

# INVOLVE

Promoting public involvement  
in NHS, public health and  
social care research  
(formerly Consumers in NHS  
Research)

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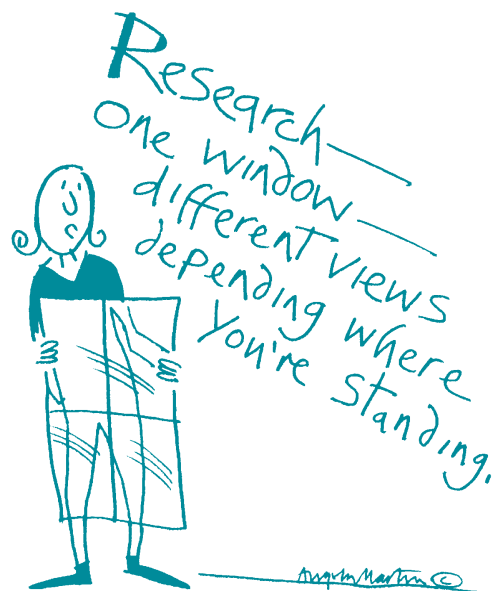
## Involving the public in NHS, public health, and social care research:

## Briefing notes for researchers

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**Second Edition**  
Edited by Roger Steel



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An audio and large print version of this booklet is available from the 'INVOLVE' Support Unit, and other formats can be made available on request (see back cover for details)

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## Who is this booklet for?

This booklet is designed for researchers with no previous experience of involving members of the public, and for people who use services, as active partners in research. It is an introductory document which contains references for further reading on the subject of involvement.

## About this edition

The first edition of this booklet (published in 2000) was developed by a group of people who use services, and researchers who have a commitment to, and experience of, public involvement in health research.

Initially, seven people took part in a workshop led by Jane Bradburn to develop the first edition. They and other members of the public and researchers then made comments on the draft that came out of this process. The drafts were written by Bec Hanley and edited by Sarah Thomas.

This second edition is a revision of the first, written to include the more recent work of INVOLVE in the Policy Research Programme (PRP)<sup>1</sup>. We also wish to reflect the rapidly changing climate of public involvement in research since the first edition of this booklet was published.

This edition was edited by Roger Steel, and drafts were sent out for comment to a number of people who use health and social care services, as well as to researchers and professionals in the public health and social care field.

Special thanks to the following people, who

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- Alan Boyd
- Phil Brough
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- Anna Sartori.

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## About the language used in this booklet

In this edition we use the terms **'the public'** and **'people who use services'** rather than 'users', 'consumers', 'patients' or 'lay people'.

In the context of this publication, we define **'the public'** and **'people who use services'** as:

- patients
- informal (unpaid) carers
- parents/guardians
- users of health and social care services
- disabled people
- members of the public who are the potential recipients of health promotion programmes, public health programmes, and social services interventions
- groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services.
- organisations that represent people who use services

We use the terms **‘the public’** and **‘people who use services’** to make a distinction between those who are professionally engaged in health or social care research, and those who are ultimately ‘end users’ of research in health and social care.

We recognise that there is no single acceptable term used by this range of people to describe themselves. We are all potential users of health and social care services. However, people who get involved in research and development (R&D) and do not have other, ‘professional’ roles (such as doctor, nurse, researcher, social worker, etc.) have a distinct, complementary role to play in the research process.

We also recognise that many people who use services, as well as some people who are targets of public health programmes, are often stigmatised or marginalised. For some, this might be as a result of using the services. This situation is sometimes made worse by the experience of being ‘researched on’ by others. Self-organisation in the service user and disabled people’s movement has led to the development of approaches to research which are ultimately empowering and which often challenge the traditional distinctions between the roles of researcher and service user, and in some cases that of commissioner and service user.

By **‘involvement’** in research we mean that people who use services are active partners in the research process rather than ‘subjects’ of research. We also include in these terms people who use services doing their own research. Many people describe public involvement in research as doing research **with** or **by** the public rather than to, about, or for the public.

Members of the public have been involved in R&D for many years and in many different ways. This involvement can occur during any or all of the processes involved in R&D:

- setting the research agenda
- commissioning research
- undertaking research
- interpreting research
- disseminating the results of research
- getting findings put into practice.

There are different levels of involvement. A number of factors influence the degree of participation that people might have (see the section on the stages of public involvement in R&D on page 19).

The Department of Health defines **‘research’** as work designed to provide **new knowledge**, whose findings are potentially of value to all, that is, **generalisable**.<sup>2</sup> It defines **‘development’** as the testing and evaluation of new ways of doing things.

- It focuses on how well innovations actually work in practice.
- It includes service development only if it is linked with new knowledge and is generalisable.
- It does not include service development concerned with local implementation of research findings.

We recognise that this is just one of a number of definitions of research. However, for the purpose of this booklet we will use the Department of Health definition as a general guide.

# INVOLVE and the Support Unit

'Consumers in NHS Research'<sup>3</sup> was first set up by the Department of Health's Director of Research and Development in 1996. In 2003, the group was renamed INVOLVE, to better reflect its extended remit to include R&D commissioned in the Policy Research programme (PRP) in the Department of Health. This is concerned with social care and public health as well as medical and health services research.

INVOLVE aims to ensure that people's involvement in R&D improves the way that research is prioritised, commissioned, undertaken and disseminated. We believe that the involvement of the public in the research process leads to research that is more relevant to the public and more likely to be used. If research reflects the needs and views of the 'end user' it is more likely to produce results that can be used to improve practice in health and social care.

The INVOLVE group is supported by a small team based in Eastleigh in Hampshire, which is employed by the University of Leeds as part of the National Cancer Research Network. The Support Unit:

- provides information, advice, and support to members of the public interested in research, researchers and those working within the NHS research programmes and the Policy Research Programme (PRP).
- gives practical support to the INVOLVE group
- produces publications on the involvement of the public in research
- runs a website: [www.invo.org.uk](http://www.invo.org.uk)

- maintains a public database of research projects which involve or have involved people who use services
- organises seminars, workshops and conferences on public involvement in research.

If you would like more information on our work, please contact the Support Unit (our contact details are on the back cover).



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# SECTION 1: Introduction

## 1.1 This booklet

This booklet aims to give researchers working within the NHS, social care and public health fields some guidelines on how best to involve the public in their work. There are some excellent examples of good practice in involving people who use services, and we believe that this booklet will be of particular use to researchers new to, or just starting to involve the public. We hope that it will also be read by members of the public who are involved in R&D in health and social care so that they know about the good practice that we are suggesting researchers follow.

We have also produced a complementary booklet for members of the public who are interested in getting involved in research called 'Getting Involved in Research: A Guide for Consumers.' (Royle, J. Steel, R. et al, 2001 - See Appendix 4 'Useful references')

People who use services take part in many different types of research. As far as possible, we have tried to make this booklet relevant for all types of NHS, public health and social care research.

The guidelines we offer here are not set in stone - they are suggestions based on our experience and on the experience of others. If you would like to make a comment on anything included within this booklet, please get in touch with the Support Unit - contact details are on the back cover.

There are other guides to involving the public in service development in general, but they are not specific to research. For in-depth guidance that addresses different approaches to the involvement of specific groups of people who use services in the development of those services, we recommend 'Asking the Experts' (Baulcombe et al - See Appendix 5 'Useful references') from the Community Care Needs Assessment Project (CCNAP). We also recommend visiting the Supporting People website (<http://www.spkweb.org.uk>) where 'A guide to user involvement for organisations providing housing related support services' can be downloaded. (See Appendix 4 'Useful references')

This booklet begins by looking at **why** it is important to involve people who use services in R&D and offers some suggestions about overcoming some of the barriers to their involvement.

We then look at the **different levels** of involvement in R&D, and ask you to think about whether you want to consult people who use services, collaborate with them, or ask them to take control of a research project.

Next, we offer some general guidelines on involving people who use services in R&D - **who** to involve and **how** to involve them.

Then we talk about how to involve people who use services at the **different stages of R&D**, beginning with the identification of research topics and ending with an evaluation of the research process.

Finally, we include some **checklists** about the practicalities of involvement, particularly in relation to committees and resources. Throughout the booklet, we have tried to address the questions that researchers most frequently ask the Support Unit.

The booklet contains a range of examples of projects where people who use services or members of the public have been involved in research in different ways. These examples will give you ideas about ways to involve people who use services, based on the experience of others, but they are not meant to be definitive. We recognise that there are many different approaches, and there is always room for new innovative practice. A database of research projects that have involved the public is available on the INVOLVE website ([www.invo.org.uk](http://www.invo.org.uk)). This provides a much wider range of examples.

## 1.2 Why involve the public in research and development?

There are many reasons for involving people who use services in R&D. We outline some of them below. Being clear about **why** you want to involve people will help you to identify **who** it is appropriate to involve and how best to involve them.

### **People who use services will be able to offer different perspectives.**

You may be an expert in your field, but that does not mean to say you can see all the perspectives on what occurs in the area of your research interest. Even organisations who specialise in services and research in a

particular service area have a view from the 'inside looking out' and do not necessarily understand how their activities are experienced by those on the 'outside looking in.' Without this kind of involvement the picture is incomplete.

### **People who use services can help to ensure that the issues that are identified and prioritised are important to them and therefore to health care, public health and social care services as a whole.**

We know that people who use services can identify research topics that have not previously been identified by researchers or clinicians.



Research with people who had had joints replaced, demonstrated that their priorities for research in this area differed markedly from the research that was actually being prioritised in joint replacement.<sup>4</sup> People in the HIV/AIDS field, as well as in many other areas, have identified and helped to prioritise research topics that would not otherwise have been researched.<sup>5</sup>

### **Public involvement can help to ensure that money and resources aren't wasted on research that has little or no relevance.**

For example, a cancer research open day was arranged in Sheffield in 2001 to allow people who used cancer services and professionals to present and discuss their experiences. The aim was to ensure that

people who used services were involved in and could influence the development of cancer services, practice and research in the Trent area. Clear themes arose from the discussion in the workshops on the day, and these were subsequently used to form a new research agenda within the network.<sup>6</sup>

**People who use services can help to ensure that research doesn't just measure outcomes that are identified and considered important by professionals.**

Sometimes, researchers on their own cannot identify outcome measures that are important for people who use services. People who use services are ultimately the end users of research, and are in the best position to identify issues that arise from their own experience. For this reason, many researchers involve people who use services in the development of outcome measures, or ask people to develop outcome measures for themselves. For example, Shaping Our Lives, a user-controlled organisation, has developed service user perspectives on the debate about outcomes in community care.<sup>7</sup> The Social Policy Research Unit at York has also done work in this area.<sup>8</sup>

**People who use services can help with the recruitment of their peers for research projects.**

Some people who use services are suspicious about researchers' motives and may be unwilling to become involved in research. The involvement of a voluntary organisation or self-help group can often assist in recruitment. For example, Maternity Alliance, a group representing the interests of people who use maternity services, assists researchers with recruitment through their networks.<sup>9</sup>



**People who use services can help access other people who are often marginalised, such as people from black and minority ethnic communities.**

For example, research to develop practice guidelines for Primary Healthcare Teams to meet South Asian carers' needs, recruited and trained male and female bi-lingual interviewers from four main South Asian communities. This was vital in establishing links with the communities, recruiting carers who were caring in isolation, and engendering trust in carers in voicing their concerns and feelings.<sup>10</sup>

**People who use services can help to disseminate the results of research and work to ensure that changes are implemented.**

It is important to most people that the results of relevant research are put into practice and therefore that research results are properly disseminated. Many voluntary organisations, and other organisations representing or controlled by people who use services, carry summaries of the latest research, written in user-friendly language, in their newsletters and magazines. Voluntary and user-controlled organisations also work to ensure that people receive care based on the latest research evidence. For example, members of Rotherham Cancer Service User Forum were involved in a study to investigate patient satisfaction in relation to how the diagnosis of cancer is

given. The group was involved in all stages of the project and afterwards presented the findings of the research to consultants at the hospital and to an MP. They also developed guidelines using the findings of the research.<sup>11</sup>

**Involvement in research, done well, can help empower people who use services.**

Involvement in research often provides a route to effecting change and improvement in issues which concern people most. It can also help raise self-esteem and improve employment prospects, especially if it includes training. Involvement in itself can sometimes be 'therapeutic.'

The Sainsbury Centre for Mental Health has devised a model for the evaluation of services called User Focused Monitoring (UFM). Service users were involved in evaluating a number of sites as researchers. They reported improvements in their confidence and self-esteem as a result of their involvement.<sup>12</sup>



**The involvement of the public is also becoming an increasing political priority.**

Since 1997 there have been a number of Department of health policy documents<sup>13</sup> that emphasise the importance of public involvement. For example:

- A First Class Service: Quality in the new NHS (1998)
- Patient and public involvement in the new NHS (1999)
- Research and Development for a First Class Service - R&D Funding in the New NHS (2000)
- A Quality Strategy for Social Care (2000)
- A Research and Development Strategy for Public Health (2001)
- Shifting the Balance of Power (2002).

The development of Health Improvement Programmes, local authority Best Value Reviews, and the Framework for Community Care Charters are further examples of initiatives towards greater public involvement in health and social care services.

The Research Governance Framework for Health and Social Care was first published in 2001. (See Appendix 4 'Useful references'). It sets out a framework for the governance of research in health and social care. The standards it identifies apply to research undertaken under the jurisdiction of the Department of Health, such as in the NHS and in Councils with Social Services responsibilities.

On public involvement it currently says: "Participants or their representatives should be involved wherever possible in the design, conduct, analysis and reporting of research. Social care research has a long tradition of the involvement of participants in research. The Consumers in NHS Research (INVOLVE) group has established the principle that major advisory bodies in NHS R&D programmes should normally have at least two consumer representatives."

A second edition draft of the Research Governance Framework for Health and Social care was published in August 2003.<sup>14</sup>

At the time of writing, consultations are being carried out to develop a separate implementation plan for social care research governance, because the organisational and ethical environment in which social care research takes place is distinct from that of health.

INVOLVE believe that involving the public in an appropriate way improves the way that research is commissioned, prioritised, undertaken and disseminated. Involvement should be done as a routine matter of good practice, not just because it is 'policy'.



## Reasons that are given by some researchers for not involving members of the public in R&D - and some responses...

If you're already convinced of the value of involving people and you don't need to convince others, please skip this section. If, however, you come across opposition to involving people, you might find this section helpful.

**“One or two people who use services can't be representative of all the relevant groups.”**

It is not reasonable to expect one or two people to be representative of all people who use similar services. But then it's not reasonable to expect one doctor to be representative of all doctors either. It might be helpful to think about seeking people's **perspectives** rather than representativeness. If you want a range of perspectives, involve a range of people, and give the people you

do involve the time and resources to network with other people.

