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Jargon Buster

Explanations of some of the terms commonly used in research

A

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.

Advisory Group
Many research projects have an advisory group (or steering group) that 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 involves examining and processing all of the research data together, in order to answer the questions that the project is trying to address. It may involve identifying patterns or themes, or using statistical methods to compare groups or treatments. It is often done with specialist computer software.

B

Baseline data
This is data collected on patients at the beginning of a clinical study or trial, before any intervention has taken place.

Bias
This describes anything that distorts or otherwise affects the study in such a way that the findings deviate from the 'truth'. It may relate to a number of different elements such as the opinion of the researcher(s) or how they chose the participants for the research.

BioResource
NIHR BioResource is made up of thousands of volunteers, both with and without health problems, who are willing to be approached to participate in research studies investigating the links between genes, the environment, health and disease. There are fourteen centres across the UK including Cambridge BioResource.

BioResource- Rare Diseases
NIHR BioResource- Rare Diseases is part of NIHR BioResource and has been established to recruit participants with rare diseases and their relatives. It aims to drive identification of causes of disease, improve rates of diagnosis and enable studies to develop and validate treatments.

Blinding
A blinded study/trial is one where the research participants do not know whether they are receiving the treatment that is being tested or the placebo/current treatment. If the clinicians or researchers also do not know, then this is known as a "double blind" study.

BRC
Biomedical Research Centre. These are partnerships between leading NHS organisations and universities that aim to combine facilities and expertise to boost research. The NIHR funds 20 BRCs in England, including the Cambridge BRC.

C

Case control studies
A type of study design used to investigate causes of diseases. People with a particular outcome/condition of interest ('cases') are compared with a group of patients without the outcome ('controls') to determine whether the cases have an 'exposure' in common that is not present or is less present in the control group. The 'exposure' could be genetic, an infection or an experience (eg. malnutrition, smoking) that caused or contributed to the development of a condition.

Clinical research
Clinical research is the study of health and illness in people, with the aim of finding better ways to prevent, diagnose and treat disease. It may involve direct interaction with patients (eg. clinical trials or observational studies), clinical samples (eg. blood, urine or tissue), and test results (eg. X-

rays, scans) or data from health records or surveys.

Clinical trial
Clinical trials compare an experimental treatment or behavioral intervention with either a placebo or the best treatment currently available. They test whether the new 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.

Cohort studies
These studies are sometimes known as "follow up studies". These are studies that begin with a group of people (the cohort) who are free from disease but who have a potentially disease causing 'exposure' (risk factor) in common (eg. smoking, a DNA variant, exposure to air pollution). The cohort is followed up over a period of time to see the development of new cases of the outcome of interest. Cohort studies provide the strongest information about the causation of disease and the most direct measurement of the risk of developing disease. They can also be used when, for practical or ethical reasons, it is not possible to perform a randomised controlled trial (RCT).

Collaboration
Collaboration describes researchers working together with an external partner in order to benefit from skills, expertise and experience that are outside the researchers' knowledge, enhancing production of quality research. Cambridge researchers collaborate with experts from all over the world, and it is one of the factors that contribute to their success. Members of the public are also a vital source of skills, experience and expertise that can benefit research through collaboration as active, on-going partners 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.

Confidence Interval (CI)
The confidence interval is a statistical term (often known as the CI). It is the range within which the true size of effect (which is never known exactly) lies, within a given degree of certainty. For example, a 95% Confidence Interval is the interval which includes the true value in 95% of cases. Smaller confidence intervals represent more 'confidence' in the size of the true effect.

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 do not include participant's names. This confidentiality can only be broken in extreme circumstances where it is essential for the person's care, treatment or safety or where it is required by a court order, e.g. in a criminal investigation or 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 can include 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 about research priorities and funding.

Controls
People in the comparison group in a clinical trial, who receive the usual treatment or a placebo while the experimental group receives the treatment being tested.

Credibility
This is a criterion for evaluating the quality or trustworthiness of a piece of qualitative research. It refers specifically to the extent to which the researcher's findings are compatible with the participants' perceptions.

Critical Appraisal
The process of assessing and interpreting research

evidence, by systematically considering the results of the research, establishing its validity and how relevant it is to the study at hand.

D

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 place safeguards to protect the confidentiality of the information they collect about research participants. They should explain in the patient information sheet:

- How the participants' data will be collected
- How it will be stored securely
- What it will be used for
- Who will have access to the data that identifies participants
- How long it will be kept
- How it will be disposed of securely

Dissemination
Dissemination is the communication of the findings of a research project to a wide range of people who might find it useful. This can be done through:

- Producing reports (often these are made available on the Internet)
- Publishing articles in journals or newsletters
- Issuing press releases
- Giving talks at conferences

It is also important to feed back the findings of research to research participants.

