Glossary of Terms

This glossary of terms provides public partners and lived-experience representatives with simple definitions of terms often used in SIGN guidelines.

Abstract - A brief summary of a research study. It should tell you why the study was done, how the researchers went about it and what they found.

Analysis - An analysis of data involves examining and processing research data to answer the questions that the project is trying to consider. It involves identifying patterns and finding the main themes, and is often done with special computer software.

Bias - In research, bias can be described as deviation from 'true' results. It happens when something distorts the results. Bias can affect the findings of studies and how they are reported. If bias exists, health decisions may be made on incorrect information. Researchers and clinicians try to identify possible sources of bias, so they can eliminate or compensate for possible bias.

Blinding - Participants and researchers do not know which treatment individuals are being given.

Carer - A relative, friend or partner who provides (or plans to provide, or used to provide) a significant amount of care to another person on a regular basis, but not necessarily through living with them.

Case - Participant taking part in a study.

Case-control Study - Patients with a particular disease or condition are identified or 'matched' with people who don't (controls). Data is then collected, for example by looking back at medical records or by asking them to recall their own history. Case-control studies are concerned with what caused a condition rather than how it should be treated.

Case Study - A case study describes the medical history of someone in the form of a story.

Causal relationship - A causal relationship develops when an intervention causes a change in an outcome. For example, you are a smoker and you only walk to the local shop each morning. You are very breathless and quit smoking and start to take longer walks. You start to feel much better, less breathless and are able to walk further.

You would probably conclude that giving up smoking has caused the change. There is clearly an association between the two. A researcher however, would question this.

You might have had an undiagnosed chest infection which was causing the breathlessness, you might have changed your diet or the air quality in your area may have improved. These are known as confounding variables.

Clinical research – A way of looking at 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 patients' records or the data from health and lifestyle surveys.

Clinical Trial - A research study which compares a new or different type of treatment with the best treatment currently available, or with a placebo. They test whether a new or different treatment is 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 study - Cohort studies are used to find out what happens to patients over a length of time. For example, they could investigate how long patients with acute low-back pain take to recover. Cohort studies may have a control group who will be followed for the same length of time.

Concealment method - The process used to make sure that the researcher entering a person into a clinical trial does not know whether the person will be getting the new treatment being tested or a placebo. In other words, the method used to decide which patients get which treatment must be hidden (concealed) from the investigators. It must be impossible for investigators to guess who is getting which treatment.

Confidentiality - During a research project, the researchers must put data-protection measures in place to make sure that all the information collected about the people who are taking part in the study is kept confidential. Researchers must get these people's permission, in writing, before they look at their medical or social-care records.

Any information that might identify the people in the study cannot be used or passed on without those people's permission. 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 - that is, if it is:

- vital for the person's care, treatment or safety
- needed under a court order (for example, in a criminal investigation), or
- necessary to protect the public.

Confounding variable - An extra factor that hasn't been taken into account that can affect the outcome of a study. If researchers do not account for confounding variables it could mean their study is neither valid nor reliable. For example, a study might examine the association between a vegetarian diet and the risk of heart disease.

Confounding variables would be other factors that can influence the risk of heart disease, such as exercise, family history, and smoking. The study could not reliably make the association between being vegetarian and suffering from heart disease unless it took these other factors into account.

Consensus – General agreement from a group of people.

Considered judgement - Even when evidence is available, decisions may not always be clear cut and benefits and harms of treatments may need to be debated. The balance may be different for different patient groups or individuals.

Guideline group members consider the evidence, clinical expertise and patient preferences when making recommendations.

Consultation - Consultation involves asking people not directly involved in the research, for example, specialists in the area or members of the public, for their views, and then using those views to help make an informed decision.

Consultation can be about any part of the research process - from identifying topics for research through to thinking about the effects of the research findings. Having a better understanding of people's views should lead to better decisions.

Control group - In a clinical trial, a control group is generally a group of people who do not receive any kind of treatment. This group will be compared with the experimental group to study the effects of the intervention.

Critical appraisal - 'Critical appraisal' is the name we give to the process of reading and assessing scientific and medical papers.

Data - 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 given to other people (for example, in reports, graphs or diagrams).

Database - An organised collection of information that can be easily accessed, managed and updated.

Data protection - All personal information is protected in the UK by the Data Protection Act (1998). Researchers have to put all necessary measures in place to protect the confidentiality of the information they collect about the people who are taking part in the research. They should use the patients' information sheet to explain:

- how the 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 the people who are taking part in the study
- how long it will be kept, and
- how it will be destroyed securely.

