

# Cerebral palsy: diagnosis and management in children and young people

Appendices A-D, F, H-I, K

*NICE Guideline*

*Methods, evidence and recommendations*

*30 June 2016*

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Health and Clinical Excellence*



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# 1 Appendices

## 2 Appendix A: Scope

3

### 4 NATIONAL INSTITUTE FOR HEALTH AND 5 CARE EXCELLENCE

#### 6 SCOPE

##### 7 1 Guideline title

8 Cerebral palsy: the diagnosis and management of cerebral palsy in children and  
9 young people

##### 10 1.1 Short title

11 Cerebral palsy

##### 12 2 The remit

13 The Department of Health has asked NICE: 'To prepare a clinical guideline on the  
14 diagnosis and management of cerebral palsy'. This guideline will take account of the  
15 existing NICE guideline on spasticity in children and young people with non-  
16 progressive brain disorders.

##### 17 3 Need for the guideline

##### 18 3.1 Epidemiology

19 a) Cerebral palsy describes a group of permanent disorders of the  
20 development of movement and posture, causing activity limitation,  
21 resulting from non-progressive disturbances (structural abnormalities) that  
22 occurred in the developing fetal or infant brain. There is general  
23 consensus of an upper age limit of 2 years for onset of the non-  
24 progressive brain disturbance and 5 years for clinical or developmental  
25 diagnosis. Patterns of motor disorder are generally subdivided into spastic,  
26 dyskinetic (including dystonic) and ataxic forms, depending on the area of  
27 the brain that is mainly involved.



- 1 b) Although defined primarily as a motor disorder, cerebral palsy is often  
2 accompanied by disturbances of sensation, perception, cognition,  
3 communication and behaviour, and by epilepsy and musculoskeletal  
4 problems. Recognising the interrelationship of these associated disorders  
5 and managing them is an essential part of the overall management of  
6 cerebral palsy.
- 7 c) Cerebral palsy registers using agreed definitions of the syndrome have  
8 shown a prevalence of 2.0–3.5 per 1000 live births in developed countries.  
9 Prevalence is inversely associated with gestational age and with birth  
10 weight. Prevalence has been reported as 90 cases per 1000 live births in  
11 babies with a birth weight of 1000 g, compared with 1.5 cases per 1000  
12 live births for babies weighing 2500 g or more.
- 13 d) Cerebral palsy is attributable mostly to events that occur before birth or in  
14 the neonatal period, with about 10–20% of cases resulting from  
15 intrapartum asphyxia. Only about 10% of cases arise from later events  
16 such as head injury or central nervous system infection (meningitis or  
17 encephalitis).
- 18 e) In addition to prematurity and low birth weight, a wide range of risk factors  
19 for cerebral palsy exist, including multiple pregnancy and especially  
20 stillbirth or infant death of a co-twin, placental abnormalities, birth defects,  
21 meconium aspiration, emergency caesarean section, birth asphyxia,  
22 neonatal seizures, respiratory distress syndrome, hypoglycaemia and  
23 maternal, fetal or neonatal infection.
- 24 f) It is important that disorders resulting from a progressive brain injury are  
25 distinguished from cerebral palsy. Although in cerebral palsy the causative  
26 brain injury is static, the secondary musculoskeletal problems and motor  
27 manifestations change over time. Typically, abnormalities of movement  
28 and posture are first recognised during infancy or early childhood, and  
29 secondary disability can then be progressive. Attention should be paid to  
30 the evolution of the condition. If this differs from the pattern expected with  
31 cerebral palsy then other disorders should be considered, such as genetic  
32 and metabolic disorders and disorders resulting from progressive brain

1 injury. In children and young people with dystonia the possibility of a  
2 dopamine-responsive disorder should be considered.

3 g) Severe cerebral palsy can be associated with a reduced life expectancy.  
4 The effect may be minimal, but if gross and fine motor functioning,  
5 independent feeding, mental and visual capacities are severely impaired,  
6 survival to 40 years of age may be as low as 40%. Causes of early death  
7 may include pulmonary aspiration and pneumonia, accidents, associated  
8 disorders (for example, congenital heart disease) and delayed recognition  
9 of illness. Prognosis is an important issue that should be discussed with  
10 people with cerebral palsy and their family members and carers as  
11 appropriate. It can also potentially influence the approach to treatment.

## 12 **3.2 Current practice**

13 a) Management of cerebral palsy depends on a multidisciplinary team of  
14 many specialists, across primary, district and regional services. The  
15 multidisciplinary team works with the child or young person with cerebral  
16 palsy, and their family members and carers as appropriate, to optimise  
17 development and minimise the impact of the brain impairment and  
18 comorbidities. The focus of social and clinical care during childhood and  
19 into young adulthood, which also involves colleagues from social care and  
20 education, is on facilitating function and inclusion, minimising 'activity  
21 limitation' and enabling individual 'participation'. These concepts are in line  
22 with the World Health Organization (WHO) framework, the International  
23 Classification of Functioning, Disability and Health, in which participation  
24 refers to involvement in life situations across a number of functional  
25 domains, including self-care, relationships, education and, later,  
26 employment. This focus on functional ability and quality of life is key to  
27 managing cerebral palsy, with the perspective of the child or young person  
28 and their family members and carers at the centre of all decisions.

29 b) Many specialists and experts may contribute to the recognition, diagnosis  
30 and management of cerebral palsy. The movement disorder itself is  
31 generally picked up either because of antenatal or neonatal concern about  
32 a potential brain impairment (from causes such as infection, epilepsy,

- 1           prematurity or early hypoxic ischaemic damage) or by concerns raised  
2           during routine developmental screening (late sitting, standing and walking  
3           or early motor asymmetry).
- 4 c)       The primary care service for most families is the local child development  
5           team that supports health visitors and GPs. This team includes community  
6           paediatricians, physiotherapists, occupational therapists, speech and  
7           language therapists, nurses and preschool developmental teams. Other  
8           professionals, including specialised therapists, psychologists, orthotists,  
9           dietitians, hospital-based paediatricians, a variety of neurology and  
10          neurodisability experts, and orthopaedic and general surgeons, are often  
11          involved in care.
- 12 d)      A variety of care pathways for cerebral palsy exist, depending on the  
13          nature and degree of impairment. The spectrum of severity varies with  
14          regard to gross and fine motor functioning, bimanual manipulation,  
15          feeding, communication and associated disorders. Appropriate  
16          assessments and interventions differ depending on the age and level of  
17          functional ability of the child or young person.
- 18 e)      In addition to difficulties that the child or young person has with movement,  
19          posture and mobility, attention may need to be given to aspects such as  
20          communication, comfort and overall quality of life. Treatment may be  
21          needed for comorbidities such as epilepsy, gastro-oesophageal reflux,  
22          constipation or aspiration pneumonia. In particular, oro-motor problems  
23          that affect swallowing and feeding, and hence nutrition, may be of central  
24          importance. Difficulties with saliva control that result in drooling can have a  
25          serious adverse effect on the wellbeing of the child or young person and  
26          their family members and carers. Vision, hearing, cognitive, behavioural  
27          and psychological difficulties occur more frequently than in the general  
28          population.
- 29 f)      Cerebral palsy is a lifelong condition, and this is an important perspective  
30          when considering clinical management. Service provision during the  
31          transition of healthcare from paediatric services to adult services is of

1 critical importance. Preparing the young person and their family members  
2 and carers for this major change is crucial.

### 3 **4 The guideline**

4 The guideline development process is described in detail on the NICE website (see  
5 section 6, 'Further information').

6 This scope defines what the guideline will (and will not) examine, and what the  
7 guideline developers will consider. The scope is based on the referral from the  
8 Department of Health.

9 The areas that will be addressed by the guideline are described in the following  
10 sections.

#### 11 **4.1 Population**

##### 12 **4.1.1 Groups that will be covered**

13 a) Children and young people from birth up to their 25th birthday who have  
14 cerebral palsy.

