*
After your involvement
Insert details eg After your involvement, we will ask you to give us feedback about what it was like, whether you got the right support, whether you felt you were able to make a valuable contribution and so on.
Thank you on behalf of insert organisation name   Signed on behalf of organisation name   Name of service user representative/project advisor   Signature   Date

Insert logo here

Sample contact sheet for service user representative/project advisor
(delete this title when you have customised the form)

Contact information
Insert name of project, activity, group or committee

Service user representative/project advisor name:
Name
Role
Email
Phone
Name
Role
Email
Phone
Name
Role
Email
Phone
Name
Role
Email
Phone

Sample training needs analysis form for service user representative/project advisor
(delete this title when you have customised the form)

Training needs analysis for service user representative/project advisor

The   insert name of organisation   would like to identify any training needs you may require. Once we have this information, we will be in a stronger position to offer suitable support, if needed. **Your name**
Relevant work experience (voluntary or paid)
Training already attended
Current training needs
Please indicate by ticking the relevant boxes how you rate your skill level. 1 = no skills 2 = some skills 3 = reasonable skills 4 = quite skilled 5 = very skilled
General skills
Communication skills (eg listening skills, getting your point of view across in discussions, etc) Skill level no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled Being confident and assertive Skill level no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled Presentation skills (eg speaking in public, delivering presentations) Skill level no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled Committee skills (eg preparing for meetings, dealing with agendas and minutes) Skill level no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled

Sample training needs analysis form for service user representative/project advisor
(delete this title when you have customised the form)

Computer skills
Everyday computer skills (eg using Windows, organising computer files)   Skill level   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled   Using the internet and email   Skill level   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled   Using Microsoft programmes (eg Word and Excel)   Skill level   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very skilled
Are there any specific programmes or computing skills that you feel you would like to receive more training in?

Knowledge of   insert name of organisation   and mental health research
When answering these questions, please use the following scale: 1 = no knowledge   2 = some knowledge   3 = enough knowledge to get by   4 = quite knowledgeable   5 = very knowledgeable   Knowledge of the insert name of organisation   and what it does   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very knowledgeable   Knowledge of what is happening in mental health research   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very knowledgeable   Knowledge of how to find out what is happening in mental health research   (eg knowledge of useful websites and databases)   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very knowledgeable   Knowledge of different kinds of research (eg qualitative and quantitative)   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very knowledgeable   Knowledge of how to peer review mental health research study documents   (eg reviewing a study protocol or patient information sheet)   no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very knowledgeable   Knowledge of the UK research environment   (eg knowledge of how research is carried out in the NHS and in universities)

Insert logo here

Sample training needs analysis form for service user representative/project advisor
(delete this title when you have customised the form)

no skills 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ very knowledgeable
Can you tell us if you have any preference about the format of training events? Would you prefer face-to-face training courses, or would courses online via a computer be okay?
Can you tell us if you have any preference about where training events are held? Would you be willing to attend training events if held in another part of the country?
Anything else to say? Please use this space if there is anything else you would like to say about your training needs that you have not already put on the form.
Thank you for filling in this form. Please return it to: insert details

Involvement evaluation form for service user representative/project advisor
Insert organisation name

What is the purpose of this form?
• To record your reflections after being involved as a service user representative/project advisor at a meeting or event. • To provide information to help improve the experience and effectiveness of service users involved as service user representatives/project advisors.
What will happen to this information?
• We will collate and analyse the data. • The amalgamated data along with anonymised comments will be used to inform the evaluation and improve the experience and effectiveness of service users involved as service user representatives/project advisors. • The evaluation and anonymised comments may be included in reports.
Please complete and return this form to:
Answering the questions
Where options are given, please tick the relevant box. In the case of the scale 1-5 please use as follows: 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high If any of the questions are not relevant then please ignore or put N/A. Any comments you want to add are welcome.
You and the meeting/event
Your name (optional): Your role and responsibility in the meeting/event: Name of meeting/event: Date of meeting/event:

Sample involvement evaluation form for service user representative/project advisor
(delete this title when you have customised the form)

Before the meeting/event
How long before the meeting/event did you receive the paperwork?

on the day ☐

1-3 days ☐

4-7 days ☐

more than 7 ☐

Was this sufficient?

yes ☐

no ☐

If not sufficient then how long before the meeting/event would you have liked the paperwork?

In what way did you receive the papers?

by email ☐

printed copy ☐

Was this best for you?

yes ☐

no ☐

If no, how would you have liked to receive them?

How clear were the papers?

