

1 Public Information Pack (PIP)

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

So what is it all about?



INVOLVE

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

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NHS

**National Institute for
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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 1) 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.

INVOLVE aims to promote and support active public involvement in NHS, social care and public health **research**. Active **involvement** in research is different from simply taking part in a study. It is about research that is done **with** members of the public, not **to, about** or **for** them. For example, where members of the public become part of an advisory group, decide the research topic, become involved in the design of a study, or work as **research partners** on a project.

We believe it is vital for members of the public to be involved in research. Research which reflects the needs and views of the public in this way, can lead to more relevant research and is more likely to produce results that can be used to improve practice in health and social care.

In 2001, Consumers in NHS Research (later to become INVOLVE) published a guide called '**Getting involved in research: A guide for consumers**' (**Royle, Jane and others, 2001**). The guide was developed with members of the public who had a range of different experiences of public involvement in research. We would like to acknowledge and thank all the people who were involved in producing that first guide as it has been invaluable in developing this information pack.

Public involvement in research is a rapidly developing and important field and thus we needed to update the information to include some of the more recent examples, references, views and knowledge. We also wanted to reflect the fact that INVOLVE now supports and promotes public involvement in public health and social care research and development, as well as in the NHS. This new Public Information Pack is a replacement for the previous guide.

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 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 a member of the public with little or no experience of public involvement in research, this pack 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.



1 What is PIP?

1.4 How we developed the Public Information Pack

To help us redesign the pack, we sent out a questionnaire to INVOLVE newsletter readers as well as visitors to our website. We also set up a small advisory group, which included two members of the public with experience of public involvement in research, Carey Ostrer and Jenny Walton. This group has had the task of overseeing all the different stages in the development of the pack. In addition, 16 members of the public with a wide range of knowledge and experience of public involvement in research participated in a workshop. The workshop identified the main topics and sub-topics to be included in the information pack. Subsequently, workshop participants commented on draft copies of different chapters of the pack.

After further revisions and changes, an additional 6 people commented on the whole booklet.

TwoCan Associates (www.twocanassociates.co.uk) worked with us on two particular aspects of the pack. Initially they organised, facilitated and reported on the workshop. They also produced a Jargon Buster (glossary) for the pack, the result of which is **Booklet 4**.

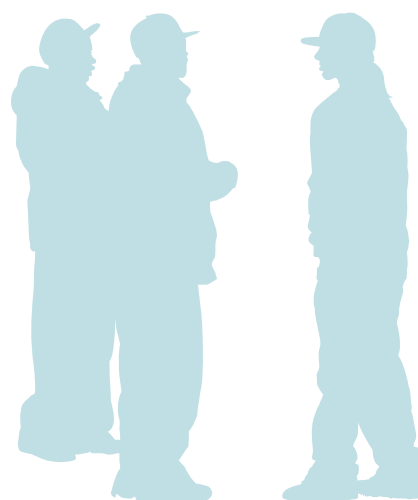
“ I couldn't believe more strongly in the value those who have experienced ill health can bring to research, both as advisors and co-researchers. ”

1.5 How you can contribute to the Public Information Pack

Public involvement in research is a rapidly developing field. One of the reasons why we have chosen to create the information pack as four booklets is so that we can periodically update individual booklets without replacing all of it.

Part of the updating process will be to reflect on the feedback that we receive from people who have read and used the pack. For instance, you may know of other examples of good practice to include in the pack or you may have suggestions for other booklets. We would like to know what you think.

So, if you are interested in sharing your experience, or if you have any comments to make, please get in touch with us by telephone or email.



In my experience...

“ Coming to terms with life after diagnosis of cancer of the vulva, when my mind was no longer reeling from shock, absolute helplessness and isolation, I found myself doing what so many people affected by cancer do – asking “why?” I needed to find out as much as possible about the reasons for the existence of my own cancer, or any type of cancer.

But I was too old to start on that long journey which would end up with the necessary qualifications to help me become a professional researcher, so I looked at ways of helping in an advisory capacity – giving the ‘user’ perspective of how research could be carried out effectively. This led on to becoming a co-researcher in the Macmillan Listening Study – a marvellous opportunity to work alongside the professionals in a study exploring what

cancer patients thought was meant by the word ‘research’, and what they believed were important areas for research not already being considered.

I also joined my own cancer network’s consumer research panel (CRP), one of the three pilot groups initiated by Macmillan and the National Cancer Research Network. This entails working with other lay people revising research protocols, reviewing information to be given to subjects of trials, etc.

Not surprisingly, the opportunity to work as part of the team for this INVOLVE information pack is a satisfying way of helping other lay people understand how to become involved in research. ”

Jenny Walton

(Jenny was part of the advisory group for developing the Information Pack.)



1 What is PIP?

In my experience...

“ I have been able to observe the arena of academic research in various university research departments specialising in mental health/ill-health for about 6 years. I couldn't believe more strongly in the value those who have experienced ill health can bring to research, both as advisors and co-researchers.

But how do you actually influence research? In my experience a research design that doesn't consider relevant service user information in the beginning will miss key opportunities in the development of the investigation.

It's hard work, and I have had to remind myself that “Rome wasn't built in a day...” I have to be optimistic, and have faith in people's power to change things for the better, even when up against the vested interests of individuals and organisations that prefer the status quo. But I have not felt alone, there are many who have been before me, and much work being done now.

1 in 4 has or will experience mental ill-health. Until the age of 30 I lived a pretty full life, and knew little about mental ill-health. A critical life-change triggered a crisis. It was because of the way I was handled by health services that my interest in trying to improve things through influencing research was triggered. I am convinced that had I been dealing with professionals who were more knowledgeable, I would not have been as ill as I became, for so long.

Based on my own experiences, I would be selective about research I agree to give my time, energy and

expertise to. I would want to find out my 'job description' for the project, not be the lone service user voice in the investigation, and discuss the design of the research plan. I would want to know what areas of the investigation I would be expected to influence and add value to. I would want to know this in order to make up my mind as to whether the professional researchers were really interested, or whether they were just ticking the 'user involvement box' in order to obtain funding.

The world of research is highly competitive, but it doesn't necessarily follow that those who get the funding are the best. Good user involvement involves more work for the research team, but investigation that doesn't have this dimension usually leaves out crucial questions that are likely to have a big effect on the findings. This of course influences how you and I survive our periods of illness, and how successful we will be at promoting good health.

