

Babies, children and young people's experience of healthcare

Supplement 1: Glossary and abbreviations

NICE guideline NG204

Supplement 1

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Contents

Glossary.....	5
Abbreviations	16

Glossary

Term	Definition
Abstract	Summary of a study, which may be published alone or as an introduction to a full scientific paper.
Accessible	Something (for example, a service or information format) designed in a way so that people who have a disability or impairment are able to use it with a similar level of time, effort and skill needed to someone who does not.
Arm (of a clinical study)	Subsection of individuals within a study who receive one particular intervention, for example placebo arm.
Assent	Agreement given by a child or young person to a course of action or procedure, when they are not legally empowered to give consent.
Association	Statistical relationship between 2 or more events, characteristics or other variables. The relationship may or may not be causal.
Baseline	The initial set of measurements at the beginning of a study (after run-in period where applicable) with which subsequent results are compared.
Bias	Influences on a study that can make the results look better or worse than they really are. Bias can occur by chance, deliberately or as a result of systematic errors in the design and execution of a study. It can also occur at different stages in the research process, for example during the collection, analysis, interpretation, publication or review of research data. For examples see Confounding factor, Performance bias, Publication bias Selection bias.
Blinding	The practice of keeping the investigators or subjects of a study ignorant of the group to which a subject has been assigned. For example, a clinical trial in which the participating patients or their doctors are unaware of whether they (the patients) are taking the experimental drug or a placebo (dummy treatment). The purpose of 'blinding' or 'masking' is to protect against bias. See also double-blind study and single-blind study.
Clinician	A healthcare professional who provides patient care. For example a doctor, nurse or physiotherapist.
Cluster randomised	A type of randomised controlled trial in which groups of subjects (as opposed to individual subjects) are randomised.
Cochrane Review	The Cochrane Library consists of a regularly updated collection of evidence-based medicine databases including the Cochrane Database of Systematic Reviews (reviews of RCTs prepared by the Cochrane Collaboration).
Cohort	A group of people sharing some common characteristic (e.g. patients with the same disease), followed up in a research study for a specified period of time.
Cohort study	A study with 2 or more groups of people – cohorts – with similar characteristics. One group receives a treatment, is exposed to a risk factor or has a particular symptom and the other group does not. The study follows their progress over time and records what happens.
Comorbidities	The presence of more than one disease or health condition in an individual at a given time
Comparative group	The group in the study who do not receive the treatment/procedure or who receive the norm treatment. This group is used to measure against the treatment/procedure being investigated.
Concealment of allocation	The process used to ensure that the person deciding to enter a participant into an RCT does not know the comparison group into which

Term	Definition
	that individual will be allocated. This is distinct from blinding and is aimed at preventing selection bias. Some attempts at concealing allocation are more prone to manipulation than others and the method of allocation concealment is used as an assessment of the quality of a trial.
Confidence interval (CI)	<p>There is always some uncertainty in research. This is because a small group of patients is studied to predict the effects of a treatment on the wider population. The confidence interval is a way of expressing how certain we are about the findings from a study, using statistics. It gives a range of results that is likely to include the 'true' value for the population. The CI is usually stated as '95% CI', which means that the range of values has a 95 in 100 chance of including the 'true' value. For example, a study may state that "based on our sample findings, we are 95% certain that the 'true' population blood pressure is not higher than 150 and not lower than 110". In such a case the 95% CI would be 110 to 150.</p> <p>A wide confidence interval indicates a lack of certainty about the true effect of the test or treatment – often because a small group of patients has been studied. A narrow confidence interval indicates a more precise estimate (for example if a large number of patients have been studied).</p>
Confounding factor	Something that influences a study and can result in misleading findings if it is not understood or appropriately dealt with. For example, a study of heart disease may look at a group of people who exercise regularly and a group who do not exercise. If the ages of the people in the 2 groups are different, then any difference in heart disease rates between the 2 groups could be because of age rather than exercise. Therefore age is a confounding factor.
Consent	Agreement (which can be verbal, non-verbal or written) to a course of action or procedure after a discussion of the risks and benefits.
Containment holding	Placing both hands firmly but gently on a baby and holding the position very still, to provide reassurance and comfort.
Continuous outcome	Data with a potentially infinite number of possible values within a given range. Height, weight and blood pressure are examples of continuous variables.
Contraindicated	A situation in which a medication or treatment should not be administered
Control group	A group of people in a study who do not receive the treatment or test being studied. Instead, they may receive the standard treatment (sometimes called 'usual care') or a dummy treatment (placebo). The results for the control group are compared with those for a group receiving the treatment being tested. The aim is to check for any differences. Ideally, the people in the control group should be as similar as possible to those in the treatment group, to make it as easy as possible to detect any effects due to the treatment.
Cost–benefit analysis (CBA)	Cost-benefit analysis is one of the tools used to carry out an economic evaluation. The costs and benefits are measured using the same monetary units (for example UK pounds) to see whether the benefits exceed the costs.
Cost–consequence analysis (CCA)	Cost-consequence analysis is one of the tools used to carry out an economic evaluation. This compares the costs (such as treatment and hospital care) with the consequences (such as health outcomes) of a test or treatment with a suitable alternative. Unlike cost–benefit analysis or cost-effectiveness analysis, it does not attempt to summarise outcomes in a single measure (such as the quality adjusted life year) or in financial terms. Instead, outcomes are shown in their natural units (some of which may be monetary) and it is left to decision-makers to determine whether, overall, the treatment is worth carrying out.

