

2 Public Information Pack (PIP)

How to get actively involved in NHS,
public health and social care research

Getting started



INVOLVE

Promoting public involvement in NHS,
public health and social care research

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NHS

***National Institute for
Health Research***

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Using this Public Information Pack

This booklet is one of a series of four booklets that make up the Public Information Pack. If you only have this booklet (Booklet 2) and would like the whole Pack, then please get in touch with us at **INVOLVE** (contact details are given at the end of this booklet).

As you read the different booklets, you will notice that some words or phrases are written in **pink** and others are in **blue**.

Names or words written in **blue** mean that you can find out more information by looking in **Booklet 3 – ‘Finding out more’**. For example, these could be details about books or articles, or information about an organisation or group such as the **‘Social Services Research Group’**.

Words written in **pink** mean there is a definition of what the word means to us, in **Booklet 4 – ‘Jargon Buster’**.

References

When we refer to books, reports or articles in the main text, we give the name of the main author, followed by the year when it was written. For example, **(Faulkner, Alison 2004)** refers to an article written by Alison Faulkner in 2004. Full details of the article can be found at the end of each chapter in the ‘References’ section, as well as in **Booklet 3**.



1 What is PIP?

1.1 What is this Public Information Pack?

Welcome to the **INVOLVE** Public Information Pack (PIP). This pack is for **members of the public** (for example, service users, carers, patients) who are interested in getting involved in **NHS, public health or social care research**. It is made up of four booklets that have been produced by INVOLVE, with support and advice from the public. In particular, Carey Ostrer and Jenny Walton have worked closely with us through all stages of the compilation of PIP, providing a public perspective and helping us to ensure we cover the kinds of information people need, when first getting involved in research.

The four booklets in the Information Pack are:

Booklet 1 – So what is it all about?

In this booklet, there are four chapters. This booklet, gives some background information about **research** and public involvement, and why it is important to get involved in research.

Booklet 2 – Getting started

In this Booklet there are four chapters. This booklet describes some of the different ways you can get involved in research, suggests questions to ask before deciding whether to get involved, as well as giving ideas about how to get started.

Booklet 3 – Finding out more

This booklet provides information about some of the different organisations that are involved in research which may be useful to know about. It also lists details of the articles, reports and books that we refer to in the other booklets.

Booklet 4 – Jargon Buster

Booklet 4 is a jargon buster providing a glossary of some of the words used in the other booklets. These definitions have been developed for INVOLVE by TwoCan Associates working in consultation with a panel of researchers and a panel of people who use services.

1.2 Who is the Public Information Pack for?

This pack is for **members of the public** (for example, service users or carers) who are thinking about getting actively involved in research either in partnership with researchers or by carrying out their own research. It is mainly aimed at people who have little or no experience of active **involvement in research**. For more information about what we mean by getting actively involved in research, **see Booklet 1, see Chapter 3**.

The information pack will:

- explain some of the basic ideas of public involvement in research
- help you think through what you might like to do
- help you get started.

This pack is **not**:

- an introductory guide to **research**
- about being a **participant** or research 'subject' in a research project.

If you are thinking of getting involved in research, this booklet is for you.

1.3 How you can use the Public Information Pack

You don't need to read all four booklets, but it is probably helpful if you have a copy of the whole pack, as one booklet will often refer you to information given in other booklets.

We recognise that this pack will not be accessible to everybody. If you or someone you know finds it difficult or impossible to use this pack, please contact us at **INVOLVE** and we will do our best to help.



2 Opportunities to get involved

What this chapter is about:

This chapter explains the different ways you can get involved in research, and helps you think through what might be best for you.

The key messages are:

Research activities in health and social care research are very varied.

Some research activities suit some people more than others.

It is useful to think about what sort of research activities suit you best.



2.1 So what are the opportunities?

This chapter will help you find out what you could be involved in, and what it might be like to get involved in various research activities. It aims to give you a feel for what the opportunities are, and to help you think through what you might want to do.

Chapter 4 in this booklet tells you more about the practicalities of **how** to start to get involved and where you can find out more.

There are many different ways to get involved in health and social care **research**. There are a broad range of research topics, methods, research organisations and approaches. There are likely to be more openings for active **involvement** in some kinds of research than others at the moment, but this may change. Some research, such as community-based research will probably present more opportunities for active involvement than other types of research.

Within these different types of research there are a variety of research activities. Some may be easier or more interesting than others. Which ones they are will depend on a number of factors, such as the research organisation, the research methods, and also your own particular preferences, interests and experiences as a patient, **carer**, **service user**, or **member of the public**.

Everyone will be different regarding how much time and energy they want to commit, and with what they feel comfortable. Some research organisations and projects offer a lot of support and training, while others give less, or none at all.

There are a number of ways for you to get actively involved in research without you having to travel anywhere, as you may be able to take part through writing, discussion groups or telephone conference calls.

For other pieces of work a large amount of travel may be needed as there will be regular face-to-face meetings.

Some research happens very quickly and is very short term, whereas other research may take place over a number of years.

The examples that follow should give you a taster of the potential activities available. The range of activities available is growing, so please think of this as an expanding list!

Membership of a group or committee

a) Commissioning boards and panels

You may be asked to be part of a research **commissioning board** or panel. These groups are often set up by research **commissioners** to advise them which research projects they should fund.

INVOLVE has produced a guidance document about being a member of a commissioning board, which gives you more information about what it involves. **INVOLVE (2006)**.

In my experience...

