Additional Contribution

Research Jargon Buster

Direct Impact Research Group

¹ Wakefield
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Introduction

This jargon buster has been written by a group of service users and carers for other service users and carers involved in carrying out research.

The world of research can be a confusing and scary place particularly when you don’t understand the language. Sometimes a simple explanation can help to de-mystify some of the jargon that is used and make it easier to understand. Research is meant to help us in improving and developing services. We hope that you find this ‘jargon buster’ useful and find that research can be fun.

Basic terms used in this jargon buster

Service user
A person who uses, or is engaged with, services or has used services in the past.

Service user involvement
Being involved in improving and changing services.

Carer
A person who cares for a person who is, or has been, a user of services.

Research and development
A study or investigation to discover new information or knowledge to improve services.

Evaluation
A way of finding out whether a service or programme is doing what it set out to do. It assesses whether its aims, objectives, outputs and outcomes are being met.

Survivor researcher
A person who has used services who then uses that experience in carrying out research.

Participant
Someone who takes part in a study or project.

Jargon Buster

Academic
A person who is educated to a high level and has a lot of knowledge about a particular subject. They have usually presented and written papers for conferences and journals.

Analyse
Making sense of and understanding information that has been collected. Examining the cause and result by looking for changes, themes and outcomes.

Article
A piece of writing on a particular subject. Usually written for a journal (see ‘journal’).

Audio tape recording
Interviews in the course of research may be recorded on tape with the interviewee’s consent.
Chief/lead investigator
The researcher who is the lead for a research project and has responsibility for ensuring the project stays on track, has NHS and ethical approval, is carried out according to the protocol, that any changes are notified to the NHS and Ethics Committee, and that the safety and well being of participants is a priority. See also ‘Research Governance’.

Clinical trials
A trial of a new medicine or treatment, or of an existing medicine or treatment in a new area, to test whether it works or leads to improvements.

Collaboration
Working together, in partnership, to achieve the desired results and to ensure that everyone is going in the same direction. There are different stages of collaboration, they are as follows:
- Consultation
- Partnership
- Service user or carer commissioned
- Service user or carer Controlled or led
- Dissemination

Confidentiality
Not disclosing personal information about a research participant unless there is a risk to the person or someone else. Data collected during a research project should always be anonymised.

Consent forms
Participants must consent to take part in a research project. Consent forms record their written consent to take part. The participant, a carer or advocate sign the form to say they understand the purpose of the research, what they are being asked to do in taking part in the research, that they can withdraw if they wish, and have had any questions answered.

Consultation
Asking for advice, information, views, and opinions, either from individuals or groups.

Data
Data is information. This information may be in the form of numbers, from things that have been measured and counted, or it may be in the form of words e.g. from interviews, narratives, or accounts of events.

Data protection
Data collected during a research project must be kept securely to prevent anyone outside the study accessing the information. Researchers have to be aware of their responsibilities under the Data Protection Act.

Debriefing
This takes place after interviews and allows interviewers time to share concerns, any issues that have arisen, what went well and what did not go well. Debriefing is sometimes offered to research participants, particularly if they have been talking about distressing issues.

Dissemination
This usually takes place at the end of a project and involves sharing information and findings from the research with others. Examples are written reports, presentations, and journal articles.

Diversity
Researchers need to be aware of the need to avoid bias and be inclusive of the age, culture, disability, gender, sexuality, or religion of research participants.
Effect size
In a quantitative study (see ‘Quantitative research’), if the results show that there is a difference between the groups within the study, it is important to know the size of the difference (effect size) as well as whether the study is statistically significant (see ‘Statistical significance’).

Effectiveness
Has a treatment, intervention, or a service achieved what it should have achieved – does it do what it says on the tin?

Ethics
Making sure that the research is relevant and not harmful. The researcher must ensure confidentiality and data protection for participants. Consent of participants must be sought and obtained.

Ethical approval
Health related research projects have to be approved by the organisation where the research is to take place (NHS approval) and by the Local or Multi-centre Research Ethics Committee. See also ‘Ethics’ and ‘Research Governance’.

Focus Group
A discussion with a group of people to gather information and different points of view about a particular topic.

Grounded theory
Grounded theory is developed from data. The theory is discovered in the data by reading it and looking for relationships between different categories of data.