15 b) Subgroups to be considered:

- 16 • recognised subgroups within the cerebral palsy population, depending  
17 on level of cognitive disability and functional disability (for example,  
18 Gross Motor Function Classification System levels I to V), and age  
19 ranges will be considered where appropriate.

##### 20 **4.1.2 Groups that will not be covered**

21 a) Adults 25 years of age and older.

22 b) Children and young people with a progressive neurological or  
23 neuromuscular disorder.

#### 24 **4.2 Setting**

25 a) All settings in which NHS-commissioned health and social care is  
26 provided.

## 1 **4.3 Management**

### 2 **4.3.1 Key issues that will be covered**

#### 1.1.1.13 **Diagnosis and assessment**

4 a) Determining the key clinical and developmental manifestations of cerebral  
5 palsy at first presentation in order to help with early recognition.

6 b) Identifying risk factors for cerebral palsy that may:

- 7 • inform the need for enhanced surveillance  
8 • help in diagnosing the underlying cause of cerebral palsy  
9 • facilitate early intervention.

10 c) Identifying the key information to be obtained from history and  
11 examination, including developmental screening to help in determining the  
12 underlying cause of cerebral palsy.

13 d) Identifying 'red flags' that might suggest a neurodevelopmental disorder  
14 other than cerebral palsy, such as progressive neurological or  
15 neuromuscular disorders.

16 e) Determining the potential value of MRI of the brain in cerebral palsy.

17 f) The prognosis for children and young people with cerebral palsy in relation  
18 to:

- 19 • ability to walk  
20 • ability to talk  
21 • life expectancy.

22 g) Identifying common and important comorbidities associated with cerebral  
23 palsy and the subgroups most at risk of these comorbidities.

24 h) Determining an effective approach to investigating difficulties with eating,  
25 drinking and swallowing in children and young people with cerebral palsy,  
26 including:

- 27 • clinical observation

- 1                   • videofluoroscopic swallow studies (VF) and fiberoptic endoscopic  
2                   evaluation of swallowing (FEES).

#### 1.1.1.23 Interventions

- 4 i)               Managing mental health problems in children and young people with  
5               cerebral palsy.
- 6 j)               Determining the effectiveness of interventions in tackling communication  
7               difficulties in children and young people with cerebral palsy.
- 8 k)               Determining the effective management of difficulties with eating, drinking  
9               and swallowing in children and young people with cerebral palsy.
- 10 l)              Determining the effective management of difficulties with saliva control  
11              (drooling) in children and young people with cerebral palsy.
- 12 m)             Nutritional management in children and young people with cerebral palsy.
- 13 n)             Assessing and managing pain, discomfort, distress and sleep disturbance  
14             in children and young people with cerebral palsy.
- 15 o)             Interventions to reduce the risk of reduced bone mineral density and low-  
16             impact fractures in children and young people with cerebral palsy.
- 17 p)             Managing difficulties associated with the processing of sensory and  
18             perceptual information in children and young people with cerebral palsy.
- 19 q)             Identifying social care needs that are specific to children and young people  
20             with cerebral palsy and their family members and carers.
- 21 r)             Communication, information and support needs that are specific to  
22             children and young people with cerebral palsy and their family members  
23             and carers.
- 24 s)             The role of the multidisciplinary team in the care of children and young  
25             people with cerebral palsy.
- 26 t)             Aspects of the transition from paediatric to adult health services that are  
27             specific to the needs of young people with cerebral palsy and their family  
28             members and carers.

- 1 Note that guideline recommendations will normally fall within licensed indications;
- 2 exceptionally, and only if clearly supported by evidence, use outside a licensed
- 3 indication ('off-label use') may be recommended. The guideline will assume that
- 4 prescribers will use a drug's summary of product characteristics to inform decisions
- 5 made with individual patients.

#### 6 **4.3.2 Issues that will not be covered**

- 7 a) Management of spasticity and co-existing motor disorders.
- 8 b) Skin care, including management of pressure ulcers.
- 9 c) Laboratory investigations for progressive neurological and neuromuscular
- 10 disorders.
- 11 d) Management of cognitive impairment and learning difficulties.
- 12 e) Management of bladder dysfunction (urinary retention and incontinence)
- 13 and bowel dysfunction (constipation and soiling).
- 14 f) Management of gastro-oesophageal reflux disease.
- 15 g) Management of respiratory complications such as pulmonary aspiration.
- 16 h) Management of visual and hearing impairment.
- 17 i) Management of epilepsy.

#### 18 **4.4 Main outcomes**

- 19 a) Health-related quality of life.
- 20 b) Functional independence, including self-care and independence in
- 21 activities of daily living.
- 22 c) Ability to communicate.
- 23 d) Participation (including social, education and work).
- 24 e) Psychological wellbeing (for example, depression or anxiety).
- 25 f) Degree of pain.

- 1 g) Nutritional status.
- 2 h) Wellbeing of parents and carers

### 3 **4.5 Review questions**

4 Review questions guide a systematic review of the literature. They address only the  
5 key issues covered in the scope, and usually relate to interventions, diagnosis,  
6 prognosis, service delivery or patient experience. Please note that these review  
7 questions are draft versions and will be finalised with the Guideline Development  
8 Group.

#### 9 **4.5.1 Diagnosis and assessment**

- 10 a) What are the key clinical and developmental manifestations of cerebral  
11 palsy at first presentation?
- 12 b) What are the risk factors for developing cerebral palsy and what is their  
13 prevalence?
- 14 c) What are the causes of cerebral palsy in resource-rich countries?
- 15 d) What clinical manifestations should be recognised as 'red flags' that  
16 suggest a progressive neurological or neuromuscular disorder rather than  
17 cerebral palsy?
- 18 e) In children and young people with cerebral palsy, what is the effectiveness  
19 of an MRI scan in determining the cause of cerebral palsy?
- 20 f) In children and young people with cerebral palsy, what is the effectiveness  
21 of an MRI scan in determining prognosis?
- 22 g) What comorbidities are associated with cerebral palsy in children and  
23 young people and what is their prevalence, including prevalence in  
24 relevant subgroups?
- 25 h) In children and young people with cerebral palsy, what are the symptoms  
26 and signs of mental health problems?



- 1 i) In children and young people with cerebral palsy, which investigations are  
2 useful in evaluating difficulties with eating, drinking and swallowing  
3 (including clinical assessment, VF and endoscopic examination)?
- 4 j) In children and young people with cerebral palsy who are otherwise  
5 unable to communicate, what are the signs that suggest pain, discomfort,  
6 distress and sleep disturbance?
- 7 k) In children and young people with cerebral palsy, what are the common  
8 causes of pain, discomfort, distress and sleep disturbance?
- 9 l) In children and young people with cerebral palsy, what are the risk factors  
10 for reduced bone mineral density and low-impact fractures?
- 11 m) In children and young people with cerebral palsy, what are the clinical and  
12 developmental prognostic indicators in relation to:
- 13 • the ability to walk
  - 14 • the ability to talk
  - 15 • life expectancy?
- 16 **4.5.2 Interventions**
- 17 n) In children and young people with cerebral palsy, what interventions are  
18 effective in managing of mental health problems?
- 19 o) In children and young people with cerebral palsy, how effective is clinical  
20 therapy focusing on oro-motor function in improving speech (for example,  
21 speech and language therapy strategies)?
- 22 p) In children and young people with cerebral palsy, what communication  
23 systems (alternative or augmentative) are effective in improving  
24 communication (for example, eye gaze computerised technologies)?
- 25 q) In children and young people with cerebral palsy, what interventions are  
26 effective in managing difficulties with eating, drinking and swallowing?
- 27 r) In children and young people with cerebral palsy, what interventions are  
28 effective in managing poor saliva control (drooling)?