“ Commissioned by NIMHE [National Institute for Mental Health England], a team of one service user, two carers and two researchers developed the website www.csip.org.uk/ClinicalTrials. To find out what carers, service users and researchers wanted the site to cover, the team and I researched and reviewed the literature and interviewed carers, service users and researchers. We compiled information for service users and carers about taking part in a trial, information for researchers about involving service users and carers, a pilot register of public funded trials and a glossary. ”

U Hla Htay

2 Opportunities to get involved

Example

Joseph Rowntree Foundation Research Programme about Older People

The **Joseph Rowntree Foundation** funded a programme of research, which was developed by and with older people working on a steering group with officers, researchers and policy advisers, to **commission** the research. Older people were in the majority on the Steering Group. The programme examined the priorities which older people themselves defined as important for “living well in later life”.

In addition to acting as commissioners of research, older people acted as researchers, co-researchers, interviewers, reference group members (to inform project development), members of project advisory groups, peer

reviewers (to comment on and scrutinise findings and conclusions) and users of research findings.

The report states that one of the key messages from the programme of research, is that if programmes or strategies about older people do not have the fullest possible involvement of older people in their development they are unlikely to stand the test of time.

You can find a summary of the main findings from 18 completed projects, and information about the steering group, on the Joseph Rowntree Foundation website. Joseph Rowntree Foundation (2004) Findings: Older people shaping policy and practice. Reference 044. www.jrf.org.uk/knowledge/findings.



In my experience...

“ The level of participation varies from one person to the next. However the primary and essential contribution a research partner makes is simply to point out during project meetings what seems obvious but has been missed. ”

Pam Richards

b) Ethics committees

The job of an **ethics committee** is to make sure research that is carried out respects the dignity, rights, safety and well-being of the people who take part. Increasingly, ethics committee approval is needed for social care as well as health research. Ethics committee members include researchers and health and social care professionals as well as **members of the public**. Ethics committees meet regularly to decide whether or not to approve the research proposals that are submitted to them. Members of ethics committees usually serve a set term of office. You can find out more about the work of NHS ethics committees by visiting the **National Research Ethics Service (formerly the Central Office for Research Ethics Committees (COREC)** website.

c) Advisory groups and steering groups

The terms **advisory group** and **steering group** are often used interchangeably. Being part of an advisory group is a good way of having some influence over what research is done or how it is done. Many research projects have an advisory or steering group, which helps to develop, support, advise and **monitor** the project. The group sometimes includes **people who use services**, and **carers**, as well as researchers and other health and social care professionals. A steering group might only meet a couple of times a year because its role is to offer advice and help keep a research project on course. On the other hand, another steering group may be involved in more intensive work, meeting regularly to make decisions about the research.

In my experience...

“ I work with a group of other Rheumatology patients as a Research Partner at the Bristol Royal Infirmary. As such, we join research steering groups for the full term of each project and participate throughout the whole research process, often identifying other research topics or questions without even realising it.

As steering group members we contribute our own experience and personal insight. Although it can initially be daunting for those of us who have not been involved in research before, it soon becomes apparent that our perspective is valued and adds another dimension that had previously been omitted. We assist with the design and management of a project, right through to making the final results of the research known, for example via our own patient networks or at conferences and, where appropriate, help with implementation. ”

Pam Richards

2 Opportunities to get involved

Members of commissioning boards, ethics committees and steering groups, usually have to do a lot of reading in preparation for meetings. Sometimes **lay summaries** are available and there are opportunities to discuss the papers before the meeting. These activities usually require travel to attend meetings.

Commenting on or contributing to written documents

a) Research grant applications

This is a chance to get involved at an early stage in research. You could be asked to contribute your views to plans for some research, or to work with researchers to write some sections of a **research proposal**. Alternatively you may have an idea about some research that needs to be done and you could take the lead role in applying for funding. If the application receives funding, you may be interested in continuing to be involved in the research. For example, you could get involved by becoming a member of the steering group that will guide the research, or by becoming a member of the research team carrying out the research.

INVOLVE has produced a guidance document about getting involved in research grant applications, which gives you more information about what it involves – **INVOLVE (2006)**.



In my experience...

“ Our lay advisory group, which is part of a university research organisation, is composed of consumers and their carers for the diabetes condition, so our aim is to advise all researchers on every aspect of their studies from first thoughts to final dissemination and beyond. They deal with the psychological aspects of the subject. We are trained to look wider at the whole subject and not to apply it to ourselves. We are in research not reassurance. ”

Geoffrey Aitchison

“ I was part of a service user and carer group that developed a tool for looking at the quality of services in Mental Health – QUEST = Quality, User-led, Evaluating of Service, Tool. I got involved because I felt that measuring quality is a key role that users and carers can play and very empowering. Service users and carers worked together and trained in research techniques. Service users and carers set the agenda. It was a great project but at the end no commitment by services to fund the project despite a need that remains unmet, and a motivated group of people. Like all things – people thought a great idea and really good piece of work but it went down a black hole like so many service user led projects due to lack of funding. ”

Sarah Taylor

b) Peer reviewing

You might be interested in reading **research proposals** or research reports to make comments on them. This is often called **peer review**. Peer review is used to check the quality and importance of research proposals and research reports. It is also sometimes called refereeing.

Commissioners use peer review to ask people with relevant knowledge or experience to provide written opinions about research proposals to help decide whether the research should be funded. These peer reviewers can include members of the public as well as other researchers and health professionals.

Peer reviewing is also used at other times. For example, research commissioners often ask people to peer review final reports of projects and journal editors often seek peer review when articles are submitted to them for publication.

As a member of the public you will be asked to comment on the research from your personal **perspective** or the perspective of members of the public more generally. It will help to make sure that the research is more relevant and acceptable to people who should benefit from the research. You will usually carry out the peer review on your own at home (or work). However, you may be asked to peer review with other people. INVOLVE has produced a guidance document about peer reviewing research proposals, which gives you more information about what it involves – **INVOLVE (2006)**.

c) Reviewing the literature

Some research involves searching for, reading and **analysing** research and other information on a particular subject. Gathering the information together is often known as a 'literature search' and analysing it is known as a 'literature review'. This is usually done at the very beginning of a research project

to pull together what is already known about the subject being researched, or it can be a project on its own. Literature reviews involve looking at both published research, as well as research in the **grey literature**.