**“Trained or 'professionalised' members of the public can't reflect the views of 'typical' patients - it's always the usual suspects.”**

It's important to think about your reasons for involving people who use services. If you want two people who use services to sit on a research steering group, you will want to be able to involve those who are willing and able to participate in meetings, and who are able to put their views across to a variety of individuals with a range of professional expertise. These 'representatives' may not be 'typical', but they will be able to contribute important insights from a patient/user/public perspective and will be also able to access and present a range of people's views. Bear

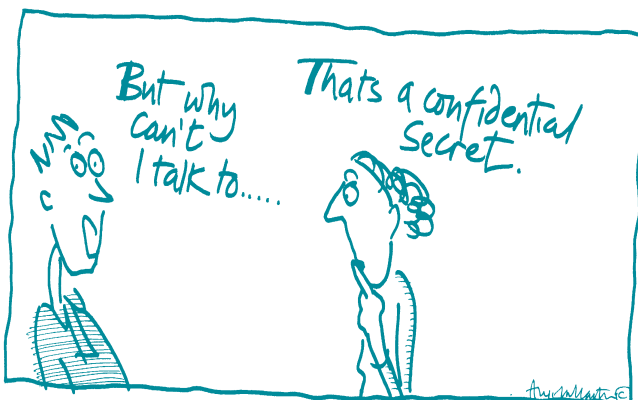
in mind too that just because people become actively involved and 'research articulate' doesn't mean they have stopped using services.

**“People won't understand the research.”**

Many people who use services have been involved in research projects that have addressed complex issues or used challenging methodology. For example, people from the HIV/AIDS community have been involved in the design and management of a number of complex randomised controlled trials. Users of cancer services have designed research projects to look at a variety of treatments and interventions. Complex ideas in research can be readily learned if they are explained without jargon.

**“There are too many problems about confidentiality.”**

There are issues about confidentiality that you will need to address when you involve people who use services in health and social care research - but this does not mean that there is a need to exclude them from the research process. If you are looking at patient records, agree a confidentiality policy to cover all of those involved - the people who use services and the researchers. It is important that everyone understands the confidentiality policy and what is expected of them.



**“Health and social care professionals can act as advocates for people who use services - that's their job”**

In fact, research shows that people who use services often have different priorities for research. For example, in Australia the National Breast Cancer Centre carried out a study to discover the views on priorities for research in breast cancer as seen by various stakeholders, both researchers and 'patients.' They found that the women saw priorities differently from researchers. They made 'risk factors' their highest priority for research, a topic that came fairly low on the scale for clinicians, researchers and policy makers. Even when health professionals are patients they may have a dual agenda.

**“If people who use services are emotionally engaged in the topic of study, how can research be objective when they also take part in the research design or process?”**

No one is entirely objective or neutral. People who use services bring a particular knowledge based on their experience of the issue. Many researchers have found that people who use services keep research focused on the fundamental reasons for undertaking a research project, and ensure that it remains relevant to the needs of those at the receiving end of services. They do not find that involving people who use services compromises the 'scientific' value of the research.

However, everyone involved in a research project, including members of the public, should be encouraged to consider where they might turn for support if the research they are involved in is personally upsetting.

### **“It will be too expensive and time consuming.”**

Involving members of the public will cost more money and take more time. However, not involving them can compromise the relevance and perhaps the quality of the research to the extent that it may not be worth doing at all. Increasingly research funders and commissioners are encouraging researchers to submit proposals that budget for people’s involvement.

### **“Members of the public may have unrealistic expectations of research and its implementation.”**

This need not be a problem if you are clear about how long research can take, what will be involved, and the potential for it to be put in to practice. This should be explained before people make a decision as to whether or not to get involved.

## **Why members of the public choose to get involved in R&D**

People who use services may have a number of reasons for wanting to get involved in R&D:

- to improve treatment services for themselves and those who come after them
- for many people research may be a means to an end and they are likely to want to know what will happen as a result of research
- to identify problems related to the treatment or service they are offered
- to influence the research agenda in a way that makes research more effective

- to identify gaps in knowledge related to specific treatments or conditions that they feel need research
- to ensure that the issues that are a priority for people are addressed
- to ensure that future R&D is relevant to the needs of a specific group of people
- to identify existing research which is not being disseminated or implemented, that could improve treatments or services
- many users of health and social care services are stigmatised, and involvement in or doing research can be a useful way of challenging this
- to ensure that R&D is undertaken in an ethical way
- some people have altruistic motives and simply want to ‘give something back’ to the health and social care services from which they may feel they have derived benefit
- as key stakeholders in health and social care they may consider they have a right to be involved.

When you seek to involve the public in a research project, it is important to understand their reasons for wanting to become involved, as well as explaining your reasons for wanting to involve them.



## 1.3 Levels of public involvement in R&D

### Consultation ↔ Collaboration ↔ User control

In this booklet we describe three different levels of involving people who use services in R&D - consultation, collaboration and user control - which are really on a continuum of involvement.

We recognise that there is a role for each of these levels of involvement within health and social care R&D. We describe what we mean by these terms below. These are used throughout the rest of the booklet to help you to decide how much you want to involve people. It is important that you are clear about which level of involvement you are seeking from people you want to involve.

### Consultation

When you consult people who use services about research, you ask them for their views and use these views to inform your decision-making. For example, you might hold one-off meetings with people who use services to ask them for their views on a research proposal. You will not necessarily adopt those people's views, but you may be influenced by them.

#### **Advantages of this type of involvement:**

- It enables you to obtain people's views without having to commit yourself to acting on them.
- It can be fairly simple.
- If you've never involved people who use services before, this can feel quite a 'safe' way to start.

#### **Disadvantages:**

- Many people who use services find it frustrating to be asked their views without any commitment to act on them. This can mean that it is difficult to develop effective partnerships in the long term.
- Some organisations representing or run by the public may decline to get involved in consultations, arguing that it is a waste of their time if they are not seen as partners in the research process - particularly if their views have been ignored in the past.
- There is a real danger of 'consultation fatigue' for individuals and organisations who are frequently targeted. This can sometimes lead to ill health.
- You can miss out on ideas because people's responses are constrained by your agenda.

#### **Example**

Older people, patients and carers were consulted in a study to determine whether public involvement would help to solve some of the ethical problems associated with research into thrombolysis for acute ischaemic stroke and its inherent risks. It was found that those consulted generally supported the development of a randomised controlled trial, and most would be prepared to accept the risks of treatment and take part in a clinical trial. The consultation process was found to be very valuable - significant changes were made to the trial information leaflets and the trial consent procedures were refined, leading to an ethically acceptable trial design.<sup>15</sup>



# Collaboration

Collaboration involves active, on-going partnership with members of the public in the R&D process. For example, people who use services might take part in a steering committee for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

## Advantages:

- By involving people who use services you increase the likelihood that the outcome measures, assessment criteria and evaluation are relevant to research participants
- People who use services can help to access research participants
- They can help with recruitment and informed consent
- They can help to interpret and understand data
- People who use services are likely to feel more ownership of the project and therefore of the results. This means they are more likely to actively disseminate the findings.

## Disadvantages:

- Collaboration of any kind can be time consuming
- Collaboration can involve extra cost - for example in the payment of travel and other expenses for people to attend meetings
- This involves an active commitment from the researcher to collaborate, which means that control over research will be shared rather than being controlled only by the research professionals. This loss of power

might be perceived as a disadvantage by researchers

- Researchers may require additional skills, such as in facilitation and negotiation
- Additional resources may be required, for example, the time and costs involved in support, training, and producing plain English summaries of research papers.

A useful reference for exploring collaborative methods further is Trevide and Wykes (See Appendix 4).

## Example

A representative of the National Childbirth Trust became a full member of a research team involved in a study to identify the research priorities of community midwives. She was involved in all aspects of undertaking the research, providing a strong voice for people who use these services throughout the research process. She was also able to facilitate access to users of maternity services whose views were a central part of the research findings.<sup>16</sup>



## Example

In March 2001 the Medical Research Council was commissioned by the Department of Health to provide it with a clear picture of what scientific research has revealed about the epidemiology and the causes of autism. Three groups of scientists examined the research evidence. Importantly, for the first time in an MRC research review, questions and other extensive input from lay people were incorporated from the outset.

The Autism Lay Group was set up by the MRC to work with the scientists reviewing the existing research on autism with a view to identifying areas of future research. The group consisted of representatives of autism charities, parents of autistic children and two members of the MRC Consumer Liaison Group. The members of the lay group, in consultation with their networks, formulated a set of questions which they wanted, if possible, to be answered by research. The independent scientists were tasked with reviewing all research, attempting to answer the questions and identifying future research priorities. A final report, agreed by both the lay group and the scientists, would go to the Department of Health. A major issue was that of 'grey' literature. Many group members had strong beliefs in small-scale, un-peer reviewed research which they felt might be neglected by the reviewers. Scientists then agreed to look at such research submitted to them. Towards the end of the process there seemed to be a much clearer understanding by both the lay and the scientific members of the purpose of the review and each others' roles.<sup>17</sup>

## User control

User-controlled research might be broadly interpreted as research where the locus of power, initiative and subsequent decision making is with service users rather than with the professional researchers. It does not mean that service users undertake every stage of the research, or that 'professional' researchers are necessarily excluded from the process altogether.

There are some very specific reasons why user-controlled research is important to long-term service users and disabled people. It is often the preferred, and sometimes the only legitimate research from the point of view of some service user groups who have become disillusioned with the mainstream research approaches. This is because the experience of many service users has been that traditional approaches can often be unhelpful, and ultimately have disempowering effects on their lives.

Some user-controlled research, but not all, is known as 'emancipatory research' where the object of the research is to help liberate participants from the social stigma and marginalisation they experience.

User-controlled research is an important option with a strong track record in the social care field. Often innovative, it can provide important new information which might not have been accessible through other research approaches. (See the references to papers by Barnes, Beresford, Evans and Fisher, and Faulkner in Appendix 4 'Useful references').

Research of this kind is frequently funded through charitable trusts such as the Joseph Rowntree Foundation, but at the time of

writing, still relatively little user-controlled research has been funded by the NHS and PRP.

### Advantages:

- The research is likely to address questions which may not have been considered by researchers
- Innovative user-driven approaches can often reveal evidence otherwise missed by 'professional' researchers
- There will be a commitment from the people who use services and their organisation(s) to disseminate the results of research and to influence change in practice
- The development of new research skills among 'professional' researchers, clinicians and people who use services
- Involvement in user-controlled research can be an empowering experience for service users who are often marginalised
- Professionals who are interested in better service outcomes from the point of view of people who use services are more likely to absorb and implement recommendations from this kind of research.

### Disadvantages

- This type of involvement requires researchers to hand over the 'ownership' of a project to people who use services. Some researchers (and funders) find this difficult or unacceptable
- Potential for 'bias' - although this problem is not exclusive to user-controlled research, as all research has a potential bias
- The research may not be perceived as independent

- There may not be enough time or money to undertake training in research methods and approaches, should this be necessary.



### Example

All Best Value Reviews undertaken by local authorities are expected to consult with users of the services that are under review. In this groundbreaking piece of work from Wiltshire, a project group of disabled people took a lead role, designing and undertaking research on Direct Payments,<sup>18</sup> based on the Best Value 4C's framework of challenge; compare; compete and consult. This involved survey work, user led interviews, diary work, cost analysis and literature reviews.

The experience gained in this innovative, user-led review has been used to produce 'Users' Best Value: A guide to user involvement good practice in Best Value Reviews' - a publication funded by the Joseph Rowntree Foundation.

The work was undertaken in collaboration with the University of Bath Research and Development Partnership, and had the full support of senior social services management at Wiltshire County Council.<sup>19</sup>

## Which level of involvement is best?

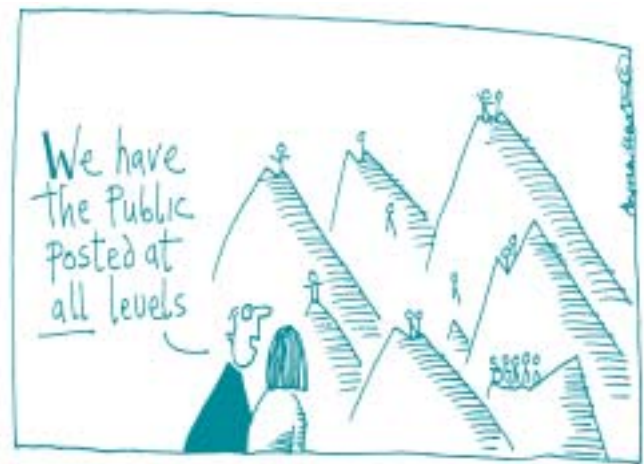
There is no single right answer to this question. Different types of involvement will be appropriate for different research projects. This will depend on the researchers, the people you wish to involve, the research topic and method, and the requirements of the funding body. In any single research project, you might consult and collaborate with people who use services or they might lead at different stages of the project.

Involvement is a multi-faceted activity and subject to a range of different interpretations. We have provided a basic model designed to help you think some of this through, but there are other models for participation, for example, the 'Ladder of Participation' developed by Arnstein and 'A Guide to Effective Participation' by Wilcox both of which explore involvement and participation in more depth. (See Appendix 4 'Useful references').

Whether you really have good public involvement in your project is as much a question to ask those you are involving as it is one to ask yourself. Involvement is not just about having an extra person around the table, it is also about the quality of the relationship they have with the project as a whole. This includes such factors as the quality of communication and information, the opportunity to actually contribute and have contributions valued and incorporated, and how professional and institutional power is used. It might also be about whether they are paid or not. These factors become increasingly critical when considering the involvement of traditionally stigmatised or

marginalised people in research. For example, does the experience of involvement and the research itself actually benefit these groups or does it simply maintain a status quo? Would it be better to support user-controlled research by these groups instead?

The involvement of people who use services, when done well, positively affects not just **what** is done in research, but also the **way** it is done.



# SECTION 2: Before you start...

## 2.1 Whom should I involve?

This booklet is all about the importance of building good relationships with people who use services and the organisations that seek to represent them. Once you have developed such relationships, you will have a clearer knowledge about priorities and ways of working, which should make ongoing collaboration more effective.

To address the question about whom to involve, you first need to think about the aims and objectives of your R&D programme or project. Prepare a brief 'person specification' to enable you to think more clearly about whom you might involve, but be flexible.

Ask yourself what range of experience, perspectives and expertise you need from people who use services to ensure your project is sufficiently tested and well informed. You will also need to ask yourself what support and training you are willing to offer them, if any. We recommend that you involve two or more people who use relevant services, so that they are less likely to be isolated amongst a group of professionals. Often the best way to start is to go to organisations such as self-help groups or voluntary organisations to hear their views collectively.

