OPEN ARMS Jargon Buster

# Jargon buster

Below are some explanations of the words commonly used in research that you may come across. We hope you find these definitions useful; you can also download the guide here.

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### A

### Advisory Group

A group of people set up to advise on research projects who help give feedback on research aims and methods. These can include patients, caregivers, service users, members of the public, and other experts or professionals not involved in the research project. Advisory groups may also be known as steering groups or steering committees.

### Accessibility

Accessibility is creating solutions or adjustments that allow disabled people to access and engage with what they need, such as events or daily activities, in a similar manner to non-disabled people.

### Accountability

Accountability is being held responsible for your actions and any consequences or further impacts they may lead to.

### Arthritis (including osteoarthritis, inflammatory arthritis, Rheumatoid arthritis)

Arthritis is a medical condition that causes pain, inflammation, and stiffness in the joints. This can impact a person’s mobility and ability to carry out daily activities. Some of the main types of arthritis include osteoarthritis, inflammatory arthritis, and rheumatoid arthritis.

### B

### BRC

BRC stands for Biomedical Research Centre. These are research organisations across the UK that are run by the National Institute for Health Research, also known as NIHR, together with local universities. The Oxford BRC is run by Oxford Health NHS Foundation Trust and the University of Oxford.

### C

### Clinical research

Clinical research is any research that studies health and disease in humans. This includes research that studies ways to prevent, diagnose. or treat diseases.

### Clinical trial

A clinical trial is a specific type of clinical research that tests if and how a new treatment or intervention work in humans. Clinical trials usually find out how effective a new treatment is by comparing against a placebo or against the treatment that is currently available.

### Code of conduct

A set of rules of ethical behaviour, usually within an organisation.

### Collaboration

Collaboration is working together. Here, collaboration means researchers working with patients, the public, and other experts to make their research better by including experience and knowledge from the collaborators that the researchers’ may not have been aware of.

### Committee Group

A group of people overseeing and monitoring a research project.

### Confidentiality

Confidentiality means keeping patient and participant information safe and private. Researchers who use patient or participant information must make sure the data are safely protected and that they have permission from the patients or participants to use their data.

### Conflicts of Interest

When a person may have a financial or social reason that could help them benefit from a certain outcome of a situations, or may mean they are not unbiased or neutral.

### Conference

A gathering, often over several days, of researchers within a specific field of study to share their research and new ideas. Conferences may also be known as congresses.

### Consultation

A consultation is the act of getting information, advice, or an opinion from someone. In research, a public consultation means asking the public what they think about a research project or potential research project.

### D

### Data

Data are pieces of information that are gathered during research to be analysed, such as numbers, words, symbols, etc.. The word data is plural and the singular version of the word is datum.

### Data Protection

Data protection is the steps researchers must take to keep their information safe and private. In the UK, researchers must follow laws in the Data Protection Act of 1998 and the General Data Protection Regulation of 2018, also known as GDPR.

### Data Protection Impact Assessment

A Data Protection Impact Assessment (DPIA) is carried out to help identify and minimise the data protection risks of a project.

### Disease

A disease where a function of the body or the body’s cells no longer works properly and causes medical conditions or medical problems.

### Dissemination

Dissemination is the sharing of research findings and results to anyone who may benefit from it.

### E

### Ethics

Ethics are a moral system based on a person’s world view. Researchers use a common understanding of ethics to guide fair and decent decision-making to prevent harm to patients and the public. Usually, an independent Research Ethics Committee will review a potential research project to decide if it is fair and ethical.

### F

### Focus Group

A small group of people gathered to discuss an idea or topic in depth. Often used before new research studies begin to guide what questions to ask.

### G

### H

### I

### L

### Lay (person)

A layperson is someone who is not an expert or professional within any specific field of study.

### Lay Summary

A lay summary is a short summary of a research publication or research proposal written in plain language. These are non-technical summaries written in a way so that everyone can understand the research that is being discussed.

### M

### Musculoskeletal System

The musculoskeletal system is a system in the body that involves the muscles and skeleton and the tissue that hold them together, such as cartilage, tendons, and ligaments.

### Medical Sciences Division

The Medical Sciences Division (MSD) is a centre for excellence for biomedical and clinical research and teaching. It is a division within the University of Oxford. NDORMS (see NDORMS) is a department within the MSD division.

N

### NIHR

The National Institute for Health Research, also known as NIHR, is an organisation that funds and coordinates clinical research in the UK. It is run by the UK government.