The **Cochrane Collaboration** carry out **systematic reviews** of health care **interventions**. The public can become involved in all stages of the review process and can receive training from Cochrane.

d) Information leaflets

You might write or help write a **patient information leaflet** to help recruit people to take part in a study. Your understanding of the issues for people with a similar experience to you can be valuable in telling them what they want to know about the research in language that they can understand. Recruiting enough people to be **participants** in research is a key part of developing good research studies. You may also be able to advise on how to successfully approach people who have had similar experiences.

e) Designing questionnaires

If you like thinking through approaches to gaining good quality information from people in a research study, you might like to be involved in designing **questionnaires**. You could help to write a questionnaire from scratch or you might be asked to comment on a draft document written by other people. This could be something that you do with other people as part of a group discussion, or you could be asked to provide written comments by post.

If you have experience of the circumstances being researched, you are more likely to know how to approach people who have had similar experiences. This should help you to word questions in a way that is more sensitive and better focused.

2 Opportunities to get involved

Example

Public and Patient Involvement in Research Project (PPIRes)

The Public and Patient Involvement in Research Project (PPIRes) was established to identify good practice in involvement of the public in R&D and to incorporate this into a locally owned project in the Norwich area. The project involves an induction and training programme for volunteers to join a research panel. Local researchers are able to make contact with the panel to seek their help with research projects. Activities of panel members have included involvement on committees, and reviewing research proposals and patient information sheets and consent forms. The training included: an introduction to the NHS; beginning the research process; research methods – how to answer questions; examples of good practice; research governance and ethics; and turning research findings into practice.

Howe and others (2006) Ensuring public and patient participation in research: a case study in infrastructure development in the UK Research and Development consortium. Primary Health Care Research and Development, Volume 7, pages 60-67

For further information contact Jacqueline Romero the PPIRes Co-ordinator, (01603 307404) jacqueline.romero@norfolk-pct.nhs.uk.

Collecting information or data

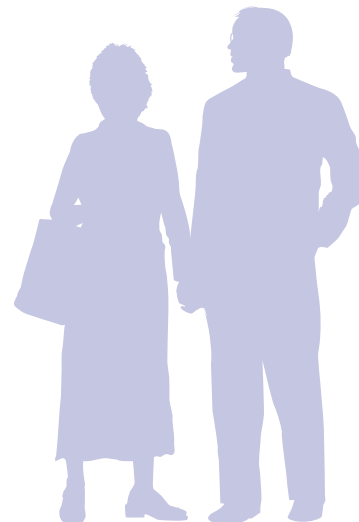
a) Running a focus group

A **focus group** is a small group of people brought together to talk about a topic of the research. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions or problems. You might be someone with direct experience of the circumstances being researched, so it may be easier for participants with a similar experience to trust you and therefore provide more open and honest views. Running a focus group needs particular skills for which you could be trained. Keeping a group of people on track may be quite demanding, but it can also be very rewarding and interesting.

b) Interviewing

Some, but not all research involves interviewing people. In research, an **interview** is where a researcher asks questions to obtain information from the person (or people) being interviewed. This can be done face to face or by telephone. There are different approaches to interviewing, but usually there are a set of topics to discuss. Again, if you have experienced similar circumstances to the people you are interviewing there is more likely to be empathy between you.

There may sometimes be quite a lot of travel involved when doing face to face interviews, depending on the size of the project. However, you might be able to do telephone interviews from home.



Example

Involvement in stroke services

People from South Asian communities were recruited and trained to work as community researchers. With the project co-ordinator they ran focus groups with community representatives. Issues raised by these focus groups were used to develop a framework for questions to interview potential service users, past stroke service users and/or their carers. The community researchers carried out, translated and verified the interviews. They also assisted in analysing the information collected during the interviews and will assist in producing a report that will be used to inform stroke service redesign.

Malcolm Auton (2006) Stroke services need to take account of cultural/religious issues to be equitable. This paper was presented at the INVOLVE Conference in September 2006. The abstract can be downloaded from INVOLVE's website: www.invo.org.uk/Conference2006.asp.

Analysing research data

If you are involved throughout a research project, you may have the opportunity to be involved in the **analysis** of the data. This involves examining and processing the **data**, identifying patterns and drawing out the main themes.

Writing up and sharing the findings of research

a) Writing research reports and/or lay summaries

It is important that research can be understood by all of us and not just the research community. You could be involved in commenting on research reports, writing **lay summaries** of research in which you have been involved, or helping to write the research report. This may help make the research results accessible to more people.

b) Communicating the findings of research

It is also important to think about how the findings of research can be **disseminated** to a wider audience. You can help by writing reports and articles for newsletters and giving talks to groups. You may also get involved in writing articles for journals.



2 Opportunities to get involved

Example

How a group of service users were involved in undertaking a research project about palliative care

The 'Influencing Palliative Care Project' involved a researcher and service users with a range of long-term, life limiting conditions working together over a three year period. The project was interested in what people with progressive conditions identified as their needs. The Service User Research Advisory Group was active at all stages from the design of the project through to telling people about their research findings. The group consisted of 9 people in all over the time span of the project. They conducted individual interviews and small discussion groups with 25 people who had a range of conditions that they referred to as life limiting.

"Making sense of the research information (analysis) we had collected was a very big job and was conducted collectively. The research information was analysed following guidelines and was a thoughtful process. When we put all the information together the pile was over four inches deep and contained over 140,000 words."

Cotterell, Phil and others (2006)
Participatory palliative care research.
INVOLVE Summer newsletter.

A full copy of the report of this study can be found at the following website address: www.sxrc.nhs.uk/consortium_activity/0258.htm or contact Phil Cotterell: phil.cotterell@wash.nhs.uk.
01903 285222 ext 4188.