Remember that there are different types of organisation - for example, self-help groups, voluntary organisations that campaign for improved services, pressure groups, user-controlled organisations, advocacy groups

and so on - but not all will be interested in your work. There are also different categories of people who use services:

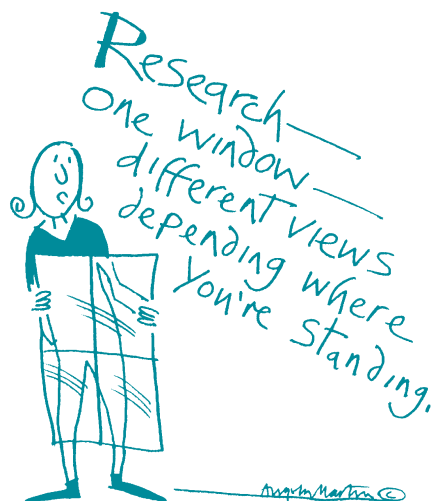
- patients and potential patients
- informal (unpaid) carers
- people who use health and social services
- members of the public who may be targeted by health promotion programmes
- organisations that represent the interests of people who use health and social care services
- groups asking for research because they believe they have been exposed to potentially harmful substances or products e.g. asbestos or pesticides.

You'll need to think about which people are the most appropriate to involve. Ultimately, who is the 'end user' of your research? For example, you may want input from people who have experienced the specific condition, situation, service or treatment you are addressing in your research project, in order to ensure that the issues you are covering are relevant to them as 'end users.' It would therefore be more appropriate where possible to involve someone with direct experience. A carer, for example, does not have the same perspectives as the person for whom they are caring, so might not be an effective 'proxy.' If carers were the 'end users' of the research then the reverse would apply. In some types of research such as in childcare, however, the different needs and perspectives of carers, parents and children may be interdependent.

Often considerable thought needs to be put in to the question of exactly who **are** the appropriate people to involve, given the purpose of the research. Even if your research is about informing practitioners about approaches to practice, the end user is ultimately the person on the receiving end of the practice, and his or her perspectives should be included.

You'll also need to think about the broad topic area that you hope to address. If you plan to look at a research project related to people affected by Alzheimer's Disease, for example, you might contact the local and/or national Alzheimer's Society.

However, your research may be about a more general topic, so you should consider who could be most appropriately involved, given that people who use services will have different perspectives and experiences. Will they present a broad or limited range of views? This will affect where you will go to find them. You are likely to need to include people who use services with a variety of perspectives in order to get a rounded view. It is better to bear in mind the different interests of different groups and include different viewpoints instead of choosing between one or the other.



## Example

Four lay representatives from the National Institute of Clinical Excellence (NICE) Appraisal Committee who were all members of patient organisations, (Changing Faces, Motor Neurone Disease Association, MIND and Harrow Primary Care Trust), were involved in stage one of a project to explore a method of gathering patient/carer/family views of different technologies for the NICE appraisal process. This was known as the Patient Impact Assessment or PIA and the project was hosted by Birmingham University.

Not only were the representatives involved in all stages of development, but also they had suggested the idea for the research in the first place. Their input helped to keep the project grounded in the basics of patient/carer/family needs, and helped to keep written material accessible and jargon free.<sup>20</sup>

People who use services get involved in research for different reasons, and it might be important to be clear about what these are in each case. This can help you understand how to keep them interested in your work.

Consider that some people may choose not to become involved in your work - because their aims do not match yours, because they do not have the time, or because the emotional or practical costs of involvement may be too high.

Consider also that there is research for which people who use services have identified a need themselves, e.g. community surveys instigated by residents as part of community development.

## Example

An acute Trust in receipt of NHS R&D funding decided to involve two people who used services in their research committee. They agreed that they needed to recruit people who:

- could take a broad view of a variety of topic areas and research methods
- had the confidence and experience to take an active part in the committee meetings
- had the time and confidence to read research proposals and reports
- were prepared to reflect the views of people who use services at committee meetings
- would be able to access the views of a wide range of other people who used services.

## 2.2 How can I identify people to involve? Building relationships

You may need to contact several different organisations that represent or are controlled and run by people who use services. Here are some potential routes to contacting people who use services:

- your local NHS Patient Advice Liaison Service (PALS)
- your local Council for Voluntary Service (CVS)
- The Voluntary Agencies Directory, available from the National Council for Voluntary Organisations (NCVO)
- the World Wide Web - for example: [www.findsupport.co.uk](http://www.findsupport.co.uk)

[www.ukselfhelp.org.uk](http://www.ukselfhelp.org.uk)

[www.synergy-health.co.uk](http://www.synergy-health.co.uk)

[www.volresource.org.uk](http://www.volresource.org.uk)

- NHS, Social Care and Public Health organisations e.g. - GP surgeries, or local Primary Care Trust (PCT) offices
- local public libraries (ask to see their local organisations folder at the information desk)
- local Social Services offices
- NHS Direct Online
- Race Equality Councils
- Citizen's Advice Bureau and welfare rights services
- area regeneration projects
- patient, service user support groups - e.g. MIND
- user controlled groups (local and national)
- self help groups (local and national)
- Yellow Pages, local Thomson Directory
- advertising through local media and newsletters
- advertising in local surgeries, waiting rooms, libraries, social services reception areas etc. or organising an 'event' or special evening.

You'll also need to think about the different communities who might have an interest in your research area. For example, will your research affect older people? If so, you should also think about contacting local older people's organisations. Similarly, if you are planning to carry out research in an area where there is a significant ethnic minority population, make links with these local communities, don't expect them to come to you.

When you approach people to get involved in R&D, be ready to tell them in simple, unambiguous language about:

- the project you are asking them to become involved in (or inviting them to undertake) and its background
- why you are approaching them
- what you are asking from them
- the level of involvement they can expect and why (consultation, collaboration, user control)
- what resources you can offer to enable them to contribute effectively
- the benefits to them
- how long it is likely to take
- who the research will benefit
- potential risks

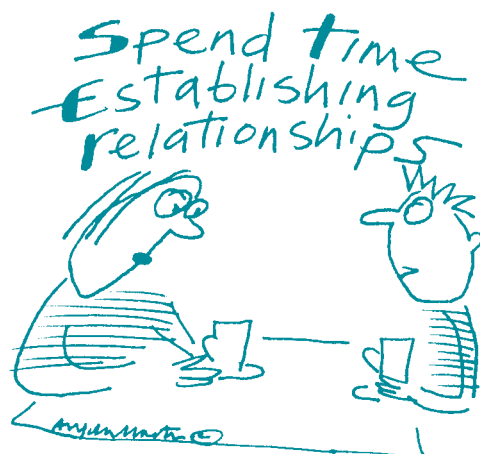
Before you invite people who use services to join your research project, remind yourself about the aims and objectives of the project and what the 'person specification' of the people you want to involve needs to be. The person specification might also depend on the degree of support and training you are willing to offer people involved in your project, and the degree to which you are willing to use user-friendly or accessible language. You'll find that having to explain your research in user-friendly terms can help clarify your own thinking, and help communication between professionals from different specialist backgrounds.

In order to better understand the perspectives of people who use services, spend time developing a relationship with them. Visit the people or their organisations on their own ground. Expect some of them to be sceptical. Look at examples of their work.

Ask to see newsletters and annual reports and ask them to explain what they do. People are more likely to co-operate if they feel that their contribution is respected and valued.

Ask people about how and when they would like to be involved. For example, it may not be easy or appropriate for a woman who has recently been diagnosed with breast cancer to become extensively involved in a research project in this area. She may prefer to become involved at a later stage.

Sometimes a 'job or role description' can be useful. A job description is about the job you want people to do, whereas a 'person specification' is about the kind of person you are looking for. A 'job description' can act as a kind of 'contract', stating what you can expect of people (e.g. 'to maintain an independent consumer view') and what they can expect of you (e.g. 'your views will be respectfully received, and fully discussed'). It is always better to negotiate a 'job description' with the person it applies to from the beginning if this is possible. Don't just use job descriptions for the lay members; make sure professionals also get them. See Appendix 1 for examples.





## Example

Over 35 people attended Warwick Diabetes Care's (WDC's) first public meeting, which had attracted both local radio and newspaper attention. WDC had been keen to engage with users to ensure that the educational programmes and research activity are relevant to people who are living with diabetes. The evening began with a post-it note exercise where people were asked to write down their own ideas about what diabetes research needs to be carried out. 26 research questions came out of this exercise which a small workshop group later arranged into themes.

The chair of a local Diabetes UK group was asked to present some of her ideas as to why she wanted to be involved with this initiative. She told the meeting what her questions and concerns were. Participants were then asked to talk to someone they did not know and answer some of these questions in relation to themselves.

There were two presentations from WDC professionals, about its role and current research. Participants then chose one of four workshops for the remainder of the evening. These covered: the development of a job description for user involvement, receiving training, and the role of users in the delivery of diabetes educational programmes. One workshop looked at patient information leaflets for studies in development and experienced the real work that continued participation in the WDC user group would bring.

The evening was felt to have been a great success. Both users and WDC participants worked hard to begin developing relationships with each other based upon trust and sincerity. The WDC research and education team exposed their work to the very people they could least afford to disappoint. The rewards were manifold on this occasion and user group views have resulted in changes to research proposals being submitted for funding or ethical approval.

WDC has since developed a newsletter to distribute widely to all those involved.<sup>21</sup>

## Involving members of the public from marginalised communities

Researchers often find it difficult to access people from marginalised communities effectively. One answer to this difficulty is to ask these communities - or organisations that speak on behalf of these communities - to do this themselves, and ensure you resource them to do so. So, for example, if your research is connected with learning difficulties, you could approach People First,

- an organisation of people with learning difficulties - on either a local or national level. Organisations like People First are likely to be able to access people with learning difficulties more easily than you, as they will already have a relationship with them.

For example, it is useful to approach black and ethnic minority groups where they are and try to understand their culture. This can be achieved by visiting elders, religious leaders etc. and building a relationship based on mutual trust. Without this there is a risk

of marginalising them further. You will need to be aware that sometimes community leaders and organisations may not wholly 'represent' those communities, so it is important to check. You should also check whether or not you are approaching the right community.

Contacting relevant national organisations that may have produced guidelines on working with particular groups or communities may be helpful. Again, 'Asking the Experts' gives some in-depth information about the involvement of these groups. (See Appendix 4 'Useful references').

Bear in mind that many marginalised communities are understandably uneasy about having research done 'to' or 'for' them. They are much more likely to work with researchers who want to collaborate with them on research that has been identified by the community as a priority, or researchers who are willing to support them to undertake their own research (see the section on user-controlled research on page 10).



## Example

In 1998 the REU, a leading national agency working to develop appropriate social care services to Britain's black and ethnic minority communities, undertook a project looking at the experience of young black disabled people (aged 16 to 25 years) on independence and independent living. The project involved young black disabled people in an advisory group of professionals as well as in two reference groups made up of young black disabled people in different areas of the UK. Their role was to act as a point of reference at different stages of the research. For example, their views were sought about the type of questions the researchers intended to ask young people. Their comments led researchers to change some of the questions on the interview schedule, as well as some of the approaches to this work, in particular that researchers address information to the young black disabled people themselves rather than their parents or carers.

Once the fieldwork was done and the draft report completed, the young black and ethnic minority disabled people were provided with the opportunity to assess and review the researchers' analysis of the interviews, to guard against the tendency of past research to abstract and distort the experiences of black people.

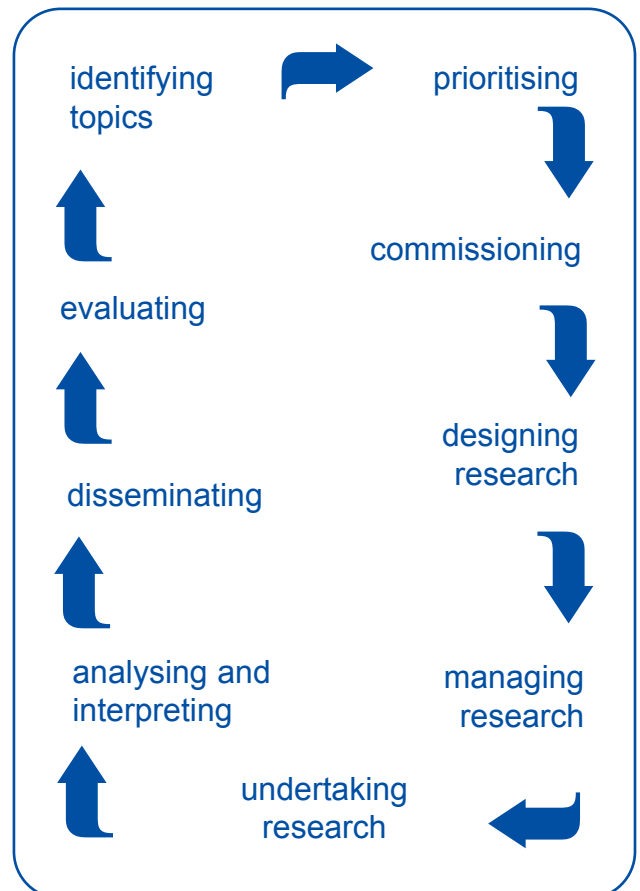
Two of the young people who had been interviewed for the research gave their suggestions on the layout, wording and content of the report. In addition, a young black man with learning difficulties working for a disability organisation offered his advice independently.<sup>22</sup>

# SECTION 3: Involving the public at the different stages of the R&D process

## 3.1 Is it best to start by involving the public at a particular stage of the R&D process?

Involving people who use services does not mean that they must be involved in every task or at every stage of the R&D process. Enable people to focus their energy on what they can do and what they wish to do, as you do with other members of the research team.

You could start by involving the public at any stage in the R&D process. However, we recommend you start by involving people at as early a stage as possible and then follow the process through (see diagram). You are less likely to involve people successfully if you merely want them to help you to disseminate the results of your research project.



**Public involvement at different stages of the research process**



## 3.2 Involving the public in identifying topics for research

This is one of the most powerful ways to involve people who use services in R&D, as it enables them to have a say about what will be researched. 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'll 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.

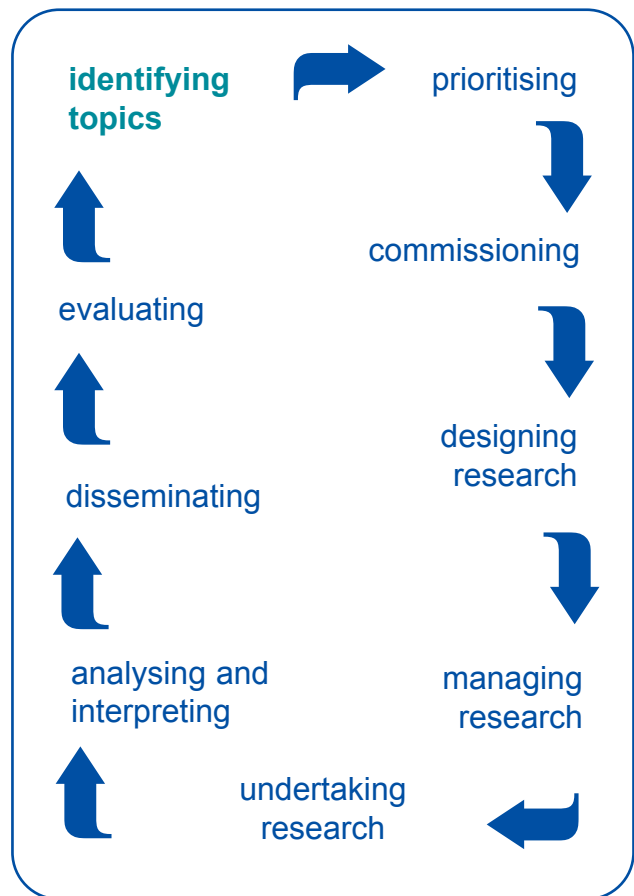
Recognise that different people who use services, and the different organisations which seek to represent them, may have different priorities, just as different researchers and clinicians do.