Term	Definition
Cost-effectiveness analysis (CEA)	Cost-effectiveness analysis is one of the tools used to carry out an economic evaluation. The benefits are expressed in non-monetary terms related to health, such as symptom-free days, heart attacks avoided, deaths avoided or life years gained (that is, the number of years by which life is extended as a result of the intervention).
Cost-effectiveness model	An explicit mathematical framework which is used to represent clinical decision problems and incorporate evidence from a variety of sources in order to estimate the costs and health outcomes.
Cost-minimisation analysis (CMA)	Cost-minimisation analysis is a type of economic evaluation which can be used when the alternatives being compared have equivalent clinical effectiveness. The costs of alternatives are compared in order to determine which is the cheapest.
Cost–utility analysis (CUA)	Cost–utility analysis is one of the tools used to carry out an economic evaluation. The benefits are assessed in terms of both quality and duration of life, and expressed as quality adjusted life years (QALYs). See also Utility.
Credible interval (CrI)	The Bayesian equivalent of a confidence interval.
Cross-over study design	A study comparing two or more interventions in which the participants, upon completion of the course of one treatment, are switched to another. A problem with this study design is that the effects of the first treatment may carry over into the period when the second is given. Therefore a crossover study should include an adequate ‘wash-out’ period, which means allowing sufficient time between stopping one treatment and starting another so that the first treatment has time to wash out of the patient’s system.
Cross-sectional study	The observation of a defined set of people at a single point in time or time period – a snapshot. (This type of study contrasts with a longitudinal study, which follows a set of people over a period of time.)
Cultural sensitivity	Knowledge, awareness and respect for other people’s cultural background, identity and differences, without making assumptions about them.
Decision analysis	An explicit quantitative approach to decision-making under uncertainty, based on evidence from research. This evidence is translated into probabilities, and then into diagrams or decision trees which direct the clinician through a succession of possible scenarios, actions and outcomes.
Dichotomous outcomes	Outcome that can take one of 2 possible values, such as dead/alive, smoker/non-smoker, present/not present (also called binary data).
Discounting	Costs and perhaps benefits incurred today have a higher value than costs and benefits occurring in the future. Discounting health benefits reflects individual preference for benefits to be experienced in the present rather than the future. Discounting costs reflects individual preference for costs to be experienced in the future rather than the present.
Dominance	A health economics term. When comparing tests or treatments, an option that is both less effective and costs more is said to be 'dominated' by the alternative.
Double-blind study	A study in which neither the subject (patient) nor the observer investigator/ clinician) is aware of which treatment or intervention the subject is receiving. The purpose of blinding is to protect against bias.
Drop-out	A participant who withdraws from a trial before the end.
Economic evaluation	An economic evaluation is used to assess the cost effectiveness of healthcare interventions (that is, to compare the costs and benefits of a healthcare intervention to assess whether it is worth doing). The aim of