Managing a research project

You may decide that your experience and knowledge forms the basis of a research project and you would like to share the responsibility for the research. This role could mean that you work with **researchers** to apply for the research funding and are then involved in all of the research activities, with the added task of shared supervision of the project.

On the other hand, you could decide to be part of a **user controlled research** project – that is, a project that is actively controlled, directed and managed by **service users** and their service user organisations. Some people who use services decide to do their own research. This is usually because they feel that the research would be better if it was controlled by service users.

Chapter 4, includes some suggestions for how you might start your own research project.

2.2 What might it feel like to be involved?

There are many different research situations in which you could take part and many different organisations with which you could be working, so it is difficult to be specific about what it might be like to be involved. Some researchers are very good at involvement, but others may be new to it and this can affect how it feels to work with them. In any new situation, it may be a little uncomfortable to start with until everyone gets used to the arrangements.

Ease of getting involved

Some organisations expect you to fit in with what they already do, others will make considerable adjustments to support your needs and enable you to participate as an equal stakeholder. Some research organisations will offer training and **mentoring**, whereas in other organisations you might need to ask for this kind of help if you feel that you need it. Although there may be big differences between organisations, it is important to remember that public involvement in research is still a developing area, and many organisations are still learning how to do it well.

Don't forget the importance of your role!

It is your experience which will help make this research relevant instead of researchers wasting time and money looking at issues that in practice are not helpful to the people they hope to help. You are not expected to be a scientist or to understand all the technical aspects of the research, but the research needs to be relevant to people like you.

Confidence

A useful tip for building confidence is to think about what you **do** know, instead of worrying about what you don't know. The more you focus on what you do know, the more you will realise how much you can contribute and the more you will learn from what is going on around you.

Sometimes, just by being there, you can help different professionals work better together. For example, having to use plain language, can help them understand each other better, too. Research can be very complex, but it is often the apparently simple question or comment from the service user or carer that may be the key to resolving a whole problem.

In my experience...

“ When you have decided to follow a particular line of interest, try and understand who the influencers are in the field that you want to support. Be flexible and be prepared to get involved in some initiatives and say no to others – based on your own passions and focus.Above all – keep in touch with those directly affected by the relevant disease or illness....

...never offer excuses for your 'ignorance'. It seems to me that often the most apparently naïve question could well get to the heart of an issue that others have not picked up on. ”

Lester Firkins

“ Often the most apparently naïve question could well get to the heart of an issue. ”

2 Opportunities to get involved

Working alone

Not all research activity is carried out with others: you may be working from home, or out interviewing on your own. However, you may need just as much support in these situations as you do in a meeting. It is important to know who and when you can contact someone for support.

'Ground rules' and written agreements

Some research groups have found that agreeing ground rules or having written agreements for working together have been a helpful way forward. For example, you might agree that all papers should be written in, or summarised in plain English. Other ground rules might be about respect and listening.

If you are someone who has a long-term illness, you might want to negotiate what happens if you are particularly unwell for a period of time and you are unable to be involved. This could be important for everyone concerned in knowing how best to work together.

Being clear

It is important to be fairly clear about what you feel comfortable with before you decide to get involved. You may want to ask some questions of a researcher or a research organisation before you decide to work with them. In **Chapter 3, 'Questions, Questions...'** we have suggested some questions to guide you.

2.3 Deciding which research to get involved in

You probably already have a number of skills and personal qualities that could be used in research situations even if you haven't done any research before. For example, you may be good at writing, working with numbers, or helping people you are talking to feel comfortable and valued. Many of these skills can be used in the research activities you might be involved in. Don't forget that you will learn as you go along in research, and you might also be offered training. So it may help to think broadly about your skills as well as the types of activities that interest you.

If you have yet to find a research activity in which to be involved then **Chapter 4, 'How do you start to get involved?'**, may be able to help.

Think broadly about your skills as well as the types of activities that interest you.

2.4 References

INVOLVE (2006)

Getting involved in research grant applications: guidelines for members of the public. P1

INVOLVE (2006)

Peer reviewing research proposals: Guidelines for members of the public. P2

INVOLVE (2006)

Being a member of a Commissioning Board: Guidelines for members of the public. P3

These are three guidelines written by Jane Royle and Maryrose Tarpey for members of the public who are interested in getting involved in the commissioning of research. They are available to download from the publications section of the INVOLVE website www.invo.org.uk or by phoning the INVOLVE Support Unit: 02380 651088.



3 Questions, questions...

What this chapter is about:

This chapter suggests some questions you might want to ask before you decide if you want to get involved.

The key messages are:

Be prepared to ask some questions.

Some of your questions will be about the research project, the research organisation or the research team. But you will also need to ask yourself some questions to decide what you want to contribute and what you are interested in doing.

The answers that you get should help you make a decision about whether you want to get involved.



3.1 Why it's useful to ask questions

Before deciding whether or not to get involved in **research** you may want to find out more about the organisation or the research project. For example, depending on your personal perspective, knowing who funds a research programme may be of no interest to you. Alternatively it may be either a significant positive or negative factor that helps you make a decision about getting involved.

Often, experiences of **public involvement in research** are very rewarding and positive but it would be dishonest of us not to advise you that some people's experiences have been unrewarding and negative. So how can you tell if your experience of involvement is likely to be a good one or not?

Some people have suggested that there are principles and indicators that will help determine whether public involvement in a research project will be successful or not.

Asking questions should help you find out about the practical side of getting involved in research and to get a sense of what kind of experiences you might have to offer. You might already have been provided with some useful information, perhaps a flyer, a leaflet or a reference to a website which may give you some of the answers.

If you are thinking about carrying out a **user controlled research** project you might still find some of these questions useful to ask but you might have to provide more of the answers for yourself. For example, instead of asking a research team who is funding the research project, you may have to ask yourself, where can I get funding?