### Options for public involvement:

- People who use services are consulted about research topics
- They collaborate with researchers to identify research topics
- They identify topics for research themselves

### People who use services are consulted about research topics

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. You can use a number of different methods to identify



research topics with people. These include:

- surveys (although you would probably need to involve people who use services in designing surveys)
- inviting people to an event to 'thought shower' ideas (this involves collecting people's spontaneous ideas on a flip chart)
- workshops or focus groups
- outreach work
- taped interviews
- peer group interviews
- work with independent facilitators (to reduce the risk of researchers influencing the agenda too much.)

Refer to section 4.2 for what you'll need to consider providing for some of these methods.

You may find that some people do not have ideas about the research questions that they would like to see addressed. If this is the case, ask about problems that people who use services experience, such as the conditions or treatment in question, or the barriers that prevent a good quality of life. Consider asking about the issues people who use services find important: What didn't work? What could be improved? What are their ideas about their condition or treatment? What about possible side effects?

Don't make any assumptions in advance, but be prepared to check out your ideas with them. The aim is to generate a dialogue that will enable both you and the people who use services involved to learn how to define research questions together.

Ask the questions in a way that shows you are prepared to listen and respond to the answers you get. Some topics may be identified that are not appropriate for research at the present time, or are not suitable for research at all. It is helpful to think about who you can refer people who use services to if their topics are more relevant to audit, service delivery or service planning. It may also be helpful to talk through how their concerns can be incorporated into research questions.



## Example

The National Co-ordinating Centre for Health Technology Assessment (NCCHTA), the largest of the three national NHS research programmes, has a website on which people can submit suggestions for research topics.

Every year, the Health Technology Assessment (HTA) programme carries out a process of consultation to identify future research priorities and to identify potential topics for National Institute of Clinical Excellence (NICE) appraisal and guidance. The website has a downloadable help sheet about how best to submit suggestions for research topics.<sup>23</sup>

## People who use services collaborate with researchers to identify topics for R&D

You can collaborate with the public to identify topics using similar methods to those outlined in the section above. However, there will be a difference in the way you use the methods. In collaboration you are working **with** people who use services instead of 'extracting' knowledge **from** them, as in consultation.

Using a collaborative approach, you may find that the research question you end up with is drawn from the ideas of a number of different organisations and individuals, both professional and those representing people who use services. We've found it useful to record these influences at the beginning of the research project.

## People who use services identify topics for research

Groups of people who use services may meet to identify research topics that are of interest to them. Organisations supporting the interests of people who use services may also identify priorities for research through general contact with the people, complaints they have received, and calls to helplines.



### Example

Following concerns expressed by a local GP of high callout rates in an area of South Devon and consultation with local people, statutory and voluntary organisations, a three-year community health development project was funded by the Health Authority in 1995.

In one area some residents expressed concerns about damp and condensation within their houses, and children reported having asthma. The residents asked for research into this. The community worker supported them to undertake a questionnaire-based survey of 96 council houses and tenants using a pictorial guide to condensation/damp and mould drawn by one resident. Dampness was reported by 64% of residents and 56% reported a health problem, the most common being asthma.

In response to this survey, an inter-agency steering group, including a tenant representative, was formed to put forward a research proposal to address these problems. Following much lobbying by the group, agreement was gained in 1998 from the Council Housing Committee that £600,000 of the maintenance budget, over three years, would be allocated to address the problems identified. Funding was obtained from the regional NHS Research and Development Committee to evaluate the proposed improvements. The community worker was appointed as research co-ordinator, which provided a continuous link with residents and agencies.

Although changing over the three year period of the project, tenant representatives continued to be involved throughout. Their role was crucial to the process, and included being advocate for other residents, reviewing all written material for its accessibility (including the research questionnaires) and advising the use of appointments for interviews. Finally they have been involved in informing others about the lesson learnt from the project.<sup>24</sup>

### 3.3 Involving the public in **prioritising** topics for research

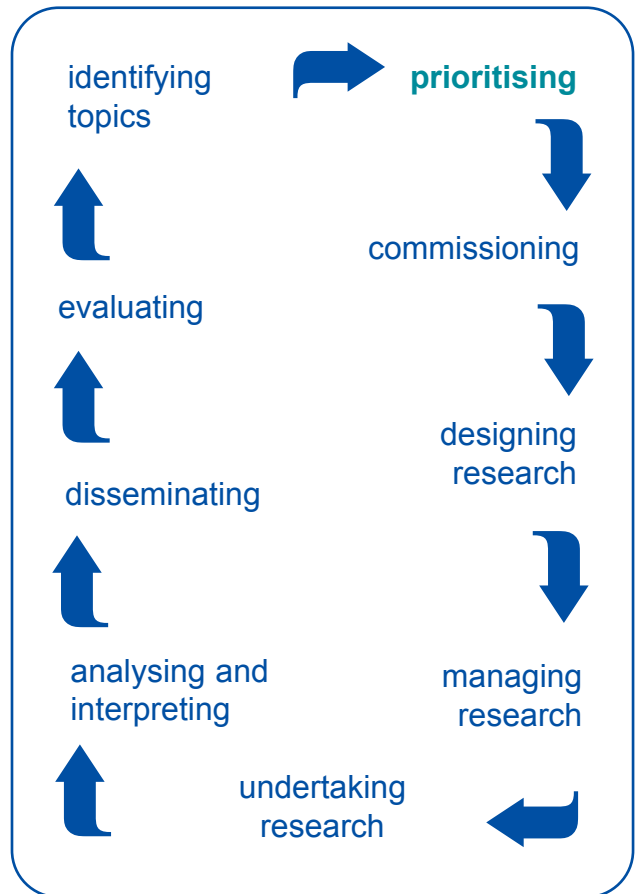
#### Options for public involvement:

- People who use services are consulted about prioritising R&D topics
- They collaborate with researchers to prioritise topics for R&D
- They 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. See the guidelines on how to identify people on page 15 for more information.

If you consult people about the priorities for research, ensure you feed back the results of the prioritisation process. And explain why their priorities were, or were not, prioritised.



#### Example

The Academic Palliative Medicine Unit at the University of Sheffield held a Cancer Open Day where patients met with cancer professionals. Patients’ views on research priorities were elicited through one of the workshops on the day and used to inform the research agenda.

The Unit later set up a Consumer Panel funded by the North Trent Cancer Research Network to continue this work. The funding is sufficient for providing administrative support, expenses and payment for involvement.

The panel has been recruited from a wide variety of sources, and currently there are 13 members. A two-day training was provided for the new panel members. Part of the panel’s role is concerned with prioritisation of topics for research.<sup>25</sup>



## Example

In the initial stages of a project based at the University of Brighton investigating sexual expression, physical disability and professional practice, 19 user groups were invited to consider the study's relevance to their members. Additionally their views were sought in defining the research questions.

Some of these user groups facilitated direct contact with their membership and 46 individuals made contact with the researcher. Contact was via telephone, letter, and email. Key themes emerged from this consultation.<sup>26</sup>

### **People who use services collaborate with researchers to prioritise topics for R&D**

This is mostly carried out by involving people who use services on committees that prioritise research topics. Before you approach anyone, think clearly about the aims of involving people who use services in the prioritisation process - are you looking for people who have access to the views of others, people with similar experiences, or people who can offer just their personal experience of a particular condition or treatment? You may want to consider equal representation of people who use services and professionals on committees to prioritise research or perhaps have more users than professionals to balance the power.

It is important to be clear about how decisions will be made: e.g. consensus, advisory, or voting. And what happens when there are unresolved differences? We suggest you use the checklist on page 39 if you plan to involve people who use services in prioritisation through committees.

## Example

The Service Research User Enterprise (SURE) at the Institute of Psychiatry came about as a result of two initiatives. The first was the involvement of service users in research and on the steering group of the Centre for Recovery in Severe Psychosis (CRiSP), and the second, a conference to establish the research priorities of service users hosted by the R&D Director and the South London & Maudsley NHS Trust.

SURE's core aim is to encourage and establish collaborative research between users and clinical academics at the Institute. All SURE's employees are users or ex-users of mental health services. A key part of SURE's work is supporting the Consumers' Research Advisory Group (CRAG), a local group of service users who delegate two of their members to sit on the R&D steering group accompanied by a SURE worker. The whole group receives the R&D papers and advises those delegated of the most important issues.<sup>27</sup>

### **People who use services prioritise topics for R&D**

To our knowledge, people who use services have not been asked to work alone to agree priorities for R&D in the NHS or Policy Research Programme. This doesn't mean it shouldn't happen, only that it hasn't happened to date. Please let us know of any examples you may have.



## 3.4 Involving the public in commissioning research

### Options for public involvement:

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

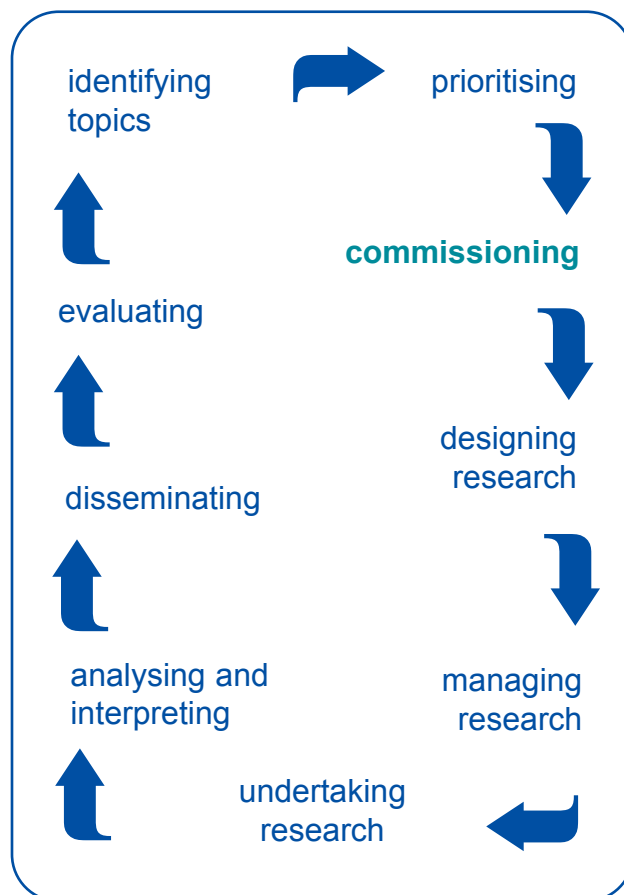
### People who use services are consulted about which research to commission

People who use services may be consulted about which research to commission in a number of ways, including: sending surveys to people to ask their views; carrying out interviews or focus groups with people; or 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.

### People who use services collaborate with research funders to commission research

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 are



relevant to them. Some people may not feel confident about commenting on the details of methodology, but would be very happy to comment on the relevance of the questions being addressed, whether the research will address quality-of-life issues, the approach being used and so on.

- Recognise that people who use services from national organisations may have different expertise than that of local groups. National organisations may employ researchers or research managers with particular expertise in this area. Local groups will often be dependent on volunteers, but equally a high level of expertise has been developed in some local networks.
- People who use services may prefer to review proposals as a group. Not only does this help them gather a range of perspectives for the task, it also ensures they can offer each other peer support.

## Example

Quality Research in Dementia (QRD) was launched in 1999 as the Alzheimer's Society's expanded research programme. QRD draws on the experience and expertise of carers, people who have dementia, researchers, care practitioners and scientists to initiate, fund and develop research into dementia.

The QRD Advisory Network is a large group of carers, people with dementia, scientists and researchers, working together to advise and help the QRD programme. They are involved in initiating, funding, and developing research.

Members of the network help decide which research projects should get funding. All proposals are expected to carry a lay summary, and carers and people affected by dementia are involved in peer reviewing proposals. Applicants are expected to make changes to their proposals based on review comments made on a standard feedback form. The final Grant Panel is a mix of consumers and professionals and has an independent chairperson.<sup>28</sup>

You can also involve people who use services on committees that commission research. They can ensure that researchers look at the issues that are important to the people affected by the condition or intervention addressed in the research study.

If you do plan to involve people on commissioning groups, refer to our guidelines on involving people who use services on committees on page 39.

## People who use services commission research

People who use services may commission research that is a priority for them. To our knowledge, this has not happened within the NHS or Policy Research Programme to date (with the exception of some Community Health Councils when they were operating), but that doesn't mean it shouldn't happen in the future. It does happen extensively in the voluntary and community sector.

## Example

Age Concern commissioned research to explore how older people could become more involved in their GP practice and to evaluate their impact. Age Concern is a voluntary/charitable organisation, and was able to obtain National Lottery Charities Board funding for the project. This was an action research project involving six GP practices, five of which successfully initiated meetings with older patients. At the close of the project, four of the five practices were continuing to hold meetings with some of their older patients, and making changes to the practices and the buildings in which they were situated, as a result.<sup>29</sup>

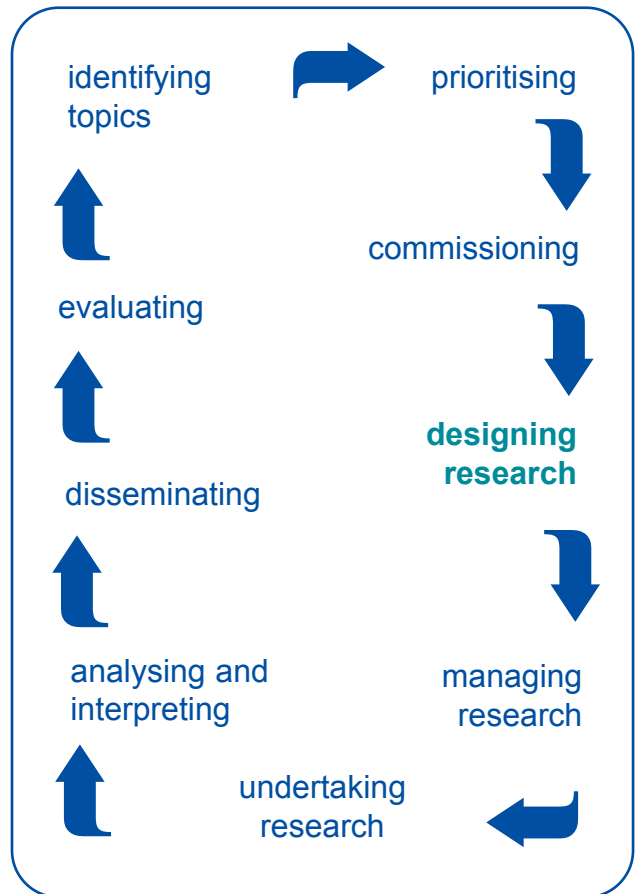


## 3.5 Involving the public in designing research

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 for funding. 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 (see section 4.2). In designing your research you should also be aware of any ethical implications for the people you are inviting to be involved in the research (see the list of useful references at the end of this booklet for further reading on ethical considerations).