Term	Definition
	<p>an economic evaluation is to maximise the level of benefits – health effects – relative to the resources available. It should be used to inform and support the decision-making process; it is not supposed to replace the judgement of healthcare professionals.</p> <p>There are several types of economic evaluation: cost–benefit analysis, cost–consequence analysis, cost-effectiveness analysis, cost-minimisation analysis and cost–utility analysis. They use similar methods to define and evaluate costs, but differ in the way they estimate the benefits of a particular drug, programme or intervention.</p>
Effect (as in effect measure, treatment effect, estimate of effect, effect size)	A measure that shows the magnitude of the outcome in 1 group compared with that in a control group. For example, if the absolute risk reduction is shown to be 5% and it is the outcome of interest, the effect size is 5%. The effect size is usually tested, using statistics, to find out how likely it is that the effect is a result of the treatment and has not just happened by chance.
Effectiveness	How beneficial a test or treatment is under usual or everyday conditions.
Effectiveness reviews	Evaluation of how beneficial a test or treatment is under everyday conditions.
Efficacy	How beneficial a test, treatment or public health intervention is under ideal conditions (for example in a laboratory).
EQ-5D (EuroQoL 5 dimensions) or EQ-VAS	A standardised instrument used to measure health-related quality of life. It provides a single index value for health status.
EQ-VAS (EuroQoL Visual analogue scale)	A standardised instrument used to measure health-related quality of life, using a visual analogue scale.
Evidence	Information on which a decision or guidance is based. Evidence is obtained from a range of sources including RCTs, observational studies, expert opinion (of clinical professionals or patients).
Evidence based	The process of systematically finding, appraising and using research findings as the basis for clinical decisions.
Evidence table	A table summarising the results of a collection of studies which, taken together, represent the evidence supporting a particular recommendation or series of recommendations in a guideline.
Exclusion criteria (clinical study)	Criteria that define who is not eligible to participate in a clinical study.
Exclusion criteria (literature review)	Explicit standards used to decide which studies should be excluded from consideration as potential sources of evidence.
Extended dominance	If Option A is both more clinically effective than Option B and has a lower cost per unit of effect when both are compared with a do-nothing alternative, then Option A is said to have extended dominance over Option B. Option A is therefore more cost effective and should be preferred, other things remaining equal.
Extrapolation	An assumption that the results of studies of a specific population will also hold true for another population with similar characteristics.
Fixed-effect model	In meta-analysis, a model that calculates a pooled effect estimate using the assumption that all observed variation between studies is caused by random sample variability. Studies are assumed to be estimating the same overall effect.
Focus and reference groups	A series of focus and reference groups with children and young people were held to obtain their views and opinions, and these were considered by the committee as part of their review of the evidence.
Follow-up	Observation over a period of time of an individual, group or initially defined population whose appropriate characteristics have been assessed in order to observe changes in health status or health-related variables.

