National Institute for Health and Care Excellence

Cerebral palsy in adults

Glossary and abbreviations

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Contents

Glossary

Term	Definition
Abstract	Summary of a study, which may be published alone or as an introduction to a full scientific paper.
Adolescence	Period from around the onset of puberty to adulthood (different legal definitions in different countries – usually 16-18).
Advance care plan	Defined by international consensus as 'Aprocess that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of an advance care plan is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.' (Sudore et al [2017]) Defining advance care planning for adults).
Alternative and augmentative communication (AAC) system/ intervention	Alternative and augmentative communication systems are a variety of methods (for example signing, use of visual symbols and eye gaze technology) that can be used to help people with disabilities communicate with others. These systems or methods of communications can be used as an alternative to speech or to supplement it.
Analgesics	Medicines given to reduce pain.
Anthropometry	Measurements of body size, such as height, weight, head circumference and skin fold thickness. Used to assess normal patterns of growth.
Anticonvulsant therapy	Treatment to manage and minimise the risk of seizures usually epileptic seizures. This is usually a medicine but there are other ways of preventing epileptic seizures such as diet therapy inducing ketones and epilepsy surgery.
Anticonvulsants	Medicines used to prevent or treat seizures.
Anxiety	An emotional state where the person may have physical symptoms such as sweating or fast heart rate as well as a feeling of fear that something bad is going to happen.
Arm (of a clinical study)	Subsection of individuals within a study who receive one particular intervention, for example placebo arm.
Aspiration or risk of aspiration	Aspiration occurs when food, fluid or other material passes through the vocal cords and into the airways. People may be considered at risk of aspiration if they have poor swallowing skills, poor cough reflex or have had previous episodes of aspiration.
Assistive technology	Technology used to improve a person's ability to carry out a task of daily living. This may be a communication device or equipment that helps with feeding, care, environmental management or mobility.
Association	Statistical relationship between 2 or more events, characteristics or other variables. The relationship may or may not be causal.
Attention Deficit Hyperactivity Disorder (ADHD)	A behavioural disorder where a person is both inattentive with poor concentration span and poor attention skills, and is also impulsive and overactive. It may occur in isolation but may accompany other neurodevelopmental problems.
Attrition bias	Systematic differences between comparison groups for withdrawal or exclusion of participants from a study.
Autism / Autistic Spectrum Disorder (ASD)	ASD is a neurodevelopmental disorder affecting social interaction, communication, interests and behaviour. It is characterised by a limited range of repetitive activities, poor verbal and non-verbal communication and poor social interaction with other people. Some children and young people have some but not all of the features of autism and may be described as having an autistic spectrum disorder
Available case analysis (ACA)	Analysis of data that is available for participants at the end of follow-up.

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Term	Definition
Baseline	The initial set of measurements at the beginning of a study (after run-in period where applicable) with which subsequent results are compared.
Before-and-after study	A study that investigates the effects of an intervention by measuring particular characteristics of a population both before and after taking the intervention, and assessing any change that occurs.
Behavioural difficulties	Or Emotional Behavioural Difficulties (EBD). Behaviour or Emotional responses that are so inappropriate for a child's age that they adversely affect their function and performance.
Benzodiazepines	A group of psycho-active medicines used for a variety of medical problems. In children and young people with cerebral palsy, they would most often be used to reduce muscle spasticity (increased tone), to treat or prevent seizures or reduce anxiety.
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.
Body Mass Index (BMI)	A value calculated form weight of person divided by height squared. It helps decide if a person is underweight, normal weight, overweight or obese.
Bone Mineral Density (BMD)	A measure of the amount of calcium and other minerals in bone. It is measured through use of X-rays (usually dual energy X-Rays – DEXA, or CT scans). This helps predict the strength of bone and the risk of minimally or a-traumatic fractures.
Botulinum toxin type A	This is a neurotoxin produced by the bacterium Clostridium Botulinum that blocks the release of the neurotransmitter Acetylcholine from nerve terminals. Type A is one of seven serologically distinct toxin types. It is manufactured by laboratory fermentation of C Bot cultures Therapeutically it can be injected into muscle to reduce over-activation and tone or salivary glands to reduce production and release of Saliva.
Carer (caregiver)	Someone who looks after family, partners or friends in need of help because they are ill, frail or have a disability.
Case series	Report of a number of cases of a given disease, usually covering the course of the disease and the response to treatment. There is no comparison (control) group of patients.
Case-control study	A study to find out the cause(s) of a disease or condition. This is done by comparing a group of patients who have the disease or condition (cases) with a group of people who do not have it (controls) but who are otherwise as similar as possible (in characteristics thought to be unrelated to the causes of the disease or condition). This means the researcher can look for aspects of their lives that differ to see if they may cause the condition. Such studies are retrospective because they look back in time from the outcome to the possible causes of a disease or condition.
Cerebro-spinal fluid (CSF) investigations	Measurement of protein, glucose, blood cells and testing for infection in CSF. This is usually done in testing for meningitis but other conditions can be diagnosed in this way, including progressive movement disorders where levels of certain neurotransmitter levels are altered.
Challenging behaviour	Behaviours that affect the quality of life, participation or threaten the safety of the individual or others.
Child	A person aged 1 year to 11 years.
Childhood	From birth through to around the onset of puberty.
Cholinergic	Relating to nerve cells where acetylcholine is a neurotransmitter.

