

Explaining the words we use

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On one training course, people had a choice of badges to wear. One said, 'I speak NHS' and the other said, 'I do not speak NHS.'

The table below¹ lists many of the acronyms and technical terms used in health research. NHS jargon is explained with this [free app](#). A similar jargon buster for social care is available [here](#) with an online version [here](#). There is also a specialist glossary on service improvement [here](#).

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.
Active Involvement	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.
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.
AHSN	Academic Health Science Network

¹ Sources:

- National Institute for Health Research Jargon Buster
- South Yorkshire Strategic Local Priority Group Patient and Public Involvement Glossary of Research terms developed from the 'INVOLVE' Jargon buster
- Research Jargon Buster from Staley K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh.

AMRC	The Association of Medical Research Charities
Analysis	Data analysis involves examining and processing of 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.
Applied Research	Applied research is original investigation undertaken in order to acquire new knowledge with a specific practical aim in view.
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
Brainstorm	A way to get a face-to-face group to generate ideas that was developed by Alex Osborn. It has four rules: (a) don't judge or criticise ideas; (b) be freewheeling – the wilder the idea, the better; (c) go for quantity – the more ideas you have, the better; (d) build on the ideas of fellow group members. Group brainstorming doesn't actually work ² .
BRU	Biomedical Research Unit – part of the National Institute for Health Research. It has been claimed that in 2013, there are more BRUs in the East Midlands than any other region.

² "One of the first studies to demonstrate this was conducted in 1963 by Marvin Dunnette. Dunnette divided each set of 48 men into 12 groups of 4... Each foursome was given a problem to brainstorm. The results were unambiguous. The men in 23 of the 24 groups produced more ideas when they worked on their own than when they worked as a group. They also produced ideas of equal or higher quality when working individually. The one exception in online brainstorming... Groups brainstorming electronically, when properly managed, not only do better than individuals, research shows; the larger the group, the better it performs... Participants in brainstorming groups usually believe that their group performed much better than it actually did, which points to a valuable reason for their continued popularity – group brainstorming makes people feel attached. A worthy goal, so long as we understand that social glue, as opposed to creativity, is the principal benefit. Psychologists usually offer three explanations for the failure of group brainstorming. The first is *social loafing*: in a group, some individuals tend to sit back and let others do the work. The second is *production blocking*: only one person can talk or produce an idea at once, while the other group members are forced to sit passively. And the third is *evaluation apprehension*, meaning the fear of looking stupid in front of one's peers." (Cain S (2012) *Quiet: the power of silence in a world that can't stop talking*. London: Penguin.)

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. Although PPI should involve carers, they tend to get less attention than people who use services ³ . The term is disliked by many of the people to whom it refers; they do not necessarily recognise themselves as carers but as parents, children, siblings or friends. It can also be offensive to the people who receive support: they may not perceive their so-called carers as caring for them, but as friends or family members with whom they share a reciprocal relationship – they care about one another.
CC	Coordinating Centre
CCF	Central Commissioning Facility
CEBD	Centre for Evidence Based Dermatology
Chief Investigator	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 takes overall responsibility for the trial.
CLAHRCs	<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>
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.

³ Jasmine Synnott reviewed 500 studies listed in the Mental Health Research Network database of research and found 44% specified carer involvement.

Clinical 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	<p>Commissioning usually involves:</p> <ul style="list-style-type: none"> • 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.
Commissioning Panel or Board	A Commissioning Panel or 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.

Consent	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.
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: <ul style="list-style-type: none"> • 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.
CRB	Criminal Records Bureau – now the DBS
CRN	Clinical Research Network – part of NIHR
CSP	The NIHR Coordinated System for gaining NHS Permission, to carry out research
CTRU	Clinical Trials Research Unit
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: <ul style="list-style-type: none"> • 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.
DH	Department of Health

Dissemination	<p>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:</p> <ul style="list-style-type: none"> • producing reports (often these are made available on the Internet) • publishing articles in journals or newsletters • issuing press releases • giving talks at conferences. <p>It is also important to feedback the findings of research to research participants.</p>
Emancipatory research	<p>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 peoples' lives. 'Professional' researchers may be brought in as advisers or have specified roles within the project.</p>
Empowerment	<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>
Engagement	<p>The Health Research Authority defines this as "Where people are given information about research and can discuss it with researchers and research organisations." NIHR Involve define it⁴ as: <i>Engagement – where information and knowledge about research is provided and disseminated. Examples of engagement are:</i></p> <ul style="list-style-type: none"> • <i>science festivals open to the public with debates and discussions on research</i> • <i>open day at a research centre where members of the public are invited to find out about research</i> • <i>raising awareness of research through media such as television programmes, newspapers and social media</i> • <i>dissemination to research participants, colleagues or members of the public on the findings of a study.</i>
Ethics	<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>

⁴ <http://www.invo.org.uk/posttypesource/what-is-public-involvement-in-research/>

Ethics Committee	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.
Expenses	Legitimate and costs incurred by an employee/researcher or volunteer in the performance of agreed work. Wherever possible, receipts are submitted in support of the expense claim.
Experimental Development	Experimental development is systematic work, drawing on existing knowledge gained from research or practical experience that is directed to producing new materials, products or devices, to installing new processes, systems or services, or to improving substantially those already produced or installed.
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.
First Global Patient	Drug companies who are running clinical trials count any study that recruits participants in more than one country as a 'global' trial. As soon as the study is ready to start, they track which country is quickest at actually getting started. The first patient who receives the first visit for assessment or intervention after informed consent has been achieved is designated the 'first global patient'. The countries that most often win this race are viewed as attractive places to undertake research.