- 1 s) In children and young people with cerebral palsy, what interventions are  
2 effective in maintaining adequate nutritional status?
- 3 t) In children and young people with cerebral palsy, what interventions are  
4 effective for managing problems associated with difficulties in processing  
5 of sensory and perceptual information?
- 6 u) In children and young people with cerebral palsy, what interventions are  
7 effective in managing pain, discomfort, distress and sleep disturbance with  
8 no known cause?
- 9 v) In children and young people with cerebral palsy, what interventions are  
10 effective in preventing reduced bone mineral density and low-impact  
11 fractures?
- 12 w) What are the specific social care needs of children and young people with  
13 cerebral palsy and their family members and carers (for example, use of  
14 equipment such as hoists, access to buildings and transport, and respite  
15 care)?
- 16 x) What specific information and support is needed by children and young  
17 people with cerebral palsy and their family members and carers?
- 18 y) What are the specific elements of the process of transition from paediatric  
19 to adult services that are important for young people with cerebral palsy  
20 and their family members and carers?

#### 21 **4.6 Economic aspects**

22 Developers will take into account both clinical and cost effectiveness when making  
23 recommendations involving a choice between alternative interventions. A review of  
24 the economic evidence will be conducted and analyses will be carried out as  
25 appropriate. The preferred unit of effectiveness is the quality-adjusted life year  
26 (QALY), and the costs considered will usually be only from an NHS and personal  
27 social services (PSS) perspective. Further detail on the methods can be found in The  
28 guidelines manual.

1 **4.7 Status**

2 **4.7.1 Scope**

3 This is the final scope.

4 **4.7.2 Timing**

5 The development of the guideline recommendations will begin in October 2014.

6 **5 Related NICE guidance**

7 **5.1 Published guidance**

8 **5.1.1 Other related NICE guidance**

- 9 • Pressure ulcers (2014) NICE guideline CG179
- 10 • Autism: the management and support of children and young people on the autism  
11 spectrum (2013) NICE guideline CG170
- 12 • Urinary incontinence in neurological disease (2012) NICE guideline CG148
- 13 • Spasticity in children and young people with non-progressive brain disorders  
14 (2012) NICE guideline CG145
- 15 • The epilepsies (2012) NICE guideline CG137
- 16 • Autism in children and young people: recognition, referral and diagnosis of  
17 children and young people on the autism spectrum (2011) NICE guideline CG128
- 18 • Common mental health disorders. (2011) NICE guideline CG123
- 19 • Selective dorsal rhizotomy for spasticity in cerebral palsy (2010) NICE  
20 interventional procedure guidance 373
- 21 • Constipation in children and young people (2009) NICE guideline CG99
- 22 • Depression in children and young people (2005) NICE guideline CG28

23 **5.2 Guidance under development**

24 NICE is currently developing the following related guidance (details available from  
25 the NICE website):

- 26 • Gastro-oesophageal reflux disease in children and young people. NICE guideline.  
27 Publication expected January 2015.

- 1 • Challenging behaviour and learning disabilities. NICE guideline. Publication
- 2 expected May 2015.
- 3 • Transition from children's to adult services. NICE guideline. Publication expected
- 4 February 2016.

## 5 **6 Further information**

6 Information on the guideline development process is provided in the following  
7 documents, available from the NICE website:

- 8 • How NICE clinical guidelines are developed: an overview for stakeholders the
- 9 public and the NHS: 5th edition
- 10 • The guidelines manual.

11 Information on the progress of the guideline will also be available from the NICE  
12 website.

13

## 1 **Appendix B: Stakeholders**

- 2 5 Boroughs Partnership NHS Foundation Trust
- 3 Action Cerebral Palsy
- 4 Acupuncture Association of Chartered Physiotherapists
- 5 Alder Hey Children's NHS Foundation Trust
- 6 Allergan Ltd UK
- 7 Allocate Software PLC
- 8 Anglia community leisure
- 9 Aquatic Therapy Association of Chartered Physiotherapists
- 10 Association for Dance Movement Psychotherapy UK
- 11 Association of Anaesthetists of Great Britain and Ireland
- 12 Association of British Neurologists
- 13 Association of National Specialist Colleges
- 14 Association of Paediatric Chartered Physiotherapists
- 15 Barnardo's
- 16 Belfast Health and Social Care Trust
- 17 Birmingham Women's NHS Foundation Trust
- 18 Birmingham Women's Health Care NHS Trust
- 19 Birmingham Women's Hospital NFT
- 20 Bobath Centre for Children with Cerebral Palsy
- 21 British Academy of Childhood Disability
- 22 British Association for Community Child Health
- 23 British Association for Music Therapy
- 24 British Association of Bobath Trained Therapists
- 25 British Association of Occupational Therapists
- 26 British Association of Prosthetists & Orthotists
- 27 British Dietetic Association
- 28 British Medical Association
- 29 British Medical Journal
- 30 British Nuclear Cardiology Society
- 31 British Paediatric Neurology Association
- 32 British Paediatric Respiratory Society

- 1 British Psychological Society
- 2 British Red Cross
- 3 British Society for Children's Orthopaedic Surgery
- 4 British Society for Disability and Oral Health
- 5 British Society of Paediatric Gastroenterology Hepatology and Nutrition
- 6 British Society of Paediatric Radiologists
- 7 British Society of Rehabilitation Medicine
- 8 Caplond Services
- 9 Cardiff and Vale University Health Board
- 10 Care Quality Commission
- 11 CareTech Community Services
- 12 Cerebra
- 13 Cerebral Palsy Sport
- 14 CHANGE
- 15 Chartered Society of Physiotherapy
- 16 Childpsychology.london
- 17 Chroma
- 18 CLEAR Cannabis Law Reform
- 19 CMV Action UK
- 20 Cochrane UK
- 21 College of Occupational Therapists
- 22 College of Paramedics
- 23 Croydon Council
- 24 Cumbria Partnership NHS Foundation Trust
- 25 CWHHE Collaborative CCGs
- 26 Department of Health
- 27 Department of Health, Social Services and Public Safety - Northern Ireland
- 28 Disabled Living
- 29 East and North Hertfordshire NHS Trust
- 30 Essex County Council
- 31 European Academy of Childhood Disability
- 32 Freshwinds
- 33 Full of Life

- 1 GP update / Red Whale
- 2 Great Ormond Street Hospital
- 3 Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network
- 4 Guy's and St Thomas' NHS Foundation Trust
- 5 Health and Care Professions Council
- 6 Health and Social Care Information Centre
- 7 Healthcare Improvement Scotland
- 8 Healthcare Quality Improvement Partnership
- 9 Healthwatch Bristol
- 10 Healthwatch Darlington
- 11 Helen and Douglas House
- 12 HemiHelp
- 13 HQT Diagnostics
- 14 Humber NHS Foundation Trust
- 15 Hywel Dda University Health Board
- 16 Inspiration Healthcare Limited
- 17 International Cerebral Palsy Society
- 18 James Cook University Hospital
- 19 James Paget Hospital
- 20 JT Healing
- 21 Lancashire Care NHS Foundation Trust
- 22 Liverpool University
- 23 LSP Bio Ltd
- 24 Mac Keith Press
- 25 Manchester Mental Health & Social Care Trust
- 26 MAP BioPharma Limited
- 27 Mastercall Healthcare
- 28 Medical Directorate Services
- 29 Medicines and Healthcare Products Regulatory Agency
- 30 Medtronic
- 31 Mencap
- 32 midwifeexpert.com
- 33 Milton Keynes Hospital NHS Foundation Trust