### Options for public involvement:

- People who use services are consulted about the design of the research project
- They collaborate with researchers to design the research project
- They design the research project



### People who use services are consulted about the design of a research project

You can do this by:

- asking for written comments on a research proposal
- discussing research proposals in focus groups
- asking for comments about written information to be supplied to those invited to participate in the research - for example information sheets and consent forms
- asking people to highlight any potential difficulties - with literacy or sight for example - within community groups
- recruiting people to a research advisory group/committee
- other methods through which people can feed back e.g. audio tapes

## Example

In a small randomised controlled trial to pilot the feasibility of a full-scale clinical trial of water softeners in the treatment of atopic eczema, two eczema sufferers registered with the Cochrane Skin Group were asked to advise on the study design prior to commencement of the trial. Many useful and constructive ideas were made at the design stage. For example, a question was added to the questionnaire about usual bathing habits, the sampling frame was reassessed, and consideration was taken of variables to control for.<sup>30</sup>

## Example

In research to develop and evaluate an instrument to assess adverse effects of cytotoxic chemotherapy, patients ensured that the instrument was relevant to those who use it in practice by helping to design the research instruments. They informed what the chemotherapy instrument scale should look like, how it should be used, and prioritised items for inclusion on the scale.<sup>31</sup>

## People who use services collaborate with researchers to design the research project

Many people who use services have collaborated with researchers to design research projects. The involvement of people who use services in the design of a research project can lead to research that is more relevant to the needs of people and which is more likely to encourage people to take part. You could collaborate with people who use services at this stage in the research process through:

- committees - see the general guidelines on page 39
- joint applications for funding
- focus groups or other discussions
- agreeing with people that they will design particular elements of the research project - for example, many people who use services have been responsible for producing written information in user-friendly language
- employing people as consultants to the research team

## People who use services design the research project themselves

See our general guidelines on user-controlled research on page 10.



## Example

In a research project to develop and evaluate a family-based programme to increase physical activity among individuals at high risk of diabetes, families worked with the facilitators to develop the programme and helped to define the contents and numbers of interactions for the programme. They also provided feedback on the acceptability of the recruitment approach and programme, and were involved in the design of a questionnaire assessing beliefs about increasing physical activity. The project is funded by the Medical Research Council, NHS Research & Development, the Royal College of General Practitioners, Department of Health/MRC Nutrition Initiative, and Diabetes UK.<sup>32</sup>

## Example

Young people from the Children's Society, the Foyer Accommodation Project and Barnados were involved in an action research project about improving the health and well-being of socially excluded young people. They decided on the issues which affected their health and designed and drew up the interview schedule. They identified areas which made them ill that are not ordinarily thought to 'cause' ill health, such as violence, abuse, accommodation, poverty, negative family relationships and being in 'care.'<sup>33</sup>



## Example

In order to encourage a more holistic approach to treating mental ill health, some user-led research aims to identify coping strategies used by psychiatric inpatients. Training, support and funding were provided by the Strategies for Living project at the Mental health Foundation. Service users chose the topic and carried out the research from start to finish, including designing the research instrument. It is hoped that the research will give providers ideas for developing psychiatric hospital services.<sup>34</sup>

## 3.6 Involving the public in managing research

### Options for public involvement:

- People who use services are consulted about the management of research
- They collaborate with researchers to manage the research
- They manage the research for themselves

### People who use services are consulted about the management of research

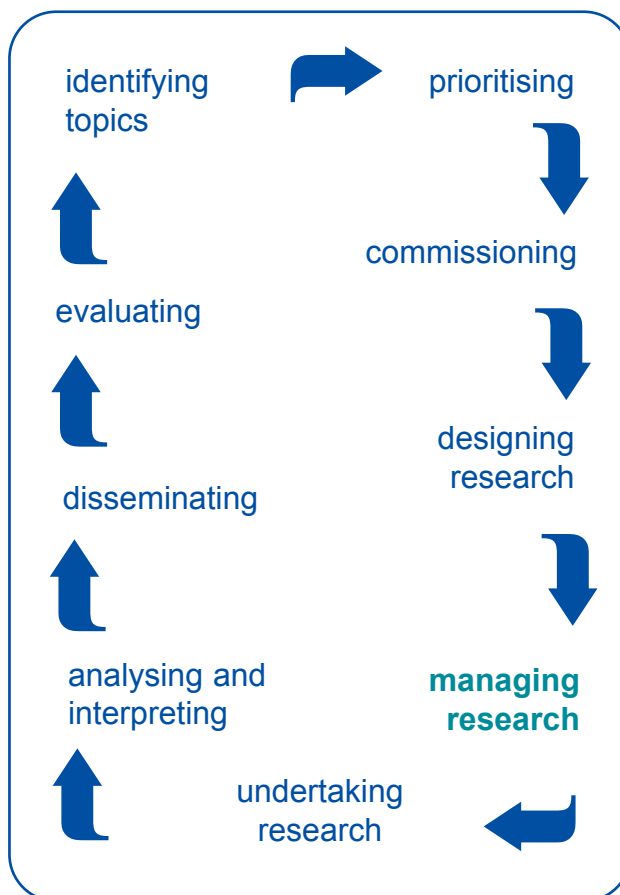
See our general comments on consultation on page 8 if you plan to consult people about the management of a research project.

### People who use services collaborate with researchers to manage research

This kind of involvement is usually undertaken through a committee or steering group. See our guidelines on involving people who use services in committees on page 39.

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 up to.

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.

There are now many examples of people who use services sitting on research steering groups and management committees with a range of results. For example, members of the National Cancer Research Network Consumer Liason Group, which is led by cancer patients, sit on a wide range of cancer

drug trial steering committees.<sup>35</sup> Often the involvement of people who use services has led to better communication between professionals from different disciplines, because the language used has been that of plain English rather than that of the specialist.

### Example

A research project to identify the needs and unmet needs of disabled children, and to identify experiences of service provision for disabled children and their families, included users of a Family Resource Centre in Liverpool on a management group. The group monitored the direction of the research, and users of the service contributed to developing a relevant research methodology.<sup>36</sup>

### People who use services manage the research for themselves

See our section on page 10 about user-controlled research.

### Example

Torrige Special Friends are a small charitable organisation formed of parents and carers of children with profound disabilities. During 1998 they carried out research on the educational, health and social care needs for families with children with profound disabilities. This study of views and experiences gathered evidence that would be needed to help the group approach service providers regarding meeting unmet needs. Members of the group who were parents and carers managed the research. One of the group received training at the School of Social Entrepreneurs and the University of Nottingham. These skills were shared with the group, enabling them to manage and carry out the research in a way that would provide evidence of need.

The research was presented to Heads of Education, Health and Social Services Child Policy Officers, and the findings were circulated to district social services managers, as well as other parents and carers. The ability of parents to organise themselves to produce evidence and work with service providers contributed to a culture of parent-carer participation in other areas of development. By 2001 this had led to parent-carer consultation forums being established.<sup>37</sup>



## 3.7 Involving the public in **undertaking** research

### Options for public involvement:

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

### People who use services are consulted about the research process

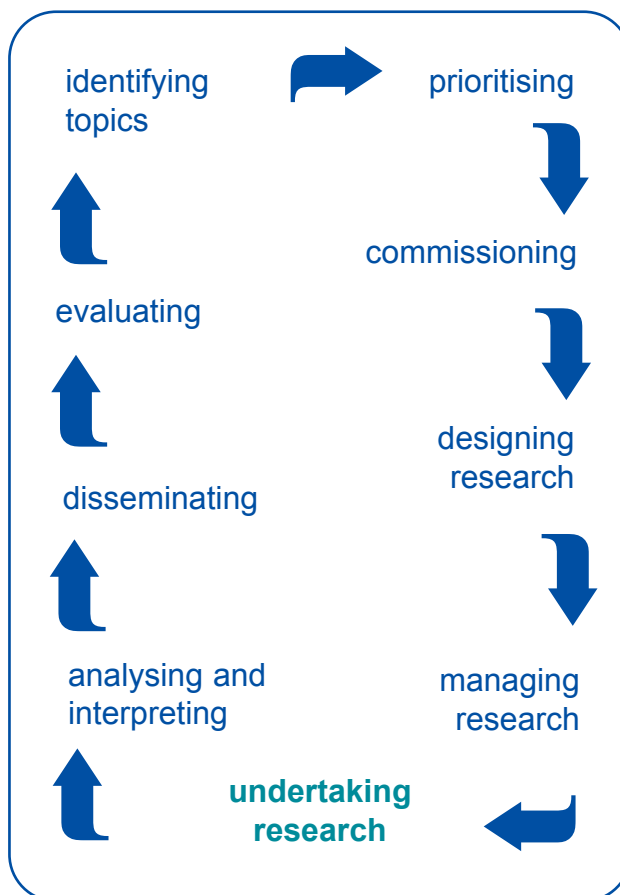
Meetings may be used during the research process to let people who use services know that the research is being undertaken and what it is about. This is particularly important if the topic is a sensitive one.

As well as informing people who use services about the research, meetings can also help with response rates to questionnaires and make the first contact if interviews are to be carried out. 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.

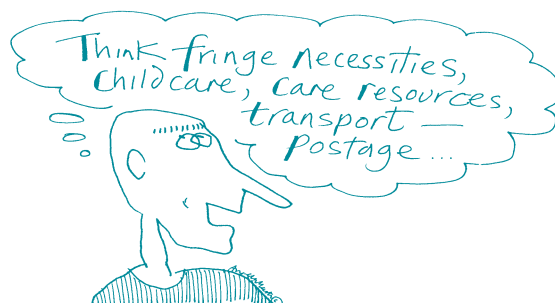
### People who use services collaborate with researchers to carry out research

Members of the public and their organisations have access to a range of networks. They should therefore be able to help you to access particular communities, help with consent, gather data, and so on. If you are collaborating with people to undertake research, ensure that you:

- Are clear about the role you are asking people to undertake - a job description is helpful here (see Appendix 1).



- Are as explicit as possible about the research. Ensure that the research questions and the research method are clear.
- Offer training to people who use services in the research methods you are adopting, if they do not have experience in this area.
- Offer payment to people who use services for their expertise. Some people may be happy to volunteer 'free' time, but this should not be assumed. This can apply to any stage of the research process. (See 'A Guide to Paying Members of the Public Actively Involved in Research' Appendix 5).





### **Example**

In July 2001, an evaluation of service users' perspectives of the ECT service at Fieldhead Hospital, Wakefield, was commissioned. This involved interviewing patients some time after they had undergone a course of ECT. The focus of the evaluation was on the quality of the service and was not intended to replicate other research by asking for people's views on ECT treatment.

Representatives of the Service User Forum were involved on the Project Board from the outset. However, the Board were initially uncertain whether service user representatives should be involved in the Project Team that would carry out the interviews. It was felt that ECT was an emotive subject and the possibility of introducing bias into the study would be increased. The issue was revisited and a decision was taken to interview in pairs, with one member of the pair being a research assistant and the other a service user representative. The service user representatives were volunteers and were recruited from the Service User Forum and the Trust service user and carer research group, Direct Impact.<sup>38</sup>

### **People who use services carry out the research themselves**

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.

### **Example**

A service user is running a research project funded by the former London NHS region to find out from 16-21 year olds of many backgrounds why they go or do not go to primary care if they have mental health problems. The project also involves them in developing youth friendly standards for primary care. The service user is carrying out interviews and running groups, and they are being co-supervised by the Service User Research Enterprise (SURE).<sup>39</sup>

### **Example**

The Black Community Safety Project, a non-governmental organisation, wanted to undertake a community safety review in a neighbourhood of Leicester. The object was to identify safety issues for ethnic minority residents and make recommendations for action. They obtained local funding, and recruited and supported 10 local people as researchers. They were trained with the input of the Centre for Social Action at DeMontfort University.

The local researchers interviewed and collected the views both of individuals and from five major ethnic minority groups in the area. As well as collecting information about crime, people were asked to suggest solutions to the many issues faced in the community.<sup>40</sup>

## 3.8 Involving the public in analysing and interpreting the results of research

### Options for public involvement:

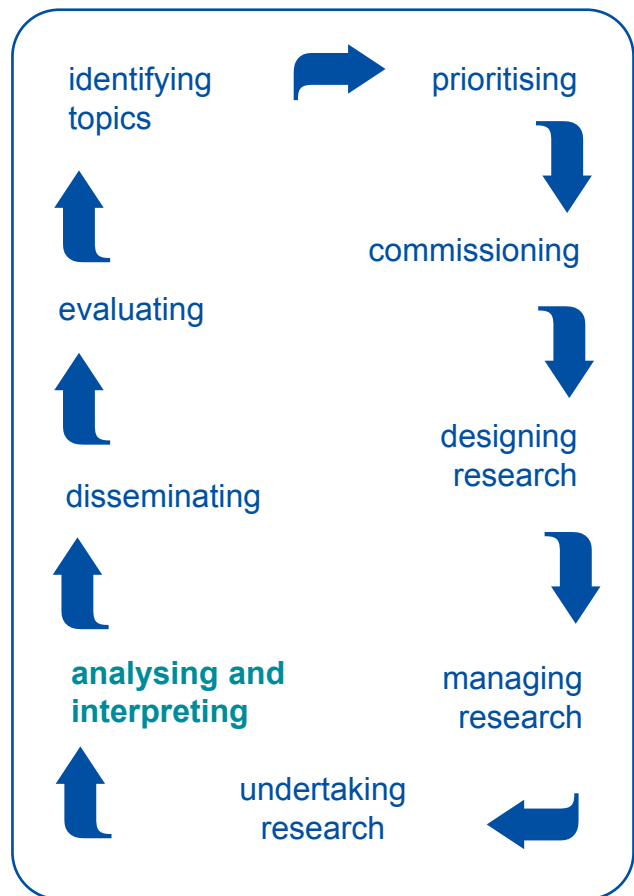
- People who use services are consulted about the analysis and interpretation of research results
- They collaborate with researchers to analyse and interpret the results of research
- They analyse and interpret the results of research themselves

### People who use services are consulted about the analysis and interpretation of research results

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 to be produced.

### People who use services collaborate with researchers to analyse and interpret the results of research

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 analyse and interpret the results of research

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.

### Example

An action research project involved refugees and asylum seekers in exploring their service needs. Also involved were local Salford people, and practitioners from local community services. This ongoing project could not have existed without the involvement of people who are refugees and asylum seekers. They shape the project through analysing results and identifying options for further action.<sup>41</sup>

### 3.9 Involving the public in disseminating the results of research

People who use services are most likely to want to see research being 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.