Working with INVOLVE on this information pack has been a positive experience for me, and I think, for the staff at INVOLVE who have a terrific amount of expertise built up over the years. That doesn't mean that we have always agreed, that it hasn't been hard work, or that the unexpected hasn't happened. We hope we have produced something useful to you in influencing the research of the future. Good luck! ”

Carey Ostrer

(Carey was part of the advisory group for developing the Information Pack.)

1.6 Reference

Royle, Jane and others (2001)

**Getting involved in research:
A Guide for Consumers.**

This is now out of print and hard copies are no longer available but it can be downloaded from the publications section of our website www.invo.org.uk

The Public Information Pack (PIP) 2007 replaces this publication.



2 Research unravelled

What this chapter is about:

This chapter explains what research is and what it involves.

The key messages are:

Research is a way of gaining new knowledge.

There are many different definitions and types of research.

Research is important to help us make better decisions and improve treatments and services.

We all use research skills in our daily lives.



2.1 What is research?

The term **research** means different things to different people, but it is essentially about finding out new knowledge that could lead to changes to treatments, policies or care.

People's knowledge of health and social care research will differ depending on their experience of it. For example, some people will have experience of being part of a large national study where tests and samples are taken in hospital. Others will have experience of smaller local studies, perhaps answering researchers' questions in their own home or in a community setting. Others will have no experience at all.

Health and social care research includes the following types of research:

NHS research

NHS research is health research carried out in the NHS or funded by the NHS. It can include research into drug treatments and medical devices, research about where people are treated, and how staff provide care to patients. NHS research can take place in local hospitals or GP clinics, or at a national level, for example:

- A study based in a GP surgery looking at people's experience of long term chronic pain
- A **randomised controlled trial** to look at the best treatment for people with bowel cancer

Example

Some definitions of research from people who took part in the INVOLVE workshop to help us write PIP

"Research is about finding answers, or even identifying important questions."

"What do people think about something and what evidence is there."

"Scientific investigation to discover facts."

"Research means different things to different people and when one talks about research an explanation of exactly what is meant, and what it entails, should also follow. Research to me means conducting surveys, talking to people, establishing their points of view then completing questionnaires."

"Investigating a subject and trying to get a result and understand what it is all about."

"To delve into, find answers, and implement! Such as market research when trying to improve customer or 'service users' services."

A definition from the Learning Difficulties Research Team

'Research is about finding answers to questions and doing it in a planned way. There are different types of research. We did research about what people think and feel, and what has happened to them.'

Learning Disabilities Research Team (2006) Let me in – I'm a researcher: Getting involved in research, Department of Health, March 2006, page 16.

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

2 Research unravelled

In my experience...

“ In general, before joining the group our understanding of research meant school projects and searching for information on the internet, but now we are learning about research ethics and different methods of research and analysis. We are identifying what we think should be priorities for research into young people’s health and are looking at how different research methods could be used to explore these issues. We are also learning who our views will be fed back to and what they will be used for. What we have found useful is knowing we are linked to the consortium and what we are expected to do. At each meeting we have an outline of the day, information, and a map of how to go to the venue. After each meeting we get a report on what we did, and this contains quotes on what we have said. This is good as it shows we have been listened to. We enjoy the fact that there is no pressure to come to every meeting and that we are thanked with a voucher – but this isn’t the only reason why we come! We enjoy the variety of activities we do in the group.”

Young People’s Public Health Reference Group

Public health research

Public health is concerned with promoting good health, preventing disease and protecting populations from hazards, rather than treating illnesses. It covers topics like the control of infectious diseases, vaccinations, and helping people to adopt healthy lifestyles.

For example:

- the best ways to help people who want to stop smoking
- how Bird Flu spreads to humans

Social care research

Social care refers to a range of services provided across different settings, usually supporting people in the community. These include care for older people, residential care, fostering for children, and support services for mental health service users, disabled people, people with learning difficulties and carers.

Social care research involves finding out new knowledge (or testing out existing ideas) to do with social care – it might look at:

- People’s experience of using different home care services
- The best ways to train new foster parents

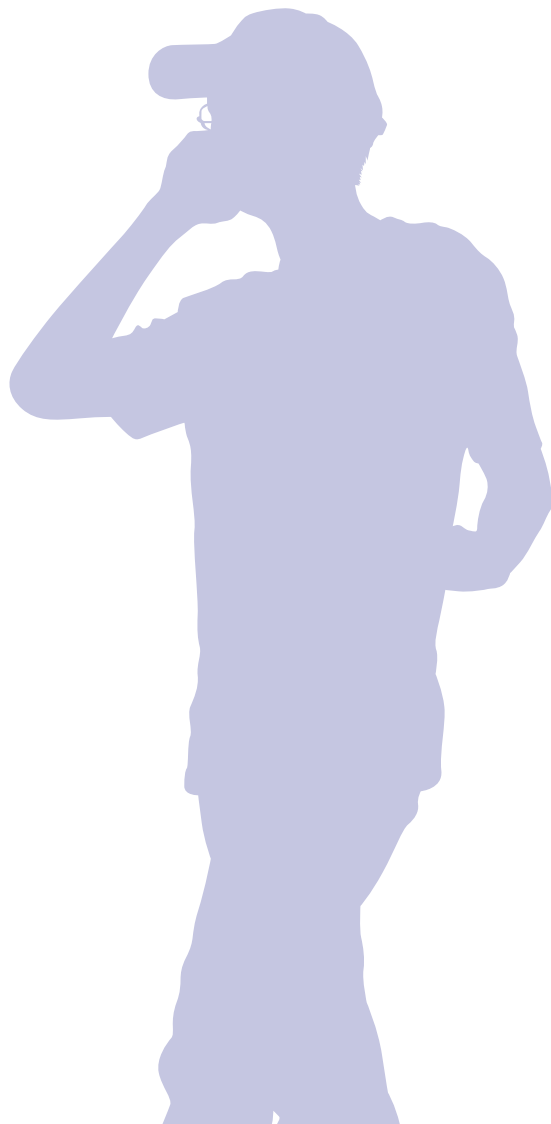
What is the ‘D’ in the term ‘Research and Development’ (‘R&D’)?

You may hear people talking about ‘R&D’, which is short for ‘research and development’. Development refers to using the latest and most reliable research to develop and improve products, devices, processes and services. For example, research that explores some of the difficulties people have using wheelchairs, which is then taken forward to develop improved wheelchairs.