Term	Definition
Forest plot	A graphical representation of the individual results of each study included in a meta-analysis together with the combined meta-analysis result. The plot also allows readers to see the heterogeneity among the results of the studies. The results of individual studies are shown as squares centred on each study's point estimate. A horizontal line runs through each square to show each study's confidence interval. The overall estimate from the meta-analysis and its confidence interval are shown at the bottom, represented as a diamond. The centre of the diamond represents the pooled point estimate, and its horizontal tips represent the confidence interval.
Generalisability	The extent to which the results of a study hold true for groups that did not participate in the research.
Gold standard	A method, procedure or measurement that is widely accepted as being the best available to test for or treat a disease.
GRADE, GRADE profile. GRADE-CERQual	A system developed by the GRADE Working Group to address the short-comings of present grading systems in healthcare. The GRADE system uses a common, sensible and transparent approach to grading the quality of evidence. The results of applying the GRADE system to clinical trial data are displayed in a table known as a GRADE profile.
GRADE-CERQual	A modified form of GRADE to assess the confidence in the evidence from qualitative research.
Harms	Adverse effects of an intervention.
Health economics	Study or analysis of the cost of using and distributing healthcare resources.
Health-related quality of life (HRQoL)	A measure of the effects of an illness to see how it affects someone's day-to-day life.
Heterogeneity	The term is used in meta-analyses and systematic reviews to describe when the results of a test or treatment (or estimates of its effect) differ
Imprecision	Results are imprecise when studies include relatively few patients and few events and thus have wide confidence intervals around the estimate of effect.
Inclusion criteria (clinical study)	Specific criteria that define who is eligible to participate in a clinical study.
Inclusion criteria (literature review)	Explicit criteria used to decide which studies should be considered as potential sources of evidence.
Incremental cost	The extra cost linked to using one test or treatment rather than another. Or the additional cost of doing a test or providing a treatment more frequently.
Incremental cost effectiveness ratio (ICER)	The difference in the mean costs in the population of interest divided by the differences in the mean outcomes in the population of interest for one treatment compared with another.
Incremental net benefit (INB)	The value (usually in monetary terms) of an intervention net of its cost compared with a comparator intervention. The INB can be calculated for a given cost-effectiveness (willingness to pay) threshold. If the threshold is £20,000 per QALY gained then the INB is calculated as: (£20,000×QALYs gained) minus incremental cost.
Indirectness	The available evidence is different to the review question being addressed, in terms of population, intervention, comparison and outcome (PICO).
Intention-to-treat analysis (ITT)	An assessment of the people taking part in a clinical trial, based on the group they were initially (and randomly) allocated to. This is regardless of whether or not they dropped out, fully complied with the treatment or switched to an alternative treatment. Intention-to-treat analyses are often used to assess clinical effectiveness because they mirror actual

Term	Definition
	practice: that is, not everyone complies with treatment and the treatment people receive may be changed according to how they respond to it.
Internal validity	How well an experiment is done and if it is clear that the variable being tested is what is causing the measured effect.
Intervention	In medical terms this could be a drug treatment, surgical procedure, diagnostic or psychological therapy. Examples of public health interventions could include action to help someone to be physically active or to eat a more healthy diet.
Length of stay	The total number of days a patient stays in hospital.
Lost to follow-up	Patients who have withdrawn from the clinical trial at the point of follow-up.
Markov model	A method for estimating long-term costs and effects for recurrent or chronic conditions, based on health states and the probability of transition between them within a given time period (cycle).
Mean	An average value, calculated by adding all the observations and dividing by the number of observations.
Mean difference	In meta-analysis, a method used to combine measures on continuous scales (such as weight), where the mean, standard deviation and sample size in each group are known. The weight given to the difference in means from each study (for example how much influence each study has on the overall results of the meta-analysis) is determined by the precision of its estimate of effect.
Median	The value of the observation that comes half-way when the observations are ranked in order.
Meta-analysis	A method often used in systematic reviews. Results from several studies of the same test or treatment are combined to estimate the overall effect of the treatment.
Methodology	Systematic, theoretical analysis of the methods applied to a field of study.
Minimal important difference (MID)	Threshold for clinical importance which represents the minimal important difference for benefit or for harm; for example the threshold at which drug A is less effective than drug B by an amount that is clinically important to patients.
Morbidity	A diseased condition or state
Multidisciplinary team	A team with members from different healthcare professions (including for example, oncology, pathology, radiology, nursing)
Multivariate model	A statistical model for analysis of the relationship between 2 or more predictors, (independent) variables and the outcome (dependent) variable.
National surveys	A review of recent national surveys of children and young people's views on healthcare was carried out. The findings of these surveys were considered by the committee as part of their review of the evidence.
Net monetary benefit (NMB)	The value (usually in monetary terms) of an intervention net of its cost. The NMB can be calculated for a given cost-effectiveness (willingness to pay) threshold. If the threshold is £20,000 per QALY gained then the NMB is calculated as: (£20,000×QALYs gained) minus cost.
Network meta-analysis (NMA)	Meta-analysis in which multiple treatments (that is, 3 or more) are being compared using both direct comparisons of interventions within RCTs and indirect comparisons across trials based on a common comparator.
Non-judgemental	Not criticising or demonstrating a negative attitude about another person's feelings or actions, based on personal opinions or personal biases.

