

## South Yorkshire Strategic Local Priority Group Patient and Public Involvement Glossary of Research terms

Developed from the INVOLVE 2007 jargon buster <http://www.invo.org.uk/resource-centre/jargon-buster/> (updated in 2017)

Term	Definition
<b>Abstract</b>	This is a brief summary of a <b>research</b> study and its results. It should tell you why the study was done, how the <b>researchers</b> went about it and what they found.
<b>Action research</b>	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.
<b>Active Involvement</b>	Active involvement of patients and the public (PPI's) in research refers to the process by which PPI's become involved in research processes, such as helping to design the research, recruiting to, and managing the research.
<b>Advisory Group</b>	Many research projects have an advisory group (or <b>(Steering Group)</b> steering group). The group helps to develop, support, advise and <b>monitor</b> the project. The group often includes people who use services, <b>carers</b> , researchers and other health and social care professionals, who can provide relevant advice.
<b>Analysis</b>	Data analysis involves examining and processing <b>(data analysis)</b> research <b>data</b> , 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.
<b>Audit</b>	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.
<b>Basic research</b>	Basic research aims to improve knowledge and

	<p>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.</p>
<b>Carer</b>	<p>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.</p>
<b>Chief Investigator</b>	<p>The Chief Investigator is the person who has initiated the trial, developed the trial design and the methods that will be used to answer the research question, and applied for funding to support the research. He/she is generally an expert in the area of research they have applied to undertake, and take overall responsibility for the trial.</p>
<b>NIHR Collaborations for Leadership in Applied Health Research and Care CLAHRCs</b>	<p>Nine NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) have been established in England to undertake high-quality applied health research focused on the needs of patients and to support the translation of research evidence into practice in the NHS.</p> <p>CLAHRCs are collaborative partnerships between a university and the surrounding NHS organisations, focused on improving patient outcomes through the conduct and application of applied health research. They will create and embed approaches to research and its dissemination that are specifically designed to take account of the way that health care is increasingly delivered across sectors and a wide geographical area.</p>
<b>NIHR CLAHRC for South Yorkshire</b>	<p>The mission of the NIHR CLAHRC for South Yorkshire is to undertake, over the next five years, high quality, strategic, applied research and related education in order to enable a 'step change' in the way research is delivered and services are designed in South Yorkshire; and to foster knowledge transfer that will improve the quality and effectiveness of health care delivery across South Yorkshire.</p>
<b>Clinical research</b>	<p>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</p>

	analyse the information in patient records, or the data from health and lifestyle surveys.
<b>Clinical trial (trial)</b>	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.
<b>Collaboration</b>	Collaboration involves active, on-going partnership with <b>members of the public</b> in the research process. For example, members of the public might take part in an <b>advisory group</b> for a research project, or collaborate with researchers to design, undertake and/or <b>disseminate</b> the results of a research project.
<b>Commissioner</b>	A commissioner is the person (or organisation) who asks for a piece of research to be carried out.
<b>Commissioning</b>	Commissioning usually involves: <ul style="list-style-type: none"> <li>• identifying funding for a piece of research</li> <li>• preparing a <b>research brief</b></li> <li>• advertising the research topic</li> <li>• selecting a shortlist of researchers who apply to undertake the research</li> <li>• arranging for <b>proposals</b> to be <b>peer reviewed</b></li> <li>• making a decision about which researchers are going to be awarded the funding</li> <li>• agreeing a contract.</li> </ul>
<b>Commissioning Board</b>	A Commissioning Board is a group of people who <b>Commissioning Panel</b> oversee the <b>commissioning</b> process. It is made up of research funders, researchers, health and/or social care professionals and often includes people who use services and carers.
<b>NIHR Comprehensive Clinical Research Network (CCRN)</b>	The NIHR CCRN provides: <ul style="list-style-type: none"> <li>• a clinical research infrastructure to support a high quality portfolio of clinical research studies and facilitate patient participation into studies</li> <li>• NHS Service Support Costs which were previously provided through other NHS R&amp;D funding streams</li> <li>• and deploys resources for research management in order to ensure that the NIHR research portfolio is delivered to the highest standards of research governance.</li> </ul>