### NDORMS

The Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences is a world leading centre for research to improve treatment for musculoskeletal diseases. It is a partnership between Oxford University Hospitals NHS Foundation Trust and the University of Oxford.

### O

### OPEN ARMS

Our patient and public involvement group is called the Oxford Patient Engagement Network for Arthritis and Musculoskeletal Conditions.

### Orthopaedics

Orthopaedics is a field of medicine that focuses on the musculoskeletal system

### P

### Participant

A participant is someone who volunteers to take part in a study or trial. Participant may sometimes also be known as “subjects”.

### Participatory research

Participatory research is research that depends on participants to volunteer to take part. Usually, the research project will focus on an issue or aspect of a disease that is important to patients, caregivers, and service users. In participatory research, participants are usually involved in the designing the project and gathering information.

### Patient information sheet / leaflet

Patient information leaflets are also known as PILs. These are documents that researchers must provide to participants in their research project that explain what the study is about and what will be expected of the participants. This is to help participants make informed decisions about whether or not to join a study.

### Patient partner

Patient partners are collaborators in research who may be involved in helping to design, develop, or monitor research projects.

### Patient and public involvement

Patient and Public Involvement is also known as PPI. In research, PPI means bring the experiences and knowledge of patients and the public into the discussion to help create better research. This could be anything from help designing a new research project, to giving feedback on a completed research project, to sharing new research findings.

### Peer review

Peer review is a system of making sure that research findings are accurate and valid. This involves sharing a research paper with other experts and professionals before it is published to review. These reviewers then comment on the research paper, including both the methods and the findings, and can suggest ways to make it better.

### Protocol

A protocol is a method for carrying out an activity. A research protocol outlines exactly what the researchers plan to do, what data they plan to collect, and how. This helps Research Ethics Committees decide if a potential research project is ethical.

### Publication

A publication is a method of making research findings public. Usually, this means publishing a peer-reviewed research paper in a medical journal, or presenting a poster at a conference, but it can also mean other ways of sharing information such as reports, books, or websites.

### Q

### R

### R & D

Research and development, also known as R&D, is the process of researching and investigating a new product, such as a drug.

### RACE

The Research into Inflammatory Arthritis Centre Versus Arthritis (RACE) is a collaborative project between the Universities of Birmingham, Glasgow, Newcastle and Oxford.

### RDS

The Research Design Service provides support for researchers to develop and apply for grant applications to the National Institute for Health Research (see NIHR).

### Rehabilitation

Rehabilitation is helping someone return to the normal level of health or normal way of living, for example after a surgery or an accident.

### Reimbursement

Reimbursement is when you pay someone back for money they have already spent.

### Representative

A representative is someone who acts or speaks on behalf of someone else or on behalf of a group. In research, a representative usually represents patient groups or the public.

### Research

Research is process of investigating something through experiments to find out new information.

### Research governance

Research governance is the sets of rules that researchers must follow to make their research is ethical, safe, and trustworthy. in the UK, NHS researchers must follow the Research Governance Framework for Health and Social Care from the government’s Department of Health.

### Research partner

A research partner is someone who is involved in leading, designing, or carrying out a research project. A research partner can be from any background, including patients, the public, or other professionals, and are equally respected and responsible for the research project.

### Research proposal

A research proposal is a document that researchers write when they are first designing a new research project. Proposals are usually sent to whoever is providing the money for the research project to help decide if they want to fund it. A proposal should include the overall aim of the research, the main questions the researchers want to answer, a plan for how they carry out the research, who will be involved, and plans for how long it will last and how much it will cost.

### Review

A review publication is a peer-reviewed article in a medical journal is an overview of different research that summarises everything that is known about a particular disease or topic.

### Role

The position or purpose something or someone has in a given situation, organisation or society.

### S

### Stakeholder

A stakeholder is anyone who is interested or a research project or might be affected the outcomes. This can include researchers, people who fund the research, patients, and the public.

### T

### Terms of reference

This refers to the scope and limitations of an activity or area of knowledge.

### Traumatic injury

A traumatic injury is a sudden and severe injury that needs immediate medical attention.

### Trial

 A trial, or clinical trial, is a type of research project that investigates the effect of a new treatment or product on people.

### U

### User researcher

 A user researcher is someone who is a patient or service user of health and/or social care services and is also a researcher.

### V

### Volunteer

A person who freely offers to take part or undertake a task without being paid.

Adapted from INVOLVE’s Jargon Buster

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.