Term	Definition
Non-randomised	When subjects of a study are not allocated to a specific treatment/group at random.
Number needed to treat (NNT)	The average number of patients who need to be treated to get a positive outcome. For example, if the NNT is 4, then 4 patients would have to be treated to ensure 1 of them gets better. The closer the NNT is to 1, the better the treatment. For example, if you give a stroke prevention drug to 20 people before 1 stroke is prevented, the number needed to treat is 20.
Observational study	Individuals or groups are observed or certain factors are measured. No attempt is made to affect the outcome. For example, an observational study of a disease or treatment would allow 'nature' or usual medical care to take its course. Changes or differences in one characteristic (for example whether or not people received a specific treatment or intervention) are studied without intervening. There is a greater risk of selection bias than in experimental studies.
Occult	Hidden, or difficult to observe directly
Odds ratio (OR)	<p>Odds are a way to represent how likely it is that something will happen (the probability). An odds ratio compares the probability of something in one group with the probability of the same thing in another.</p> <p>An odds ratio of 1 between 2 groups would show that the probability of the event (for example a person developing a disease, or a treatment working) is the same for both. An odds ratio greater than 1 means the event is more likely in the first group. An odds ratio less than 1 means that the event is less likely in the first group.</p> <p>Sometimes probability can be compared across more than 2 groups – in this case, one of the groups is chosen as the 'reference category' and the odds ratio is calculated for each group compared with the reference category. For example, to compare the risk of dying from lung cancer for non-smokers, occasional smokers and regular smokers, non-smokers could be used as the reference category. Odds ratios would be worked out for occasional smokers compared with non-smokers and for regular smokers compared with non-smokers.</p> <p>See also Confidence interval, Relative risk.</p>
Opportunity cost	The loss of other healthcare programmes displaced by investment in or introduction of another intervention. This may be best measured by the health benefits that could have been achieved had the money been spent on the next best alternative healthcare intervention.
Outcome	The impact that a test, treatment, policy, programme or other intervention has on a person, group or population. Outcomes from interventions to improve the public's health could include changes in knowledge and behaviour related to health, societal changes (for example a reduction in crime rates) and a change in people's health and wellbeing or health status. In clinical terms, outcomes could include the number of patients who fully recover from an illness or the number of hospital admissions, and an improvement or deterioration in someone's health, functional ability, symptoms or situation. Researchers should decide what outcomes to measure before a study begins.
p value	The p value is a statistical measure that indicates whether or not an effect is statistically significant. For example, if a study comparing 2 treatments found that one seems more effective than the other, the p value is the probability of obtaining these results by chance. By convention, if the p value is below 0.05 (that is, there is less than a 5% probability that the results occurred by chance) it is considered that there probably is a real difference between treatments. If the p value is 0.001 or less (less than a 1% probability that the results occurred by chance), the result is seen as highly significant. If the p value shows that

Term	Definition
	there is likely to be a difference between treatments, the confidence interval describes how big the difference in effect might be.
Parents or carers	Parents or carers refers to the primary care-givers for a baby or child at any given time. This can include birth or adoptive parents with parental responsibility, other members of the extended family who provide care such as siblings, grandparents, aunts and uncles, or others nominated by the parents or legal guardians. For looked-after children or those who lack mental capacity it can also include those acting instead of parents such as a social worker, key worker, foster carers or guardians.. It does not refer to nurses, healthcare assistants or other healthcare professionals who are acting in their professional capacity.
Pairwise analysis	A process of comparing entities in pairs to judge which of each entity is preferred, or has a greater amount of some quantitative property.
Performance bias	Systematic differences between intervention groups in care provided apart from the intervention being evaluated. Blinding of study participants (both the recipients and providers of care) is used to protect against performance bias.
Placebo	A fake (or dummy) treatment given to participants in the control group of a clinical trial. It is indistinguishable from the actual treatment (which is given to participants in the experimental group). The aim is to determine what effect the experimental treatment has had over and above any placebo effect caused because someone has received (or thinks they have received) care or attention.
Placebo effect	A beneficial (or adverse) effect produced by a placebo and not due to any property of the placebo itself.
Positive touch	Human touch which aims to give babies the experience of touch that is not for a clinical purpose, but is given tenderly, lovingly and gently and that responds to and does not ignore their behaviour.
Post-hoc analysis	Statistical analyses that are not specified in the trial protocol and are generally suggested by the data.
Power (statistical)	The ability to demonstrate an association when one exists. Power is related to sample size; the larger the sample size, the greater the power and the lower the risk that a possible association could be missed.
Prevalence	The prevalence of a disease is the proportion of a population that are cases at a point in time.
Primary care	Healthcare delivered outside hospitals. It includes a range of services provided by GPs, nurses, health visitors, midwives and other healthcare professionals and allied health professionals such as dentists, pharmacists and opticians.
Primary care	Services provided in a community setting, outside secondary care, with which patients usually have first contact
Primary outcome	The outcome of greatest importance, usually the one in a study that the power calculation is based on.
Prognosis	A probable course or outcome of a disease. Prognostic factors are patient or disease characteristics that influence the course. Good prognosis is associated with low rate of undesirable outcomes; poor prognosis is associated with a high rate of undesirable outcomes.
Prognostic factors	Disease characteristics that influence the course of the disease and which are used to predict the likely outcome
Prospective study	A research study in which the health or other characteristic of participants is monitored (or 'followed up') for a period of time, with events recorded as they happen. This contrasts with retrospective studies.