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Term	Definition
Clinical audit	A systematic process for setting and monitoring standards of clinical care. Whereas 'guidelines' define what the best clinical practice should be, 'audit' investigates whether best practice is being carried out. Clinical audit can be described as a cycle or spiral. Within the cycle there are stages that follow a systematic process of establishing best practice, measuring care against specific criteria, taking action to improve care and monitoring to sustain improvement. The spiral suggests that as the process continues, each cycle aspires to a higher level of quality.
Clinical effectiveness	How well a specific test or treatment works when used in the 'real world' (for example when used by a doctor with a patient at home), rather than in a carefully controlled clinical trial. Trials that assess clinical effectiveness are sometimes called management trials. Clinical effectiveness is not the same as efficacy.
Clinical efficacy	The extent to which an intervention is active when studied under controlled research conditions.
Clinician	A healthcare professional who provides patient care. For example a doctor, nurse or physiotherapist.
Clotting disorders /hyper coagulation in mother	Conditions where a mother has a disorder where her blood clots easily. This may affect the blood supply in the placenta and is thought to be a risk factor for cerebral palsy.
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 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.
Communication difficulties	This describes the range of problems that a child may have with expression and understanding. This includes problems with speech and non-verbal forms of expression, understanding what is being said to them, understanding emotions, using words and grammar and speaking fluently.
Comorbidity	A disease or condition that someone has in addition to the health problem being studied or treated.
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 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)	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. 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).

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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.
Congenital Infection	Infection acquired before a baby is born.
Constipation	Bowel movements which are infrequent and hard to pass.
Construct validity	This assesses how well a test measures what it claims to test.
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.
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.
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–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.
Criterion-related/concurrent validity	This compares measuring something in a test with an outcome at the same time. Used to assess psychological tests e.g. does a psychology assessment in school compare well with what the teacher's assessment of the child's performance.
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.
Depression	A state where a person has a low mood, loss of motivation and unwillingness to participate in usually enjoyed activities.

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Developmental delay	A child not meeting the developmental milestones at an appropriate age
Developmental neurodisability	Impaired function due to a disorder affecting the developing brain that affects a child's quality of life, activity and participation.
Diaphyseal region	
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.
Drop-out	A participant who withdraws from a trial before the end.
Dual Energy X-Ray Absorptiometry (DEXA) scan	A scan that measures bone density – Dual Energy X-Ray Absorptiometry. It estimates BMD against population standards and as such it is important in practice to compare with age appropriate comparative groups.
Dysarthria	Dysarthria is the difficulty a person has due to problems with the muscles involved in speaking.
Dyskinesia	Abnormal, uncontrollable or involuntary movements. There are many different types of dyskinesia with symptoms that range from minor tics to full-body movements.
Dysmenorrhea	Painful menstruation / period pain.
Dysphagia	Difficulty in swallowing.
Dyspraxia	Dyspraxia is the difficulty a person has with planning and carrying out a task in a smooth, efficient and coordinated manner.
Dystonia	Dystonia is a pattern of sustained disturbed muscle contraction causing abnormal posture and frequent involuntary movements in some adults with cerebral palsy.
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 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. 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.
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
Efficacy	How beneficial a test, treatment or public health intervention is under ideal conditions (for example in a laboratory).
Electronic assistive technology	Any piece of equipment, or system, that is electronically powered (mains electricity and/or battery), with the purpose to increase, maintain, or