2.2 Why do we need research?

Health and social care research can help to:

- find out what people think about services
- identify health and social inequalities
- evaluate how effective services are
- improve treatments and services
- improve the environment, health and wellbeing of a local population
- identify people at risk of getting ill and help to prevent illness
- identify the best use of resources
- test treatments to make sure they are safe and effective
- ensure services and treatments are relevant to the **public**



2.3 Who does research?

Many of us use a variety of research skills in our daily lives to find out information.

For example:

- asking a sales assistant questions to find out about a product we are interested in buying, such as a car, or television
- reading different newspaper and magazine articles about a product or service to compare what they have to say on a subject
- searching on the internet to find out information

In health and social care research, a whole range of different people carry out research including:

- practitioners (e.g. social workers, nurses and clinicians)
- social scientists (e.g. health service researchers, statisticians and health economists)
- scientists (e.g. chemists, biologists)
- **user researchers** and members of the public

Some spend their whole time doing research, whereas others carry out research alongside other roles, such as being a practitioner.

Researchers usually undergo some kind of training to do research, but the type and length of training varies. Often researchers work together as part of a team with people with different backgrounds and experiences, and from different organisations.

**We all use
research skills
in our daily lives.**

2 Research unravelled

Some research is carried out nationally or internationally and can involve researchers in different organisations and countries, whereas other research is carried out in just one area, for example within one hospital or local community. Health and social care research is carried out in a range of different organisations such as universities, hospitals, social services departments, voluntary and user led organisations, and in private companies.

As a member of the public, a specialised knowledge of research is not needed in order to be involved in it. What is important is that you are able to bring your own knowledge and experience of being a user of health and/or social care services to the research process. You are expert about your own experience – and therefore your perspectives have a key part to play in the process of research and development.

In my experience...

“ I knew literally nothing about research. To me it was something scientists and academics did. The Hello group was my first experience of getting involved in research. My understanding of research is entirely different now. ”

Elaine Jones

2.4 The different stages of research

One way of understanding research is to think about the different stages of research. Members of the public can be involved in all these stages:

- Funding – how research is funded and applied for
- Carrying out research – collecting information, analysing and reporting
- Dissemination – communicating the research findings
- Development – putting research into practice

Funding of research

a) How research is funded

There are various local and national organisations that fund health and social care research, for example:

- **National Institute for Health Research (NIHR), Department of Health**
- **NHS Trusts and Primary Care Trusts**
- Voluntary organisations (e.g. **Joseph Rowntree Foundation, Macmillan Cancer Support, Alzheimer's Society**)
- Research Councils (e.g. **Medical Research Council, Economic and Social Research Council**)
- Industry (e.g. pharmaceutical companies)

Research usually starts with decisions being made about what research needs to be funded. In some research programmes the topics for research are decided in advance by research **commissioners**.

Example

In 2005, the **Service Delivery and Organisation Programme** decided that research was needed on the effect of patient choice on access to care and so they invited researchers to send in research proposals to carry out research on this topic.

In other research programmes it is up to researchers to put forward proposals for specific research projects, that they wish to undertake. This is called responsive funding.

Example

The **National Institute for Health Research, Research for Patient Benefit Programme**, invites researchers to send in research proposals on any topic that is of importance to the NHS and is about everyday practice in the health service.

Members of the public are increasingly getting involved in advising research commissioners and **researchers** about what broad areas of research should be funded (sometimes referred to as 'identifying and prioritising' topics).

Often research commissioners invite people with relevant knowledge and experience to form a **commissioning board** or panel to advise on which research projects they should fund. A commissioning board is a group of people who oversee the commissioning process. It is made up of research funders, researchers, health and/or social care professionals and may include members of the public (e.g. service users, carers).

b) Applying for research funding

Obtaining funding for research can be complicated. Often researchers have to compete for the money to carry out their research plans. To apply for funding, you usually complete a **research proposal** or **research grant** application form. The application form asks for specific information including a description of the research and why it needs to be done, information about who will be doing it, and a detailed estimate of how much the research will cost. Research commissioners are increasingly asking researchers to include information about their plans for public involvement in the research.

Sometimes, members of the public work with researchers or take the lead in applying for funding for research that they are interested in.

To find out more about public involvement in research grant applications, see INVOLVE's guidelines on 'Getting involved in research grant applications' **INVOLVE (2006)**.

Carrying out research

Once funding has been agreed the research may also need permission from an **ethics committee** and **research governance** before it can get under way.

Carrying out the research includes collecting information, for example by sending out questionnaires or interviewing people, **analysis** and interpretation of the information collected followed by writing up the findings of the research.



2 Research unravelled

In my experience...

“ Before I became involved in research I didn't really know what research was really. I thought it involved distributing and filling in questionnaires. I had never considered doing any work with or around research.

My first experience of research was when I was doing some voluntary work with health visitors. They mentioned the project and explained they were looking for members of the community to carry out the research. It sounded interesting and I felt it would be a good way to give something back to my community. I immediately put my name forward and after an informal interview I was chosen as a community researcher, along with others.

The project started with training into postnatal depression, as that was the subject to be researched, and research methods including focus groups, interviews, using equipment, etc. The training was very useful and interesting. We all had the same training together as a group, that included all the community researchers and health professionals.

The health professionals had already identified some participants for the research, but we as researchers also recruited some participants. We carried out the research in groups of two or more researchers and a health professional. This worked well as it gave us confidence and support.

After the research was completed a lot of interest was shown, this led to myself and other community researchers delivering presentations on our involvement in the project. I enjoyed my first experience of research very much. I have continued to be involved in other research projects. The whole group met up regularly and shared information, experiences and supported each other. I gained a lot of experience, training and confidence from the project, which has led to my present role as health trainer. ”

Zarqa Riaz

Dissemination – communicating the research findings

Dissemination involves communicating the findings of the research to a wide range of people who might find it useful. This can be done through writing reports and articles, giving talks, producing a DVD or audio tape on the research.

It is also very important to feedback the findings of the research to the research **participants** who took part in the study.

Development – putting the research into practice

If the findings of the research are to be **implemented** this is usually done by health or social care practitioners or managers. However not all research is used or results in changes or developments to policy, services or treatments. Some of the reasons for this are:

- other information also needs to be taken into account when making decisions
- limits on funding prevent some research findings being put into practice
- sometimes the findings are controversial and agreement cannot be reached as to how to take them forward
- sometimes research does not provide the answers and more research is needed

At the end of the research project, research commissioners may involve members of the public in monitoring or **evaluating** the research to see what it has achieved, as well as to help identify what questions remain, or new questions and topics that have arisen.

Booklet 2 describes in greater detail the opportunities for public involvement in all these research activities.