Term	Definition
Protocol (review)	A document written prior to commencing a review that details exactly how evidence to answer a review question will be obtained and synthesised. It defines in detail the population of interest, the interventions, the comparators/controls and the outcomes of interest (PICO).
Publication bias	Publication bias occurs when researchers publish the results of studies showing that a treatment works well and don't publish those showing it did not have any effect. If this happens, analysis of the published results will not give an accurate idea of how well the treatment works. This type of bias can be assessed by a funnel plot.
Qualitative review	A review that analyses descriptive data to gain an understanding of reasons, opinions, or preferences.
Quality adjusted life year (QALY)	A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality-of-life. One QALY is equal to 1 year of life in perfect health. QALYS are calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a scale of 0 to 1). It is often measured in terms of the person's ability to perform the activities of daily life, and freedom from pain and mental disturbance.
Quality of life	See Health-related quality of life.
Quantitative review	A review that analyses numerical data to determine differences between interventions.
Random effect model	In meta-analysis, a model that calculates a pooled effect estimate using the assumption that each study is estimating a different true treatment effect due to real differences between studies. Observed variation in effects are therefore caused by a combination of random sample variability (within-study variation) and heterogeneity between studies (between-study variation). The overall effects is an average of the estimated true study effects.
Randomisation	Assigning participants in a research study to different groups without taking any similarities or differences between them into account. For example, it could involve using a random numbers table or a computer-generated random sequence. It means that each individual (or each group in the case of cluster randomisation) has the same chance of receiving each intervention.
Randomised controlled trial (RCT)	A study in which a number of similar people are randomly assigned to 2 (or more) groups to test a specific drug or treatment. One group (the experimental group) receives the treatment being tested, the other (the comparison or control group) receives an alternative treatment, a dummy treatment (placebo) or no treatment at all. The groups are followed up to see how effective the experimental treatment was. Outcomes are measured at specific times and any difference in response between the groups is assessed statistically. This method is also used to reduce bias.
Recruitment bias	When proper randomisation is not achieved when recruiting individuals, meaning that the sample obtained may not be representative of the population intended to be analysed.
Reference standard	The test that is considered to be the best available method to establish the presence or absence of the outcome – this may not be the one that is routinely used in practice.
Regimen	A plan or regulated course of treatment
Relative risk (RR)	The ratio of the risk of disease or death among those exposed to certain conditions compared with the risk for those who are not exposed to the same conditions (for example the risk of people who smoke getting lung

