Glossary of Common Research Terms

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	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 study is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.
Association	A relationship between two characteristics, such that as one changes, the other changes in a predictable way. For example, statistics demonstrate that there is an association between smoking and lung cancer. In a positive association, one quantity increases as the other one increases (as with smoking and lung cancer). In a negative association, an increase in one quantity corresponds to a decrease in the other. Association does not necessarily imply a causal effect. Also called correlation.
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.

Bias	[In statistics.] A systematic error or deviation in results or inferences from the truth. In studies of the effects of health care, the main types of bias arise from systematic differences in the groups that are compared (selection bias), the care that is provided, exposure to other factors apart from the intervention of interest (performance bias), withdrawals or exclusions of people entered into a study (attrition bias) or how outcomes are assessed (detection bias). Reviews of studies may also be particularly affected by reporting bias, where a biased subset of all the relevant data is available.
Blinding	In a controlled trial, it is the process of preventing those involved in a trial from knowing to which comparison group a particular participant belongs. The risk of bias is minimised when as few people as possible know who is receiving the experimental intervention and who is receiving the control intervention. Participants, caregivers, outcome assessors, and analysts are all candidates for being blinded. Blinding of certain groups is not always possible, for example surgeons in surgical trials. The terms single blind, double blind and triple blind are in common use, but are not used consistently and so are ambiguous unless the specific people who are blinded are listed. Also called masking.
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.
Causal effect	An association between two characteristics that can be demonstrated to be due to cause and effect, i.e. a change in one causes the change in the other. Causality can be demonstrated by experimental studies such as controlled trials, for example, that an experimental intervention causes a reduction in mortality. However, causality can often not be determined from an observational study.
Case study	A study reporting observations on a single individual. Also called anecdote, case history, or single case report.
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.
Co-applicant	A researcher who will have intellectual input into, and part ownership of, the research if the application is successful; he/she is expected to be actively involved in the project.
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 study, or collaborate with researchers to design, undertake and/or disseminate the results of a research study.
Cohort study	An observational study in which a defined group of people (the cohort) is followed over time. The outcomes of people in subsets of this cohort are compared, to examine people who were exposed or not exposed (or exposed at different levels) to a particular intervention or other factor of interest. A prospective cohort study assembles participants and follows them into the future. A retrospective (or historical) cohort study identifies subjects from past records and follows them from the time of those records to the present. Because subjects are not located by the investigator to different interventions or other exposures, adjusted analysis is usually required to minimise the influence of other factors (confounders).
Commissioner	A commissioner is the person (or organisation) who asks for a piece of research to be carried out.
Commissioning	Commissioning is the process of awarding funding to researchers to explore relevant research topics. It usually involves: identifying funding for a piece of research; advertising the research topic; arranging for applications to be peer reviewed; making a decision about which researchers are going to be awarded the funding; and agreeing a contract.
Commissioning Panel	A Commissioning Panel 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 carers and people who use services.
Confidentiality	During a research study, 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 study, they are not allowed to include people's names. This confidentiality will only be broken in extreme circumstances, for example, 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.
Convenience sample	A group of individuals being studied because they are conveniently accessible in some way. This could make them particularly unrepresentative, as they are not a random sample of the whole population. A convenience sample, for example, might be all the people at a certain hospital, or attending a particular support group. They could differ in important ways from the people who haven't been brought together in that way, for example, they could be more sick or less sick.
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. Ideally researchers 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
Descriptive study	A study that describes characteristics of a sample of individuals. Unlike an experimental study, the investigators do not actively intervene to test a hypothesis, but merely describe the health status or characteristics of a sample from a defined

	population.
Dissemination	Dissemination involves communicating the findings of a research study 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.
Economic analysis	This is a comparison of the relationship between costs and outcomes of alternative healthcare interventions.
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 study.
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 study.
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 study can be evaluated as it goes along or right at the end. An evaluation can measure how well the study 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 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.
Experimental Research	A study in which the investigators actively intervene to test a hypothesis and 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.
Funder	
Good Clinical Practice	A standard for the design, conduct, performance, monitoring, auditing, recording, analyses, and reporting of clinical trials that's provides assurance that the data and reported results are credible and accurate, and that the rights, integrity, and confidentiality of trial subjects are protected.
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.
Health Economics	The study of how scarce resources are allocated among alternative uses for the care of sickness and the promotion, maintenance and improvement of health, including the study of how healthcare and health-related services, their costs and benefits, and health itself are distributed among individuals and groups in society.
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.
Hypothesis	An unproved theory that can be tested through research. To properly test a hypothesis, it should be pre-specified and clearly articulated, and the study to test it should be designed appropriately. See also null hypothesis.