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.
GCP	Good Clinical Practice
GP	General Practitioner
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.
HIEC	Health Innovation and Education Cluster
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.
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	<p>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. NIHR Involve explain it⁵ this way: <i>Involvement – where members of the public are actively involved in research projects and in research organisations. Examples of public involvement are:</i></p> <ul style="list-style-type: none"> • <i>as joint grant holders or co-applicants on a research project</i> • <i>involvement in identifying research priorities</i> • <i>commenting and developing patient information leaflets or other research materials</i> • <i>undertaking interviews with research participants</i> • <i>user and/or carer researchers carrying out the research.</i>
IPS	<p>Individual Placement and Support. The term is also used widely to refer to intensive support to assist people with mental health difficulties to obtain and retain waged employment in the open market.</p>
INVOLVE	<p>Part of NIHR – established to promote PPI in research. There is also an independent organisation that uses the same name in lower case that does similar work – see below.</p>
Involve	<p>A separate organisation established to promote participation in democratic society There is also a part of NIHR called INVOLVE – see above.</p>
Involvement	<p>The Health Research Authority defines this as “Where people are actively involved in the conduct of research studies and in the work of research organisations.”</p> <p>The term 'involvement' means the active involvement of people in research processes so that research is carried out with or by members of the public, rather than to, about, or for them. Patient and public involvement in research can occur in a range of ways, a variety of roles and different contexts throughout the research cycle. Examples of such involvement include the setting of research agendas, prioritising of research topics, commissioning research, reviewing applications for research funding, performing study design, promoting creativity of research methods, collecting data, developing written material such as information sheets, analysing research data, publicising and disseminating research findings, implementing research findings and monitoring and evaluating the implementation of research findings. In user controlled or user led research, users develop, take forward and drive a research study. Others may adopt the roles of advisor or co-researcher.</p>

⁵ <http://www.invo.org.uk/posttypresource/what-is-public-involvement-in-research/>

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.
LETB	Local Education and Training Board
Letter of Access	A document giving formal permission to be on NHS premises for the purposes of research
Members of the public ('the public' or 'publics')	<p>INVOLVE uses this term to cover</p> <ul style="list-style-type: none"> • 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. <p>Other organisations have different definitions of this term</p>
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.
MRC	Medical Research Council

Mutually exclusive and collectively exhaustive	This is a phrase used to describe good categories when designing the answers to a multiple choice question. Each category should be entirely different from the others, so there is no overlap and people can fall into one and only one (mutually exclusive). When combined, all the categories should cover all possible options (collectively exhaustive). This is like laying tiles on a kitchen floor so that there are no overlapping tiles and no gaps.
NETSCC	The NIHR Evaluation, Trials and Studies Coordinating Centre
NHS	National Health Service
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: <ul style="list-style-type: none"> • 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
NICE	From April 2013, NICE will start producing guidance and quality standards in relation to social care as well as health, and to reflect this the Institute will become known as the National Institute for Health and Care Excellence.
National Institute for Health Research	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.
NIHR Research Design Service	The National Institute for Health Research's Research Design Services (NIHR RDSs) aims 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.
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
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'.

Participation

The Health Research Authority defines this as “Where people are recruited to and take part in research studies.” Involve define it⁶ like this: *Participation – where people take part in a research study. Examples of participation are:*

- *people being recruited to a clinical trial or other research study to take part in the research*
 - *completing a questionnaire or participating in a focus group as part of a research study.*
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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 Advice and Liaison Service (PALS)

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.

**Patient Information Leaflet/
Patient Information Sheet**

Researchers must provide a patient information leaflet leaflet/patient information sheet 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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⁶ <http://www.invo.org.uk/posttypesource/what-is-public-involvement-in-research/>