E

Ethics
Ethics is the name given to the code of practice based on a set of decent, fair and moral principles and guidelines that researchers should abide by when conducting research, in order to prevent any harm to participants. Any research that will seek to gain personal confidential information or test a new intervention or treatment on people must first get ethical approval from a Research Ethics Committee.

Exclusion criteria
There are characteristics that would make a potential participant ineligible for a trial – for example 'male sex' would be an exclusion criterion for a trial involving pregnancy.

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.

F

False negative
This is a falsely drawn negative conclusion. For example, someone has a negative test result and is told that they do not have the disease they were being tested for when they actually do have the condition.

Focus group
A focus group is a small group of people (usually about 6-10 individuals) who have common experiences or interests, brought together to talk about a topic, usually under the guidance of a facilitator. 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.

Follow-up data
Information collected after patients have been entered into a trial.

G

Genotyping
Genotyping is the process of determining differences in an individual's genetic make-up (genotype) by examining the individual's DNA sequence using biological assays and comparing it to another individual's sequence or a reference sequence.

H

Hawthorne effect
This is a psychological response in which subjects change their behaviour simply because they are subjects in a study, and not because of the research treatment.

Hypothesis
A hypothesis is a proposed explanation (or theory) for an

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observation that could be tested with further research.

I

Incidence
The number of new occurrences of a condition in a population over a period of time.

Inclusion criteria
These describe the essential conditions or attributes of people who are eligible to take part in a trial. For example, 'positive diagnosis of heart disease' would be an essential criterion for participation in a trial testing a new treatment for heart disease.

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.

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.

L

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.

M

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.

N

NIHR
The National Institute for Health Research. The NIHR is funded by the Department of Health to promote and support health research in England.

O

Odds ratio (OR)
A measure of the relationship between an exposure (for example, a new treatment) and its outcome. An OR of 1 means the treatment was no better than the control. If the OR is greater than 1, then the effects are more than those of the control, whereas if the OR is less the effects are less than those of the control treatment. Effects measured can be adverse or desirable.

Outcome measures
Outcomes measures are the variables that are measured to determine the success of a treatment or intervention. They might include physical measurements (eg. blood pressure, weight, blood glucose) or psychological measurements (eg. people's sense of well-being). Generally the variable is assessed before and after the intervention and the overall change measured to determine the outcome of the intervention. Eg. In a trial for a new blood pressure lowering drug, the outcome measure could be the change in blood pressure at the end of the trial, with a decrease in blood pressure potentially indicating a successful drug.

P

Participant
A participant is someone who takes part in a research study or trial, contributing data that allow researchers to answer a research question. Participants may contribute data by taking a new drug, providing biological samples or answering survey questions. Sometimes participants are referred to as research "subjects".

Participatory research
This is a type of research where researchers and service users or carers are partners in

a research project that addresses an issue of importance to service users or carers. Service users and carers are involved in the design and conduct of the research, and the way the findings are made available with the aim of improving people's lives and experience of care. This isn't a research method – it's an approach to research, a philosophy.

Patient information sheet / leaflet
Researchers must provide a patient information leaflet to everyone they invite to a research study, to ensure people can make an informed decision about whether to take part or not. The leaflet explains what participation 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 participation will involve on a practical level, 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.

Peer interviews
Interviews where the participants are interviewed by people who have had a similar experience to them. 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 for their views.

Peer review
Peer reviewing is where a research proposal or a report of research is read and commented on by professionals with similar research interests and expertise to the proposal/report authors. Peer review helps to check the scientific quality of a report or research proposal to identify research that should be funded or published. Members of the public can also act as reviewers to provide feedback on:

- Whether the research addresses an important and relevant question
- The methods used or proposed by researchers
- The quality of public involvement in the research

Phenotyping
The full set of an individual's observable characteristics reflecting the combined influence of genetic inheritance, genetic mutations, and environmental influences. Phenotypic data can include the results of clinical tests, scans and descriptions.

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", which 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.

Power
The power of a study is an estimated measure (using statistics) of how many participants are needed to reliably answer the research question being asked. Where the difference between the treatment and control groups is likely to be very small or difficult to measure, many more people (data points) will be needed to be sure of the results. A study that includes too few participants may not produce a reliable (statistically significant) result, even if the intervention has a true effect.

Protocol
The research protocol is a full description of the research study planned and details exactly what procedures will be used to produce the study data, in order to make sure all the research team members use the outlined methods. This is especially important where data are being collected in different locations or by different researchers. It usually includes information about:

- The question the research is aiming to answer (or the hypothesis it is hoping to test) 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 (inclusion/ exclusion criteria)
- The research method/s
- The outcome measures that will be assessed
- How the results will be analysed
- 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.

