4

Public Information Pack (PIP)

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

Jargon Buster

INVOLVE

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

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NHS
National Institute for
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PIP: Contents

Booklet 4 – Jargon Buster

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 4) 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'**.

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

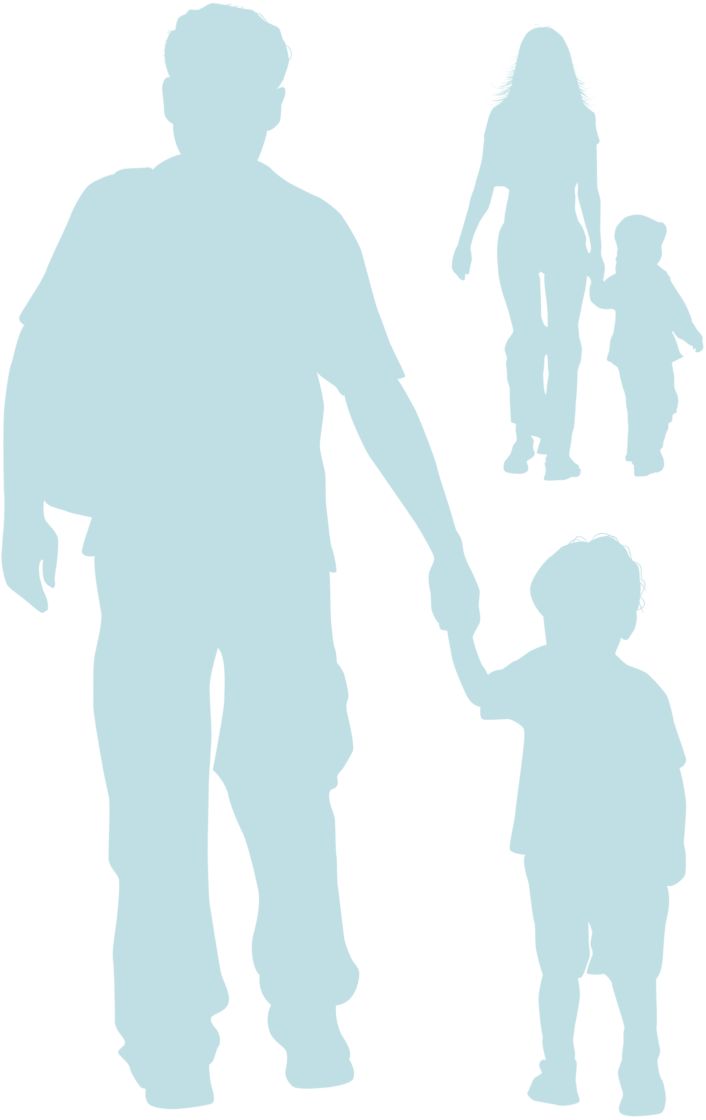
In this booklet there are four chapters. This booklet describes some of the different ways you can get involved in research, suggests questions to ask before deciding whether to get involved, as well as giving ideas about how to get started.

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.



2 Jargon Buster

2.1 What is in this booklet?

This booklet is a Jargon Buster or glossary of words. It contains the definitions of the words that you will have come across in **pink** whilst reading the other Public Information Pack (PIP) booklets. However, this is **not** a complete list of all the words that you might come across during your involvement in research.

The Jargon Buster is also available on our website where we hope to add more words in the future **www.invo.org.uk**

The definitions were developed for INVOLVE by TwoCan Associates working in consultation with a panel of researchers and a panel of people who use services. This process included, reviewing existing definitions and writing new ones where necessary, sending the draft definitions to three researchers to check for accuracy, sending a revised definition to a panel of service users to check for readability and then agreeing a final definition for inclusion in the INVOLVE Jargon Buster.

Acknowledgements

We would like to thank the following organisations for allowing us to use and draw on definitions from their glossaries:

- Alzheimer's Society Quality Research Programme
- Cochrane Collaboration
- National Electronic Library for Health
- National Institute for Mental Health (NIMHE)
- Suffolk Carers.