Diagnostic study - Aims to investigate the best way to diagnose a condition. The studies look at how well a test identifies a patient with the condition. New tests may be compared to the best test currently available.

Dissemination - Dissemination involves making the findings of, for example, a research project available 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, or
- giving talks at conferences.

It is also important to make research findings available to the people who took part in the study.

Economic study - This type of study involves assessing the cost of individual items of care against the benefits to patients.

Effect size - The amount of change created by an intervention, especially in an experimental study.

Empowerment - This is the process by which people gain the knowledge, skills and resources they need to be able to take control over decisions and resources. It often involves people becoming more confident in their own strengths and abilities. It does not always mean people take control of all decisions or all resources.

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 effects. The results of evaluations can help with decision making and planning.

Evidence – The data we use to support the recommendations we provide in the guidelines we produce.

Evidence base - 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. Health and social care professionals use this evidence to make decisions about the services they provide and what care or treatment to offer people who use their services.

Evidence table - Evidence tables summarise all the validated studies identified from the systematic review relating to each key question.

Evidence to Decision (EfD Framework) - The purpose of EtD frameworks is to help guideline development groups making recommendations move from evidence to decisions.

Exclusion criteria - Exclusion criteria are used to decide, for example, who won't be able to take part in a clinical trial. In many trials, women who are pregnant or planning to become pregnant may be excluded to avoid any possible danger to the baby.

Experimental group - A group of patients taking part in a clinical research study who receive a treatment or procedure and who are then compared to a control group.

Experts by experience - Service users and carers who are experts through their experience of illness or disability and services.

Extrapolated evidence - If there is evidence from a clinical trial about the effect of a medicine in a Japanese population, but no evidence about the effect of the same medicine in a Scottish population, then the guideline group might 'extrapolate' from the Japanese evidence about what might happen in Scottish patients. This is sometimes called 'indirect evidence' and guideline development groups will place less importance on this type of evidence.

Focus group - 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.

Generalisability - Whether research findings and conclusions from a study carried out on a sample of people can be applied to the wider population.

GP – General Practitioner.

Grey literature - Material that is less formal than a research paper in a journal or a chapter in a book. It includes internal reports, committee minutes, conference papers, fact sheets, newsletters and campaigning material. This material is becoming more and more widely available on the internet.

Guidelines - Statements to help healthcare professionals and patients make decisions about appropriate care for specific circumstances.

Guideline development group – The group of people from various health ,social care and other backgrounds, and those with lived experience, who help shape the final guideline.

HIS - Healthcare Improvement Scotland. The purpose of Healthcare Improvement Scotland is to enable the people of Scotland to experience the best quality of health and social care.

Hypothesis - An unproven theory that can be tested through research.

Implementation - Implementation is about putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policies and practice.

Inclusion criteria - Inclusion criteria help researchers decide, for example, who can take part in a clinical trial. Some trials only include people who are a certain age or at a particular stage of their illness.

Intervention - Something that aims to make a change and is tested through research. For example, giving a medicine, 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 get information from the person (or people) being interviewed. Interviews can be carried out in person or over the phone.

Journal - 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. A research paper must go through the peer review process before it can be published. The 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 people who are neither academic researchers nor health or social care professionals.

Literature review - A review of published research in a particular area. Published research is often referred to as ‘the literature’.

Literature search - A search for published medical and scientific research reports to find all the relevant research work on a particular topic.

Lived experience – People who have experience in living with or supporting/caring for someone with the condition that the guideline covers.

Members of the public - We use this term to cover:

- patients and potential patients
- people who use health and social care services
- unpaid carers and family members
- parents
- charities that represent specific health conditions, and
- organisations that represent people who use services.

Meta-analysis - A systematic review that uses statistical methods to combine the results of two or more studies that considered the same research questions.

Methodology - The techniques or processes that have been used to complete a piece of research. In other words, how information is collected and analysed.

National meeting – an open meeting held during the process that people can come to and share their views on the upcoming guideline.

Observational study - Cohort and case-control studies are collectively referred to as observational studies.

Participant (or subject) - Someone who takes part in a research project or trial. Sometimes participants are referred to as ‘subjects’ or ‘cases’.

Patient and public involvement - Involving patients, service users, carers and their representatives in their own care, and in planning, monitoring and developing health services. Patients, service users, carers and members of the public may have different views to health and social care professionals about getting the most from care providers.

Patient or public version – a version of the guideline written specifically for patients, carers and the public.

Peer review - Where a research proposal or report (such as a journal article or guideline) is read and commented on by people who have similar interests and expertise to the people who wrote the proposal or report.

Peer reviewers might be members of the public, researchers, or other professionals. Peer reviews help to check the quality of a report or research proposal.