There isn't a list of 'right' answers to any of these questions, because the right answer for one person may be the wrong answer for someone else.

Example

Guidelines for the ethical conduct of research

In 2004 a research project was carried out by mental health **service users** and **survivors**. They developed guidelines for the ethical conduct of research and reported that:

"There was considerable consensus of opinion about the underlying principles presented to participants: service user **empowerment**, equal opportunities, respect for all those involved, and the rights of researchers and **participants**. People also suggested other principles for inclusion: a commitment to change being the most notable." Page 3.

Faulkner, Alison (November, 2004)
The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors.

This is available from the **Joseph Rowntree Foundation** (JRF) bookshop <http://www.jrf.org.uk/bookshop>. It can either be downloaded free of charge or hard copies can be purchased from the JRF bookshop.

3 Questions, questions...

3.2 Questions to ask other people

The following are questions that you may find it helpful to ask other people. We have grouped questions under broad topics. There are areas of overlap between the topics so you will find some of the questions are repeated.

Whilst it may be useful to ask some questions, it is probably not a good idea to ask all of them at the same time! Also, you may not always get clear answers. This might be because it is the first time that a research team or a research organisation has involved the public in their work, so they are learning too. Or it might be because you have hit upon a complicated area, such as payments of fees (Steel, Roger 2006), where standards of good practice are developing and changing.

In my experience...

“ Before I become involved in research again I would want to know more. Where had the idea come from? What and who were involved and what had happened up to the time the group was evolved? I would advise anyone to be really sure they were interested in the subject that was to be researched. If you are over 50 as our group was then I would say forget your former careers and go into it with an open mind and also forget your preconceived ideas. Just go in with what you have learned in the “University of Life”. If you go in as a volunteer make sure your out of pocket expenses are covered. ”

Elaine Jones

Example

Principles for successful involvement

The following are eight principles identified by Rosemary Telford and others for successful involvement in research.

1. The roles of consumers are agreed between the researchers and consumers involved in the research
2. Researchers budget appropriately for the costs of consumer involvement in research
3. Researchers respect the differing skills, knowledge and experiences of consumers in NHS research
4. Consumers are offered training and personal support, to enable them to be involved in research
5. Researchers ensure that they have the necessary skills to involve consumers in the research process
6. Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research
7. Consumer involvement is described in research reports
8. Research findings are available to consumers, in formats and in language they can easily understand.

Telford, Rosemary and others (2004) What does it mean to involve consumers successfully in NHS research? A consensus study, Health Expectations, 7, pages 209-220

Skills and experience

The main reasons why you will be asked to get involved in research are because of your experiences and **perspectives** and not because of your knowledge of **research**. You should be offered appropriate information, support and/or training so that you can contribute fully.

Questions you might ask:

- what role(s) will members of the public get involved in?
- do you have a job description and person specification?
- could you tell me what skills are desirable and what are essential for the role?
- can you explain what relevant experience means?
- what training is available?
- are you looking for my personal perspective or do you expect me to consult with other people?

Research projects and research teams

As well as talking to the people who are already involved in the project or research team, you may also be able to look up information on the internet, contact a voluntary organisation or a support group that has relevant knowledge, or do some research in your local library.

Questions you might ask:

- what can I influence and what is already decided?
- how have you decided on the research topic? To whom is it important?
- who is funding the research?
- who will benefit from the research?
- how are you planning to carry out the research?
- how will involving the public make a difference to this project?

- how does the research team work together?
- will I be treated as an equal by others?
- will I be encouraged to keep asking questions?
- how are you finding members of the public to get involved?
- how many members of the public are involved?
- am I being asked to represent the views of other people or as an independent individual?
- how will you report on the public involvement in this project and any impact it has?
- what will I be responsible for and to whom will I be accountable?
- if I get involved, do I have any legal responsibilities for the research?
- has the project already started or if not, when will it start?
- for how long will it continue?
- how do you keep the research **participants** in touch with the project as it progresses?
- how will you tell members of the public about this research?

“ I would want to know what areas of the investigation I would be expected to influence and add value to. ”

3 Questions, questions...

Taking part in meetings

There are different ways in which you might take part in meetings. For example, you could be part of a **commissioning board** selecting research projects for funding, you could be part of a **steering group** which has responsibility for the overall management of a research project, or you could be a member of a research team taking part in regular team meetings.

Questions you might ask:

- in what ways do you think involving the public can make a difference to meetings and decisions?
- how many members of the public are involved?
- how frequent are meetings and how long will they last?
- how long am I committing myself to take part in these meetings?
- how much reading or preparation will I be expected to do?
- will I be sent papers or information well in advance of meetings?
- will I be able to understand what is happening during meetings?
- will I be an equal member with others on the group?
- how are people's views noted or recorded?
- what support can you offer me – before, during or after meetings?
- is the information from meetings **confidential** or can I discuss it with others who may be interested?
- am I being asked to represent the views of other people or as an independent individual?
- what do I do if I can't attend a meeting?

Payment and expenses

Some organisations pay for involvement, as well as reimbursing expenses and other out of pocket expenses, whereas others only pay expenses. Depending on what is on offer, it may affect your willingness or ability to get involved. You might find it useful to refer to **INVOLVE's** guide on payments and expenses as this explains some of the issues that could affect you (**Steel, Roger 2006**). A research team or organisation may not have the knowledge or skills to be able to advise you on your personal financial situation. However they can assist you in other ways, for example, by writing a letter of support or by putting you in touch with an employment adviser. In 2006, the Department of Health produced a guide called 'Reward and Recognition', which discusses many of the principles and practices in this area. (**Department of Health, August 2006**).