Patient Leader	Another term for a patient who offers their lived experience to improve the quality of healthcare research or services. This view is promoted by the Centre for Patient Leadership. Patient Leaders should be clear about whether they represent their own views or those of other patients, how they link with other publics and what formal responsibility they bear (for example, the Patient Leaders who become Board members in NHS Foundation Trusts share in the legal responsibility for the conduct of the Trust).
Patients and Public	The term 'patients' includes patients, carers, service users, representatives of people who use services, and individuals or groups who are affected by health or clinical research issues. The 'public' comprises people who pay for health research and health services through their taxes. Every patient is of course also a member of the public. People bring the following perspectives to their involvement: <ul style="list-style-type: none"> • lived experience of the health condition being investigated • general experience of being a patient and using health services • distinctive skills, talents or viewpoints that are not available to the research team • A pair of 'fresh eyes' and the ability to view the work from a different perspective to the researcher or clinician.
Patient and Public Involvement (PPI)	When we talk about patient and public involvement (PPI) in 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.
PCPI	Patient, Carer and Public Involvement
PCPIE	Patient, Carer & Public Involvement & Engagement
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 peers. 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: <ul style="list-style-type: none"> • 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.
Phase	Clinical trials for new drugs normally proceed four phases over many years to check safety, dosage range and side effects. The phases vary in the size and diversity of the patient group it is tried out on and the level of detail that is possible to explore. Phase 1: try it on 20-80 people; Phase 2: 100-300 people; Phase 3: 1,000-3,000 people. This can include comparing it to commonly used treatments. The drug is made available if it passes Phase 3 tests. Phase 4 trials examine particular aspects of the drug's impact.
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.
Portfolio study	Some research studies are described as a 'portfolio study', or, more correctly, and 'NIHR portfolio-eligible study. This gives the study team access to the resources and research infrastructure provided in England by the NIHR Clinical Research Network. Portfolio studies need to be of clear benefit to the NHS. For more information on the eligibility criteria click here .
Proof of Concept	This usually refers to early clinical drug development, conventionally divided into Phase I and Phase IIa (see above on Phases). Phase I is typically conducted in 10-20 healthy volunteers who are given single doses or short courses of treatment (e.g., up to 2 weeks). Studies in this Phase aim to show that the new drug has some of the desired clinical activity and that it can be tolerated when given to humans. Phase IIa is typically conducted in up to 100 patients with the disease to show that the new drug has a useful amount of the desired clinical activity, that it can be tolerated when given to humans in the longer term, and to investigate which dose levels might be most suitable for eventual marketing.
PROSPERO	This is an international register of upcoming systematic reviews in health and social care. All new Cochrane proposals after October 2013 are automatically added to PROSPERO.

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.

PPA

Patient and Public Awareness

PPE

Patient and Public Engagement – another name for PPI

PPI

Patient and Public Involvement

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.

Purposive sample

In a random sample, each member of the public has the same chance of being included. In contrast, a purposive sample is chosen deliberately to find and include a specific group. So, for example, in studying the experience of Eastern Europeans, the researcher makes sure that there are plenty of this group in the sample, rather than leaving it to chance. If a particular number are sought, then this might be called a 'quota sample'

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, 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
RAG	Red, Amber, Green
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.
RDS Recruitment	NIHR Research Design Service May refer to employing staff or to engaging people as research subjects or participants
REF	The Research Excellence Framework is used to assess the achievements of universities.
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
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". A useful summary of the difference between research, audit and service evaluation is available ⁷ .

⁷ <http://www.nres.nhs.uk/EasysiteWeb/getresource.axd?AssetID=355&type=full&servicetype=Attachment>

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.
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. 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 Passport	A document giving formal permission to undertake research

Research proposal	<p>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</p> <ul style="list-style-type: none"> • 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 • the cost.
RM&G	Research Management & Governance
RSS	Research Support Service
SDO	A programme funded by the National Institute of Health Research called 'Service Design and Organisation'.
Sensitive and specific	<p>These terms are used to describe how useful a test is in selecting the right people from group. For example, if a fishing boat set out to catch all the cod in a lake where there are only cod and haddock, the net is <i>sensitive</i> if most of the cod end up in the fishing net and <i>specific</i> if most haddock stay in the lake.</p>
Service evaluation	<p>A service evaluation will use information that is already collected to find out how the service is working. In contrast, research collects new information.</p>
Service user or user	<p>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</p>
Social care research	<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"> • 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 <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"> • people's experience of using different home care services • the best ways to train new foster parents.
Stakeholder	<p>A stakeholder is anyone who has an interest in a research project. It includes the people and organisations who are actively involved, as well as the people who might be affected by the outcomes.</p>

Statistics/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 the 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.

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.

Translation Gaps

In 2006, a report commissioned by HM Treasury⁸ defined the first 'Gap in Translation' as the difficulty in transferring learning from basic research into clinical research, and the 'Second Gap in Translation' as the difficulty in putting evidence from research into regular practice.

⁸ Cooksey D (2006) *A review of UK health research funding* London: The Stationery Office. Page 102.

Trial Steering Committee	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 a oversight on the study progress and that it is been carried out in accordance with the principles of Good Clinical Practice (GCP).
User	Often used to mean a person who uses the health or social care services that are being studied, although it can also mean a drug user, or any person who utilises the medical device, tools or outputs of the research. In this case, a user might, for example, be a teacher, parent or the person themselves.
User controlled 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
Volunteer	A formal volunteer is identified, approved and supported in undertaking unpaid activities. The National Centre for Volunteering also recognises 'informal volunteering' in which people assist others without being formally identified as a volunteer.