Hypothesis test	A statistical procedure to determine whether to reject a null hypothesis on the basis of the observed data.
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.
Informed Consent	A process by which a subject voluntarily confirms his or her willingness to participate in a particular trial, after having been informed of all aspects of the trial that are relevant to the subject's decision to participate. Informed consent is documented by means of written, signed and dated informed consent form.
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, giving people information and training.
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 reviewer	A term used by PRP CCF to refer to members of the public who undertake reviews.
Lay summary	A lay summary is a brief synopsis of a research study or a research application that has been written for members of the public, rather than for researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms.
Members of the public	Although other organisations have different definitions of this term, for us this term covers: • 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.
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 sometime has 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 why a particular method has been chosen.
Monitoring research	Monitoring research involves keeping up to date with the progress of a research study. This will include ensuring that the researchers are carrying out their research according to their research application or protocol, that the research is keeping to time and budget and that the research is being conducted ethically.
Multicentre trial	A clinical trial conducted according to a single protocol but at more than one site, and therefore, carried out by more than one investigator.
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
Observational study	A study in which the investigators do not seek to intervene, and simply observe the course of events. Changes or differences in one characteristic (e.g. whether or not people received the intervention of interest) are studied in relation to changes or differences in other characteristic(s) (e.g. whether or not they died), without action by the investigator. There is a greater risk of selection bias in observational study than in experimental studies.
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 study. 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 study. 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 and Public Involvement (PPI)	Patient and public involvement (PPI) means that members of the public and / or patients are active partners in the research process by, for example, advising on a research project, assisting in the design of a project, or in carrying out the research, rather than being the subjects of research.
Patient information	Researchers must provide a patient information leaflet leaflet/patient 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 • how the results will be shared with others • who to contact for further information.
Peer review/ refereeing	Peer reviewing is where a research application or research report is read and commented on by people with similar interests and expertise to those who wrote the application or report. It helps to check the quality of a report or research application. Peer reviewers might be members of the public, researchers, or other peers. 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 study 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.
Perspective	A (service) 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. Also referred to as patient perspective or public perspective.
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.
Population	In research this is the group of people being studied, usually by taking samples from that population. Populations may be defined by any characteristics, such as geography, age group, and certain diseases.
Power	The probability of rejecting the null hypothesis when a specific alternative hypothesis is true. The power of a hypothesis test is one minus the probability of Type II error. In clinical trials, power is the probability that a trial will detect, as statistically significant, an intervention effect of a specified size.
Primary study	This is 'original research' in which data are collected. The term primary study is sometimes used to distinguish it from a secondary study (re-analysis of previously collected data), meta-analysis, and other ways of combining studies.
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 or funder 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 such as: • 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).
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, 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 Control Trial (RCT)	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 because it means that the researcher can be sure that any differences between the groups are only due to

	the treatment. the participant. Randomisation ensures that the two groups are as similar as possible, except for the treatment they receive. This is important
Representative	A representative is 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.
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 application	This is usually a set of questions and papers that researchers have to complete to say what research they want to do and how they want to do it. It will 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. Also called a research proposal.
Research specification	Research commissioners write a research specification when they want to commission new research. This 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 application that explains how they will address the research specification.
Researcher	Researchers are the people who conduct 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 funding	Research funding is 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 application and receive positive peer review comments. Also known as research grant.
Research methods	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.
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.
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.
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.
Sponsor	An individual, company, institution, or organisation which takes responsibility for the initiation, management, and/or financing of a clinical trial.

Stakeholder	
Statistics/stats 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 term more empowering 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.
Systematic review	A review of a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant research, and to collect and analyse data from the studies that are included in the review. Statistical methods (meta-analysis) may or may not be used to analyse and summarise the results of the included studies.
Survey	A study measuring the distribution of some characteristic(s) in a population at a particular point in time.
Themed Call	Themed calls are issued by the National Institute of Health Research (NIHR) to meet an identified health challenge or government priority. Calls for funding will be promoted in advance whenever possible and clearly advertised on NIHR websites. All research programmes, including NIHR fellowships, will participate in the themed call as far as their remit allows.
User controlled	Research that is actively research/user 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-led Research	Where the service users themselves are in charge of finding out about things that affect them.
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.

Taken from the Department of Health Policy Research Programme Central Commissioning Facility Guidance Notes for Lay Reviewers.