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	improve function of individuals with disabilities. These may include communication aids, environmental controls and access to computers.
Enteral drug treatment	This is when a drug is given by mouth (oral), via a naso-gastric tube, gastrostomy tube or jejunostomy tube.
Epidemiological study	The study of a disease within a population, defining its incidence and prevalence and examining the roles of external influences (for example infection, diet) and interventions.
Epilepsy	Abnormal electrical activity in the brain leading to recurrent episodes of sensory disturbance, loss of consciousness or convulsions. Two or more of these seizures should occur more than 24 hours apart and not be triggered by a rise in temperature or inter-current illness.
EQ-5D (EuroQol 5 dimensions)	A standardised instrument used to measure health-related quality of life. It provides a single index value for health status.
Escalation plan	A record of the interventions that a person would find acceptable, in line with their values, goals and preferences. It can be used to indicate that more intensive or invasive interventions would be unacceptable to the person. For example, an escalation plan of ward-based care only, indicates that the person would not want invasive monitoring, intubation and ventilation, which are undertaken as part of intensive care.
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).
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.
Executive functions	Executive functions are cognitive processes that are important for the cognitive control of behaviour. These include planning, organising and monitoring behaviours leading to goal attainment, inhibitory control, working memory, and cognitive flexibility. As a result of injuries to the frontal lobes of the brain, these processes can be disrupted.
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.
Face and content validity	Content validity is an assessment of how well a measure looks at all aspects of a situation - an assessment of pain should look at all aspect, not simple whether a child is crying. Face validity is a subjective assessment of whether a test does what it says it does – does everyone agree that it is doing what it is supposed to do.
False negative	A diagnostic test result that incorrectly indicates that an individual does not have the disease of interest, when they do actually have it.
False positive	A diagnostic test result that incorrectly indicates that an individual has the disease of interest, when they actually do not have it.
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 estimating the same overall effect.

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Focal spasticity	An increase in the tone of muscles limited to a particular joint or area, causing muscles or to be tight, and is experienced by some adults with cerebral palsy.
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.
Fore gut dysmotility	Problems of muscle activity or co-ordination in the upper / small bowel causing lack of movement of food / fluids through the upper gut leading to increased vomiting, abdominal pain and bloating after a meal.
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.
Function	The ability to perform normal activities or actions.
Functional Classification Systems	Standardised ways of describing specific areas of function of a child with cerebral palsy. There are currently three commonly in use – Gross Motor Functional Classification System (see below), Manual Ability Classification System (MACS) and Communication Function Classification System (CFCS). These are a variety of others developed that also look at other developmental areas.
Gastrointestinal pain/discomfort	Pain arising from the gastro-intestinal tract including oesophagus, stomach, small and large bowel.
Gastrostomy tube feeding	Feeing the child through a tube that passes through the skin of the tummy straight into the stomach.
General Movement assessment (GMA)	A standardised system of close observation of a baby's spontaneous movements when awake to help predict future developmental problems
Generalisability	The extent to which the results of a study hold true for groups that did not participate in the research.
Genetic disorders (eg hereditary spastic paraparesis, progressive Dopa responsive dystonia, Retts syndrome, Pelizaeus Merzbacher syndrome)	Disorders caused by faults in a child's genes that can present with problems with movement initially presenting in a similar way to cerebral palsy.
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	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.
Gross Motor Function Classification System (GMFCS)	The Gross Motor Function Classification System or GMFCS is a 5 level clinical classification system that describes the gross motor function of people with cerebral palsy on the basis of self-initiated movement abilities. People assessed as level I would be the most able and people assessed as level V are dependent on others for all their mobility needs.
Haemophilus influenzae type B (Hib) vaccination	A vaccine used to prevent Haemophilus influenzae type b (Hib) infection.