- 1 Ministry of Defence
- 2 National Collaborating Centre for Cancer
- 3 National Collaborating Centre for Mental Health
- 4 National Collaborating Centre for Women's and Children's Health
- 5 National Confidential Enquiry into Patient Outcome and Death
- 6 National Deaf Children's Society
- 7 National Guideline Centre
- 8 National Institute for Health Research
- 9 Neonatal & Paediatric Pharmacists Group
- 10 Neuronix Medical
- 11 Newcastle University Institute of Health and Society
- 12 Newlife Foundation for Disabled Children
- 13 NHS Choices
- 14 NHS Chorley and South Ribble CCG
- 15 NHS England
- 16 NHS Hardwick CCG
- 17 NHS Health at Work
- 18 NHS Litigation Authority
- 19 NHS Lothian
- 20 NHS Mid Essex CCG
- 21 NHS North East Lincolnshire CCG
- 22 NHS Sheffield CCG
- 23 NHS Somerset CCG
- 24 NHS West Cheshire CCG
- 25 NHSCC
- 26 Northern Health and Social Care Trust
- 27 Northumbria Healthcare NHS Foundation Trust
- 28 Nottinghamshire County Council
- 29 Nursing and Midwifery Council
- 30 Nutricia Advanced Medical Nutrition
- 31 Oxford Neurological Society
- 32 Pathfinders Specialist and Complex Care
- 33 Pontefract Family Centre



- 1 Public Health England
- 2 Quality Institute for Self Management Education and Training
- 3 Rainbows Children's Hospice
- 4 Real DPO Ltd
- 5 Regard
- 6 ROC - Robert Owen Communities
- 7 Royal College of Anaesthetists
- 8 Royal College of General Practitioners
- 9 Royal College of General Practitioners in Wales
- 10 Royal College of Midwives
- 11 Royal College of Nursing
- 12 Royal College of Obstetricians and Gynaecologists
- 13 Royal College of Paediatrics and Child Health
- 14 Royal College of Pathologists
- 15 Royal College of Physicians
- 16 Royal College of Psychiatrists
- 17 Royal College of Radiologists
- 18 Royal College of Speech and Language Therapists
- 19 Royal College of Surgeons of Edinburgh
- 20 Royal College of Surgeons of England
- 21 Royal Cornwall Hospitals NHS Trust
- 22 Royal Mencap Society
- 23 Royal Pharmaceutical Society
- 24 Sandoz Ltd
- 25 Scope
- 26 Scottish Intercollegiate Guidelines Network
- 27 SeeAbility
- 28 Sheffield Children's NHS Trust
- 29 Sheffield Teaching Hospitals NHS Foundation Trust
- 30 Social Care Institute for Excellence
- 31 Society for Research in Rehabilitation
- 32 Society of British Neurological Surgeons
- 33 South Devon Healthcare NHS Foundation Trust

- 1 South Eastern Health and Social Care Trust
- 2 South Gloucestershire Council
- 3 South West London Maternity Network
- 4 South West Yorkshire Partnership NHS Foundation Trust
- 5 Southern Health & Social Care Trust
- 6 Staffordshire University
- 7 States of Jersey
- 8 Sussex Community Health NHS Trust
- 9 Talking Couch
- 10 The London Centre for Children with Cerebral Palsy
- 11 The PACE Centre
- 12 Therapy in Praxis
- 13 United Kingdom Council for Psychotherapy
- 14 University of Salford
- 15 University of Sheffield
- 16 Welsh Government
- 17 Welsh Scientific Advisory Committee
- 18 Wembley Centre for health and care, Community Dental Department
- 19 Western Health and Social Care Trust
- 20 Wrightington, Wigan and Leigh NHS Foundation Trust
- 21

## 1 Appendix C: Declarations of Interest

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
Helen Cockerill	Senior Consultant speech and Language Therapist, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Paid/unpaid lectures in NHS/university context including opinions on treatment options, based on own reading of the literature – feeding, saliva control and speech (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate
Helen Cockerill	Senior Consultant speech and Language Therapist, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Asked to write a Commentary for Developmental Medicine and Child Neurology on a paper on a communication classification system used in cerebral palsy. No financial gain. (Mar 2015)	Personal non-financial specific	Declare and participate
Helen Cockerill	Senior Consultant speech and Language Therapist, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Published a paper 'What interventions can improve the intelligibility of children with cerebral palsy who have dysarthria?' by Lindsay Pennington and Helen Cockerill, in RCSLT (Royal College of Speech and Language Therapists) Bulletin, July 2015. (Oct 2015)	Personal non-financial non-specific	Declare and participate
Helen Cockerill	Senior Consultant speech and Language Therapist, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Published a peer reviewed article in Tizard Learning Disability Review on use of videofluoroscopy in swallowing assessment, including in those with cerebral palsy. 'Assessing children's swallowing: parent and professional perceptions'. No financial gain. (June 2016)	Personal specific non-financial	Declare and participate
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire	Ongoing freelance work under the umbrella of Nutrition Ltd (director and sole employee). Includes private consultations, medico-legal work, consultancy work, speaking and writing and having an online presence via website and social media. None of this work has been specific to cerebral palsy or commissioned by the NHS in the 12 months prior to this appointment. (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London	Speaker fees for presentation at Nestle in March 2015 on fussy eating in toddlers. (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire			
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire	Attended Nutrition and Health conference in Barcelona in January 2014 with travel and accommodation and attendance fees funded by Danone. Within NICE hospitality policy. (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire	Ongoing lecturing on Dietetics and Nutrition to undergraduates and post graduate nutrition and dietetic students at London Metropolitan University. (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire	Author of chapter on autism in the text Clinical Paediatric Dietetics edited by Vanessa Shaw, published November 2014. (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire	Due to start project on freelance basis in October 2016 advising early years settings on nutrition – paid by Early Years Nutrition Partnership – a Community Interest Company – which has been started up using funds from Danone Ecosystem and Danone Early Life Nutrition. (June 2016)	Personal financial non-specific	Declare and participate
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in	Speaker fees for 2 presentations for Abbott Nutrition in October 2015 on feeding problems in autism. (June 2016)	Personal financial non-specific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire			
Zoe Connor	Paediatric Dietitian, Lewisham and Greenwich, NHS Trust Senior Lecturer in Dietetics and Nutrition, London Metropolitan University, London Freelance Dietitian, Nutritionnutrition Ltd, Warwickshire	From September 2015 have been undertaking Masters in Clinical Research via National Institute Health Research (NIHR) studentship at Coventry University – carrying out qualitative research regarding autism and feeding problems at Lewisham Hospital. (June 2016)	Personal non-financial non-specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist, Royal Hospital For Sick Children, Edinburgh	Paper accepted for publication in supplement of Developmental medicine and Child neurology on “ Long term health, social, and financial burden of Hypoxic-ischemic Encephalopathy” (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist, Royal Hospital For Sick Children, Edinburgh	Trustee of Castang Foundation, a charity that funds research into prevention and management of developmental disorders in children including cerebral palsy. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist, Royal Hospital For Sick Children, Edinburgh	Trustee of a charity Castang that funds research projects into prevention and treatment of childhood disability, including cerebral palsy. Part of this involves reviewing research proposals. No payment received for this work. (Feb 2015)	Personal non financial specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist, Royal Hospital For Sick Children, Edinburgh	Paper accepted for publication on aetiology of cerebral palsy. No payment received. (Jan 2016)	Personal Non-Financial Specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist, Royal Hospital For Sick Children, Edinburgh	Invited lecture at National Intrathecal Baclofen Conference on Spasticity management in under 19s : Experience and NICE Perspective of SDR.No funding or honorarium involved (June 2016)	Personal non-specific non-financial	Declare and participate
Charlie Fairhurst	Consultant in Paediatric	No shareholdings or financial interests in commercial		Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	sector/products. No private income with regard to cerebral palsy 2014. No competitor interests. (Nov/Dec 2014)		
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Flight and accommodation paid for as part of faculty for European Movement Therapy Guidelines – Budapest 4-6th April 2014. No faculty fee accepted. Management of spasticity in children. Within NICE hospitality policy. (Nov/Dec 2014)	Personal Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Flight paid for as speaker invitation to German Cerebral Palsy Group (ZEBRA) Munich – 5th December 2014. No speaker fee accepted by CF. Within NICE hospitality policy. (Nov/Dec 2014)	Personal Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Chief Investigator on the following trial – Use of Sativex (Cannabinoid) in children with spasticity-payment from institution for trial work 2012-2016. Accommodation and food paid for at trial meeting, Maidstone 29-30 April 2014 (Nov/Dec 2014)	Non-Personal Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Talks (no fees, hospitality or travel allowance) National Association of Paediatric Charter Physiotherapists 2013 – Pain in Cerebral Palsy (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Co-authored A Colver, C Fairhurst, P Pharoah. Cerebral Palsy. Lancet 2013; 382:1-10 (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Co-authored H Cockerill, D Elbourne, E Allen, D Scrutton, E Will, A McNee, C Fairhurst, G Baird. Speech, Communication and the use of augmentive communication in young people with Cerebral Palsy: The SH&PE population study, Child Care, Health and Development 2013 Pub online May. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Co-authored D Lumsden, C Lundy, C Fairhurst, JO Lin. Dystonia severity Action Plan: a simple grading system for medical severity of status dystonicus and life threatening dystonia. Dev Med Child Neurol 2013;55(7):71-673 (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Authored C Fairhurst. Cerebral Palsy the whys and how. Arch Dis Child Educ Pract. 2012; 97: 122-131. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Co-authored J Parr, C Buswell, K Benerjee, C Fairhurst et al. Management of drooling in children: a survey of UK paediatricians clinical practice. Child Care, Health and Development. 2012; 38(2): 287-291. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Chair of the National College Specialist Advisory Committee, RCPCH 2012-2017 (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Executive Committee's – British Paediatric Neurology Association and British Academy of Childhood Disability – 2013-2016 (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Trustee (unpaid) Whizz Kids – mobility Charity 2013-2016 (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Drug Monitoring Committee for European Medicines Agency, Botulinum Toxin A (Xeomin) in children with spasticity 2012-15. (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
Charlie Fairhurst	Consultant in Paediatric Neurodisability Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Spoke to the German Physiotherapy Association on Pain in Cerebral Palsy. Talk unpaid, no expenses. (June 2016)	Personal Non-Financial Specific	Declare and participate
Liz Keenan	Clinical Nurse Specialist In Spasticity Management (Adults) National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	I received an honorarium for speaking on spasticity in Multiple sclerosis in December 2013 to a group of Irish MS Nurses. This was a study day sponsored by Medtronic Ireland. (June 2016)	Personal financial non-specific	Declare and participate
Liz Keenan	Clinical Nurse Specialist In Spasticity Management (Adults) National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	1. Co-author on a Paper for MS Today 2015 - article on spasticity written with Louise Jarrett (CNS) No payment or financial inducement (June 2016)	Personal non-financial non-specific	Declare and participate
Liz Keenan	Clinical Nurse Specialist In Spasticity Management (Adults) National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	2. Contributed to chapters in : Spasticity Management: A Practical Multidisciplinary Guide, Second Edition, 2016, edited by Valerie L. Stevenson and Louise Jarrett No payment or financial inducement (June 2016)	Personal non-financial non-specific	Declare and participate
Bidisha Lahoti	Consultant Community Paediatrician, Community Children's Services Sunshine House Children's and Young People's Development Centre, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Teaches postgraduate students, GP trainees and medical students locally about Cerebral Palsy. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Bidisha Lahoti	Consultant Community Paediatrician, Community Children's Services	Member of the Advocacy Committee of the Royal College of Paediatrics and Child Health. The work of this committee is very	Personal Non-Financial Specific	Declare and participate



Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	Sunshine House Children's and Young People's Development Centre, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	general and not specific to cerebral palsy (Nov/Dec 2014)		
Bidisha Lahoti	Consultant Community Paediatrician, Community Children's Services Sunshine House Children's and Young People's Development Centre, Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust	Local tutor for 2 consultants undertaking the the long distance MSc Neurodisability course, Sheffield University. Unpaid. (June 2016)	Personal non-financial non-specific	Declare and participate
Athena Logothetis	Specialist Occupational Therapist, The Bobath Centre	Employed by the Bobath Centre for children with cerebral palsy and uses the Bobath concept as the main part of treatment approach. (Nov/Dec 2014)	Non-Personal Non-Financial Specific	Declare and participate
Athena Logothetis	Specialist Occupational Therapist, The Bobath Centre	Provides training to medical students about the Bobath approach and cerebral palsy (Nov/Dec 2014)	Non-Personal Non-Financial Specific	Declare and participate
Athena Logothetis	Specialist Occupational Therapist, The Bobath Centre	Taught medical students about cerebral palsy and Bobath approach in March 2015. (Mar 2015)	Personal non-financial specific	Declare and participate
Margaret Mayston	Clinical Specialist Physiotherapist, The Portland Hospital, London, and Principal Teaching Fellow, Div. Biosciences, University College London	Author/editor of book on cerebral palsy published October 2014. Small amount of royalties will be paid. Cerebral Palsy: Science and Clinical Practice Bernard Dan (Editor), Margaret Mayston (Editor), Nigel Paneth (Editor), Lewis Rosenbloom (Editor) ISBN: 978-1-909962-38-5. 648 pages. November 2014 (June 2016)	personal financial non-specific	Declare and participate
Margaret Mayston	Clinical Specialist Physiotherapist, The Portland Hospital, London, and Principal Teaching Fellow, Div. Biosciences, University College London	Regular speaker at conferences/courses on cerebral palsy as well as MSc teaching: expenses only paid except for MSc teaching. (June 2016)	Personal non-financial non-specific	Declare and participate