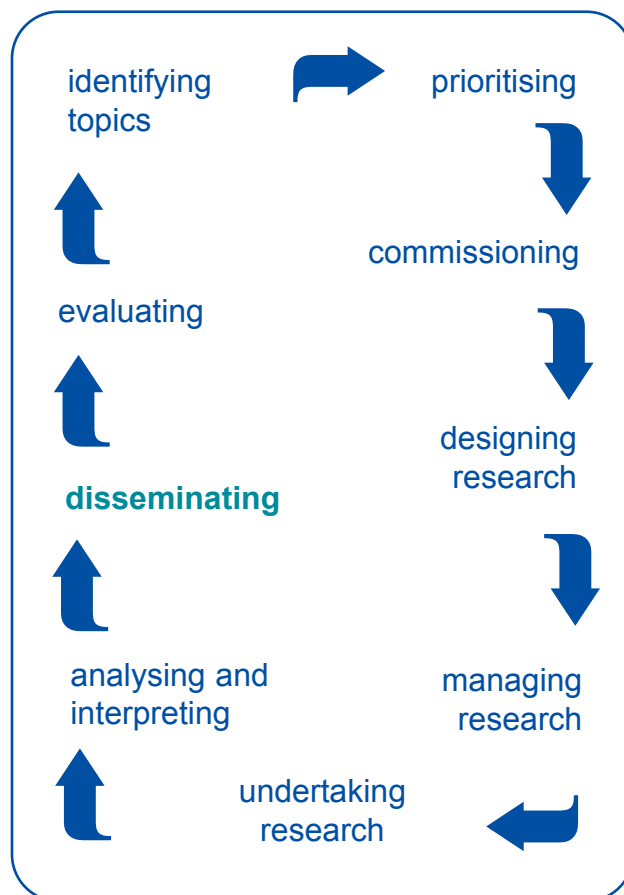
You can involve people who use services in reviewing draft research reports. This is particularly helpful if you want to produce a report that is accessible - people who use services are very good at identifying jargon. If you involve people in this way, see page 25 on people who use services collaborating with research funders to commission research. Involving the public in dissemination can also lead to other developments, such as producing guidelines for future practice.

#### Options for public involvement:

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

#### People who use services are consulted about disseminating the results of research

It is often useful to consult with people who use services about how they think the results of the research should be disseminated. They



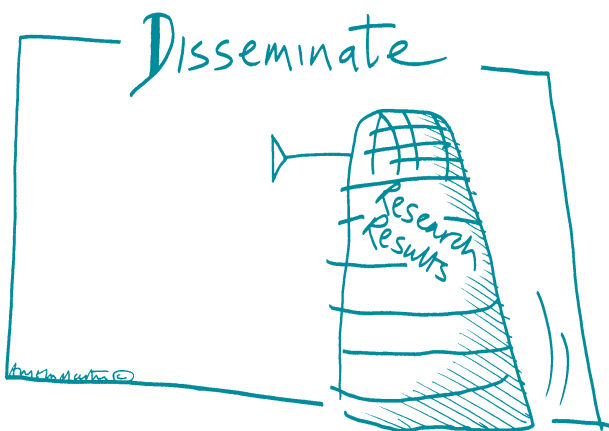
may have views about how best to reach other people and may be able to suggest other networks and publications that could be used to disseminate results. People who use services often have their own informal networks. Consultation about the results of the research is also likely to lead to informal dissemination.

#### People who use services collaborate with researchers to disseminate the results of research

It is worth producing brief progress reports or newsletters to keep people who use services informed of progress throughout a research project, rather than waiting to the end to produce a report for dissemination. You should always ensure you feed back the results of research to research participants. Report positive and negative results, not just the ones you think people (or funding organisations) will want to hear.

It is important to tell everyone involved in a research project about the results before you publish anything in the media. There is nothing more likely to alienate members of the public who have been actively involved in the research than reading about the results of your project in a newspaper or journal before knowing about it first hand. This is vital if the results of the research have direct implications for the health of participants or their families.

Members of the public may also be involved in dissemination by producing research summaries in user-friendly language for circulation to other people and those in the NHS.



### **People who use services disseminate the results of research**

People who use services can disseminate the results of research by producing articles in their newsletters and talking about the research at their meetings and conferences. (Training in making presentations may be helpful). For example, The Multiple Sclerosis Society produces summaries of research in a newsletter that is distributed to people affected by MS.

Listening to the way that people who use services report research findings and their

experience of being involved in the research process can help you summarise results in user-friendly language.

You should ensure you fund photocopying, postage and other costs if you are asking organisations that represent people who use services to disseminate the results of research.

### **Example**

In a study led by Pesticide Action Network UK, researchers assessed the degree of similarity in patterns of ill health and exposure of people to pesticides who contacted four support organisations. The study was a two-year epidemiological survey which involved 450 telephone interviews. It was a collaboration between the London School of Hygiene and Tropical Medicine, the Institute of Occupational Medicine, Edinburgh, and Imperial College. An advisory group was established for the project which included three people affected by organophosphates, and three support group organisers.

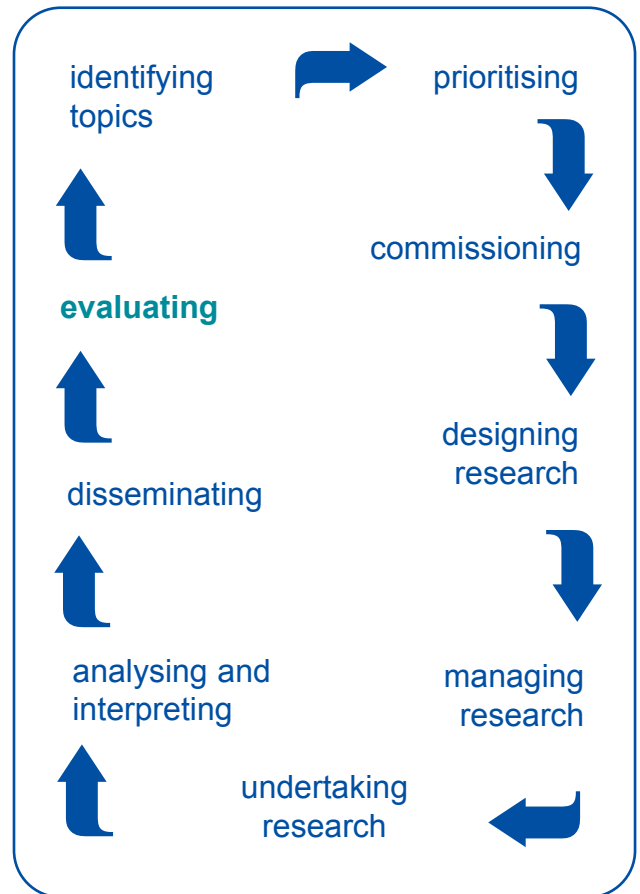
The research would not have happened if concerned individuals had not campaigned for years. They also highlighted how they felt that the involvement of special interest groups and individuals improved the quality of the research. They felt that their early and practical involvement was important in influencing the research questions. There was consumer involvement throughout the project, including the drafting of questionnaires. The organisation was then able to disseminate the work through its campaigns, publicity and events.<sup>42</sup>

### 3.10 Involving the public in evaluating 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 play 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.



The involvement of people who use services in evaluation can result in the identification of new research topics, thus completing the cycle of research and development. Consideration should be given to including this sort of evaluation in research reports.

#### Options for public involvement:

- People who use services are consulted about evaluating the research process
- They collaborate with researchers to evaluate the research process
- They evaluate the research process

#### People who use services are consulted about evaluating the research process

It may be useful to consult with members of the public who have been involved in the research when undertaking an evaluation, particularly where considering how the process of involving people worked. People

who use the services or technologies addressed in the research may have very different insights about the process of involvement and how they experienced it. It is useful to include their perspectives in an evaluation of the research.

### **People who use services collaborate with researchers to evaluate the research process**

People who use services may be involved in undertaking the evaluation. They may complete evaluation forms or rate their own skills before and after the research, in order to ascertain the ways in which they think being involved in the research process has affected them. Alternatively, they may meet with researchers to evaluate the research process on a more informal basis.

#### **Example**

INVOLVE has commissioned an evaluation of eleven London based primary care research projects which are actively involving people who use health services. The evaluation will be an opportunity for both professionals and service users alike to reflect on and evaluate their involvement, and where the process has taken them.<sup>43</sup>



#### **Example**

A research project funded by the Royal College of Nursing Institute is exploring the nature of research being conducted by mental health nurses and mental health service users and is investigating the type of involvement taking place. The lead researcher and a service user/researcher have also taken the opportunity to reflect on the process of their own collaboration, as part of the project.<sup>44</sup>

### **People who use services evaluate the research process**

People who use services may also evaluate research themselves. This may take the form of commenting on the research before or after it has been published.

#### **Example**

The PRP has funded a group of researchers with learning disabilities to design and undertake an evaluation of the quality of user involvement in a number of research studies. In addition to data collection, the group will analyse and interpret the data and design and implement a dissemination strategy. While support will be provided with training and various organisational arrangements (e.g. travel, accommodation, finance) as required, the project will be entirely self-managed by the group.<sup>45</sup>

# SECTION 4: Checklists

## 4.1 Involving members of the public in committees and working groups: a checklist

### Who to involve:

- Involve at least two people who have experience of using services - this helps to avoid tokenism and means that people can offer each other support and encouragement.
- Find people who are either used to working on committees or interested in being trained, mentored, or supported to participate, perhaps by people from their user organisation.
- Consult with people who use services and their organisations to identify the most appropriate people to invite on to your committee. Ideally, ask user organisations to support their members to get involved.
- Ensure that the people you involve have links with networks of people who use similar services, so they can consult with others and get support and encouragement when they need it.
- Don't expect a health or social care professional to sit on a research committee with a former or current patient or service user they have cared for or are currently caring for - it is likely to be unfair to both.

### When you approach members of the public...

- Be clear about the task - this will enable people to make an informed choice about whether they want to participate.



- Be clear about the basis for people's involvement on a committee - are you looking for a personal perspective, or will you be asking people to consult with their peers or organisations to offer a 'broader' view?
- Be clear about the committee's remit and what is likely to be achieved - don't raise inappropriately high expectations.
- Ensure you offer new people some form of induction and training.

### Offer resources and support:

- Think about being as inclusive as possible so that a wide range of people who use services have the opportunity to participate fully. To do this, be prepared to change the way you do things so as to make your research work more accessible in general. This is better than giving individuals 'special treatment' where they are likely to meet a specific access problem. For example, a wheelchair user should expect that the building you are using for a meeting has full wheelchair access.

- ❑ Think about emotional support for people who use services, where appropriate. For example, if you are involving people with cancer in prioritising research topics related to cancer services, this is likely to have more emotional impact on them than on other people on the research committee.
- ❑ Think about ongoing support for people who use services on committees, perhaps through a system of mentorship.
- ❑ Ensure you can pay travel and personal assistant or carer replacement costs, and make it clear in advance to the people involved how you are going to do this. If other people who use services are paid through their own or your organisation to be involved in the research process, ensure you offer to pay people for their time too.
- ❑ Ensure that people who use services have access to information resources. Give contact numbers for information services and ensure that consumer representatives have access to health care libraries and borrower entitlement.

### Before the first meeting:

- ❑ Give people sufficient background information in user-friendly language without overburdening them.
- ❑ Invite consumer contributions for the agenda before the meeting.
- ❑ Learn from the experience of other committees that have included members of the public - for example the Maternity Services Liaison Committee.
- ❑ Provide training (for members of the public and for other committee members) if necessary.

### Access:

- ❑ Schedule meetings at times and in places which are convenient to people who use services.
- ❑ Meeting places should be accessible to all participants - so, for example, if you are inviting a wheelchair user to join your committee, ensure that you meet in an accessible meeting room with parking near by, and that there is an accessible loo.
- ❑ Consider having meetings at venues where invited groups are based, not just where researchers are based.
- ❑ Think about whether you will need to use interpreters for people from different ethnic groups, bearing in mind that written material for meetings will also need to be translated. Also consider whether you will need someone to translate into sign language.
- ❑ Ensure people who use services can park if they are driving or that the venue is on a public transport route.
- ❑ If the meeting is to be mainly made up of professionals, consider a pre-meeting for people who use services about the agenda, notes, minutes etc.

### During the meeting:

- ❑ Before starting, agree 'groundrules' for how you will conduct meetings. Everyone should have the opportunity to contribute their ideas on what the groundrules should be.
- ❑ Avoid jargon in written information and in discussion. If you must use jargon, produce a glossary or spend time briefing people who use services before a committee meeting.



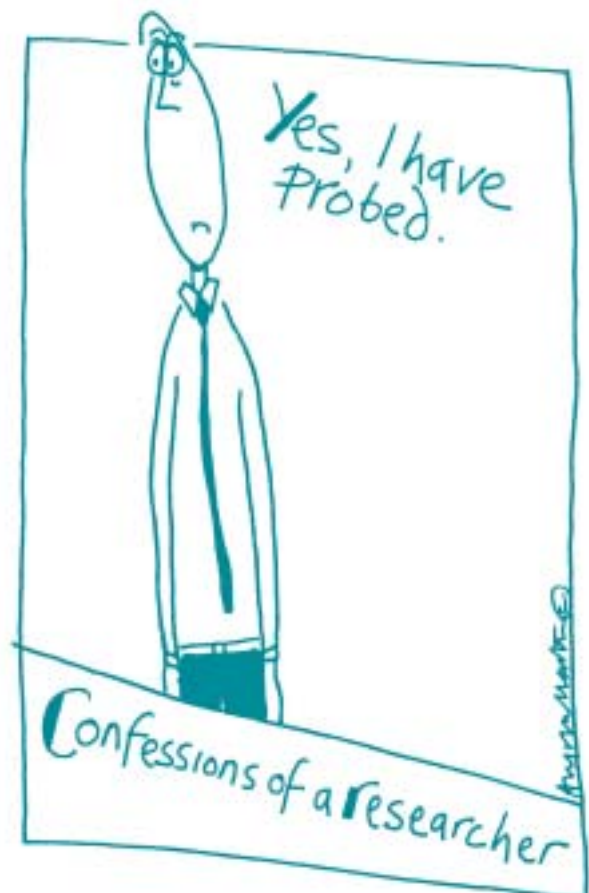


- ❑ The role of the chair is crucial. Ensure she/he supports the involvement of people who use services in the committee and makes efforts to include them during meetings.
- ❑ Particular attention is needed to involve those who do not use speech as a primary form of communication.
- ❑ Consider using an independent facilitator.
- ❑ Think about different formats for meetings - perhaps work in small groups, have sub-group meetings, have time at the end of the meeting when you review how the meeting has gone.
- ❑ Drinks should be made available because people who use services may need to take medication during meetings, or the medication they take may make them thirsty. Ideally another room should be available for people to use if they need to during meetings.
- ❑ Ensure that professionals turn up to the meeting if they have been invited. A telephone reminder is often useful.
- ❑ Plan for 'comfort' breaks i.e. for visiting the toilet, clearing heads and even to smoke outside.