2.2 Definitions

Please note that terms in **pink** link to other terms in the Jargon Buster

Term	Definition
Abstract	This is a brief summary of a **research** study and its results. It should tell you why the study was done, how the **researchers** went about it and what they found.
Action research	Action research is used to bring about improvement or practical change. A group of people who know about a problem work together to develop an idea about how it might be resolved. They then go and test this idea. The people who take part in the testing provide feedback on their experiences. They may also identify further actions that need to be researched and tested. This cycle of developing solutions and testing them is repeated until the problem has been solved.
Advisory Group (Steering Group)	Many research projects have an advisory group (or steering group). The group helps to develop, support, advise and **monitor** the project. The group often includes people who use services, **carers**, researchers and other health and social care professionals, who can provide relevant advice.
Analysis (data analysis)	Data analysis involves examining and processing research **data**, in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.
Audit	An audit of health or social care involves carrying out a systematic assessment of how well that care is being delivered. Current policy and practice is compared with an agreed standard, so that any problem areas can be identified and improved. Later, the audit can be carried out again to check that the changes made have actually made a difference.
Basic research	Basic research aims to improve knowledge and understanding, rather than finding a solution to a practical problem. It usually involves work in a laboratory – for example to find a gene linked to a disease or to understand how cancer cells grow. This kind of research can sometimes provide clues as to which avenues to explore to develop new treatments.

2 Jargon Buster

Term	Definition
Carer	A carer is a relative, friend or partner who provides (or intends to provide, or used to provide) a substantial amount of care to another person on a regular basis, but not necessarily through living with them.
Clinical research	Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or the data from health and lifestyle surveys.
Clinical trial (trial)	Clinical trials are research studies involving people who use services, which compare a new or different type of treatment with the best treatment currently available. They test whether the new or different treatment is safe, effective and any better than what already exists. No matter how promising a new treatment may appear during tests in a laboratory, it must go through clinical trials before its benefits and risks can really be known.
Collaboration	Collaboration involves active, on-going partnership with **members of the public** in the research process. For example, members of the public might take part in an **advisory group** for a research project, or collaborate with researchers to design, undertake and/or **disseminate** the results of a research project.
Commissioner	A commissioner is the person (or organisation) who asks for a piece of research to be carried out.
Commissioning	Commissioning usually involves: • identifying funding for a piece of research • preparing a **research brief** • advertising the research topic • selecting a shortlist of researchers who apply to undertake the research • arranging for **proposals** to be **peer reviewed** • making a decision about which researchers are going to be awarded the funding • agreeing a contract.

Term	Definition
Commissioning Board/ Commissioning Panel	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 often includes people who use services and carers.
Confidentiality	During a research project, the researchers must put **data protection** measures into place, to ensure that all of the information collected about the participants is kept confidential. This means that the researchers must get the participants' written permission to look at their medical or social care records. It also means that any information that might identify the participants cannot be used or passed on to others, without first getting the participants' consent. For example, when researchers publish the results of a project, they are not allowed to include people's names. This confidentiality will only be broken in extreme circumstances: where it is essential for the person's care, treatment or safety, where it is required by a court order, e.g. in a criminal investigation, or it is necessary to protect the public.
Consultation	Consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. This consultation can be about any aspect of the research process – from identifying topics for research, through to thinking about the implications of the research findings. Having a better understanding of people's views should lead to better decisions.
Consumer	The term consumer is used to refer collectively to: • people who use services • carers • organisations representing consumers' interests • members of the public who are the potential recipients of services • groups asking for research to promote good health or because they believe they have been exposed to potentially harmful circumstances, products or services.

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Term	Definition
Data	Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, e.g. in reports, graphs or diagrams.
Data protection	All personal information is protected in the UK by the Data Protection Act (1998). This means that researchers have to put in all the necessary safeguards to protect the **confidentiality** of the information they collect about research participants. They should explain in the **patient information sheet**: • how the participants' **data** will be collected • how it will be stored securely • what it will be used for • who will have access to the data that identifies participants • how long it will be kept • how it will be disposed of securely.
Dissemination	Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through: • producing reports (often these are made available on the Internet) • publishing articles in **journals** or newsletters • issuing press releases • giving talks at conferences. It is also important to feedback the findings of research to research **participants**.
Emancipatory research	With emancipatory research, people who use services, rather than professional researchers, have control of the whole research process. They plan and undertake the research, and interpret the findings. The main aim is always to empower people and improve people's lives. 'Professional' researchers may be brought in as advisers or have specified roles within the project.