Term	Definition
	cancer compared with the risk for people who do not smoke). If both groups face the same level of risk, the relative risk is 1. If the first group had a relative risk of 2, subjects in that group would be twice as likely to have the event happen. A relative risk of less than 1 means the outcome is less likely in the first group. Relative risk is sometimes referred to as risk ratio.
Reporting bias	See Publication bias.
Resource implication	The likely impact in terms of finance, workforce or other NHS resources.
Retrospective study	A research study that focuses on the past and present. The study examines past exposure to suspected risk factors for the disease or condition. Unlike prospective studies, it does not cover events that occur after the study group is selected.
Review question	The plan or set of steps to be followed in a study. A protocol for a systematic review describes the rationale for the review, the objectives and the methods that will be used to locate, select and critically appraise studies, and to collect and analyse data from the included studies.
Secondary care	Services provided by multidisciplinary team in the hospital, as opposed to the General Practitioner and the primary care team
Secondary outcome	An outcome used to evaluate additional effects of the intervention deemed a priori as being less important than the primary outcomes.
Selection bias	<p>Selection bias occurs if:</p> <ul style="list-style-type: none"> • the characteristics of the people selected for a study differ from the wider population from which they have been drawn; or • there are differences between groups of participants in a study in terms of how likely they are to get better.
Sensitivity	<p>How well a test detects the thing it is testing for. If a diagnostic test for a disease has high sensitivity, it is likely to pick up all cases of the disease in people who have it (that is, give a 'true positive' result). But if a test is too sensitive it will sometimes also give a positive result in people who don't have the disease (that is, give a 'false positive'). For example, if a test were developed to detect if a woman is 6 months pregnant, a very sensitive test would detect everyone who was 6 months pregnant but would probably also include those who are 5 and 7 months pregnant. If the same test were more specific (sometimes referred to as having higher specificity), it would detect only those who are 6 months pregnant and someone who was 5 months pregnant would get a negative result (a 'true negative'). But it would probably also miss some people who were 6 months pregnant (that is, give a 'false negative').</p> <p>Breast screening is a 'real-life' example. The number of women who are recalled for a second breast screening test is relatively high because the test is very sensitive. If it were made more specific, people who don't have the disease would be less likely to be called back for a second test but more women who have the disease would be missed.</p>
Sensitivity analysis	<p>A means of representing uncertainty in the results of an analysis. Uncertainty may arise from missing data, imprecise estimates or methodological controversy. Sensitivity analysis also allows for exploring the generalisability of results to other settings. The analysis is repeated using different assumptions to examine the effect on the results.</p> <ul style="list-style-type: none"> • One-way simple sensitivity analysis (univariate analysis) – each parameter is varied individually in order to isolate the consequences of each parameter on the results of the study. • Multi-way simple sensitivity analysis (scenario analysis) – 2 or more parameters are varied at the same time and the overall effect on the results is evaluated.

Term	Definition
	<ul style="list-style-type: none"> • Threshold sensitivity analysis – the critical value of parameters above or below which the conclusions of the study will change are identified. • Probabilistic sensitivity analysis – probability distributions are assigned to the uncertain parameters and are incorporated into evaluation models based on decision analytical techniques (for example Monte Carlo simulation).
Shared decision-making	A process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.
Significance (statistical)	A result is deemed statistically significant if the probability of the result occurring by chance is less than 1 in 20 ($p < 0.05$).
Single blind study	A study in which either the subject (patient/participant) or the observer (clinician/investigator) is not aware of which treatment or intervention the subject is receiving.
Stakeholder	<p>An organisation with an interest in a topic on which NICE is developing a clinical guideline or piece of public health guidance. Organisations that register as stakeholders can comment on the draft scope and the draft guidance. Stakeholders may be:</p> <ul style="list-style-type: none"> • manufacturers of drugs or equipment • national patient and carer organisations • NHS organisations • organisations representing healthcare professionals.
Standard deviation (SD)	A measure of the spread or dispersion of a set of observations, calculated as the average difference from the mean value in the sample.
Subgroup analysis	An analysis in which the intervention effect is evaluated in a defined subset of the participants in a trial, or in complementary subsets.
Systematic review	A review in which evidence from scientific studies has been identified, appraised and synthesised in a methodical way according to predetermined criteria. It may include a meta-analysis.
Time horizon	The time span over which costs and health outcomes are considered in a decision analysis or economic evaluation.
Treatment allocation	Assigning a participant to a particular arm of a trial.
Univariate	Analysis which separately explores each variable in a data set.
Usual activities	Activities that form part of a baby, child or young person's daily life and which may be disrupted by illness or the need to access healthcare services. This may include activities of daily living (bathing, showering, eating), interactions with family and friends, social and emotional development, education and schooling, sports, hobbies and interests, social activities and use of social media.
Utility	In health economics, a utility is the measure of the preference or value that an individual or society places upon a particular health state. It is generally a number between 0 (representing death) and 1 (perfect health). The most widely used measure of benefit in cost-utility analysis is the quality-adjusted life year, but other measures include disability-adjusted life years (DALYs) and healthy year equivalents (HYEs).