### After the meeting:

- ❑ If you agree recommendations that involve people who use services, make sure you implement them.

- ❑ Provide feedback on outcomes of the committee's work, even if no actions are taken.
- ❑ Allow sufficient time between meetings for people who use services to consult with their peers or their organisations, if they wish to do this.
- ❑ Seek feedback from members of the public about their experience of involvement in the committee - ask how things could be improved.
- ❑ Thank people for their time and allow space for closure - don't just disappear.



## 4.2 Budgeting for public involvement in R&D: a checklist

Before you involve people who use services in R&D, you'll need to think about budgeting for their involvement. The following list provides suggestions of the types of expenses you may need to think about. The extent and type of public involvement in your research will dictate which of these you may need to cover:

- Travel expenses
- Hotel accommodation costs
- Subsistence or meal allowances
- Childcare and replacement carer costs
- Cost of personal assistant(s) (PA's) of the service users' choice
- Hire of accessible venues
- Refreshment costs
- Translation and interpreting costs
- Payment of an independent facilitator
- Postage, photocopying and telephone costs
- Payment towards administrative support
- Payment for involvement - particularly if other members of the research team are being paid for their involvement, even if not by your organisation. If you do not pay a fee, think about budgeting for loss of earnings.

For more details about issues relating to expenses and paying people, see the INVOLVE publication: 'A Guide to Paying Members of the Public Actively Involved in Research.' (See Appendix 4), and the Mental Health Foundation publication 'A

Fair Day's Pay: A Guide to Benefits, service user involvement and payments.' (Scott). (See Appendix 4).



# APPENDIX 1: Ideas and drafts for job descriptions

The following are examples of 'job descriptions' for people who use services getting involved in research. Each was written for a slightly different purpose. They are presented here with the permission of the authors to give you some ideas about how to form a job description or person specification for your own project. However, we recommend you think through the issues already raised in this booklet before proceeding.

1. Job description:  
Consumer/Patient Representative on the R&D Committee  
Queen Victoria Hospital NHS Trust
2. Selection Criteria:  
Consumer panel members  
North Trent Cancer Network
3. Job description:  
Consumer panel member  
North Trent Cancer Network
4. Person specification/job description:  
(User) researchers  
Child Care Research Project  
Centre for Social Action, DeMontfort University
5. Person specification/job description  
Consumer panel member  
National Coordinating Centre for Health Technology Assessment (NCCHTA)

# 1. Job description: Consumer/Patient Representative on the R&D Committee Queen Victoria Hospital NHS Trust

1. Report to the chairman of the R&D committee
2. Attend R&D committee meetings in order to:
  - a) Help in the preparation of patient information leaflets so the patient is fully aware of:
    - What the research would involve
    - The purpose and value of the research
    - How long it would take
    - The valuable role they would play
  - b) Help to clarify wording of consent forms.
  - c) Try to identify areas where patients may feel under pressure.
3. Keep informed of how consumers are being involved in research in other Trusts.
4.
  - a) Being accessible through hospital channels as a lay contact for patients involved in research.
  - b) Attending occasionally specialist patient consumer groups as a lay contact.Through both of these feeding back any comments and ideas the patient may wish to bring to the notice of the R&D Committee.
5. To maintain confidentiality of all information obtained

## 2. Selection criteria: Consumer Panel Members North Trent Cancer Network

All candidates for the Consumer Panel will be required to attend a two-day training course at the Trent Palliative Care Centre. The course will give the candidate a firm grounding in the organisation and structure of the various research strategy groups within the North Trent Cancer Network, as well as providing them with the necessary basic knowledge to be able to understand research projects and protocols. All panel members will have to have successfully completed the course, however, it must be made clear that completion of the training course alone will not guarantee a candidate membership on the panel.

Members making up the final panel will be selected using the following post-training criteria:

- Must possess all of the essential attributes as described in the job description (see table overleaf)
- Should be able to demonstrate at least one of the desirable attributes as described in the job description (see table overleaf)
- Be able to bring with them 'life' skills/talents that could broaden the experience base of the panel

Those who are unsuccessful will be informed by letter explaining why they have not been successful and offering them the opportunity to discuss further opportunities for involvement in research with staff at the Academic Palliative Medicine Unit.

### **Panel Member Attributes from Job Description**

See table overleaf.

## Panel Member Attributes from Job Description

Factor	Essential attributes	Desirable attributes
Qualifications	<ul style="list-style-type: none"> <li>• None</li> </ul>	
Experience	<ul style="list-style-type: none"> <li>• None</li> </ul>	<ul style="list-style-type: none"> <li>• Committee experience</li> <li>• Links with consumer networks, associations, society</li> </ul>
Special Skills	<ul style="list-style-type: none"> <li>• Willingness to familiarise your self with medical and research language</li> </ul>	<ul style="list-style-type: none"> <li>• To keep up to date with current research issues</li> </ul>
Specialist knowledge	<ul style="list-style-type: none"> <li>• Knowledge of consumer perspectives</li> </ul>	<ul style="list-style-type: none"> <li>• To have an understanding of research</li> </ul>
Personal qualities	<ul style="list-style-type: none"> <li>• Good communicator</li> <li>• Ability to listen to others and express own views about consumer concerns in discussions</li> </ul>	<ul style="list-style-type: none"> <li>• Self confidence in a mixed group of professionals and consumer advocates</li> <li>• Able to respond to challenging tasks</li> <li>• Experience of receiving fairly complex agenda papers and preparing for meetings</li> </ul>

### 3. Job description: Consumer Panel Member North Trent Cancer Network

<b>Post</b>	<b>Consumer Panel for Research Member</b>
Duration	The usual term of office is 3 years
Payment	<ul style="list-style-type: none"> <li>• Payment will be made for attendance at meetings based on £5 per meeting or £15 per day</li> <li>• Travel expenses and other out of pocket expenses will also be covered</li> </ul>

#### **Background**

A consumer is someone who uses a service. The service is in this case the NHS and its consumers are patients (or potential patients), carers, long term users of services, organisations that represent these people's interests, and other groups affected by the service they receive from the NHS. They come from all sections of the population.

Among many health care professionals working within North Trent there is a growing recognition of the value of consumer involvement within the area of cancer care. Furthermore, there is increasing awareness of the obligation for research studies to include input from consumers at all stages. It has been stated that consumer involvement should not be seen as a parallel development to the Cancer Networks but be fully integrated into structures at the national, regional and local levels.

Involving consumers in research can result in a number of key benefits - improving the quality, choice and relevance of services and technologies available.

However, obtaining input from consumers can be a problematic and time-consuming process. There are issues such as recruitment, representativeness, expertise, training and continuity of input that need to be addressed. Researchers may not have the time, expertise or contacts to give these important factors their full attention. Involving consumers in the past has been on an ad hoc basis that has meant that the consumer's role has inevitably been diluted.

In order to try to overcome these difficulties we have established a Consumer Panel for Research. The Panel consists of people who have experience of cancer as patients or carers, and who are interested in research.

## Principal responsibilities

### 1. To attend the training programme for members

This is a two-day course held in Sheffield. It will help prepare you for your work as a Panel member.

### 2. To attend a number of Panel meetings a year

Three Panel meetings are held every year. These are in addition to the individual project meetings you may attend. They are an opportunity to meet your fellow Panel members and update yourself with current developments. We understand that sometimes people may be unable to attend all these meetings.

### 3. To deal with the associated paperwork of the Panel

You may be required to read certain paperwork before meetings.

### 4. At project meetings

You will be required to contribute to the discussion to ensure that consumer priorities, rather than individual priorities, are reflected, and to ensure that the final decisions take into account issues of concern to consumers overall.

### 5. To have a mentor (if required)

All new Panel members will be offered a mentor, who may be either a member of staff or an experienced member. Experienced consumer Panel members may be asked to act as a mentor in the future.

What you can expect from your mentor:

- To be welcomed at the first meeting
- To have any questions personally answered in confidence at the Panel or project meeting
- To be able to contact your mentor by telephone before and after each Panel or project meeting

### 6. Conflict of interests

Panel members are requested to declare any conflict of interest. For example, a study may be being discussed where a member of the research team may be a consultant personally known to you.



## 4. Person specification/job description: (User) Researchers Child Care Research Project Centre for Social Action, DeMontfort University

### **(User) Researchers person specification:**

- Must be able to work as part of a team
- Have a friendly and approachable manner
- Be able to encourage people to voice their views and opinion
- Be a good listener
- Enthusiastic and willing to learn new skills
- Be able to work on own initiative
- Reasonable level of literacy
- Experience of childcare through being a parent, or a childcare worker including babysitting and looking after family members
- Be able to work with groups of parents and children
- Reliable and trustworthy
- Satisfactory police check

### **(User) Researchers job description:**

- Attend the training and support sessions
- Arrange own interviews with groups, organisations and individuals as agreed
- Use agreed format for facilitating group and individual conversations with parents and or children
- Produce adequate written records of all discussions and interviews
- Be responsible to Project Co-ordinator and Research Advisor.

### **Topics covered in training include:**

- purpose of research
- qualities needed to be good information gatherers
- confidentiality
- appearance and reliability
- safety
- child protection
- asking questions, listening skills, probing and getting deeper answers
- interviewing children
- group interviews
- recording
- issues to be covered - what do we want to find out?
- who to ask
- where are good places to meet parents, young people and children?
- role-play

## 5. Person specification/job description: Consumer Panel Member National Coordinating Centre for Health Technology Assessment (NCCHTA)

### Job description - Consumer panel member

Post	Consumer panel member
Duration	The usual term of office is 4 years (but a new consumer panel member may use their first panel meeting as an opportunity to decide whether they wish to commit themselves to the full 4-year term of office)
Payment	Members are entitled to receive a committee fee so long as they are not in receipt of a full time salary from public funds during the period of their claim. If the member wishes their committee fee can be paid to their employing organisation. A daily rate of £111.18 is paid, or a higher rate of £138.71 if preparation work is required for the meeting. The fee will be liable to income tax and National Insurance contributions, deducted either by the DH (if payment is made to an individual) or by the employing organisation.

### Background

The Health Technology Assessment programme is the largest single programme within the NHS Research and Development strategy and aims to reduce uncertainty about the effectiveness and cost-effectiveness of interventions used in the NHS. The Director of the HTA programme is advised by a number of advisory panels. The role of the panels is to help decide which of the many suggestions received by the programme is prioritised for commissioning.

A consumer is someone who uses a service. The service, in this case, is the NHS and its consumers are patients (or potential patients), carers, long term users of services, organisations that represent these people's interests, and other groups affected by the service they receive from the NHS. They come from all sections of the population.

The HTA has been at the forefront of developing consumer involvement in NHS research. In June 1999 a strategy was agreed for integrating consumer perspectives into the HTA programme. The strategy states that each panel will have two consumer members. The consumer members

are required to take a broad view of a variety of topic areas and research methods and have the confidence and experience to take an active part in the panel meetings. We are looking for people who are not representative of consumers but powerful individuals who can give a generic voice to the views of consumers and be well informed by them. The main duties will involve having the time and confidence to read suggested research topics and briefing papers (vignettes) and being prepared to reflect the views of consumers at the panel meetings without representing a particular constituent group above others.

## **Principal Responsibilities**

### **1. To attend two or three panel meetings a year**

Meetings are held in London and last most of the day.

### **2. To deal with the associated paper work of the panel**

To read suggested research topics and review vignettes before the meetings.

### **3. At the panel meetings**

At the panel meetings to take notes during the discussions of preferences to prepare for voting during the meeting. Also to contribute to the discussion to ensure that the priorities reflect consumer priorities and to ensure that the final questions reflect issues of concern to consumers.

### **4. To have a mentor(if required)**

A mentor system for new consumer panel members was set up in December 1998. All new consumer panel members will be offered a mentor. Experienced consumer panel members may be asked to act as a mentor in the future.

The guidelines for consumers as to what to expect from their mentor:

- to be able to contact their mentor by telephone before and after each panel meeting
- to be welcomed at the first panel meeting
- to have questions answered at the panel meeting.

### **5. Conflicts of interest – declaration**

At the start of discussion of a vignette, panel members are requested to declare whether they could be in a position to benefit as potential applicants were the topic to be taken forward as a priority for commissioning.

## **Person specification - Consumer panel member**

See table overleaf.

## Person specification - Consumer panel member

Factor	Essential attributes	Desirable attributes
Qualifications	<ul style="list-style-type: none"> <li>• None</li> </ul>	
Experience	<ul style="list-style-type: none"> <li>• Committee experience</li> </ul>	<ul style="list-style-type: none"> <li>• Having good links through consumer networks/associations/society</li> </ul>
Special Skills	<ul style="list-style-type: none"> <li>• Willingness to familiarise your self with medical and research language</li> </ul>	<ul style="list-style-type: none"> <li>• To keep up to date with current consumer issues via consumer networks/media</li> </ul>
Specialist knowledge	<ul style="list-style-type: none"> <li>• Understanding of what having a consumer perspective means</li> </ul>	<ul style="list-style-type: none"> <li>• To have an understanding of research</li> </ul>
Personal qualities	<ul style="list-style-type: none"> <li>• Good communicator</li> <li>• Ability to listen to others and express own views in discussion</li> </ul>	<ul style="list-style-type: none"> <li>• Self confidence in a mixed group of professionals and consumer advocates</li> <li>• Able to respond to challenging tasks</li> <li>• Willingness to give feedback to the NCCHTA and help develop this area of work</li> <li>• Experience of receiving fairly complex agenda papers and preparing for meetings</li> </ul>

## APPENDIX 2: Training

At the time of writing this second edition, the number of training initiatives in the country connected to involving the public in research have been gradually increasing. These seem to be mostly local, project-led or specific to a particular circumstance or condition being researched.

Training and support enables you to involve people who have experience at the receiving end of services and initiatives, but who have not necessarily had previous experience of being involved in research. The perspectives of such people will be an important and fresh contribution to your project.

INVOLVE has commissioned some research into training for people who use services who are, or who wish to be involved in research.<sup>46</sup> This will map the training currently available and make recommendations about what training works and can be considered good practice. A report will be available early in 2004. Please contact INVOLVE if you would like a copy.