1 ☐   2 ☐   3 ☐   4 ☐   5 ☐
low   high

Were you offered the opportunity to raise queries before the meeting/event?

yes ☐

no ☐

Sample involvement evaluation form for service user representative/project advisor
(delete this title when you have customised the form)

If yes, how well were your queries answered? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high
During the meeting/event
How much did you feel able to contribute to the meeting/event? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high Do you think that the inclusion of service user representatives/project advisors had any impact on the meeting/event? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high Did the chair of the meeting or event facilitator support you? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high Did you feel supported by other members during the meeting? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high
After the meeting/event
Do you think your views were valued? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high Were you offered the opportunity to raise queries after the meeting/event? yes　　　　　　☐ no　　　　　　☐   If yes, how well were the queries answered? 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ low　　　　　　　　high

Insert logo here

Sample involvement evaluation form for service user representative/project advisor
(delete this title when you have customised the form)

Final thoughts
Overall, how would you rate your input into the meeting/event? 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high
What would help your input into future meetings/events?
Is there any information or training that might benefit you for future meetings/events like this one?
Are there any additional comments that you would like to make?
Thank you for completing this questionnaire.

Involvement evaluation form for researchers and other staff

Insert organisation name

What is the purpose of this form?
• To record your reflections after being involved in a meeting or event in which a service user representative/project advisor has participated.   • To provide information to help improve the experience and effectiveness of service users involved as service user representatives/project advisors.
What will happen to this information?
• We will collate and analyse the data.   • The amalgamated data along with anonymised comments will be used to inform the evaluation and improve the experience and effectiveness of service users involved as service user representatives/project advisors.   • The evaluation and anonymised comments may be included in reports.
Please complete and return this form to:
Answering the questions
Where options are given, please tick the relevant box. In the case of the scale 1-5 please use as follows: 1 ☐　　　2 ☐　　　3 ☐　　　4 ☐　　　5 ☐   low　　　　　　　　　　　　　　　　　high   If any of the questions are not relevant then please ignore or put N/A.   Any comments you want to add are welcome.
You and the meeting/event
Your name (optional):   Your role and responsibility in the meeting/event: Name of meeting/event: Date of meeting/event:
Before the meeting/event
Were you aware that service user representatives/project advisors would be participating?   yes　　　　　☐   no　　　　　☐

Insert logo here

Sample involvement evaluation form for researchers or other staff
(delete this title when you have customised the form)

If you were responsible for preparing or sending out the papers, how long before the meeting/event did you send out the paperwork?

On the day ☐

1-3 days ☐

4-7 days ☐

more than 7 ☐

Did the service user representatives/project advisors indicate any preference regarding the timing or way paperwork was sent out?

yes ☐

no ☐

If yes, please give details and comment on the practicality of accommodating any request.

Was there anything within the papers that you felt you had to amend, as service user representatives/project advisors would be present?

yes ☐

no ☐

If yes, please indicate what you amended.

Did the service user representatives/project advisors raise any queries before the meeting/event with you?

yes ☐

no ☐

If yes, how well were these queries answered?

1 ☐   2 ☐   3 ☐   4 ☐   5 ☐

low   high

Sample involvement evaluation form for researchers or other staff
(delete this title when you have customised the form)

During the meeting/event
Did you feel that the service user representatives/project advisors were able to contribute to the meeting/event?
1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high
Did you feel there were things you could not say because service user representatives/project advisors were present at the meeting?
yes   ☐
no   ☐
Do you think that the inclusion of service user representatives/project advisors had any impact on the meeting/event?
1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high
Did the chair, event facilitator or other group members adequately support service user representatives/project advisors?
1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high
After the meeting/event
Do you think the service user representatives/project advisors' views were valued?
1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high
Did the service user representatives/project advisors raise any queries with you after the meeting/event?
yes   ☐
no   ☐
If yes, were any queries able to be answered adequately?
1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high
Final thoughts
Overall, how would you rate input of service user representatives/project advisors into the meeting/event?
1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ low   high

Sample involvement evaluation form for researchers or other staff
(delete this title when you have customised the form)

Can you identify any information or training that might benefit you or the service user representatives/project advisors for future meetings/events like this one?
Are there any additional comments that you would like to make?
Thank you for completing this questionnaire.