<b>Name</b>	<b>Job title and organisation</b>	<b>Declaration of interest and date declared</b>	<b>Type of interest</b>	<b>Decision taken</b>
Margaret Mayston	Clinical Specialist Physiotherapist, The Portland Hospital, London, and Principal Teaching Fellow, Div. Biosciences, University College London	Associate editor Mac Keith Press who publish the journal Development Medicine and Child Neurology. Honorarium £3000 per year. (June 2016)	Personal financial non-specific	Declare and participate
Laura Middleton	General Practitioner, The Parks Medical Practice, Northamptonshire and Speciality Doctor, Helen and Douglas House Hospice Oxford.	Works part time as a speciality doctor at Helen and Douglas house hospice. Partly charitably funded. (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate
Laura Middleton	General Practitioner, The Parks Medical Practice, Northamptonshire and Speciality Doctor, Helen and Douglas House Hospice Oxford.	Gives a yearly palliative care lecture to GP trainees and is due to give a lecture on transition to the local transition group in December. (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate
Cheryl Davis	Consultant Paediatric Neuropsychologist, Sheffield Children's NHS Foundation Trust	Runs a private practice as a paediatric neuropsychologist/clinical psychologist. As part of this work sees children with cerebral palsy. (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate
Cheryl Davis	Consultant Paediatric Neuropsychologist, Sheffield Children's NHS Foundation Trust	Employee of Sheffield children's NHS Foundation Trust (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate
Cheryl Davis	Consultant Paediatric Neuropsychologist, Sheffield Children's NHS Foundation Trust	Appointed as Director for Child Neuro Psychology Services Ltd - a company offering medical legal assessment of children with brain injury including children with cerebral palsy. (Sept 2015)	Personal financial non specific	Declare and participate
Russell Peek	Consultant Paediatrician and Neonatologist, Gloucestershire Hospitals NHS Foundation Trust	Chair of Faltering Growth Guideline committee, National Guideline Alliance/NICE (June 2016)	Personal financial non-specific	Declare and participate
Lindsay Pennington	Senior Lecturer and Speech and Language Therapist, Institute of Health and Society, Newcastle	Authored papers reporting early trials (phase II) of an intervention to improve speech intelligibility, which will have been included in searches for evidence on interventions to improve speech.	Personal non financial specific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	University, Newcastle-upon-Tyne	Not published statements about the types of interventions that should be provided to improve speech intelligibility. Currently investigating the feasibility of delivering the motor learning therapy, based on a whole speech systems approach, in preparation for an application for funding for a randomised controlled trial. Funding has been awarded from NIHR RfPB <a href="http://www.nihr.ac.uk/funding/fundingdetails.htm?postid=1654">http://www.nihr.ac.uk/funding/fundingdetails.htm?postid=1654</a> (Mar 2015)		
Lindsay Pennington	Senior Lecturer and Speech and Language Therapist, Institute of Health and Society, Newcastle University, Newcastle-upon-Tyne	Conducted a systematic review for the Cochrane Library on the effects of interventions to improve the speech of children with cerebral palsy. This is currently being updated. (Mar 2015)	Personal Non-Financial Specific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	In the previous 12 months has received teaching honoraria from Almirall and received payment for participation in Bayer Healthcare's advisory board regarding Sativex. Within NICE hospitality policy. (Nov/Dec 2014)	Personal Financial Specific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Editor and author of Spasticity Management: A Practical Multidisciplinary Guide (2006). Eds. VL Stevenson and L Jarrett. Informa Healthcare. ISBN 1-84184-560-4. Receives recognition and royalties. (Nov/Dec 2014)	Personal Financial Specific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Part of spasticity management team at UCLH which runs an annual course on spasticity management which receives an educational grant from Medtronic as well as sponsorship from other organizations including Dysport and Allergan (botulinum toxin manufacturers), Symetrik (sleep systems), Bayer (Sativex). (Nov/Dec 2014)	Non-Personal Financial Specific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Through both the study day and other lectures gives speeches about spasticity management including the use of botulinum toxin and intrathecal baclofen. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Publications reviewer for MS Trust and MS Society (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Member of the British Association of Neurologists. (Nov/Dec 2014)	Personal Non-Financial Nonspecific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Paid £1800 in Feb 2013 by Bayer Healthcare to write a journal supplement for 'Guidelines in Practice' on Spasticity management in multiple sclerosis. This is currently in press. (Feb 2015)	Personal financial non specific	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Lecturing on the NS Trust MSc module – paid £150 (Oct 2015)	Personal non-specific financial	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Joint application for the following grant from the NIHR RfPB funding stream: PB-PG-1014-35012 – The Effectiveness of Peroneal Nerve Functional Electrical Stimulation (FES) for Improving Mobility in Parkinson's Disease: A Pragmatic Two Site Feasibility Study for an Assessor Blinded Randomised Control Trial (STEPS). This allows funding for a 0.5 physiotherapist post for the department for 2 years (Oct 2015)	Personal non-specific financial interest	Declare and participate
Valerie Stevenson	Consultant Neurologist, National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust	Joint author on;  Wimalasundera N, Stevenson VL. Cerebral palsy. Pract Neurol. 2016 Feb 2. pii: practneurol-2015-001184. doi: 10.1136/practneurol-2015-001184. [Epub ahead of print]. Expenses only. (June 2016)	Personal Non-Financial Specific	Declare and participate
Neil Stoodley	Consultant Neuroradiologist, Southmead Hospital Bristol and Bristol Royal Hospital for Children	Regularly instructed as an expert witness by both Claimants and Defendants (through the NHS Litigation Authority) in cases of alleged clinical negligence leading to various forms of cerebral palsy.	Personal financial non-specific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
		Renumerated for this work. (June 2016)		
Duncan Walsh	Patient or carer representative	Wife employed as Area Sales Manager by Sunrise Medical Ltd - a designer and manufacturer of disability products. (Nov/Dec 2014)	Personal Financial Nonspecific	Declare and participate
Duncan Walsh	Patient or carer representative	Employee of PACE - a charity that works with children and families of children with Cerebral Palsy and other motor disorders. (Nov/Dec 2014)	Personal Non-Financial specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Department is part of an industry funded trial into Sativex a drug used to manage spasticity. (Nov/Dec 2014)	Non-Personal Financial Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Department is part of a research trial looking at brain imaging in cerebral palsy. (Nov/Dec 2014)	Non-Personal Financial Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Ipsen (drug company) is paying department at Great Ormond Street Hospital to provide lectures for cerebral palsy specialists from Sweden on 27.11.14. Money goes to the departmental charity fund. There is no product endorsement. (Nov/Dec 2014)	Non-Personal Financial Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Academic convenor of the British Academy of Childhood Disability. Duties include organising the annual scientific meeting on all disability topics including cerebral palsy. Unpaid. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Co-authored a paper on the management of symptoms in cerebral palsy in the BMJ in October 2014. Unpaid. (Nov/Dec 2014)	Personal Non-Financial Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability	Currently writing a review paper on cerebral palsy for Practical Neurology medical journal. Unpaid. (Feb 2015)	Personal non financial non specific	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	Service, Great Ormond Street Hospital, London			
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	need to follow up/check if I have a form as this isnt on the minutes. (Mar 2015)		Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Invited Neurology team from Germany to deliver training day on ultrasound guided botulinum toxin administration. This was funded equally byt IPSEN and ALLERGAN to a total of £3000. The funding covered the costs of speakers, flights and rental of venue for course. No funding was received personally. (Oct 2015)	Non-Personal Financial Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Grant awarded by the Network Dysfunction following Paediatric Traumatic Brain Injury - awarded by Action Medical Research and Great Ormond Street Hospital Children's Charity. Named investigator on this project working with PI Prof David Sharp – Hammersmith Hospital London. There is no personal financial remuneration – all money will go to conducting the research (staff, scanning costs etc.) (Dec 2015)	Non-Personal Financial non-Specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Published review paper on cerebral palsy - Practical Neurology (Feb 2016). Expenses only. Within NICE hospitality policy. (April 2016)	Personal specific non-financial	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Delivered lecture on cerebral palsy – invitation by British Embassy in Brazil (March 2016) – flight and accommodation paid by British Embassy in Brazil (April 2016)	Personal non-specific non-financial	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	Co-organiser of 2 day training on cerebral palsy - 'Cerebral palsy more than a movement disorder' (April 16 – Great Ormond Street Hospital). Money raised goes to hospital department. (April 2016)	Non-personal specific financial	Declare and participate

Name	Job title and organisation	Declaration of interest and date declared	Type of interest	Decision taken
	Ormond Street Hospital, London			
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	named author on an abstract presented as an oral presentation at the European Academy of Childhood disability scientific meeting, Stockholm. Title – Long term utility of botulinum toxin in paediatric movement disorders. All expenses paid personally and remunerated £500 through hospital study leave budget . (June 2016)	Personal financial non-specific	Declare and participate
Neil Wimalas undera	Consultant in Paediatric Neurodisability, Wolfson Neurodisability Service, Great Ormond Street Hospital, London	May 2016 – Delivered lecture on cerebral palsy at the Association of British Neurologists Annual Scientific Meeting – no financial remuneration – paid travel expenses only. Within NICE hospitality policy. (June 2016)	Personal non-financial specific	Declare and participate

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## 2 Appendix D: Review Protocols