Term	Definition
Empowerment	This is the process by which people who use services equip themselves with the knowledge, skills and resources they need to be able to take control over decisions and resources. It often involves people building confidence in their own strengths and abilities. It does not always mean people take control over all decisions or all resources.
Ethics	Ethics are a set of principles that guide researchers who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, rights and well-being of the people taking part. They include the requirement to ask each individual to give their informed consent to take part in a research project.
Ethics Committees	The job of an ethics committee is to make sure that research carried out respects the dignity, rights, safety and well-being of the people who take part. Increasingly Ethics Committee approval is needed for health and social care research. Ethics committee members include researchers and health care professionals as well as members of the public.
Evaluation	This involves assessing whether an **intervention** (for example a treatment, service, project, or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. It can measure how well the project is being carried out as well as its impact. The results of evaluations can help with decision-making and planning.
Evidence Base	An evidence base is a collection of all the research **data** currently available about a health or social care topic, such as how well a treatment or a service works. This evidence is used by health and social care professionals to make decisions about the services that they provide and what care or treatment to offer people who use services.

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Term	Definition
Experimental Research	This type of research allows researchers to explore cause and effect. For example, experimental research would be used to see whether a **new** drug is effective in reducing blood pressure. The research design (in this example a **randomised controlled trial**) will tell the researcher whether any reduction in blood pressure is definitely due to the drug.
Experts by experience	The term 'experts by experience' refers to service users and carers, who are experts through their experience of illness or disability and services.
Focus Group	A focus group is a small group of people brought together to talk. 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 to problems.
Grey Literature	Grey literature is material that is less formal than an article in a **peer review journal** or a chapter in a book – so it's not easily tracked down. It includes internal reports, committee minutes, conference papers, factsheets, newsletters and campaigning material. However, 'grey literature' may be made available on request and is increasingly available on the Internet.
Honorary contract	Honorary contracts are required by anyone who wants to carry out research or observe people in an NHS setting, but who does not already have an employment contract or a volunteer contract with the relevant NHS Trust. The contract ensures that they are covered by NHS liability insurance, and that they are contractually bound to take proper account of the NHS duty of care.
Implementation	Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.

Term	Definition
Intervention	An intervention is something that aims to make a change and is tested through research. For example, giving a drug, providing a counselling service, improving the environment or giving people information and training are all described as interventions.
Interview	In research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the person (or people) being interviewed. Interviews can be carried out in person (face-to-face) or over the phone.
Involvement	Involvement in research refers to **active** involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research ‘subjects’). Many people describe involvement as doing research **with** or **by** people who use services rather than **to**, **about** or **for** them.
Journal	A journal is a regular publication in which researchers formally report the results of their research to people who share a similar interest or experience. Each journal usually specialises in one particular topic area. The BMJ (British Medical Journal), British Journal of Social Work and The Lancet are examples of journals.
Lay (lay person)	The term lay means non-professional. In research, it refers to the people who are neither academic researchers nor health or social care professionals.
Lay summary	A lay summary is a brief summary of a research project or a **research proposal** that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included.

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Term	Definition
Members of the public (or public)	INVOLVE uses this term to cover: • patients and potential patients • people who use health and social care services • informal (unpaid) carers • parents/guardians • disabled people • members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions • groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos) • organisations that represent people who use services. Other organisations have different definitions of this term.
Mentor	A mentor is a person willing to share their experience, knowledge and wisdom to help, guide and support someone who is less experienced. Mentors act as friends, teachers and advisers. A person who is newly involved in research can ask for a mentor to help them adjust to their new role.
Methodology	The term methodology describes **how** research is done – so it will cover how information is collected and analysed as well as **why** a particular method has been chosen.
Monitoring research	Monitoring research involves keeping up to date with the progress of a research project. This will include ensuring that the researchers are carrying out their research according to their **research proposal** or **protocol**, that the research is keeping to time and budget and that the research is being conducted ethically.
NHS research	NHS research is research carried out in the NHS or funded by the NHS. This includes research that takes place in local hospitals or GP surgeries, and larger studies commissioned by the NHS 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