Insert logo here

Sample confidential evaluation form for service user representatives/project advisors involved in a study or trial.
(delete this title when you have customised the form)

Confidential evaluation form for service user representatives/project advisors involved in a study or trial

Insert name of study/trial
Insert name of service user representative/project advisor
What was your experience of being involved as a service user representative/project advisor in this study/trial?
Did you learn anything new when working on this study?
Did you get enough support from your colleagues in this study?
If not – how do you think this can be improved?
What contribution do you think you made to this study?
Did you feel valued?
Did you feel your work was valued?
Any other comments you would like to make:
Signature: Date:

Sample confidential evaluation form for researchers about service user involvement in a study or trial
(delete this title when you have customised the form)

Confidential evaluation form for researchers about service user involvement in a trial or study

Study/trial: insert name of trial/study
Name of researcher:
What was your experience of having a service user representative/project advisor in this study/trial?
How was your research enhanced by having a service user representative/project advisor involved?
How did you support the service user representative/project advisor in their work?
Do you think this can be improved? How?
Would you involve a service user representative/project advisor in your next research project... if so why?
Any other comments you would like to make:
Signature:
Date:

Insert logo here

Role description and person specification for service user researcher

Insert name of organisation and research project

Role description
General information:
Role title: Service user researcher, name of study
Payment: £ insert payment details
Hours: flexible
Responsible to: insert name
Accountable to: insert name
Responsible for: Qualitative interviews with service users (or insert other responsibilities)
Job summary
The name of study is funded by insert details of funder. It is investigating/evaluating insert details.   insert job summary   eg Service user researchers will be recruited to conduct qualitative interviews with service users who insert more details. These interviews will investigate service users' experiences of insert details. The role will involve working as directed by the chief investigator and research associate, and attendance at group training and supervision.

	Sample role description and person specification for service user research
Insert logo here	(This sample job description and person specification is based on one prepared by Dr Brymor (Department of Mental Health Services at UCL), the research associate on the WISE study, managed by Camden and Islington NHS Foundation Trust)
	(delete this title when you have customised the form)

Main duties and responsibilities
These refer to qualitative interviews with service users. Amend as appropriate. • To contact insert number service users as directed by the study research associate. • To provide oral and written information about the study, and seek written, informed consent from service users to participate in a recorded interview. • To conduct interviews with consenting service users and digitally record these interviews. • To administer, giving £ insert figure to service users on completion of an interview and obtaining a written receipt. • To inform the study research associate promptly about the time and place of arranged interviews and when interviews have been completed. • To return study documents and equipment promptly following an interview, as directed by the study research associate. • To attend training and supervision as directed by the study research associate. • To inform the study research associate promptly of any circumstances which may hamper your ability to conduct your role competently and safely. • To inform the study research associate promptly of any concerns you have following an interview about the interviewee's safety or well-being. • To adhere to policies during work on the study, including policies on confidentiality, data protection, valuing diversity, health and safety and risk management and lone working. (Service user researchers will be given a Letter of Access that outlines these policies before working on the study. The policies will also be explained during study training.) This job description does not provide an exhaustive list of duties and may be reviewed within supervision.

Person specification
Essential:
• Mental health service user (make more specific if relevant to study). • Ability to follow procedures and direction from the study team • Good communication, listening and interpersonal skills • Reliable and trustworthy • Good organisational and time management skills • Willingness to work independently
Desirable:
• Experience of working with mental health service users (in paid or unpaid capacity) • Experience of conducting qualitative research interviews • Experience of conducting other interviews or surveys

Insert logo here

**Sample application form
for service user researcher**
(delete this title when you
have customised the form)

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Application form
Insert name of organisation, and/or research project.

Involving a broad spectrum of people who have used mental health services in research advisory bodies, research and other activities is important. If you are applying to be a service user researcher, please complete and return this form.

We are committed to protecting your privacy and security. We will only use the information you send to us in the selection. We will never wilfully disclose personal information about you to any third party without first receiving your permission to do so, or unless we are under legal obligation to do so.

Your details

Name:

Address (including postcode):

Email address:

Telephone:

1. What role are you applying for?

2. Please state briefly why you would like to become a service user researcher.

**Sample application form
for service user researcher**
(delete this title when you
have customised the form)

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3. What skills, qualities and relevant experience will you bring that will enable you to take on this role? In answering this question, please refer to the role description and the person specification.

Thank you for completing the form. Please return it, along with other relevant documentation, to insert postal or email address

Insert logo here

Sample interview questions for service user researcher
(These sample questions are based on those prepared by Dr Brymor (Department of Mental Health Services at UCL), the research associate on the WISE study, managed by Camden and Islington NHS Foundation Trust)

(delete this title when you have customised the form)

Interview questions
Please refer to role description and person specification
for service user researcher

Structure of interview
Introductions Explain format Give overview of organisation and details of job

Questions
What attracted you to apply for this post? Tell us about any previous experience relevant to the role description and person specification. Although you will be part of a team, you will have to work alone. How will you cope with working independently? For this position, good communication, listening and interpersonal skills are important. Could you give us examples of how you have demonstrated these, either in paid/unpaid work or other situations? In this post, what do you think will be the key challenges to obtaining good interviews from study participants? What do you think are the main uses of group supervision if you work in this post? Do you require any additional support to work on this study? When would you be available to work on the study? Are there any questions you would like to ask?

Explain what happens next
Check address and referee contact details

Close of interview