Abbreviations

Abbreviation	Definition
AAC	Augmentative and alternative communication
AE	Adverse event
A&E	Accident and emergency
AMSTAR	Assessing the Methodological Quality of Systematic Reviews
BCYP	Babies, children and young people
CAMHS	Child and adolescent mental health services
CASP	Critical Appraisal Skills Programme
CBT	Cognitive behavioural therapy
CCTR/CENTRAL	Cochrane Central Register of Controlled Trials
CDSR	Cochrane Database of Systematic Reviews
CEAC	Cost-effectiveness acceptability curves
CEBma	Centre for evidence-based management
CENTRAL/CCTR	Cochrane Central Register of Controlled Trials
CF	Cystic fibrosis
CFS	Chronic fatigue syndrome
CHI-ESQ	Commission for Health Improvement – Experience of Service Questionnaire
CI	Confidence interval
CICC	Children in care council
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CKD	Chronic kidney disease
CQC	Care quality commission
CrI	Credible interval
CYP	Children and young people
DA	Decision aid
DARE	Database of Abstracts of Reviews of Effects
DBS	Disclosure and barring service
DIC	Deviance information criterion
DPA	Data protection act
EBD	Experience-based design
eMIT	Electronic market information tool
EQ-VAS	EuroQoL Visual Analog Scale
F	Female
FG	Focus group
GC	Guideline committee
GP	General Practitioner
GRADE	Grading of Recommendations Assessment, Development and Evaluation
GRADE-CERQual	GRADE – Confidence in evidence from reviews of qualitative research
h, hr	Hour
HCP	Healthcare professional
HR	Hazard ratio, heart rate
HRG	Healthcare Resource Group

Abbreviation	Definition
HRQoL	Health-related quality of life
HTA	Health Technology Assessment
ICER	Incremental cost-effectiveness ratio
IPA	Interpretative phenomenological analysis
IPD	Individual patient data
IQR	Interquartile range
ITT	Intention to treat
K	Number of studies or publications
LAC	Looked after children (and care leavers)
M	Mean, male
MD	Mean difference
ME	Myalgic encephalomyelitis
MHS	Mental health service(s)
MID	Minimally important difference
N, n	Number of participants
N/A	Not applicable
N/C	Not calculable
NEC	Necrotising enterocolitis
NGA	National Guideline Alliance
NHS	National Health Service
NHSEYF	NHS England Youth Forum
NICE	National Institute of Health and Care Excellence
NIHR	National Institute of Health Research
NMB	Net monetary benefit
NNH	Number needed to harm
NNT	Number needed to treat
NR	Not reported
NRCT	Non-randomised controlled trial
NRES	National research ethics service
ns	Not significant
O:E	Observed: expected
OECD	Organisation of economic co-operation and development
ONS	Office for National Statistics
OR	Odds ratio
PAR	Participatory action research
PHR	Personal health record
PICO	Population, intervention, comparison, outcome
PICOTS	Population, intervention, comparator, outcome, timing and setting
PICU	Paediatric intensive care
PPI	Patient and public involvement
PRESS	Peer review of electronic search strategies
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	Prospective register of systematic reviews
PSA	Probabilistic sensitivity analysis
QALY	Quality-adjusted life year

Abbreviation	Definition
QoL	Quality of life
RCOG	Royal College of Obstetricians and Gynaecologists
RCT	Randomised controlled trial
ROB(IS)	Risk of bias (in systematic reviews)
ROBINS-I	Risk of bias in non-randomized studies of interventions
RCT	Randomised controlled trial
RR	Relative risk/risk ratio
SD	Standard deviation
SE	Standard error
SES	Socio-economic status
SLT	Speech and language therapy
SR	Systematic review
TA	Technology appraisal
VAS	Visual analogue scale
wk	Week
YP	Young person