2.5 How is research done?

Some research is carried out in a laboratory or an office and does not involve any direct contact with the public (e.g. **basic research**, **systematic reviews**, postal **questionnaire** surveys), whereas other research involves working closely with the public (e.g. **interviewing**, carrying out tests).

There are two main approaches to research – **quantitative** and **qualitative research**. The choice of a quantitative or qualitative approach depends on the type of information that is needed to answer a question. It is not unusual for both approaches to be used as part of one research project. Both research approaches draw on a large number of different research designs and **research methods**.

Quantitative research tends to be large-scale in its approach to the research topic as it aims to be representative of the group being researched. It focuses on numbers and asks **questions such as – ‘how often’, ‘how many’ or ‘how much’**. These questions help for example to:

- collect measurements of people’s pain on a scale from 1 to 10, or
- record information about people’s diet and lifestyle habits.

Randomised controlled trials or **systematic reviews** are examples of research designs used in quantitative research. The information is collected through various research methods such as survey **questionnaires**, tests and observations. **Statistical analysis** is then used to make sense of the information collected in this way.

2 Research unravelled

Example

A randomised controlled trial: The PRISM Trial

Researchers at the University of Aberdeen, carried out a randomised controlled trial which compared two different treatment approaches for Paget's disease of the bone. Half of the people in the study were only given medication if the Paget's disease caused pain, whereas the other half were given repeated courses of a drug (that it was thought might help with long term complications) whether or not they had any symptoms.

The National Association for the Relief of Paget's Disease worked closely with the researchers from the outset. Involvement included membership of the steering committee for the trial, providing advice to participants in the trial, and promoting the trial amongst Paget's disease patients.

**Langston, Anne and others (2005).
An integrated approach to consumer
representation and involvement in a
multicentre randomised controlled trial.
Clinical Trials, Volume 2, pages 80-87.**

In my experience...

“ What I knew about research prior to joining the Hello Group would cover a postage stamp. Research was done by university graduates. I was the person who answered the questions. My idea of research was a series of questions on a graded scale. I really had very little idea of how data was collected, used or analysed.

I think the first time I realised that yes, I was getting involved in research was when the research questions we were

to use in our project had been refined and ready to be used. When we reached this stage it was no longer a study project but a do-able project. I now have a much deeper understanding of what is involved in a research project. The area I have very little understanding of is how to cost a project and then obtain financial backing. I now realise that there is a lot more to asking questions. ”

Joan Brogden

(Note: The Hello project is a research project on older people and loneliness.)

Qualitative research focuses on people's attitudes, views and how they make sense of their experiences and the world in which they live. It asks questions such as '**what does it mean**', '**in what ways**' or '**what does it feel like**'.

Compared to quantitative research it explores aspects of a research topic in greater depth and usually with a smaller number of people. It often involves asking people for detailed descriptions and explanations. For example:

- how would you describe your pain?
- what are your views on eating fruit and vegetables every day?

Qualitative research approaches sometimes draw on **action research**, **emancipatory** or **participatory research** designs. Qualitative research methods include in-depth **interviews**, **focus groups**, diaries and videos, as well as observations. The information is analysed and reported in a non-numerical way.

Booklet 4, Jargon Buster, gives more detailed explanations of these different types of research.

2.6 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

Example

A project that involved both quantitative and qualitative research

'... We collected information – data – from researchers, service users, carers and other people involved in the studies. The data was both quantitative (consisting of numbers) and qualitative (consisting of people's words). We analysed the quantitative data to find out, for example, how many people attended training or the percentage of people who thought user involvement was useful. We then analysed the qualitative data to look for important issues to

help us understand these numbers better, for example, to find out about people's experiences of involvement.'

Angela Barnard and others (2005) PC11 Report Summary: An evaluation of consumer involvement in the London Primary Care Studies Programme, INVOLVE, page 3.

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 Spotlight on public involvement

What this chapter is about:

This chapter explains what we mean when we talk about public involvement in research.

The key messages are:

Public involvement in research is when members of the public get actively involved in the research process.

It is about research that is done 'with' or 'by' the public rather than 'to', 'for' or 'about' them. (For example, where members of the public become part of an advisory group or work alongside researchers on a project.)

Public involvement can range from being consulted about some aspect of a piece of research, through to research which is actively controlled, directed and managed by the public.

Understanding what public involvement means may help you decide **if** you want to get involved and **how** you want to be involved.

3.1 Who are 'the public'?

All the way through this Public Information Pack we talk about 'the public' and 'people who use services'. When we use these phrases we mean this to include:

- patients and potential patients
- informal (unpaid **carers**)
- parents/guardians
- people who use 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 service **interventions**
- groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services
- organisations that represent people who use services.

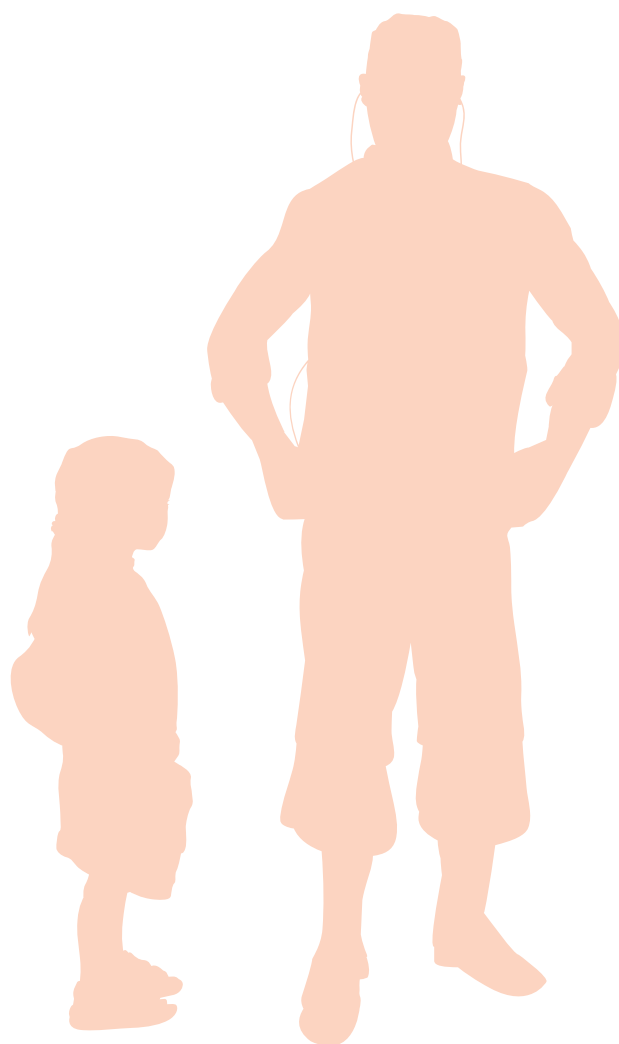
The 'public' is made up of individuals and groups who may or may not share common interests and goals. So, although we talk about 'the public' or 'people who use services', this is really just our shorthand for a very broad range of people.