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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.
Hearing impairment / difficulties	Loss of hearing that can be due to problem at any point of the hearing system from the ear cochlea, nerves going from the ear to the brain, or in the auditory part of the brain.
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.
Hydrotherapy	Physical therapy delivered in a warm swimming pool/therapy pool.
Hypertonia, hypotonia, dystonia and mixed.	Hypertonia – increased muscle resistance to externally imposed movement. Hypotonia – decreased muscle resistance to externally imposed movement. Dystonia- involuntary, sustained or intermittent muscle contractions that cause twitching and repetitive movements, abnormal postures or both. It can be precipitated by attempts to move or change position and by emotion. Mixed – combination of the above, particularly experienced at different body levels.
Imprecision	Results are imprecise when studies include relatively few patients and few events and thus have wide confidence intervals around the estimate of effect.
Incidence	The incidence of a disease is the rate at which new cases occur in a population during a specified period.
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).
Intellectual / Learning / cognitive disability	Using the intelligence quotients(IQ) people with and IQ of below 70 are classed as having such a disability.
Intellectual / Learning / difficulty	Difficulties in intellectual functioning such as reasoning, problem solving and learning.
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 practice: that is, not everyone complies with treatment and the treatment people receive may be changed according to how they respond to it.

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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.
Kappa statistic	A statistical measure of inter-rater agreement that takes into account the agreement occurring by chance
Key communication partners	People who regularly interact with the adult with cerebral palsy in any environment.. Communication may be by speech, using communication aids, signing, facial expression or a combination of these.
Kyphoscoliosis	A musculoskeletal disorder that results in an abnormal curvature of the spine (combination of kyphosis and scoliosis). This often leads to other issues in patients, such as under-ventilation of lungs and difficulty in performing day-to-day activities.
Length of stay	The total number of days a patient stays in hospital.
Licence	See Product licence.
Life expectancy	How many years a person can expect to live.
Life years gained	Mean average years of life gained per person as a result of the intervention compared with an alternative intervention.
Lifestyle changes	Changing some aspect of daily life – diet, exercise, sleeping – with a view to promoting health and wellbeing.
Likelihood ratio	The likelihood ratio combines information about the sensitivity and specificity. It tells you how much a positive or negative result changes the likelihood that a patient would have the disease. The likelihood ratio of a positive test result (LR+) is sensitivity divided by (1 minus specificity).
Loss to follow-up	Patients who have withdrawn from the clinical trial at the point of follow-up.
Magnetic Resonance Imaging (MRI)	A scan used for obtaining detailed images of internal organs.
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).
Maternal-Foetal infection	Infection that is passed form the mother across the placenta to the foetus during pregnancy.
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.
Mental health problems	Mental health problems can affect the way you think, feel and behave. More common ones include depression, generalised anxiety disorder and obsessive compulsive disorder.
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.
Metabolic bone disease	A disorder of bone strength caused by deficiencies in calcium, phosphate, magnesium, or vitamin D.
Metaphyseal region	
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

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	drug A is less effective than drug B by an amount that is clinically important to patients.
Monte Carlo	A technique used to approximate the probability of certain outcomes by running multiple simulations using random variables.
Multivariate model	A statistical model for analysis of the relationship between 2 or more predictors, (independent) variables and the outcome (dependent) variable.
Muscle tone	The normal state of continuous passive partial contraction in a resting muscle. Muscle tone is important in maintaining posture. Increased muscle tone (hypertonia) is associated with an abnormal resistance to passive stretch, while reduced muscle tone (hypotonia) is associated with floppiness of the limbs or trunk and poor posture.
Musculo-skeletal pain/discomfort	Pain coming from muscles, bones, joints and ligaments.
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 of Care	Linked groups of healthcare professionals and organisations working in an agreed and co-ordinated manner to deliver a clinical service. A network is not constrained by existing professional, organisational or institutional boundaries.
Network team	A multidisciplinary group of healthcare and other professionals working in a network of care to deliver a clinical service.
Neurodevelopmental disorder	A disorder causing impaired function due to a disorder affecting the developing brain that affects a child's quality of life, activity and participation.
Neuromuscular disorders (SMA, muscular dystrophy),	Disorders of the peripheral nervous system – anterior horn cells, nerves, or muscles producing progressive problems of motor control or function.
Non-progressive neurological disorder	A condition caused by an injury to or abnormal development of the brain that is not degenerative.
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.
Numeric Pain Rating Scale	A scale of 0-10. Patients are asked to rate their pain with 0 being no pain at all and 10 being the worst pain they have ever experienced.
Nutritional inadequacy	Insufficient nutrition to maintain growth, body weight, or maintain a state of health.
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.
Obstructive sleep apnoea and sleep apnoea	Pauses in breathing during sleep that may be due to the airway becoming blocked – for example from floppy larynx, large tonsils – or disordered neurological control of breathing (respiratory drive).
Odds ratio (OR)	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.