Questions you might ask:

- does this research have any funding for public involvement?
- what payment will I get for my involvement (if any)?
- will you cover my expenses such as childcare and travel?
- what are the procedures for getting payment and expenses?
- how long does the process of payment normally take?
- do you know what might happen to my state benefits if I get involved?
- what advice and support are you able to offer me?
- will I be given a contract or an **honorary contract**?

In my experience...

“ If I was in the same position again I would ask for as much detail of where the idea had come from? How was I to be involved? I would want a briefing on all aspects of the project; management; finance; costing and time-scale. What would my part be and the time I would need to put into the project on say a weekly basis and what the overall time-scale would be?

Another question that needs to be asked is about expenses. Even if you are a volunteer you should not be expected to cover expenses incurred from your own pocket. The question of expenses needs to be looked at carefully especially if one is in receipt of (non-contributory) state benefits. ”

Joan Brogden

Questions you might ask:

- what training are you offering for members of the public?
- would you provide me with training if I needed it?
- what support can you offer for my role?
- will I be offered a **mentor** or someone I can talk to on a regular basis?
- is there an independent source of support that I can go to?
- are there any other people who use services that are already involved and might be willing to give me some support?
- what would happen if I got ill?
- what emotional support would be available if I felt I needed it?
- what feedback will I be given about my involvement?

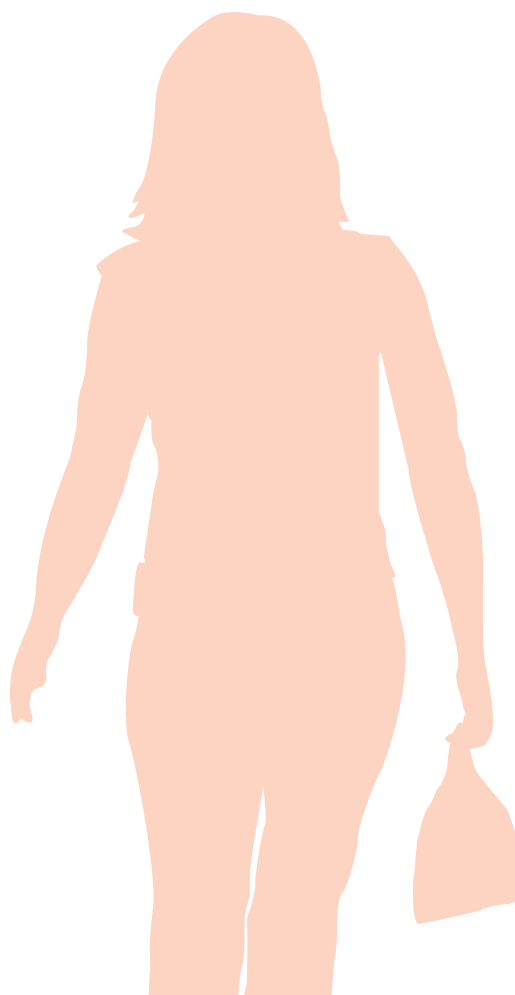
Training and other support

Training may be very helpful to you and also to any researchers who are new to involvement.

“Service users identified two key questions that they ask of training: Why do this? Why me? Training was most valued when it had a clear purpose, when it was centred around specific research tasks and real research problems, and above all when it was linked to a defined and real research project or role.”

(**Lockey, Rachael and others, 2004 p.10**)

Other forms of support instead of, or in addition to training, might also be helpful to you. If you can identify what support you would prefer, the research team or organisation may be able to help.



3 Questions, questions...

Accessibility

There may be barriers that could get in the way of your involvement. Identifying and negotiating potential barriers can make it easier for you to get involved. If you can identify any particular needs that you have, this may help researchers to try to provide you with appropriate tools and support to make their work fully accessible to you.

Questions you might ask:

- are you able to promote and support the involvement of people with disabilities?
- how accessible are the venues and facilities that will be used?
- are there any planned breaks during work time?
- would it be possible to change venues or times of meetings if needed?
- can you cater for my dietary requirements?
- what can be done to encourage speaking in clear, plain language?
- are you able to promote and support the involvement of groups or communities who are often excluded from research such as people whose first language isn't English?
- if necessary, can you provide an interpreter?
- will my cultural and spiritual requirements be understood and catered for?
- what facilities or equipment can I use freely – such as a phone, a photocopier, a library or office space?

3.3 Questions to ask yourself

The following are questions that you may find helpful to consider about your own experience, knowledge, interests and situation before you decide what you would like to get involved in.

Your experience

- what is my past and present experience?
- what does that experience mean to me, and what does it say?
- is my experience relevant or am I here to make up the numbers?

In my experience...

“ It is only in retrospect that I have realised what kind of questions would have been useful if I had been able to ask them at the beginning. My thoughts from being involved in the Hello Project are “where do I go next”. I have already done things I never expected I would do. I have learnt a lot about my own abilities.

I would say that if you have the chance to be involved in research and you have enough spare time, then get involved. The last thing you should really think about is ‘can I really do that’. We never know what we can do until we have tried. You may even get to use equipment that you would not normally come into contact with. Go for it. ”

Joan Brogden

Your knowledge

- what have I learnt from others who are in a similar situation to me?
- what have I learnt about how the health or social care services I use are seen by others in a similar situation to me?
- what have I learnt about the concerns of those with similar experiences?
- will my knowledge be valued?

Your interests

- what really fires me up?
- why do I want to do this?
- what would I like to learn?
- is this something I know or want to know more about?
- what do I want to change?
- what do I want to support?
- do I feel this research is worthwhile?

Your own situation

- what do I need to know before I can decide if I want to get involved?
- do I have time for this?
- can I afford to do this?
- if getting involved upsets me, do I have the support that I need to help me feel better?
- are there clear boundaries between my role as a member of the public and my role as a **research partner**?
- how will I know what difference my involvement has made?

3.4 References

Department of Health (August, 2006)

Reward and Recognition: the principles and practice of service user payment and reimbursement in health and social care. Second Edition.