We recognise that 'the public' also embraces the rich diversity of people in our multi-cultural society whether defined by age, colour, race, ethnicity, nationality, disability, gender or sexuality, who may well have different needs and concerns. This diversity needs to be taken into account in developing research policies, procedures and practices.

All of us are actual or potential users of health and social care services, but we think there is an important distinction to be made between the **perspectives** of people who use services and the perspectives of people who have a 'professional' role in health and social care services (such as doctors, psychiatrists,

occupational therapists, dentists, social workers, health promotion specialists, etc.).

Many different labels are used or given to people who use services. For example, terms like "patient", "**lay** person", "**survivor**", "**service user**", "**carer**", "**user**" "**consumer**", "**research partners**" and "client". It is not that one word is necessarily 'right' and another is 'wrong', but you may be more comfortable with some of these terms than others and different words have their supporters and critics.



3 Spotlight on public involvement

Example

Carr-Gomm is a national charity providing support and housing services that place individuals at the centre of planning and decision making, enabling them to have control over their lives, www.carrgom.org.uk.

“Clients from our focus groups told us that calling them a service user had a negative connotation for them and reminded them of being ill and in health services. We held a ballot for a new name and the winner was ‘client’.”

**Pam Richards, Research Partner
Rheumatology Unit, Bristol Royal Infirmary**

“The reason we are called Research Partners is because it helps to acknowledge our role as equal participants on a project along with the rest of the research steering group e.g. Principal Investigator, Clinician or Psychologist.”

Some views from people who took part in the INVOLVE workshop to help us write PIP:

“I really hate the term ‘service user’, but I’m not sure what else could be used and it’s a term taken on board by government and other bodies. Seems we are stuck with it.”

“I don’t mind what I am called – Service User is fine!”

“Yes it does matter what you are called. People become extremely confused with all the different terminology used to describe service users.”

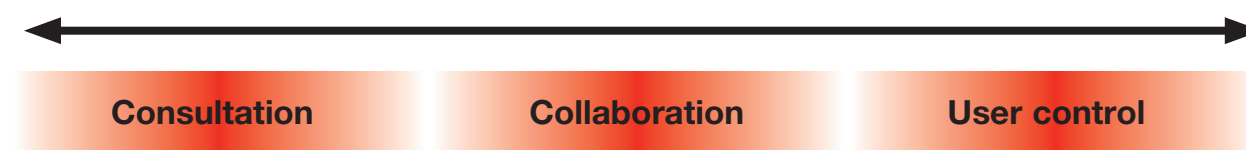
3.2 What is involvement?

When we talk about ‘**involvement**’ we mean getting actively involved in the research process itself rather than being the **participants** or subjects of the research. Many people describe public involvement in research as research that is done **with** or **by** the public and not **to**, **about** or **for** them.

The public has been involved in research and development for a number of years and in a variety of different ways. For example, this includes:

- identifying and prioritising research topics
- being part of research **advisory groups** and **steering groups**
- undertaking research projects
- reporting and communicating research findings.

One way to picture involvement is as a spectrum or three coloured rainbow that blends from **consultation** to **collaboration** and then through to **user control**.



Consultation

This is usually when you are asked for your views on something by **researchers**. For example, a research team might ask you as a member of a local gym to comment on a **questionnaire** for people who are being encouraged by their doctor to increase the amount of physical exercise that they do. This could be a one-off consultation or the research team might come back for further consultation to refine the questionnaire and check they have understood your feedback. The more closely that the research team and people who use services work together, the further this moves towards being a collaboration.

In my experience...

“ When we started out in 2001 as a result of the INVOLVE guideline book, we had no idea where it would lead us. Now we know and it's great. All we say is – get involved – you will be surprised what happens. And that's only one aspect of consumers in research. ”

Geoffrey Aitchison

Example

Consultation in a randomised controlled trial

Ali Khalid and other researchers involved stroke patients and carers in the design of a randomised controlled trial, to test the benefits of giving people oxygen immediately after having a stroke. The researchers carried out focus groups and also asked the stroke patients and their carers to complete questionnaires. The researchers asked for their views on the importance of the study, the relevance and acceptability of different measures of the benefits of the treatment, (e.g. improved communication, mood, memory), and who they felt should give consent (agreement) for individuals to take part in the study (e.g. a doctor or carer).

They helped the researchers to identify important measures that are not usually looked at in studies, and gave them other information about how patients want to be treated when they participate in research.

For more information, see the following article in Stroke:

Khalid, Ali (2006) What patients want: Consumer involvement in the design of a randomized controlled trial of routine oxygen supplementation after acute stroke. Stroke. Volume 37, pages 865-871.

An online version is available at: www.stroke.ahajournals.org/cgi/content/full/37/3/865.

3 Spotlight on public involvement

Collaboration

By collaboration we mean an active and on-going partnership in the research between researchers and people who use services. For example, you may be a member of an advisory group for a research project, be working as a **research partner** carrying out interviews, or writing up parts of a research report and then telling people about your research findings. The more that people who use services take the initiative in this relationship and influence or control decision making, then the further this moves towards being user led or user controlled.

In my experience...

“ This collaborative work brings the public a better and easier understanding and awareness of clinical trials. My involvement prompted local NHS Trust review of Clinical Trials Guidelines. ”

U Hla Htay

(Note: This project, funded by the National Institute for Mental Health in England, involved the development of the content of a website which included information about taking part in a clinical trial, and a pilot register of publicly funded trials.)

Example

The Alzheimer's Society

The Alzheimer's Society Quality Research in Dementia, awarded a research grant to carers of people with dementia as joint applicants with an academic unit. Their personal experience of caring for people with dementia ensured they included questions they felt were important, but which the researchers had not thought mattered.

INVOLVE (2003) Report of commissioning workshop, 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.