	CCRN consists of a number of Comprehensive Local Research Networks (CLRN) which are managed locally and support participation in the national portfolio of NIHR CRN CC studies.
<b>NIHR Comprehensive Local Research Network for South Yorkshire (SY CLRN)</b>	The NIHR SYCLRN is one of 25 CLRN across England which form part of the NIHR CCRN. CCRN provides support for clinical trials and other well designed studies in all areas of disease and clinical need.
<b>Confidentiality</b>	<p>During a research project, the researchers must put <b>data protection</b> 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.</p> <p>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</p>
<b>Consent</b>	Informed consent in a research study is the process by which a participant voluntarily confirms their willingness to take part in a study after they have been fully informed of all the aspects of the trial, which they need to know about, such as possible risks, number of visits, tests involved etc, in order to allow them to make a decision as to whether or not to take part. Part of this process will involve signing a consent form to show that the participant has agreed to be involved in the research study.
<b>Consultation</b>	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.
<b>Consumer</b>	<p>The term consumer is used to refer collectively to:</p> <ul style="list-style-type: none"> <li>• people who use services</li> <li>• carers</li> <li>• organisations representing consumers' interests</li> </ul>

	<ul style="list-style-type: none"> <li>• members of the public who are the potential recipients of services</li> <li>• groups asking for research to promote good health or because they believe they have been exposed to potentially harmful circumstances, products or services.</li> </ul>
<b>Consumer Research Advisory Group (CRAG)</b>	The Barnsley CRAG are a team of seven consumers and a researcher, who work closely with Barnsley's research and development department, to provide a consumer perspective to researchers on studies which will take place within the hospital setting or local community. They are generally involved at the design stage of a research project, or to review proposals.
<b>Data</b>	Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so it can be analysed, interpreted and then communicated to others, e.g. in reports, graphs or diagrams.
<b>Data protection</b>	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 <b>confidentiality</b> of the information they collect about research participants. They should explain in the <b>patient information sheet</b> : <ul style="list-style-type: none"> <li>• how the participants' <b>data</b> will be collected</li> <li>• how it will be stored securely</li> <li>• what it will be used for</li> <li>• who will have access to the data that identifies participants</li> <li>• how long it will be kept</li> <li>• how it will be disposed of securely.</li> </ul>
<b>Dissemination</b>	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: <ul style="list-style-type: none"> <li>• producing reports (often these are made available on the Internet)</li> <li>• publishing articles in <b>journals</b> or newsletters</li> <li>• issuing press releases</li> <li>• giving talks at conferences.</li> </ul> It is also important to feedback the findings of research to research <b>participants</b> .
<b>Emancipatory research</b>	With emancipatory research, people who use services, rather than professional researchers, have control of

	<p>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.</p>
<b>Empowerment</b>	<p>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.</p>
<b>Ethics</b>	<p>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.</p>
<b>Ethics Committees</b>	<p>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.</p>
<b>Evaluation</b>	<p>This involves assessing whether an <b>intervention</b> (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.</p>
<b>Evidence Base</b>	<p>An evidence base is a collection of all the research <b>data</b> 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.</p>
<b>Experimental Research</b>	<p>This type of research allows researchers to explore cause and effect. For example, experimental research would be used to see whether a <b>new</b> drug is effective in reducing blood pressure. The research design (in this</p>

	example a <b>randomised controlled trial</b> ) will tell the researcher whether any reduction in blood pressure is definitely due to the drug.
<b>Experts by experience</b>	The term 'experts by experience' refers to service users and carers, who are experts through their experience of illness or disability and services.
<b>Focus Group</b>	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.
<b>Grey Literature</b>	Grey literature is material that is less formal than an article in a <b>peer review journal</b> 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.
<b>Honorary contract</b>	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.
<b>Implementation</b>	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.
<b>Intervention</b>	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.
<b>Interview</b>	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.
<b>Involvement</b>	Involvement in research refers to <b>active</b> involvement between people who use services, carers and researchers, rather than the use of people as

	<p>participants in research (or as research 'subjects'). Many people describe involvement as doing research <b>with</b> or <b>by</b> people who use services rather than <b>to</b>, <b>about</b> or <b>for</b> them.</p>
<b>Journal</b>	<p>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.</p>
<b>Lay (lay person)</b>	<p>The term lay means non-professional. In research, it refers to the people who are neither academic researchers nor health or social care professionals.</p>
<b>Lay summary</b>	<p>A lay summary is a brief summary of a research project or a <b>research proposal</b> 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.</p>
<b>Members of the public (or public)</b>	<p>This term covers:</p> <ul style="list-style-type: none"> <li>• patients and potential patients</li> <li>• people who use health and social care services</li> <li>• informal (unpaid) carers</li> <li>• parents/guardians</li> <li>• disabled people</li> <li>• members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions</li> <li>• groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos)</li> <li>• organisations that represent people who use services.</li> </ul> <p>Other organisations have different definitions of this term.</p>
<b>Mentor</b>	<p>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.</p>
<b>Methodology</b>	<p>The term methodology describes <b>how</b> research is done – so it will cover how information is collected and analysed as well as <b>why</b> a particular method has been chosen.</p>