Term	**Definition**
Outcome measures	Outcome measures are measurements of the effects of a treatment or service. They might include physical measurements – for example measuring blood pressure, or psychological measurements – for example measuring people's sense of well-being. So if someone takes part in research, they may be asked questions, or may be asked to have extra tests to assess how well the treatment or service has worked.
Participant	A participant is someone who takes part in a research project. Sometimes research participants are referred to as research 'subjects'.
Participatory research	This is a type of research where researchers and people who use services or carers are partners in a research project. The research addresses an issue of importance to service users or carers, who are involved in the design and conduct of the research, and the way the findings are made available. The aim of the research is to improve people's lives. This isn't a research method – it's an approach to research, a philosophy.
Patient information leaflet/patient information sheet	Researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and should include details about: • why the research is being done, how long it will last, and what methods will be used • the possible risks and benefits • what taking part will practically involve, e.g. extra visits to a hospital or a researcher coming to interview someone at home • what **interventions** are being tested, or what topics an interview will cover • how the researchers will keep participants' information confidential • what compensation is available to people if they are harmed as a result of taking part in the research • who to contact for further information • how the results will be shared with others.

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Term	Definition
Peer review/ refereeing	Peer reviewing is where a **research proposal** or a report of research is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. Peer reviewers might be members of the public, researchers, or other professionals. Peer review helps to check the quality of a report or research proposal. Members of the public who act as peer reviewers may choose to comment on: • whether the research addresses an important and relevant question • the methods used by researchers • the quality of **public involvement in the research.**
Peer interviewing	Peer interviewing is where people are interviewed by others who have a similar experience to them – their peers. For example, in a project to find out about children's experiences of after school care, children with experience of using after school care may act as peer interviewers, asking other children about their experience. Some researchers believe that this kind of interviewing enables people to talk more freely about their experience.
Perspectives/ user perspectives	A user perspective is often what people with experience of using health or social services are asked to bring when they get involved in research. They are asked to provide ideas, comments and suggestions based on the unique insight they have from their knowledge and experience of life with a health condition. They cannot be representative of everyone who uses a particular service, but they can offer their own perspective, and often that of other people.
Placebo	A placebo is a fake or dummy treatment that is designed to be harmless and to have no effect. It allows researchers to test for the 'placebo effect'. The placebo effect is a psychological response where people feel better because they have received a treatment, and not because the treatment has a specific effect on their condition. By comparing people's responses to the placebo and to the treatment being tested, researchers can tell whether the treatment is having any real benefit.

Term	Definition
Protocol/ research protocol	A protocol is the plan for a piece of research. It usually includes information about: • what question the research is asking and its importance/relevance • the background and context of the research, including what other research has been done before • how many people will be involved • who can take part • the research method • what will happen to the results and how they will be publicised. A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research **ethics committee** for approval.
Public health research	Public health is concerned with promoting good health, preventing disease and protecting people from hazards, rather than treating illnesses. It covers topics like the control of infectious diseases, vaccinations, and helping people to adopt healthy lifestyles. Public health research involves finding out new knowledge (or testing out existing ideas) to do with public health – so it might address questions about: • the best ways to help people stop smoking • how Bird Flu spreads.
Qualitative research	Qualitative research is used to explore and understand people's beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about **why** people want to stop smoking. It won't ask **how many** people have tried to stop smoking. It does not collect **data** in the form of numbers. Qualitative researchers use methods like **focus groups** and interviews (telephone and face-to-face interviews).

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Term	Definition
Quantitative research	In quantitative research, researchers collect **data** in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or what proportion of children have had an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used. Quantitative researchers use methods like surveys and **clinical trials**.
Questionnaire	A questionnaire is a prepared set of written questions used to obtain information from research participants. Questionnaires can be completed on paper, using a computer or with an interviewer.
Randomised controlled trial	A controlled trial compares two groups of people: an experimental group who receive the new treatment and a control group, who receive the usual treatment or a **placebo**. The control group allows the researchers to see whether the treatment they are testing is any more or less effective than the usual or standard treatment. In a **randomised** controlled trial, the decision about which group a person joins is random (i.e. based on chance). A computer will decide rather than the researcher or the participant. Randomisation ensures that the two groups are as similar as possible, except for the treatment they receive. This is important because it means that the researcher can be sure that any differences between the groups are only due to the treatment.
Representative	As a representative, you are expected to speak on behalf of a larger group of people. If you've been asked to get involved in research as a representative of a particular group, you may want to think about how you can be confident that you are representing a wider range of people's views, rather than just offering your own **perspective**.