Example

Gypsies and Travellers in England

Researchers from the University of Sheffield carried out some research looking at the inequalities in health between gypsy travellers and non-gypsy travellers. The research included exploring the health experiences, beliefs and attitudes of gypsy travellers and their experience of accessing health care services. The project was aided by an advisory group which included 6 gypsy travellers and the secretary of the Gypsy Council.

Parry, Glenys and others (2004) The Health Status of Gypsies and Travellers in England. University of Sheffield.

The full report can be downloaded from www.shef.ac.uk/scharr/sections/ir/library/publications.html.

User control

There is no one agreed definition of **user controlled research**. But there is agreement that the main purpose of user controlled research is to improve service users' lives. User controlled research is research that is actively controlled, directed, and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned, and written up. The service users will run the research **advisory** or **steering group** and may also decide to carry out the research.

Some service users make no distinction between the terms 'user controlled' and 'user led' research, others feel that user led research has a different more vague meaning. They see user led research as research which

is meant to be led and shaped by service users but is not necessarily controlled by them. Control in user led research in this case will rest with some other group of non-service users who also have an interest in the research, such as the **commissioners** of the research, the **researchers**, or people who provide services.

If you are thinking about starting a user controlled research project then **Booklet 2, Chapter 4**, includes some suggestions for getting started.

For further information about user controlled research, you might find it helpful to read the report written by Peter Beresford and Michael Turner (**Beresford, Peter and Turner, Michael, 2005**).

Example

Women users of alcohol treatment services

Patsy Staddon, a service user researcher has carried out a four year research project in Bristol on women users of alcohol treatment services. This involved two parts, a) interviewing women who have or had alcohol problems, and b) interviewing GPs and alcohol treatment centre staff. Both sets of research were reported back to the local NHS Trust, the Primary Care Trusts, the service commissioners, local GPs and the alcohol treatment centres. She believes that to obtain good research results, service users must be involved at every stage of the research process including the idea and the design.

Patsy and the women interviewed went on to form WIAS (Women's Independent Alcohol Support), a support and social group for women in Bristol.

Patsy Staddon (2006) Service user research and why it hurts. 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.

3 Spotlight on public involvement

3.3 What kind of involvement is best?

There are so many different areas and methods of research in which you could get involved that it is not possible to identify one model of involvement as being better than all the rest. For example, a good model for getting involved in research about treatments for cancer, may not necessarily be a good one for getting involved in research about local housing needs.

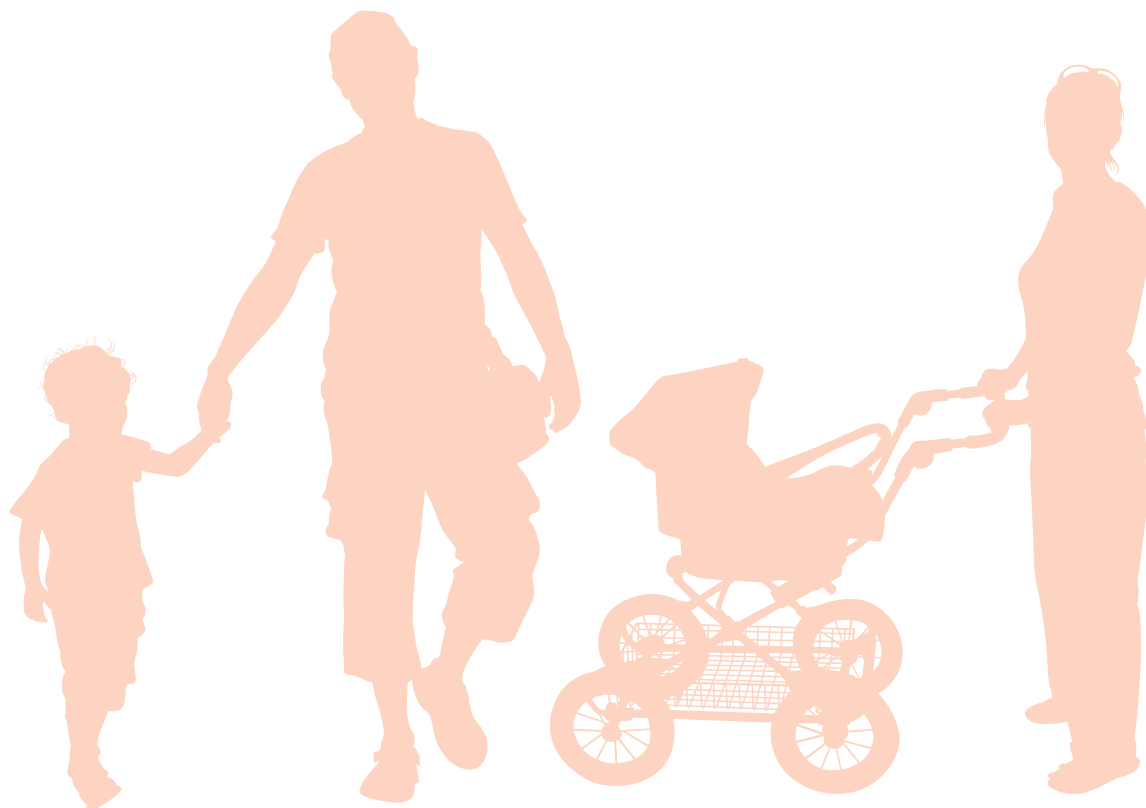
However, there are things you may want to know about the underlying values of an organisation or project before you decide whether to get involved. For example you may want information on who is funding the research or how researchers will keep the research **participants** informed about their findings.

In **Booklet 2**, we suggest how you can go about identifying some of the things that are important to you.

3.4 Reference

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.



In my experience...

“ I have been involved in a few pieces of research, pieces that have been led by the users themselves and also pieces that have been led by professional bodies. Although I much prefer the user led research, both types have been a good experience.

With the user led research we were a user group facilitated by a facilitator. With the facilitator we devised questions, carried out interviews, collated the information and presented it at a conference. And I was involved in all of the aforementioned activities.

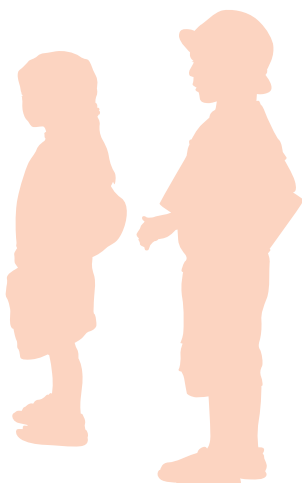
With the professional led research I was invited to take part especially to gather the BME [Black and minority ethnic] perspective on this particular piece of research. I was given a partner and supported right throughout. There was

always someone to ring or contact if I was unsure about something and we had regular team meetings. I wasn't given too much to do and was made to feel that my participation was important and valued.