Placebo - A treatment that is harmless and ineffective. It allows researchers to test for the 'placebo effect'. It is given to allow researchers to compare its effect with those of a real medicine or other intervention.

The placebo effect is a psychological response where people feel better because they have received a treatment, not because the treatment itself has a specific effect on their condition. By comparing responses to the placebo and to the treatment being tested, researchers can tell whether the treatment is having any real benefit.

Plain language – a translation of the guideline used to ensure that it is accessible to everyone.

Probability - The chances or risks of something happening (for example, the chance of throwing a six with a dice is one in six). Probability is usually described using decimal fractions, where one in six will become 0.167. Probabilities range between 0.0 and 1.0, where zero means an event will never happen and 1.0 means it is certain to happen.

Prospective study - Studies that follow patients up over a period of time.

Qualitative research - Qualitative research is used to explore and understand people's 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 telephone and face-to-face interviews.

Quantitative research - Where researchers collect data in the form of numbers (in other words, they measure things or count things).

Quantitative research might ask a question like how many people visit their GP each year, what percentage of children have had a vaccination for measles, mumps and rubella (MMR) or does a new medicine lower blood pressure more than the medicines that are currently used. Quantitative researchers use methods like clinical trials and surveys.

Questionnaire - A prepared set of written questions used to gather information from research participants. Questionnaires can be filled in on paper, using a computer, or with an interviewer.

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.

Using a 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, or no treatment.

In a randomised controlled trial, the decision about which group a person joins is random (that is, based on chance). For example, a computer program will decide rather than the researcher or the participant. Having a random selection makes sure 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.

Reliability - Whether the use of a measure, procedure or instrument gives the same result in repeated trials.

Remit - The aspects of a condition that the guideline will cover. For example the remit of a guideline may be assessment and management of adults with chronic non-malignant pain in non-specialist settings. Children would be outwith the remit.

Representative - Someone who is representing a wider group of people (for example, the public or a patient support group).

If you've been asked to get involved 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 - Carrying out experiments, trials or other studies to find out new information that could lead to changes to treatments, policies or care.

Research methods - The ways researchers collect and analyse information. These include interviews, questionnaires, diaries, clinical trials, experiments, analysing documents or statistics, or watching people's behaviour.

Research paper - Results from research studies are written up and published in scientific and medical journals as 'papers'.

Research proposal - Usually an application form or set of papers that researchers fill in to explain what research they want to do and how they want to do it. It will also cover who will be involved (both as participants and in carrying out the research), the timescale and the cost.

Retrospective study - Studies that trace what happened to people in the past.

Service user - Someone who uses or has used health and social care services because they have an illness or a disability.

SIGN – Scottish Intercollegiate Guidelines Network. Part of Healthcare Improvement Scotland.

SIGN Council – The part of the organisation that sets our policies.

SIGN Executive – The team of staff we employ to run the organisation and put SIGN Council's decisions into practice.

SIGN Patient and Public Involvement Network – a network of organisations and individuals who we work with to identify the views and experiences of people living with conditions.

SIGN Staff

- **Programme Manager** – oversees the work of the guideline development group and manages the guideline process
- **Evidence and Information Scientist** – searches medical and scientific research databases to find relevant research on the guideline topic, and decides what research can be included
- **Health Services Researcher** – carries out critical appraisal and analyses the evidence**.**
- **Guideline Co-ordinator** – provides administrative support to the guideline development group
- **Patient Involvement Advisor** – responsible for managing our activities involving patients and the public
- **Health Economist** – considers the costs involved with treatments and whether or not they are good value

Statistics and statistical analysis - Statistics is the manipulation of numbers (quantitative data) collected through research (for example, the average age if a group of people, or the number of people who use a service).

Statistical analysis uses a set of mathematical rules to analyse quantitative data. It can help researchers decide what data mean. For example, statistical analysis can assess whether any difference seen between two groups of people (for example, between the groups of people in a clinical trial) is a reliable finding or simply due to chance.

Systematic review - A systematic review brings together the results of all the studies about a particular research question that have been carried out around the world in a set time frame (for example, 2010 to 2015).

They provide a detailed and unbiased summary of the research. For example, a single clinical trial may not give a clear answer about the effectiveness of a treatment because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial.

Systematic reviews are used to bring together the results of similar trials and assess the quality of the combined evidence. Combining the results from a number of trials may give a clearer picture.

Validity - Whether the results of a study are likely to be true and free from bias.

Variable - Characteristics that vary among and between people and that can be observed and measured.

Studies normally try to concentrate on a single variable and how it changes in response to an intervention. Variables include age, gender, smoking status, and test results.