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Term	Definition
	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. 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. See also Confidence interval, Relative risk.
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.
Oral treatments	
Oro-motor control	The ability to move the muscle of the face, lips tongue and palate to feed and speak in a safe and effective manner.
Osteopaenia / Osteopenia	A condition where the mineral and protein content of the bone is reduced.
Osteoporosis	A severe form of osteopenia where the bones are now brittle and at risk of fractures and deformation.
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 there is likely to be a difference between treatments, the confidence interval describes how big the difference in effect might be.
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.

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Placebo effect	A beneficial (or adverse) effect produced by a placebo and not due to any property of the placebo itself.
Polyphmarcy	Side effects and drug interactions of multiple medicines
Polysomnography	A test carried out during sleep, which measures oxygen levels, breathing and heart rate, brain wave activity and body movements. It is used to diagnose sleep disorders.
Post-hoc analysis	Statistical analyses that are not specified in the trial protocol and are generally suggested by the data.
Postural management	A planned programme of activity using equipment to help a child or young person's posture - lying, sitting and standing. Its use should help function and comfort and reduce unwanted positioning.
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 outcome	The outcome of greatest importance, usually the one in a study that the power calculation is based on.
Product licence	An authorisation from the Medicines and Healthcare Products Regulatory Agency (MHRA) to market a medicinal product.
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.
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.
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.
Quadriplegia, diplegia, hemiplegia, monoplegia, triplegia,	Terms used to describe pattern of limb involvement in children with different patterns of cerebral palsy Quadriplegia – all four limbs affected Diplegia – legs predominantly affected although there can also be milder involvement of the arms Hemiplegia – arm and leg on one side of the body affected. Arm usually more than leg Monoplegia – only one limb affected Triplegia – three limbs affected – usually a combination of diplegia and triplegia The use of these terms have been superceded by the concept of unilateral vs bilateral involvement with focus on different functional levels of involvement as outlined by the Study of Cerebral Palsy in Europe team (SCPE).

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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.
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.
Reduced bone mineral density and low-impact fractures	The concept that if the bones have less mineral and protein, they will appear to have reduced density on DEXA scan and so will be more likely to fracture with minimal trauma.
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.
Rehabilitation engineering services	Rehabilitation engineering services are centres that design, develop and adapt technological solutions to overcome challenges to function, activity and participation for individuals with disability. This includes assessment and provision of assistive devices to help with posture, mobility and communication (for example electronic assistive technology).
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 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.
Reliability	The extent to which a test will give the same result if repeated a number of times.
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

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Term	Definition
	condition. Unlike prospective studies, it does not cover events that occur after the study group is selected.
Review	A planned clinical appointment between an adult with cerebral palsy and a healthcare professional. They may explore common concerns, physical symptoms, mental health, pain, nutrition, and communication to ensure an individualised approach to care. The healthcare professional may be the general practitioner, specialist nurse, rehabilitation specialist, or therapist. The also allows the opportunity to address general health issues in the population as they grow older.
Review of 24 hours postural needs	This is part of a 24-hour posture review that considers all the relevant postures that an individual has the ability to adopt over the 24-hour period of any given day. The 3 core postural orientations are lying, sitting and standing. An example of postural need is support and positioning in bed.
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.
Saliva Control Management	Measures to reduce the problems of drooling and choking caused by saliva. This may involve training the child to control saliva, and/or use of drugs, Botulinum Toxin A injections or surgery.
Screening	A method of identifying healthy people who may be at higher risk of developing a particular disease.
Secondary care	Care provided in hospitals.
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	Selection bias occurs if: 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.
Selective dorsal rhizotomy	A neurosurgical procedure that selectively destroys problematic nerve roots in the spinal cord.
Sensitivity	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'). 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.
Sensitivity analysis	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.