I think the benefits of getting involved in both pieces of research meant that the studies had been able to gather a true and accurate and grass roots view of the BME opinion for those study subjects. For me it was good to feel useful and that there was life after mental illness and I felt I had achieved.

Some lessons I believe were learnt, were that users can and do make useful and helpful contributions to research and add to the archives of knowledge.”

Patricia Chambers



4 Why it matters

What this chapter is about:

This chapter explains why people decide to get involved in research, the routes people have taken and some of the benefits of involvement.

The key messages are:

People get involved in research for many different reasons.

There are benefits for the research itself, for future services and treatments and for the people involved.



4.1 Why do it?

People decide to get involved in **research** for a variety of reasons. Some of these reasons are linked to personal experiences of health or social care services and some are more general, because for example, they may want to find out more and/or help improve services and treatments. (Tarpey, Maryrose 2006).

4.2 Reasons for getting involved

You may decide to get involved because:

- you have **personal knowledge and experience** which you would like the research to take into account
- you want a chance to **give something back** and help influence research to benefit others
- you are **frustrated and angry** about how you or others have been treated and welcome the chance to channel those negative experiences into something potentially more positive
- you would like the opportunity to **develop personal skills** by learning about research, receiving payment and generally gaining experience and confidence
- you want to help bring about **improvements to health and social care** services and treatments for yourself and others
- you want to help bring about **improvements to the environment, health and well-being** of your local community

Getting involved in research can help shape:

- what research is done and how
- the services and treatments being researched

In my experience...

“ My motive for involvement is because I want to help enhance the effectiveness of rheumatology research and to ensure it is targeted at issues which I think are important. ”

Pam Richards

“ I get involved in conducting research as I hope the results of such research will bring about change for-the-better of the research project. ”

David Howes

“ I became involved in research because I have found there is little knowledge, understanding or provision for those of us with long-term unseen disabilities. ”

Louise (Tarpey, Maryrose, 2006)



4 Why it matters

Example

NHS R&D Strategy

The following is a quote from the Department of Health's research strategy in 2006, about the importance of public involvement.

"We know from our experience that engaging patients and members of the public leads to research that is more relevant to people's needs and concerns, more reliable and more likely to be put into practice."

Department of Health (2006) Best Research for Best Health, NHS R&D Strategy – Section 5.3

A new national health research strategy. Available to download from the publications section of the Department of Health website www.dh.gov.uk. To order a hard copy telephone: 0870 155 54 55.

4.3 What are the benefits of public involvement to research?

Your involvement in research can help to:

- identify what research is important to fund. This may be different to the research that **commissioners** or **researchers** think should be done
- influence the way research is planned, for example by working on the **research proposal**, and how it will be carried out
- improve the experience for people taking part in the research by influencing the way the research is carried out
- influence the **outcome measures** of a research study, by suggesting measures which are important to people who use services
- increase the number of **participants** who agree to be in the research by making sure they are given good quality information and are treated with respect
- make it more likely that the findings of research are provided in user friendly ways and publicised widely so that the people get to hear about it

In my experience...

“ I don't see my role in research as simply getting things such as patient information right from the participants' point of view. I believe that patients should have a much stronger voice in setting the research agenda. The way in which much research seems to be driven by individuals' career interests is deeply disturbing and in my experience results in scarce resources being frittered away on work which makes, at best, a marginal contribution to cancer knowledge. ”

Christine (Tarpey, Maryrose, 2006)

In my experience...

“ Our high level of involvement is fuelled by the fact we see the project through from first thoughts to a live outcome where the study results are put into practice. Even then, we receive feedback that is so vital. Because of our involvement funding and ethics clearance is usually much easier. ”

Geoffrey Aitchison

Example

Joseph Rowntree Foundation Social Care and Disability Committee

The Joseph Rowntree Foundation's (JRF) Social Care and Disability Committee funded the REU (now called the Race Equality Foundation) to carry out some research with black and minority ethnic older people, to review existing research and look at how future research or development work might be taken forward. They wrote a paper which summarised existing research and they then discussed this with older people at meetings around England. They involved Asian, African and Caribbean older people and used facilitators who had community language skills to ensure that they effectively communicated with all the older people who participated.

The older people agreed that much of the research reflected their experiences, but they were concerned about the limited

involvement of older people in setting the agenda, as well as the lack of change that has resulted from the gathering of this evidence. They were clear that work in the future needed to explore how to bring about change. These discussions informed JRF's invitation to others to propose further work with black and minority ethnic older people.

Butt, Jabeer and O'Neill, Alex (2004) 'Let's move on' black and minority older people's views on research findings.

This is available from the **Joseph Rowntree Foundation (JRF)** Bookshop www.jrf.org.uk/bookshop/. It can either be downloaded free of charge or hard copies can be purchased from the JRF bookshop. The Joseph Rowntree Foundation findings for this project are available at www.jrf.org.uk/knowledge/findings.

There are benefits for the research itself, for future services and treatments and for the people involved.



4 Why it matters

Example

Influencing Palliative Care Project

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 researchers reflected that the SURAG (Service User Research Advisory Group), made a substantial influence on the research and how it was conducted. The involvement of service users in the analysis provided a fresh perspective which was quite different to research undertaken with professional researchers taking the lead. They felt that the prioritisation of independence, choice and control for people with life limiting conditions, that was a key issue highlighted in this research, can be attributed to the involvement of the SURAG.

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

4.4 What are the benefits to society and services?

One of the strongest motives people give for getting involved in research, is to help bring about improvements to health and social care and to improve existing services and treatments. Your involvement can:

- encourage research commissioners and researchers to carry out research that is useful and important to service users and carers, and likely to lead to improvements in services
- provide new information about, for example, what would help improve people's quality of life and their support needs
- influence decisions taken about new services and the ways they will be provided
- add to the range of **perspectives** of people using health and social care services and receiving treatments

In my experience...

“ I was involved in the PC11 Project – an evaluation of consumer involvement in 11 projects collectively known as the London Primary Care Studies Programme. I became involved because I'm convinced of the need for such involvement if services are to improve and was excited by the prospect of contributing to the evidence base that demonstrates the effects of involvement. ”

Angela Barnard

Example

Health First

In 2001 Health First, who focus on NHS health promotion in Lambeth, Southwark and Lewisham, supported a research project carried out by people living on two housing estates in Lambeth and members of the 'Food Availability Mapping Project'. Their research found that there were considerable local difficulties to getting cheap fruit and vegetables, and that subsidised delivery schemes were seen as a way to help people eat more fruit and vegetables.