<b>Monitoring research</b>	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 <b>research proposal</b> or <b>protocol</b> , that the research is keeping to time and budget and that the research is being conducted ethically.
<b>NHS research</b>	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: <ul style="list-style-type: none"> <li>• a study based in a GP surgery looking at people's experience of long-term chronic pain</li> <li>• a <b>randomised controlled trial</b> to look at the best treatment for people with bowel cancer</li> </ul>
<b>National Institute for Health Research (NIHR)</b>	The National Institute for Health Research (NIHR) provides the framework through which the Department of Health positions, maintains and manages the research, research staff and research infrastructure of the NHS in England as a national research facility.
<b>NIHR Research Design Services (RDSs)</b>	The National Institute for Health Research's Research Design Services (NIHR RDSs) aim to increase the volume and quality of successful grant applications for national funding competitions including NIHR funding. To do this they provide expert advice to help researchers to develop and design high quality research proposals for such competitions. Each RDS is part of the NIHR infrastructure and this support is provided free of charge.
<b>NIHR Research Design Service Yorkshire and the Humber (RDS YH)</b>	RDS YH provides advice to NHS researchers, and others working in partnership with the NHS, within South Yorkshire, West Yorkshire, North and East Yorkshire and Northern Lincolnshire, who are developing an application to a suitable funding body, particularly Research for Patient Benefit (RfPB) and all other NIHR research programmes.
<b>North Trent Cancer Research Network Consumer Research Panel (NTCRN CRP)</b>	The North Trent Cancer Research Network Consumer Research Panel has its own website at <a href="http://www.ntcrp.org.uk/">http://www.ntcrp.org.uk/</a> . The group has 40 patient and carer members who are involved in local cancer research projects. Read about their work on the site.
<b>Outcome measures</b>	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.
<b>Participant</b>	A participant is someone who takes part in a research project. Sometimes research participants are referred to as research ‘subjects’.
<b>Patient Advice and Liaison Service (PALS)</b>	PALS, were introduced (to every Health Care Trust) to ensure that the NHS has someone in place that listens to the concerns of patients and their families, and can provide on the spot help. The service aims to resolve any problems that may occur with health related issues and NHS services as quickly as possible. It also provides information about the NHS, as well as supporting patients during hospital visits, with help in getting around the hospital.
<b>Participatory research</b>	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.
<b>Patient information leaflet/ patient information sheet</b>	<p>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:</p> <ul style="list-style-type: none"> <li>• why the research is being done, how long it will last, and what methods will be used</li> <li>• the possible risks and benefits</li> <li>• what taking part will practically involve, e.g. extra visits to a hospital or a researcher coming to interview someone at home</li> <li>• what <b>interventions</b> are being tested, or what topics an interview will cover</li> <li>• how the researchers will keep participants’ information confidential</li> <li>• what compensation is available to people if they are harmed as a result of taking part in the research</li> <li>• who to contact for further information</li> <li>• how the results will be shared with others.</li> </ul>
<b>Patient and Public</b>	When we talk about patient and public involvement (PPI) in

<b>Involvement (PPI)</b>	research, we are talking about research that's carried out by patients and/or members of the public, rather than being done to, or about them.
<b>Patient and Public Involvement Forum (PPIF)</b>	The PPIF exists to ensure that there is PPI in the development and delivery of all the RDSYH's core PPI activities, and to monitor progress.
<b>Peer review/refereeing</b>	<p>Peer reviewing is where a <b>research proposal</b> 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.</p> <p>Members of the public who act as peer reviewers may choose to comment on:</p> <ul style="list-style-type: none"> <li>• whether the research addresses an important and relevant question</li> <li>• the methods used by researchers</li> <li>• the quality of <b>public involvement in the research.</b></li> </ul>
<b>Peer interviewing</b>	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.
<b>Perspectives / user perspectives</b>	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.
<b>Placebo</b>	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.

<b>Protocol / research protocol</b>	<p>A protocol is the plan for a piece of research. It usually includes information about:</p> <ul style="list-style-type: none"> <li>• what question the research is asking and its importance/relevance</li> <li>• the background and context of the research, including what other research has been done before</li> <li>• how many people will be involved</li> <li>• who can take part</li> <li>• the research method</li> <li>• what will happen to the results and how they will be publicised.</li> </ul> <p>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 <b>ethics committee</b> for approval.</p>
<b>Public health research</b>	<p>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.</p> <p>Public health research involves finding out new knowledge (or testing out existing ideas) to do with public health – so it might address questions about:</p> <ul style="list-style-type: none"> <li>• the best ways to help people stop smoking</li> <li>• how Bird Flu spreads.</li> </ul>
<b>Qualitative research</b>	<p>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 <b>why</b> people want to stop smoking. It won’t ask <b>how many</b> people have tried to stop smoking. It does not collect <b>data</b> in the form of numbers.</p> <p>Qualitative researchers use methods like <b>focus groups</b> and interviews (telephone and face-to-face interviews).</p>
<b>Quantitative research</b>	<p>In quantitative research, researchers collect <b>data</b> 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.</p> <p>Quantitative researchers use methods like surveys and <b>clinical trials</b>.</p>
<b>Questionnaire</b>	<p>A questionnaire is a prepared set of written questions used to obtain information from research participants.</p>