Available to download from the publications section of the Department of Health website [www. http://www.dh.gov.uk](http://www.dh.gov.uk). To order a hard copy telephone: 0870 155 54 55

Lockey, Rachael and others (2004)

Training for consumer involvement in health and social care research – a study of training provision and participants' experiences
Commissioned by INVOLVE.

Available to download from the publications section of the INVOLVE website www.invo.org.uk, or by phoning the INVOLVE Support Unit: 02380 651088.

Steel, Roger (2006)

Guide to reimbursing and paying members of the public actively involved in research. Revised August 2006.

Available to download from the publications section of the INVOLVE website www.invo.org.uk, or by phoning the INVOLVE Support Unit: 02380 651088.



4 How do you start to get involved?

What this chapter is about:

This chapter is about where to go to get involved in research.

The key messages are:

There are many different routes to get involved in research.

It might take time and determination to find the right opportunity for you.

It helps to make contact and develop links with other groups of people who share some of your interests.



4.1 Making contact

This booklet suggests where you could go to get involved in **research**. It describes how others have got involved in research and suggests different organisations to contact.

You may want to consider looking for opportunities in a variety of ways – for example by focusing on involvement in a particular **research topic** that interests you, or by finding out about research going on in your **local area** or **nationally**.

It isn't always easy to find exactly what you are looking for. **Public involvement** in research is still a developing area and some organisations and areas are doing more than others. It might take some time to find what you are looking for and you may need to make several enquiries, some of which could turn out to be dead ends. But don't be put off!

The different routes people have taken to get involved in research show that it often depends as much on being in the right place at the right time as having a strong interest in research to start with!

Being a member of a local group

Many people start to get involved in research through membership of a support group or voluntary organisation. Sometimes **researchers** or **research commissioners** contact voluntary organisations looking for people to get involved. Members of national charities, such as the **Alzheimer's Society**, **Disabled Living** and the **National Childbirth Trust** have all been approached in this way. For example, they have been asked to contribute to **research grant** applications, comment on **research proposals** and help decide what research should be **commissioned**.

Others have said that their organisation decided that they should do some **user led** or **user controlled** research themselves and not rely on researchers or other commissioners to decide what research should be done (**Beresford, Peter and Turner, Michael 2005**).

In my experience...

“I have osteoporosis and am an active member of my local osteoporosis support group. My group was contacted by the local hospital who had some money to do some research on preventing falls. They were looking for people to join their research steering group who had osteoporosis and had experience of falls. I thought that even if I didn't understand everything that would be said at least they would have a real live sufferer there for them all to see how terrible it can be. In fact I found I had a lot to say....and since then I've gone on to sit on another research steering group based in the hospital.”

Orla
(**Tarpey, Maryrose 2006**)

“It was a chance meeting at a talk our group had organised. Over tea I got talking to the researcher who had done a presentation of the research he was planning to do in our area on dementia. He was looking for a carer interested in doing the interviews and I got the job! I now call myself a 'user-researcher' and am hoping to work on other projects when I can.”

Martin
(**Tarpey, Maryrose 2006**)

4 How do you start to get involved?

If you are not a member of any group

Of course you may not be a member of a local or a national organisation but you can still get involved in research.

The ways that this can happen include:

- by being contacted directly, for example, by a researcher, your GP or a local social services department
- by replying to a local advertisement – perhaps in your nearest community or health centre, or in a newspaper or on the radio
- by replying to a national advertisement in the media or on a website
- by making contact with organisations that **commission** or carry out research
- by deciding to develop your own research project.

4.2 Is there a topic or issue that interests you?

Perhaps you have an interest in a particular topic, or you or a member of your family has experience of a particular condition or issue.

You can find out what is available by:

- asking your own health or social care professional (for example, health visitor, GP, physiotherapist, community development worker) if they know of any researchers working on a topic that is relevant to you
- checking out if there is a local or national organisation for the topic or issue with which you would like to get involved and contacting them. Your local library will hold publications with details of national organisations or speak to your local **Council for Voluntary Services** to see if they can help
- searching the internet for a relevant support group using **Patient UK**
- contact the **United Kingdom Clinical Research Networks (UKCRN)** to find out if they cover a health research area of interest to you.

The following are just a few examples of organisations for individual topics who actively involve the public in research:

- **Alzheimer's Society – Quality Research in Dementia Programme**
- **Macmillan Cancer Support – Cancer Voices**
- **Multiple Sclerosis Society**
- **Sure Start (children and families)**
- **Suresearch (mental health).**



4.3 Getting involved in local research

You can find out what is happening locally by looking out for local advertisements or by contacting:

- the person leading on Patient and Public Involvement at your local NHS Trust or your local NHS Trust Research and Development Department. Contact details of your NHS Trust will be in your phone directory or search online in [NHS England](#)
- the [United Kingdom Clinical Research Network \(UKCRN\)](#). They will be able to tell you about local research networks covering your region
- [Shaping Our Lives service networking website](#)
- your local [Research and Development Support Unit \(RDSU\)](#)
- your local NHS research **ethics committee**, who will have members of the public on its panel. The [National Research Ethics Service](#) has further information on research **ethics**. Your local RDSU will also be able to provide you with contact details.
- your local [Council for Voluntary Service](#) to find out if they are aware of any local research
- local service user groups e.g. [Patient and Public Involvement Forums](#) to see if they know of any local opportunities in research.
- your local authority to find out if it is aware of any **social care research** or **evaluations** being carried out. You could also try and contact the **Research Governance** lead at your local authority, who might be able to help you further. However please be aware that not all local authorities have a research department.
- a Community Development programme in your area e.g. [Sure Start](#)
- the Practice Manager at your GP surgery or health centre
- your local University who might have a number of research departments – e.g. Health, Primary Care, Public Health or Social Care. Start by searching the University website or calling the general telephone number and asking about research departments.