Based on this research, two six week pilot schemes were set up selling fruit and vegetables at community stalls and delivering to people's houses on both estates. These schemes were then evaluated by the Food Availability Mapping Project, again with support from Health First. On the basis of the findings it was agreed to set up a fruit and vegetable scheme as a not-for-profit community business on each estate. Each scheme would provide good quality, good value fruit and vegetables to local people and groups, selling at one or more places on the estates and delivering to homes.

For further information see: Food Availability Mapping Project (2001) Health Action Zone, Evaluation of pilot projects, Health First.

The report can be downloaded from:
www.healthfirst.org.uk/publications/project_reports.htm

In my experience...

“ Among the many benefits, was my hands-on experience of a ground-breaking evaluation. I learnt much about research and the wide variety of ways in which people from very different backgrounds could work together successfully.... Working in a mixed team of academics, researchers and people from a service user background was really stimulating and it was great to see in practice, how much mutual respect and sharing knowledge enriched the whole project. My own contribution to the project was one facet of that positive and creative process.

My lasting conviction from this experience is that when we are willing to value each other's knowledge and respect the differences that exist between us, then we can bring about positive and lasting change. ”

Angela Barnard

“ Personally, I enjoy talking to, and meeting people, which also helps to boost confidence and feelings of self-worth. ”

David Howes

4 Why it matters

Example

The following are two examples of the benefits for individuals of getting involved in research.

All of the service users team members who took part in the TRUE project (a collaborative research project on training in research for service users) reported that they had appreciated the opportunity the project had given them to learn new skills, meet new people and to attend specific training sessions.

Faulkner, Alison (January, 2004)
Capturing the experiences of those involved in the TRUE project: A story of colliding worlds.
Commissioned by INVOLVE.

Patient **research partners** at Bristol University, reported benefits such as being able to contribute and give something back, having something to offer that is valued, and creating something positive from the illness. They reported gaining self-confidence, empowerment and a sense of equal partnership.

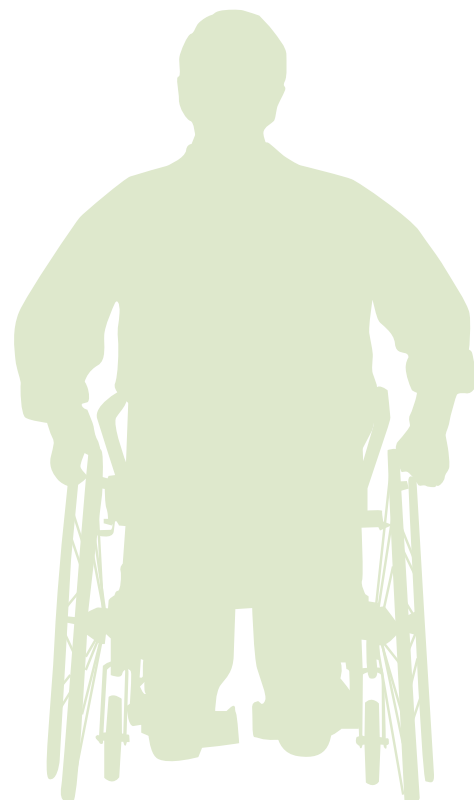
Hewlett, Sarah and others (2006)
Patients and Professionals as Research Partners: Challenges, Practicalities, and Benefits. Arthritis and Rheumatism (Arthritis Care and Research) Volume 55, Number 4, August 15th pages 676-680.

4.5 What are the personal benefits?

People who have been involved in research have described many positive benefits of getting involved (**Faulkner, Alison, 2004 and SURGE, 2005**). Some of the personal benefits people have told us about include:

- learning about research and the topic being researched
- developing a broader understanding of why research matters
- developing practical skills
- the satisfaction of making a contribution and helping to improve services.

Sometimes we hear from people who have been involved in research and found that not all their experiences were positive, for example because of lack of resources or support. In **Booklet 2** we have put together some questions you might want to think about asking before you decide to get involved, as this may help to minimise any difficulties.



Example

The TRUE Project

A report of the experiences of those involved in the TRUE project (a research project on training in research for service users) described some of the difficulties encountered in the project.

The TRUE project had originally planned and budgeted for the involvement of two service users in the project. It was decided to involve four people to manage possible absences or withdrawals from the project. However, when nine people applied to become involved, a decision was made to accept all of them, partly because it felt hard to say 'no' to people who wished to be involved. Many of the difficulties encountered during the project were felt to be mainly due to the number of people involved and the lack of resources to support this number of people.

Faulkner, Alison (January, 2004)
Capturing the experiences of those involved in the TRUE project: A story of colliding worlds. Commissioned by INVOLVE.

4.6 References

Faulkner, Alison (January, 2004)
Capturing the experiences of those involved in the TRUE project: A story of colliding worlds. Commissioned by INVOLVE. This is available to download from the publications section of www.invo.org.uk or by phoning the INVOLVE Support Unit: 02380 651088.

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 www.jrf.org.uk/bookshop/. It can either be downloaded free of charge or hard copies can be purchased from the JRF bookshop.

SURGE (Service User Research Group England) (2005)
Guidance for good practice: Service User Involvement in the UK Mental Health Research Network. These guidelines were developed with the aim of providing guidance to researchers and service users who wish to develop collaborative research projects and programmes involving service users within the UK Mental Health Research Network. The guidelines contain a literature review and guidance for good practice. The guidance can be downloaded from the service user involvement section of the **Mental Health Research Network website**: www.ukmhrn.info/dnn/.

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.

4 Why it matters

In my experience...

“ Most importantly has been the boost to my feelings of self-worth and self-esteem. I felt I now had a valued role in society. I had a SALARY too! I had a “real” job. I gained many practical skills (IT skills, presenting at conferences, research skills, etc) and general confidence. I was able to use my experiences of mental distress in a positive and informative way. I felt respected and valued by other non-mental health researchers ... being

proud to see myself as “A user researcher”. Having lots of fun and laughter with my colleagues It has been an interesting but sometimes I think, challenging experience ... I have been able to bring user research to the attention of our Trust, in an informed and assertive way. I am now a member of the R&D group....”

Alice Hicks





INVOLVE

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

INVOLVE is a national advisory body that is funded by the Department of Health to promote and support public involvement in NHS, public health and social care research and development.

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