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	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. 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).
Significance (statistical)	A result is deemed statistically significant if the probability of the result occurring by chance is less than 1 in 20 ($p<0.05$).
Spasmolytic	
Spasticity, ataxia, dyskinesia	Spasticity – a specific form of increased muscle tone (hypertonia) here one or more of the following are present. -the resistance to externally imposed movement increases with increasing speed of stretch and varies with the direction of joint movement. -the resistance to externally imposed movement increases rapidly beyond a threshold speed or joint angle. Ataxia – a disorder of control of movement that impairs balance. It may involve the trunk (truncal ataxia) or the limbs. In some children and young people it may result from sensory deficits. Dyskinesia – A term used to include movement disorders such as athetosis, chorea, dystonia and tics.
Specificity	The proportion of true negatives that are correctly identified as such. For example, in diagnostic testing the specificity is the proportion of non-cases correctly diagnosed as non-cases. In terms of literature searching a highly specific search is generally narrow and aimed at picking up the key papers in a field and avoiding a wide range of papers. See also Sensitivity.
Spinal cord disorders	Problems of movement, feeling or bowel and bladder control caused by problems of the spinal cord, such as Spina Bifida.
Spirometry	A tests that measures lung function, specifically the amount and/or speed of air that can be inhaled and exhaled. Spirometry is helpful in assessing breathing patterns that identify conditions such as asthma, pulmonary fibrosis, cystic fibrosis, and COPD.
Stakeholder	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: • 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.
Structural / Congenital Brain Malformations	Malformation of the brain during its development. Usually genetic but can be the result of infection in utero or antenatal stroke.
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.

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Supportive care	Supportive care focuses on relieving symptoms caused by serious illnesses such as respiratory failure. It can be given at any point during a person's illness to help them feel more comfortable and improve their quality of life.
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.
Transferring	Moving from one surface to another (for example from a bed to a wheelchair) independently or with assistance.
Treatment allocation	Assigning a participant to a particular arm of a trial.
True negative	A diagnostic test result that correctly indicates that an individual does not have the disease of interest when they actually do not have it.
True positive	A diagnostic test result that correctly indicates that an individual has the disease of interest when they do actually have it.
Univariate	Analysis which separately explores each variable in a data set.
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).
Young adult	A person aged 19 years to 25 years.
Young person	A person aged 12 years to 19 years.

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Abbreviations

Abbreviation	Meaning
μg	microgram
AACPDM	American Academy of Cerebral Palsy and Developmental Medicine
ABI	Acquired brain injury
A&E	Accident and emergency department
ANOVA	Analysis of variance
AQOL-6D	Assessment of Quality of Life Instrument-6D
AUC	Area under the concentration-time curve
(AUS)TOMS	(Australian) Therapy Outcome Measures
BMD	Bone mineral density
BNF	British national formulary
BoNT-A	Botulinum toxin A
BRAF	Proto-oncogene b-raf / v-raf murine sarcoma viral oncogene homolog b
BTX	Botulinum toxin
Bx	Biopsy
CASP	Critical appraisal skills programme
CDSR	Cochrane Database of Systematic Reviews
CE	Chest expansion
CENTRAL	Cochrane Central Register of Controlled Trials
CES-D	Center for Epidemiologic Studies Depression Scale
CI	Confidence interval
CMMS	Columbia Mental Maturity Scale
cMRI	Conventional magnetic resonance imaging
CNS	Central nervous system
COPM	Canadian Occupational Performance Measure
COSMIN	Consensus-based Standards for the Selection of Health Status Measurement Instruments
CP	Cerebral palsy
CPAP	Continuous positive airway pressure
CPUP	Cerebral palsy follow-up program
CSF	Cerebrospinal fluid
CT	Computerised tomography
CTCAE	Common terminology criteria for adverse events
DARE	Database of Abstracts of Reviews of Effects
DASH	Disabilities of the Arm, Shoulder and Hand
DBS	Deep brain stimulation
DCE	Dynamic contrast-enhancement
DD	Dose dense
DEXA	Dual energy X-ray absorptiometry
DTI	Diffusion tensor imaging
DVC	Direct vital capacity
EAT	Environmental assistive technology