P value
This is the probability that the result has happened by chance. Where the p value is found to be less than 0.05 (often written $p<0.05$), it means that the probability of the result happening by chance is less than 5%, or a 1 in 20 chance. P values of less than 0.05 are often considered to indicate that the observed results are unlikely to have occurred by chance, and are, therefore, 'significant'.

Q

Qualitative research
Qualitative research is used to explore and understand people's subjective beliefs, experiences, attitudes or motivations. It asks questions about how and why people behave or feel the way that they do. Often the term "holistic' is used, meaning that the complexities of human behaviour are preserved in the study. For example a qualitative research approach might ask questions about why people want to stop smoking (or why they don't), rather than measuring characteristics of smokers and non-smokers or enumerating the number of people who smoke. Qualitative researchers use methods like focus groups and interviews (telephone and face-to-face interviews).

Quantitative research
In quantitative research, researchers use objective measurements to produce numerical data that can be analysed using statistical methods. 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.

R

R & D
Research and Development, which covers both 'basic' (pre-clinical,) research and clinical research, as well as research into improving existing treatments, service delivery and user experience.

Randomised controlled 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 the participant. Randomisation ensures that the two groups are as similar as possible, except for the treatment they receive. This is important because it means that the researcher can be sure that any differences between the groups are only due to the treatment.

Representative
Representatives speak or act 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 range of people's views in addition to your own perspective.

Research Ethics Committee
Ethics committees are made up of professionals and service users who consider the ethical implications of the proposed research protocol and its potential outcomes. Such committees typically include active or retired researchers, legal and philosophical experts and 'lay' members (members of the public). If the committee has ethical concerns about the

proposal (for example, if they believe the research may cause avoidable harm, seeks to test an unjustifiable treatment or unfairly favours or disadvantages one group over another) then they may not approve it and it cannot be funded. In this instance, if the concerns are minor, the researchers may be given the opportunity to amend or clarify the proposal, or it may be rejected all together.

Research governance
Research governance is a process that oversees research to ensure it 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
A sum of money awarded to a research professional, group or institution to allow them to carry out their proposed program of research. Grants can be funded by the government or through charities and philanthropy, and may cover an entire program of research, smaller individual projects, staff costs or equipment. Research grants are generally limited in both value and time (for example £1 million pounds over 3 years), which means that lead researchers need to continually apply for research grants so that their research can continue. In 2016/17, less than 25% of submitted NIHR grant proposals were successful, which means on average, principal investigators write 4 research proposals for every one that is successful!

Research methods
Research methods are the ways researchers collect and analyse information. So, research methods include techniques such as interviews, questionnaires, diaries, observational studies, clinical trials, experiments, analysing documents or statistics, and observing people's behaviour (among many others!).

Research partner
The term research partner is used to describe people who get actively involved in research, to the extent that they are seen by their 'professional' colleagues as a partner, rather than someone who might be consulted occasionally. Partnership suggests that researchers and service users/carers have a relationship that involves mutual respect and equality.

Research proposal
This is a document (or, more commonly, a set of documents) that describes a proposed or intended program of research that researchers are seeking funding for. 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 timescale and the cost.

Review
A summary of the literature that aims to give an overview of the 'field' at that moment in time. Reviews are often commissioned by research journals, who approach leading academics to draw together individual studies on a topic to synthesise an overview.

Risk
The chances of a particular outcome happening to an individual.

S

Significance
Significance is a term to describe how certain we are that the outcome of an experiment is 'true', that it did not happen merely by chance. Generally, this is agreed to be the case where the likelihood of something occurring by chance is less than 5%, though it should be noted that 5% ($p<0.05$) is an arbitrary cut off (See also P Value.)

Stakeholder
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.

Systematic review
Systematic reviews aim to bring together the results of <u>all</u> studies addressing a particular (very specific) research question that have been carried out around the world. They provide a comprehensive and unbiased summary of the research on that question. 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. Systemic reviews differ from ordinary reviews in that they aim to provide the answer to a very specific question, rather than provide an overview of the general field.

T

Translational research
The process of turning research findings and discoveries into practical applications that are of benefit to patients. This can include turning results from 'basic' research into pre-clinical studies or testing new treatments and drugs in humans.

Trial
A study of the effects of an intervention.

U

User controlled research
User controlled research is research that is actively controlled, directed and managed by service users and 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.

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.

V

Validity
This refers to the soundness or rigour of a study. A study is valid if the way it is designed and carried out means that the results are unbiased - that is it gives you a true estimate of clinical effectiveness of a treatment.

Adapted from INVOLVE's Jargon Buster

We hope you find these definitions useful. Please let us know if there are other terms you feel would be useful to add, or if there are any definitions which are unclear. We welcome feedback on all our resources.