### D.1.3 Risk factors

Item	Details
Review question	What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early recognition?
Objective	The aim of this review is to identify the most important risk factors for developing cerebral palsy with the view to providing information for parents and carers and to inform the need for more frequent assessment and early intervention.
Language	English
Study design	Systematic reviews of observational studies Observational studies: <ul style="list-style-type: none"> <li>• Prospective cohort studies</li> <li>• Retrospective comparative cohort studies</li> </ul> Observational studies (prospective and retrospective) with sample size > 50 participants Only studies dated 2000 and beyond will be considered as interventions from 2000 onwards have developed to minimise the impact of the risk factors.
Population and directness	Infants, children and young people with a risk factor listed below (see the risk factors list)  If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.
Stratified, subgroup and adjusted analyses	Stratified analyses: <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> Sensitivity analysis: including and excluding studies with a high risk of bias.
Risk factors to be considered	Prevalence of risk factors in children and young people with cerebral palsy: <p><u>Antenatal factors</u></p> <ul style="list-style-type: none"> <li>• Infections (e.g. rubella, toxoplasmosis, CMV, herpes simples) – maternal TORCH</li> <li>• Multiple pregnancy</li> <li>• Intrauterine growth retardation</li> <li>• Haemorrhagic events</li> </ul> <p><u>Perinatal</u></p> <ul style="list-style-type: none"> <li>• Hypoxic ischemic events at term/post term</li> <li>• neonatal encephalopathy</li> <li>• Apgar score at 10 min (Low/very low below 4/3)</li> <li>• Neonatal sepsis</li> </ul>



Item	Details
	<p><u>Post natal</u></p> <ul style="list-style-type: none"> <li>• Extreme prematurity 24 - 27 (+6 days) weeks gestational age)</li> <li>• Premature 28 - 31 (+6 days) weeks gestational age</li> <li>• Late premature babies (32-37 weeks gestational age)</li> <li>• Infections: meningitis and encephalitis</li> <li>• Clotting disorders /hyper coagulation in mother</li> <li>• Trauma/non-accidental injury</li> </ul>
Comparison	Children and young people (and if applicable infants) with the risk factor who developed cerebral palsy compared to those with the risk factor who did not develop cerebral palsy.
Outcomes	Prevalence/proportion of risk factors
Importance of outcomes	Critical outcomes: Prevalence/proportion of risk factors
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): Publication date 2000+</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed according to the process described in the NICE guidelines manual (2012).</li> </ul> <p>Synthesis of data:</p> <ul style="list-style-type: none"> <li>• If comparative cohort studies are included, the minimum number of events per covariate to be recorded to ensure accurate multivariate analysis.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	<p>Note any data that will or will not be assessed, including data relevant for health economic analyses, e.g.:</p> <p>Only tools that are externally validated will be assessed</p> <p>Note all individual adverse event frequencies in case needed for health economic model</p>

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## D.2.2 Causes of cerebral palsy

Item	Details
Review question	What are the most common causes of cerebral palsy in resource-rich countries?
Objective	The aim of this review is to identify the prevalence of the most common causes for cerebral palsy with the view to providing information for parents and carers.

Item	Details
Language	English
Study design	<p>Systematic reviews of observational studies</p> <ul style="list-style-type: none"> <li>• Observational studies:</li> <li>• Prospective cohort studies</li> <li>• Retrospective cohort studies</li> <li>• Cross sectional studies</li> <li>• Registry data</li> </ul> <p>Only observational studies above sample size of 250 participants will be included (prevalence review). To include studies from:</p> <ul style="list-style-type: none"> <li>• UK</li> <li>• Europe</li> <li>• North America</li> <li>• Australia</li> <li>• New Zealand</li> </ul>
Population and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years of age.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Groups that will be reviewed and analysed separately:</p> <p>Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic) Severity of functional disability (GMFCS levels)</p>
Causes to be considered	<ul style="list-style-type: none"> <li>• Congenital brain malformations (e.g. mal-development of brain folding [gyri and sulci] and non-genetic conditions such as congenital infections)</li> <li>• Periventricular leucomalacia/ damage of the white matter/ white matter injury</li> <li>• hypoxic ischaemic injury (including perinatal and antenatal injury and stroke)</li> <li>• Intraventricular haemorrhage</li> <li>• Acquired traumatic injury</li> <li>• Congenital and acquired infection</li> <li>• Kernicterus</li> <li>• Neonatal encephalopathy</li> <li>• Neonatal Hypoglycaemia</li> </ul>
Comparison	Not applicable
Outcomes	Proportion/percentage of causes in cerebral palsy
Importance of outcomes	<p>Critical outcomes:</p> <p>Proportion/percentage of causes in cerebral palsy</p>
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): Publication date 2000+</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	Appraisal of methodological quality:

Item	Details
	<ul style="list-style-type: none"> <li>The quality of the evidence for an outcome (i.e. across studies) will be assessed using GRADE according to the NICE guidelines manual (2012).</li> <li>The quality of the evidence of each study will be assessed using the tool developed and published by Munn et al. 2014 for studies reporting prevalence.</li> </ul>
Equalities	Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	

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## D.3.2 Clinical and developmental manifestations of cerebral palsy

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Item	Details
Review questions	<p>What are the key clinical and developmental manifestations that are predictive of cerebral palsy at first presentation?</p> <p>What are the best tools to identify clinical and developmental manifestations of cerebral palsy at first presentation?</p>
Objective	To identify the key clinical and developmental manifestations of cerebral palsy at first presentation that can assist health professionals (community, primary or secondary) to predict cerebral palsy in infants and children and tools that can be used to identify those clinical and developmental manifestations.
Language	English
Study design	<ul style="list-style-type: none"> <li>Systematic reviews of observational studies</li> <li>Observational prospective and retrospective studies.</li> <li>Observational studies (prospective and retrospective) with sample size &gt; 50 participants.</li> </ul>
Population size and directness	<p>Infants and children from birth to 11 years of age (by the end of primary school) at first presentation in whom a diagnosis of cerebral palsy is subsequently made.</p> <p>Control: age matched infants and children</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered</p>
Subgroups and sensitivity analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic) Severity of functional disability (GMFCS levels)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p> <p>The following groups will be assessed separately:</p> <ul style="list-style-type: none"> <li>• Age ranges (under 8 months and above 8 months)</li> <li>• Low risk infants and children</li> </ul> <p>Confounders:</p> <ul style="list-style-type: none"> <li>• gestational age</li> <li>• multiple birth</li> <li>• socioeconomic status</li> <li>• hypoxic events</li> <li>• neonatal sepsis.</li> </ul>
<p>Clinical and developmental manifestations of CP (diagnostic and prognostic)</p>	<p><u>Clinical manifestations</u></p> <ul style="list-style-type: none"> <li>• Abnormality of movement</li> <li>• Under 8 months</li> <li>• Excessive crying/irritability</li> <li>• Feeding difficulties</li> <li>• Asymmetry of movement (gross and fine)</li> <li>• Abnormal muscle tone</li> <li>• Over 8 months old</li> <li>• Asymmetry of movement</li> <li>• Feeding difficulties</li> <li>• Persistent toe walking (equinus)</li> </ul> <p><u>Developmental manifestations</u></p> <ul style="list-style-type: none"> <li>• Delayed motor milestones</li> <li>• Under 8 months</li> <li>• Delayed sitting</li> <li>• Above 8 months</li> <li>• Delayed walking</li> <li>• Tools to identify clinical and developmental manifestations:</li> <li>• General Movement Assessment</li> <li>• Bayley Scale of Infant Development</li> <li>• Amiel-Tison neurological assessment</li> <li>• Infant Motor Profile</li> </ul>
<p>Reference tests</p>	<p>Diagnosis of cerebral palsy</p>
<p>Outcomes</p>	<p>Question 1</p> <ul style="list-style-type: none"> <li>• Risk of cerebral palsy (RRs, ORs, aRRs, aORs)</li> </ul> <p>Question 2</p> <ul style="list-style-type: none"> <li>• Sensitivity: the proportion of true positives of all cases diagnosed with CP in the population</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Specificity: the proportion of true negatives of all cases not-diagnosed with CP in the population.</li> <li>• Positive Predictive Value (PPV): the proportion of patients with positive test results who are correctly diagnosed.</li> <li>• Negative Predictive Value (NPV): the proportion of patients with negative test results who are correctly diagnosed.</li> <li>• Area under the Curve (AUC): are constructed by plotting the true positive rate as a function of the false positive rate for each threshold.</li> <li>• Likelihood ratios</li> <li>• Prevalence of true positives</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <p>Question 1</p> <ul style="list-style-type: none"> <li>• Risk of cerebral palsy (RRs, ORs, aRRs, aORs)</li> </ul> <p>Question 2:</p> <ul style="list-style-type: none"> <li>• Sensitivity: the proportion of true positives of all cases diagnosed with cerebral palsy in the population</li> <li>• Specificity: the proportion of true negatives of all cases not-diagnosed with cerebral palsy in the population.</li> </ul>
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): None.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> <li>• For cohort studies which report associations between manifestation and diagnosis, the NICE checklist based on Hayden JA, Cote P, Bombardier C (2006) Evaluation of the quality of prognosis studies in systematic reviews. <i>Annals of Internal Medicine</i> 144: 427–37 will be used to assess bias.</li> <li>• For prognostic studies, multivariate analysis will be used.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	<p>Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.</p>
Notes/additional information	