	Questionnaires can be completed on paper, using a computer or with an interviewer.
<b>Randomised controlled trial</b>	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 <b>placebo</b> . 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 <b>randomised</b> 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.
<b>Representative</b>	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 <b>perspective</b> .
<b>Research</b>	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".
<b>Research brief</b>	<b>Research commissioners</b> 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 <b>research proposal</b> that explains how they will address the research brief.
<b>Researcher</b>	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.

<p><b>Research governance</b></p>	<p>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.</p>
<p><b>Research grant</b></p>	<p>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 <b>research proposal</b> and receive a positive <b>peer review</b>.</p>
<p><b>Research methods or techniques.</b></p>	<p>Research methods are the ways researchers collect and analyse information. So research methods include interviews, questionnaires, diaries, <b>clinical trials</b>, experiments, analysing documents or <b>statistics</b>, and watching people's behaviour.</p>
<p><b>Research network</b></p>	<p>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:</p> <ul style="list-style-type: none"> <li>• cancer</li> <li>• medicines for children</li> <li>• diabetes</li> <li>• dementia</li> <li>• mental health</li> <li>• stroke.</li> </ul> <p>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.</p>
<p><b>Research partner</b></p>	<p>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.</p>

<b>Research proposal</b>	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 <b>participants</b> and in carrying out the research), the time-scale and the cost
<b>Service user or user</b>	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.
<b>Sheffield Emergency Care Forum</b>	This is a group of patients and members of the public who provide the public and patient point of view in research studies. They provide assistance to researchers throughout all the stages of a project, from the proposal stage, in the steering group stage and through to the stage where results are made available to the general public.
<b>Social care research</b>	<p>Social care refers to a range of services provided across different settings, usually in the community. These include:</p> <ul style="list-style-type: none"> <li>• home care, day care and residential care for older people</li> <li>• residential care and fostering for children</li> <li>• support for parents of disabled children</li> <li>• supporting mental health service users, physically disabled people and people with learning difficulties</li> <li>• support for carers</li> </ul> <p>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:</p> <ul style="list-style-type: none"> <li>• people's experience of using different home care services</li> <li>• the best ways to train new foster parents</li> </ul>
<b>Statistics and statistical analysis</b>	<p>Statistics are a set of numbers (<b>quantitative data</b>) obtained through research. For example, the average age of a group of people, or the number of people using a service.</p> <p>Statistical analysis uses a set of mathematical rules to analyse <b>quantitative data</b>. 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 <b>clinical trial</b>) is likely to be a reliable finding or simply due to chance.</p>
<b>Survivor researcher</b>	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

	<p>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.</p> <p>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.</p>
<b>Systematic review</b>	<p>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 <b>clinical trial</b> 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.</p>
<b>Trial Steering Committee</b>	<p>A committee put together in order to provide overall supervision of how the trial is running. Ideally its membership is made up of an independent chairman, and may include at least two other independent members, a PPI representative, trial manager, statistician, other relevant experts and the Chief Investigator. Involvement of independent members provides protection for the study participants and the Chief Investigator as these members are external to the study, and thus can offer an unbiased opinion. The group should meet initially when ethical approval has been obtained, then at six monthly intervals throughout the study, unless the chair feels they need to meet more frequently. The committee should provide an oversight on the study progress and that it is being carried out in accordance with the principles of Good Clinical Practice (GCP).</p>
<b>User controlled research / user led research</b>	<p><b>User controlled research</b> is research that is actively controlled, directed and managed by <b>service users</b> 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 <b>advisory</b> or <b>steering group</b> and may also decide to carry out the research.</p> <p>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.</p>

	They see <b>user led research</b> 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 <b>commissioners</b> of the research, the <b>researchers</b> or people who provide services.
<b>User researcher</b>	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.

We would like to acknowledge that the following glossaries were also utilised in order to develop our SLPG PPI glossary:-

NIHR Glossary

Cancer Research UK

Cancer Network

Clinical Trials Toolkit

Diabetes research Network