## APPENDIX 3: Text notes

1. The PRP is funded by the Department of Health and commissions research in both social care and public health areas. INVOLVE has widened its remit to cover research commissioned by the PRP as well as continuing involvement with research commissioned by the NHS.
2. This definition is taken from the draft strategic framework for the use of the NHS R&D Levy. NHS Executive (1999).
3. Originally the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme.
4. Dieppe P. (2000) **'Relation between agendas of the research community and the research consumer'** Lancet: 355:2037.
5. Epstein S. (1996) **'Impure Science'** Berkeley: University of California Press.
6. Hunt J. (2002) **'How cancer service users can influence research and practice'** Nursing Times Vol 98 Issue 33 p32.
7. For more information see the Shaping Our Lives website: [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)
8. The Social Policy Research Unit at York has recently produced an Outcomes Resource Pack, designed to encourage a user-focused outcome approach in social care practice: Nicholas E, Quershi H, and Bamford C. (2003) **'Outcomes into Practice: A Resource Pack'** Social Policy Research Unit: University of York
9. See the Maternity Alliance website at: [www.maternityalliance.org.uk](http://www.maternityalliance.org.uk)
10. Katbamna S. (1997) **'Experiences and Needs of Carers from South Asian Communities'** Nuffield Community Care Studies Group, University of Leicester.
11. Cooke J. (1998) M.A. dissertation: **'A study to investigate patient satisfaction in relation to how the diagnosis of cancer is given'** Dept. of Sociological Studies, University of Sheffield.
12. Rose D. (2001) **'Users' Voices'** Sainsbury Centre for Mental Health.
13. All Department of Health policy documents.
14. Department of Health (2001) **'Research Governance Framework for Health and Social Care'**
15. Koops L, Lindlay R. (2002) **'Thrombolysis for acute ischaemic stroke: consumer involvement in design of new randomised controlled trial'** BMJ 2002;325:415 (24 August).
16. Clement S, Reed B, Sandall J, Wilson J, Free C, Oxenham J. (2000) **'A study to identify the research priorities of community midwives: Final Report'** NHS Executive London Region, Primary

Care Programme.

**17.** MRC Review of Autism Research: Causes and Epidemiology. December 2001

**18.** 'Direct Payments' is a scheme whereby local authorities hand over funds to disabled people in order to purchase services and equipment of their own choice. This is the alternative to services being 'prescribed' by social services departments where disabled people have little control.

**19.** The full report, '**User's Best Value: A guide to good practice in user involvement in Best Value Reviews**' by Clare Evans and Angie Carmichael, is published for the Joseph Rowntree Foundation, Wiltshire & Swindon Users' Network and the University of Bath YPS (ISBN 1 84263 075 X, price £13.95) It is available from York Publishing services Ltd, 64 Hallfield Road, Layerthorpe, York, YO31 7ZQ, Tel: 01904 430033, E-mail: [orders@yps.ymn.co.uk](mailto:orders@yps.ymn.co.uk). Add £2.00 packing and postage per order.

**20.** For further information contact Sally Crowe, Project Co-ordinator, Crowe Associates, 12 Draycott Road, Southmoor Oxon. OX13 5BY. Telephone: 01865 821343 E-mail: [sally.crowe@ntlworld.com](mailto:sally.crowe@ntlworld.com)

**21.** Dr Jackie Sturt, Warwick Diabetes Care User Group, Centre for Primary Health Care Studies, University of Warwick, Coventry CV4 7AL. Telephone: 02476 573753. E-mail: [jackie.sturt@warwick.ac.uk](mailto:jackie.sturt@warwick.ac.uk)

**22.** For more information on this research and the work of the REU (formerly Race Equality Unit) contact REU, Unit 35 Kings Exchange, Tileyard Road, London N7 9AH.

**23.** <http://www.hta.nhsweb.nhs.uk/main.htm>

**24.** Video made by West of England University on behalf of the Institute of Housing, to be used as part of a training in Housing Management as an example of good practice and partnerships at the University and Institute of Housing Conference, April 2000.

- Report: Gibson G, Wayne J. '**Housing Management for Sustainable Communities**' Institute of Housing, South West.
- Basham, M. (June 2000) '**Partnerships leading to healthier living - The Watcombe Housing Project**' Journal of Community Health UK, June 2000 edition.
- Somerville M, Basham M, Foy C. et al. (2002) '**From local concern to randomised trial: the Watcombe Housing Project**' Health Expectations 2002; Vol 5; Number 2. 127-135.

**25.** Hunt et al. 2002 '**How cancer service users can influence research and practice**' Nursing Times Vol 98, No 33, August 2002.

- Stevens T, Wilde D, Hunt J, Ahmedzai S. (2002) '**Overcoming the challenges to consumer involvement in cancer research**' Health' Expectations, 6, pp.81-88.

**26.** Project ongoing to 2005. Further details from Lorna Couldrick, University of Brighton, Clinical Research Centre, School of Health Professions, Darley Road, Eastbourne, East Sussex BN20 7UR. E-mail: [couldric@dialstart.net](mailto:couldric@dialstart.net)

**27.** Rose D. '**We are SURE!**' Institute of Psychiatry/South London & Maudsley NHS Trust, R&D Update Issue 6 Nov 02. Obtainable from [www.iop.kcl.ac.uk/RandD](http://www.iop.kcl.ac.uk/RandD)

- 28.** For further information see:  
[www.qrd.alzheimers.org.uk/consumers.htm#](http://www.qrd.alzheimers.org.uk/consumers.htm#)
- 29.** Sheppard B. (1998) **'A voice for older Londoners in the GP surgery'** London Age Issue 22 (Age Concern, London). Also **'A Voice for Older Londoners in the Doctor's Surgery'** Age Concern London, (2000). ISBN 1-870-70923-3. Details of the report can be found at [www.aclondon.org.uk](http://www.aclondon.org.uk)
- 30.** Dr Kim Thomas, Clinical Trials Manager, Centre of Evidence Based Dermatology, Ward C51, South Block, Queen's Medical Centre, Nottingham NG7 2UH.
- 31.** Brown V, Sitzia J, Richardson A, Hughes J, Hannon H, Oakley C. (2001) **'The development of the Chemotherapy Symptom Assessment Scale (C-SAS): a scale for the routine clinical assessment of the symptom experiences of patients receiving cytotoxic chemotherapy'** International Journal of Nursing Studies, 38:497-510.
- 32.** Project finishes 2004. Further information from Dr Kate Williams, Trial Co-ordinator, University of Cambridge, General Practice and Primary Care Research Unit, Department of Public Health and Primary Care, Institute of Public Health, Robinson Way, Cambridge CB2 2SR. Telephone: 01223 330324.
- 33.** More information from Elizabeth Lightowler, Children and Families Research Unit, DeMontfort University, Scraftoft Campus, Leicester LE7 9SU.  
 E-mail: [elightowler@dmu.ac.uk](mailto:elightowler@dmu.ac.uk)
- 34.** Faulkner A, Layzell S. (2000) **'Strategies for Living: The Research Report'** Book, London, Mental Health Foundation, 83 Victoria Street, London SW1H 0HW.  
 Telephone: 020 7802 0300.  
 E-mail: [mhf@mhf.org.uk](mailto:mhf@mhf.org.uk)  
 Website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)
- 35.** For further information contact Tony Stevens, National Cancer Research Network Co-ordinating Centre, Arthington House, Cookridge Hospital, Hospital Lane, Leeds LS16 6QB. Telephone: 0113 392 7570.  
 E-mail: [t.stevens@cancermed.leeds.ac.uk](mailto:t.stevens@cancermed.leeds.ac.uk)
- 36.** For further information contact Professor Michael Preston-Shoot, Researcher, Liverpool John Moores University, School of Applied Social Sciences, 1 Myrtle Street, Liverpool L7 4DN. Email: [m.prestonshoot@livjm.ac.uk](mailto:m.prestonshoot@livjm.ac.uk)
- 37.** Sainsbury K. (1998) **'Researching education, health and social services needs amongst families of children with profound disabilities'** Torridge Special Friends.
- 38.** For more information, please contact Dr Virginia Minogue on 01924 327431, or Una Parker c/o Direct Impact, The PALS Office, 01924 328656.
- 39.** For more information contact Tanya Graham, Institute of Psychiatry, Primary Care Mental Health, Health Services Research, Department PO 28, De Crespigny Park, Denmark Hill, London SE5 8AF.  
 Telephone: 020 7848 0150  
 E-mail: [t.graham@iop.kcl.ac.uk](mailto:t.graham@iop.kcl.ac.uk)
- 40.** For more information contact Jennie Flemming, Consultant, Centre of Social Action, DeMontfort University, Scraftoft Campus, Scraftoft, Leicester LE7 9SU.



Telephone: 0116 257 7777.  
E-mail: [jflemming@dmu.ac.uk](mailto:jflemming@dmu.ac.uk)  
Web: [www.dmu.ac.uk/~dmucsa](http://www.dmu.ac.uk/~dmucsa)

**41.** Salford RAPAR Project: Contact Dr Rhetta Moran, Revans Institute for Action Learning Research. Tel: 0161 295 5277.  
E-mail: [rmoran@salford.ac.uk](mailto:rmoran@salford.ac.uk)

**42.** Pesticide Action Network UK, Eurolink Centre, 49 Effra Road, London SW2 1BZ.  
Tel: 020 7274 8895 Web: [www.pan-uk.org](http://www.pan-uk.org)

**43.** For further information, contact the INVOLVE Support Unit. Contact details on back cover.

**44.** Research still ongoing. For further information contact Alice Hicks or Julia Jones, Royal College of Nursing Institute, Radcliffe Infirmary, Woodstock Road, Oxford OX2 6HE. E-mail: [alice.hicks@RCN.org.uk](mailto:alice.hicks@RCN.org.uk)

**45.** More details about this work, or contact details for the learning disability research group can be obtained from Carol Lupton at the PRP. E-mail: [carol.lupton@doh.gsi.gov.uk](mailto:carol.lupton@doh.gsi.gov.uk)

**46.** Lockey R, Sitzia J, Gillingham T, Millyard J, Miller CM, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J. (2003) **'The TRUE Project: Training for consumer involvement in health and social care research: a study of training provision and participants' experiences'** Worthing: Worthing and Southlands Hospitals NHS Trust.

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Price £30 (£15 to service users and survivors) plus 10% packing and postage  
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## APPENDIX 5: About the authors

**Bec Hanley** Following work in community development and community action, Bec Hanley became the UK's first patient's advocate in an acute NHS Trust. Bec then became actively involved in leading work on the involvement of patients and service users in research and development, project managing citizens' juries in health at the King's Fund. She directed work to support Consumers in NHS Research (now INVOLVE) for five years. More recently Bec has been head of research and information for the Multiple Sclerosis Society. She now works independently, supporting further extension of public involvement in research and service development, both in the statutory and voluntary sectors.

**Jane Bradburn** is a freelance research and development consultant in user involvement who has undertaken innovative projects involving users in research, primarily cancer service users. She managed the Voices in Action Project for the College of Health and remains involved as a trainer. (Voices in Action is a 3 - year Department of Health funded project that aims to provide training and support for lay representatives in the health services). She is completing a PhD on user involvement in cancer services at the South Bank University in London. Jane chaired the Patient Empowerment sub-group of Consumers in NHS Research and is a consumer advisor to the Medical Research Council, Breast UK, and the Knowledge Management for Health Reference Group. She has published a number of articles in

consumer involvement and advocacy.

**Sarah Thomas** currently works as a senior research officer at the NSPCC and manages a programme of research on child protection. She has formally worked for the Consumers in NHS Research Support Unit, and for Portsmouth University. She has written a PhD that examines foster carers' experiences of looking after children with emotional and behavioural difficulties and has co-authored a book entitled 'State Child Care: Looking After Children?' (Jessica Kingsley, 1999). Sarah has a particular interest in user involvement in research and is a member of the Toronto Group.

**Marian Barnes** has worked in a research and development capacity on user involvement and citizen participation for over 15 years. She has been involved in co-research with older people and with carers, and is currently working with users of mental health services in this capacity. She is Director of Social Research in the Department of Social Policy and Social Work at Birmingham University and is leading on community involvement for the team undertaking national evaluation of Health Action Zones.

**Clare Evans** is a disabled person with a background in social work and education. She was a non-executive director of East Wiltshire Healthcare NHS Trust 1993 - 1997. She was the founder and first director of Wiltshire and Swindon Users Network and is currently manager of the Leonard Cheshire

Disabled Peoples Forum. She was Director of Joseph Rowntree funded user-controlled research which produced a guide to user involvement in Best Value reviews. In these posts she has led the development of models of user organisations supporting involvement, including in research. She has written several publications on user involvement.

**Heather Goodare** was treated for breast cancer in 1986/7. Formerly an academic editor, after her cancer experience she trained as a counsellor and worked with the cancer support group Crawley Cancer Contact. From 1995 to 1999 she represented patients on the Editorial Board of the British Medical Journal and from 1997 to 2003 was a member of the Advisory Committee of the Cochrane Cancer Network. She chairs the consumer advocacy group BREAST UK. She has contributed to medical and psychosocial journals and books, translated *An Introduction to Psycho-Oncology* by Patrice Guex, and edited *Fighting Spirit: the stories of women in the Bristol breast cancer survey* (Scarlet Press 1996). At the time of going to press she is involved in user-led research on improving cancer care in the Crawley area.

**Marcia Kelson** is a Senior Research Fellow at the College of Health, a national charity that aims to promote patient interests in the NHS. Marcia has a national reputation for her work promoting patient, carer and public involvement in the NHS. She is the author of numerous policy and practical guidance documents, many of which have been widely circulated and influenced practice throughout the NHS. She is currently collaborating with the National Institute of Clinical Excellence (NICE) to promote effective user and carer

involvement in the development of clinical guidelines.

**Alastair Kent** is the Director of the Genetic Interest Group (GIG) - the UK alliance of charities and support groups for people affected by genetic disorders. GIG's mission is to promote the development of the scientific understanding of genetics and the part that genetic factors play in health and disease, and to see the speedy transfer of this new knowledge into improved services and support for the treatment of currently incurable conditions. Before he joined GIG, Alastair worked for several voluntary organisations on issues concerning policy, service development and disabled people.

**Sandy Oliver** As a member of The National Childbirth Trust for nine years, Sandy brought research evidence to health service people and a consumer perspective to health services research. Eight years ago she joined the Social Science Research Unit at the Institute of Education, University of London, where she develops training and support for lay and professional users of research in Evidence-Informed Policy and Practice in Education and Health. She is currently supporting consumer involvement in the NHS Health Technology Assessment Programme and researching how people identify and prioritise research topics, and how they peer review proposals. She is an Honorary Visiting Fellow at the UK Cochrane Centre.

**Jan Wallcraft** works for the Sainsbury Centre for mental health as a senior researcher on the User Survey of the User Movement in England. She recently completed a PhD called 'Turning Towards Recovery: Mental

Health Users' Experience of Treatment in Crisis.' Previously, Jan worked at the Mental Health Foundation.

**Roger Steel** has worked for INVOLVE's Support Unit as Development Worker since December 2000. Prior to this his background was in Community Development within the voluntary sector. This included generic advocacy and work with children and families as a Family Group Conference Co-ordinator. He also worked for eight years with a national mental health organisation, chiefly in project management. As part of his work with INVOLVE he has co-authored 'Getting Involved in Research: A Guide for Consumers' (2001) and is author of 'A Guide to Paying Members of the Public Actively Involved in Research' (2003) and 'A Consultation Document on Involving Marginalised and Vulnerable Groups in Research' (2003). However, much of his capacity building work with the Unit brings him into active contact with a broad range of people who use services, their organisations, researchers and research managers.



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