In my experience...

“ I saw an advertisement in the local paper for Older People to be trained in research methods and to carry out a research project on behalf of a University and a Charity that specialised in older people’s services.

I thought that it sounded interesting. Older people being wanted for a University training course, free or subsidised. On successful completion of the training, (I was awarded) a Certificate in Research Methods (For Older People). (I then worked on) an interesting research project, “Housing Decisions in Older Age” – especially after our own experience.

I completed the project and thoroughly enjoyed the experience. I have since gone on to carry out other projects and been involved in many workshops related to research in health and social services. ”

Alan
(Tarpey, Maryrose 2006)

4 How do you start to get involved?

4.4 Getting involved at a national level

Some national research organisations involve the public in a variety of ways. The different opportunities for involvement in research are listed in **Chapter 2**.

National organisations often advertise when they have a vacancy, but contact them and let them know you are interested. Ask to go on their mailing list which could give you the chance to become familiar with their work. Some national organisations have local branches or they may happen to be based near where you live.

- **National Institute for Health Research (NIHR) research programmes**
- **Cochrane Collaboration**
- **National Institute for Health and Clinical Excellence (NICE)**
- **UK Clinical Research Collaboration (UKCRC)**
- **Shaping Our Lives**
- **Joseph Rowntree Foundation**
- **INVOLVE**

A new website was launched at the beginning of 2007, called **People in Research**. It is a website which helps members of the public make contact with organisations that want to actively involve people in **clinical research**. It is a **UK Clinical Research Collaboration (UKCRC)** project that has been led by **INVOLVE** www.peopleinresearch.org.

In my experience...

“ It’s quite hard to say **EXACTLY why** I became involved in research, but **how** is easier. I started out as a lay representative with one of the Royal Colleges. The trigger was an advertisement for volunteers in *The Guardian*. I was looking for any volunteering opportunity rather than a specifically health-related role, but this one seemed to gel with my experience and interests. ”

Christine
(Tarpey, Maryrose 2006)



4.5 Taking the lead and doing your own research

You may decide that you are interested in carrying out your own research and this could be done in a number of different ways:

- you or the organisation to which you belong might be interested in **commissioning** a piece of research
- you might like to work in partnership with researchers on an idea for a research project
- or you could decide to carry out a piece of research either on your own, or with other communities or people who use services.

It is difficult to carry out a research project in isolation so make links and talk to other service user organisations involved in research. **Shaping Our Lives networking website** has details of user controlled organisations some of which might be involved in research. The **INVOLVE** research database (www.invo.org.uk/Database.asp) has details of research projects where the public have been actively involved in the research.

Funding your research project

Getting funding for research can be difficult and complicated. Some funding bodies require you to work in collaboration with researchers in an organisation or University. Others, such as the **Big Lottery**, fund voluntary and community organisations. To apply for funding you usually have to complete a **research proposal** form. Research funders are highlighted in the Organisation section, in **Booklet 3**.

Training

To help you increase your knowledge, and create and develop your ideas, you might want to consider training, either for yourself or for other researchers involved in the project.

Contact your local **Research and Development Support Unit (RDSU)** for information on courses they are running and to see if they are open to the public. These might be short courses on research skills and methods, or they might have information on longer, more detailed courses.

Contact the Research and Development Department at your local **NHS Acute (Hospital) Trust** to see if they are running, or are aware of, any research courses in which you can participate.

RD Learning has a database of health related research courses across the UK.

Your local college, University or the **Open University** are also good sources for information on training courses.

The **Association for Research in the Voluntary and Community Centre (ARVAC)** is a good source of information for community organisations looking for training in community research.

The **Critical Appraisal Skills Programme (CASP)** is a Programme at the Public Health Resource Unit in Oxford, which includes workshops and resources on understanding research evidence.

The training section of the **INVOLVE** website (www.invo.org.uk/Training.asp) has details of trainers with experience of training service users in research, and also of training researchers to involve service users in their research.

4 How do you start to get involved?

4.6 Still no luck?

Probably the most important thing is to keep going!

- If nothing is currently available, give your contact details and ask to be informed when any opportunities arise. After a while, if you don't hear anything, call back to remind people of your interest
- Network with others who share your research interests – possibly by joining service user organisations
- Sign up to receive newsletters from all the groups or organisations that you have come across who share your research interests.

In my experience...

“ My journey started in 2001 when our 25 year old son died from vCJD (the human form of Mad Cow Disease). Until that time I was quite content with my job working at a bank, but clearly this was a life-changing event, and I soon realized that I wanted to 'put something back'. I started by joining the Human BSE Foundation – the patient group that supports vCJD families, and was their Chairman until September 2003. To do this job properly I knew that I had to understand the medical and scientific world that surrounds the disease. I needed to get to know who the prime 'movers and shakers' were. One thing led to another and in October 2003, I was appointed as Assistant Chair of the Prion-1 Trial Committee. ”

Lester Firkins

Make contact through INVOLVE

- Join our mailing list to get our newsletter and find out about the work others are doing.
- Look at our INVOLVE website
 - view the website news and noticeboard
 - sign up for email alerts from the INVOLVE website
 - join the INVOLVE discussion forum, post a message, and find out who is looking for people to get involved.

4.7 References

Beresford, Peter and Turner, Michael (2005) User controlled research: its meaning and potential. INVOLVE.

Available to download from the publications section of the INVOLVE website www.invo.org.uk or by phoning the INVOLVE Support Unit: 02380 651088.

Tarpey, Maryrose (2006) Why people get involved in health and social care research: a working paper, INVOLVE Support Unit

Available to download from the publications section of the INVOLVE website www.invo.org.uk or by phoning the INVOLVE Support Unit: 02380 651088.



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Promoting public involvement in NHS,
public health and social care research

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