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Abbreviation	Meaning
EBRT	External beam radiotherapy
ECG	Electrocardiography
ED	Emergency department
EMG	Electromyography
EQ-5D	EuroQol 5 dimensions
FAM	Functional Assessment Measure
FES	Functional electrical stimulation
FET	(18)f-fluoro-ethyl-l-tyrosine
FEV	Forced expiratory volume
FIM	Functional Independence Measure;
FIM+FAM	The addition of 12 FAM items to the FIM, specifically addressing cognitive and psychosocial function (FIM+FAM).
FN	False negative
FP	False positive
GAD	Generalised Anxiety Disorder Questionnaire
GAS	Goal Attainment Scale
GDI	Gait deviation index
GMFCS	Gross motor function classification system
GMFM	Gross motor function measure
GP	General practitioner
GRADE	Grading of Recommendations Assessment, Development and Evaluation
GTR	Gross total resection
HCP	Healthcare practitioner
HRQoL	Health-related quality of life
HTA	Health Technology Assessment
ICD-9	International classification of diseases (9th edition)
ICER	Incremental cost effectiveness ratio
ICF	International Classification of Functioning, Disability and Health
ICH	Intrathecal haemorrhage
INB	Incremental net benefit
IPG	Implantable pulse generator
IQ	Intelligence quotient
ITB	Intrathecal baclofen
ITT	Intention-to-treat analysis
IV	Inverse variance
LOS	Length of hospital stay
MACS	Manual ability classification
MCPHCS	The Melbourne cerebral palsy hip classification system
MD	Mean difference
MDT	Multidisciplinary team
M-H	Mantel-Haenszel
MID	Minimally important difference
MMSE	Mini-Mental State Examination

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Abbreviation	Meaning
MRI	Magnetic resonance imaging
MST-CP	Malnutrition Screening Tool for Cerebral Palsy
MUST	Malnutrition Universal Screening Tool
n	Number of participants in intervention/control groups
N	Number of participants in the study
NCEPOD	National Confidential Enquiry into Patient Outcome and Death
NGA	National Guideline Alliance
NHS	National Health Service
NHSRC	National Health Systems Resource Centre
NICE	National Institute for Health and Care Excellence
NIH	National Institute for Health
NIV	Non-invasive ventilation
NMB	Net monetary benefit
NNT	Number needed to treat
NOS	Not otherwise specified
NR	Not reported
NRS	Numerical rating scale
OR	Odds ratio
OS	Overall survival
PAICP	Pain Assessment Instrument for Cerebral Palsy
PaR	Partial resection
PET-CT	Positron emission tomography - computed tomography
PET-MRI	Positron emission tomography - magnetic resonance imaging
PGM	Programme
PHQ-9	Patient Health Questionnaire 9 question depression scale
PPI	Patient and public involvement
QALY	Quality-adjusted life year
QoL	Quality of life
QUADAS	Quality assessment of diagnostic accuracy studies
QUEST	Quality of Upper Extremity Skills Test
rCBV	Relative cerebral blood volume
RCT	Randomised controlled trial
RoB	Risk of bias
RR	Risk ratio
SD	Standard deviation
SDR	Selective Dorsal Rhizotomy
SE	Standard error
SF-36	36 items short from survey
SLT	Speech and language therapy
SMD	Standardized mean difference
TBI	Traumatic brain injury
TN	True negative
TP	True positive
TOM	Therapy outcome measure

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Abbreviation	Meaning
TOMS	Therapy Outcome Measures-Swallowing
TUG	Timed up and go
VAS	Visual analogue scale
VC	Vital capacity
VO_2	Oxygen volume
WHO	World Health Organization

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