Term	Definition
Research	The term research means different things to different people, but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care. The definition used by the Department of Health is: "The attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods".
Research brief	**Research commissioners** write a research brief. The brief describes why they want to commission a piece of research, what questions the research should address and sometimes how the research should be carried out. It might include information about when the research needs to be completed and how much money is available. Researchers then write a **research proposal** that explains how they will address the research brief.
Researcher	Researchers are the people who do the research. They may do research for a living, and be based in a university, hospital or other institution, and/or they may be a service user or carer.
Research governance	Research governance is a process aimed at ensuring that research is high quality, safe and ethical. The Department of Health has a Research Governance Framework for Health and Social Care, which everyone involved in research within the NHS or social services must follow.
Research grant	Research grants are given to enable researchers to carry out a particular piece of research. They might amount to millions of pounds for a major study about genetics for example, or a few hundred pounds for a local study about people's experience of using a particular service. Usually, in order to get research grants, researchers have to write a **research proposal** and receive a positive **peer review**.
Research methods or techniques	Research methods are the ways researchers collect and analyse information. So research methods include interviews, questionnaires, diaries, **clinical trials**, experiments, analysing documents or **statistics**, and watching people's behaviour.

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Term	Definition
Research network	Research networks aim to bring together people who have an interest in research about a particular condition or group of people. Networks might be national or local. The Department of Health supports research networks to promote research in specific areas. These include: • cancer • medicines for children • diabetes • dementia • mental health • stroke. These networks encourage researchers to work together and improve the quality of research. Outside the NHS there are other types of research networks. For example, the Alzheimer's Disease Society and the Multiple Sclerosis Society support research networks of service users and carers who are actively involved in research.
Research partner	The term research partner is used to describe people who get actively involved in research, to the extent that they are seen by their 'professional' colleagues as a partner, rather than someone who might be consulted occasionally. Partnership suggests that researchers and service users/carers have a relationship that involves mutual respect and equality.
Research proposal	This is usually an application form or set of papers that researchers have to complete to say what research they want to do and how they want to do it. It will also cover the aim of the research, what the research questions are, who will be involved (both as **participants** and in carrying out the research), the time-scale and the cost.
Service user or user	A service user is someone who uses or has used health and/or social care services because of illness or disability. Some people do not like this term because they feel it has negative connotations.

Term	Definition
Social care research	Social care refers to a range of services provided across different settings, usually in the community. These include: • home care, day care and residential care for older people • residential care and fostering for children • support for parents of disabled children • supporting mental health service users, physically disabled people and people with learning difficulties • support for carers Social care research involves finding out new knowledge (or testing out existing ideas) to do with social care – so social care research might address questions about: • people's experience of using different home care services • the best ways to train new foster parents.
Statistics and statistical analysis	Statistics are a set of numbers **(quantitative data)** obtained through research. For example, the average age of a group of people, or the number of people using a service. Statistical analysis uses a set of mathematical rules to analyse **quantitative data**. It can help researchers decide what data means. For example, statistical analysis can assess whether any difference seen between two groups of people (e.g. between the groups of people in a **clinical trial**) is likely to be a reliable finding or simply due to chance.
Survivor researcher	Survivor is a term some people who have used health or social care services use to describe themselves – they see this as a more empowering term than 'patient' or 'sufferer'. For example, some people who have used mental health services or who have experienced mental or emotional distress call themselves survivors of the psychiatric system. Some people who have recovered from cancer call themselves cancer survivors. If someone describes themselves as a survivor researcher, they are making a statement about the fact that they have used health or social care services as well as being a researcher.

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Term	Definition
Systematic review	Systematic reviews aim to bring together the results of all studies addressing a particular research question that have been carried out around the world. They provide a comprehensive and unbiased summary of the research. For example, one **clinical trial** may not give a clear answer about the effectiveness of a treatment. This might be because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial. So systematic reviews are used to bring the results of a number of similar trials together, to piece together and assess the quality of all of the evidence. Combining the results from a number of trials may give a clearer picture.
User controlled research/user led research	**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 term user controlled and user led research, others feel that user led research has a different, vaguer 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.
User researcher	A user researcher is someone who uses or has used health and/or social care services because of illness or disability, who is also a researcher. Not all researchers who use health or social care services call themselves user researchers. Calling yourself a user researcher is making a statement about your identity as a service user as well as a researcher.

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.

If you would like to know more about what we do, please contact us:

INVOLVE
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD

Web: www.invo.org.uk
Email: admin@invo.org.uk
Telephone: 02380 651088
Textphone: 02380 626239

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