Health of the Nation Outcome Scales - HoNOS
This is a clinical outcome measure used in mental health services. It is made up of 12 scales that are used to rate different aspects of working age adult service user’s mental and social health.

Hypothesis
A prediction or a theory which is tested by gathering data.

Information sheets
They tell people what a research project is about, what they are being asked to do if they take part, and what will happen to the information that is collected.

Interviews
A type of conversation where one person (the interviewer) asks questions of another (the interviewee) to gather information on a research topic.

Investigation
Looking into an issue and assessing information and facts.

Journal
1. A record of events (similar to diary), treatment or activities that research participants are asked to keep in the course of a project.
2. A publication containing papers written by researchers, service users and carers, academics or students.

Literature search
The gathering and analysing of information from different sources e.g. library, internet, books, magazines, journals etc.

Methodology
The stages of research; the way you go about it; the methods used.
Observation
A method of enquiry that involves the researcher in watching the actions or behaviour of people or groups of people over a period of time.

Participant observation – the observer or researcher becomes part of the group they are observing.

Outcomes
This is the effect, the result and is something that can be measured.

Pilot study
Something that is done before the main study starts to test that the methodology and the questions are correct and provide the information the researcher wants to collect.

Power of a study
If a study contains very few participants, it will have very little power to detect real differences between groups. Studies with large numbers of participants will have high power to detect even very small effects. (See ‘Effect size’ and ‘Statistical significance’).

Protocol
This is the map or plan for your research. It sets out the proposal and the stages of the project including the aims and objectives, background, methods, how the data will be collected and analysed, and how results will be reported.

Qualitative research
This emphasises the quality of information that is being collected. Information is usually gathered in a less structured way than for quantitative research e.g. through interviews or focus groups. The data will provide in depth information on behaviour, attitudes or views, how something is experienced or how someone experiences a service or treatment, rather than facts and figures. Sample sizes are usually small and not generalisable to the wider population.

Quantitative research
This produces measurable data, usually in the form of numbers, and deals with facts, figures, and measurements.

Questionnaire
A list of questions designed to gather information about a topic or a project.

Randomised Control Trials
A study where people are randomly allocated to groups. For example, one group receives a treatment (the treatment group) and one does not and is known as the control group. The results of the study are compared.

Randomly allocating people to groups makes sure there is no bias on the part of the researcher. It also means that any differences that are found between the groups are as a result of the treatment.

Report writing
Putting the findings from research into a report which can be shared with relevant people. The report usually includes an introduction, methodology, results, discussion and recommendations.

Research and Development Approval
Health related projects have to be approved by the organisation where the research is to take place as well as by the Research Ethics Committee.
Research Governance
This sets the standards for research, improves the quality of research and promotes good practice. It is for everyone who takes part in, manages, or undertakes research. It is also for organisations who host research and for those who fund research.

Research Governance Framework for Health and Social Care
The framework sets out the standards and good practice for those carrying out research in health and social care.

Research question
An idea for a project that has been turned into a question to be investigated.

Results
The findings from data and information collected and analysed as part of a research project.

Software e.g. SPSS, NVIVO
These are statistical software packages that can analyse quantitative or qualitative data. The data is entered into the software programme which can then be used to produce results, statistics and reports. Diagrams and graphs can also be produced. SPSS – Statistical Package for the Social Sciences.

Sponsor
Someone who funds and supports research. They have a responsibility to make sure that the research is ethical and does not harm anyone.

Statistics
When we measure and count things we get numbers which we call data. We describe and analyse the data using methods called statistics or statistical procedures.

Statistical significance
When data from a quantitative study (see ‘Quantitative research’) is said to be ‘statistically significant’, this means that an effect has been shown as a result of for example, a treatment or therapy. The same results should be achieved by someone else doing the same study.

Because something is statistically significant, it does not mean that it will be significant for clinical practice. The differences may be too small to make a difference to clinical practice.

Survey
A way of collecting information (data) from a population or group of people. This may involve questionnaires or interviews and an example of this method is the national Census.

User focussed monitoring (UFM)
UFM is an approach that involves people in monitoring and evaluation who have had direct experience of using services. Service users are involved in such activities as setting up questionnaires, doing interviews and focus groups, and sharing and finding information.

Workshop
This involves a group of people coming together to listen and share information and opinions. It may involve small discussion groups and/or presentations.