## D.4.1 Red flags for other neurological disorders

Item	Details
Review question	What clinical manifestations should be recognised as 'red flags' that suggest a progressive disorder rather than cerebral palsy?
Objective	To identify the most important clinical manifestations that suggest a progressive disorder.
Study design	<ul style="list-style-type: none"> <li>• Prospective observational studies</li> <li>• Retrospective observational studies reporting clinical and developmental manifestations at diagnosis in children with a progressive neurological disorder, or other neuromuscular disorder not due to cerebral palsy.</li> </ul> <p>Observational studies (prospective and retrospective) with sample size &gt; 50 participants.</p>
Population size and directness	<p>Children, young people and adults up to 25 years of age with possible or presumed cerebral palsy</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Subgroups and sensitivity analyses	<p>The following groups will be assessed separately:</p> <ul style="list-style-type: none"> <li>• Age ranges (under 2 year old and above 2 year old)</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
clinical markers	<ul style="list-style-type: none"> <li>• Regression of speech</li> <li>• deterioration of vision</li> <li>• Regression of acquired motor skills</li> <li>• Lack of obvious risk factors for cerebral palsy</li> <li>• Family history</li> <li>• Severe muscle wasting</li> </ul>
Reference standard	Not applicable
Outcomes	<p>Differential diagnosis of:</p> <ul style="list-style-type: none"> <li>• Neurometabolic (leukodystrophy; mitochondrial disorder)</li> <li>• Neuromuscular (SMA, muscular dystrophy)</li> <li>• Tumours (benign and malignant)</li> <li>• Genetic disorders (hereditary spastic paraparesis, progressive dystonia, Rett Syndrome)</li> <li>• Spinal cord disorders</li> </ul>
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): None.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p>

Item	Details
	See appendix E for full strategies
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists according to the process described in the NICE guidelines manual (2012)</li> <li>• Data analysis</li> <li>• Meta-analysis will not be conducted</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Add the groups identified in the scoping phase that need to be considered – see impact assessment form
Notes/additional information	Only tools that are externally validated will be assessed

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## D.5.2 MRI and identification of causes of cerebral palsy

Item	Details
Review question	Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed cerebral palsy and if so in which subgroups is it most important?
Objective	<p>Cerebral palsy is a descriptive term incorporating many non-progressive aetiologies. The pathogenesis is dependent upon structural abnormalities of the developing brain occurring in the ante, peri or post-natal phases. The particular underlying structural pathology observed is dependent on the stage of fetal or neonatal brain development at the time of insult.</p> <p>Some genetic and progressive disorders may mimic cerebral palsy in their early stages and might be identified by MRI. The addition of MRI to aetiological assessment might potentially identify such individuals.</p> <p>This review aims to examine whether there is increased diagnostic certainty regarding the aetiology of suspected cerebral palsy by conducting an MRI to help reveal the pathological basis in comparison to routine clinical assessment alone and whether there is correlation with the extent of cerebral damage is observed.</p> <p>This in turn may help clinicians to provide information for parents on which is the likely aetiology of their child's cerebral palsy.</p>
Language	English
Study design	<ul style="list-style-type: none"> <li>• Systematic reviews of observational studies</li> <li>• Observational studies: <ul style="list-style-type: none"> <li>• retrospective or prospective cohorts</li> <li>• cross-sectional studies, e.g. based on registry data</li> </ul> </li> </ul>
Population and directness	<p>Infants, children and young people aged up to 25 years with suspected or confirmed cerebral palsy.</p> <p>Observational studies (prospective and retrospective) with sample size &gt; 50 participants.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and	Stratified analyses:

Item	Details
adjusted analyses	<ul style="list-style-type: none"> <li>• timing of birth (preterm vs term)</li> <li>• children with clear history of full term HIE/neonatal encephalopathy</li> <li>• children with no clear history or unusual developmental progress.</li> <li>• Stratified analyses:               <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> </ul> </li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> Sensitivity analysis: including and excluding studies with a high risk of bias.
Intervention	<ul style="list-style-type: none"> <li>• Magnetic resonance imaging + clinical assessment</li> <li>• Magnetic resonance imaging + clinical assessment + neonatal cranial ultrasound</li> <li>• Magnetic resonance imaging + clinical assessment + neonatal cranial ultrasound + other blood, urine or Cerebro-spinal fluid (CSF) investigations</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• Clinical assessment alone</li> <li>• Clinical assessment + neonatal cranial ultrasound</li> <li>• Clinical assessment + neonatal cranial ultrasound + other blood, urine or Cerebro-spinal fluid (CSF) investigations</li> </ul>
Outcomes	The accuracy in identifying the proportion of participants with each neuroimaging pattern against aetiology: <ul style="list-style-type: none"> <li>• Considered aetiology changed after MRI performed</li> <li>• Recognition of the following patterns of abnormality for aetiology:               <ul style="list-style-type: none"> <li>• Periventricular leucomalacia / white matter injury</li> <li>• Deep grey matter / basal ganglia lesions (typical of Hypoxic ischemic injury)</li> <li>• Diffuse encephalopathy</li> <li>• Brain Malformations (e.g. mal-development of brain folding [gyri and sulci] and non-genetic conditions such as congenital infections)</li> <li>• Focal ischaemic infarct or haemorrhagic lesions</li> <li>• Confirmation/ruling out of genetic or progressive movement disorders (as per study)</li> </ul> </li> </ul>
Importance of outcomes	Recognition of the following patterns of abnormality for aetiology: <ul style="list-style-type: none"> <li>• Periventricular leucomalacia / white matter injury</li> <li>• Deep grey matter / basal ganglia lesions (typical of Hypoxic ischemic injury)</li> <li>• Diffuse encephalopathy</li> <li>• Brain Malformations (e.g. mal-development of brain folding [gyri and sulci] and non-genetic conditions such as congenital infections)</li> <li>• Focal ischaemic infarct or haemorrhagic lesions</li> </ul>
Setting	All settings in which NHS-commissioned health and social care is provided
Search strategy	Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase Limits (e.g. date, study design): None Supplementary search techniques: No supplementary search techniques were used. See appendix E for full strategies
Review strategy	Appraisal of methodological quality:



Item	Details
	<p>The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</p> <p>Data analysis: A list of excluded studies will be provided following weeding Evidence tables and an evidence profile will be used to summarise the evidence</p>
Equalities	No special groups were identified
Notes/additional information	<p>Key papers/guidance: American Academy of Neurology (AAN) guideline recommends that all cases of cerebral palsy of unknown origin undergo neuroimaging: Korzeniewski 2008: A systematic review of neuroimaging for cerebral palsy, Journal of Child Neurology, Vol 23, No 2, pp 216-217. Krägeloh-Mann I, Horber V. The role of magnetic resonance imaging in elucidating the pathogenesis of cerebral palsy: a systematic review. Dev Med Child Neurol 2007;49:144-51.</p>

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## D.6.2 MRI and prognosis of cerebral palsy

Item	Details
Review question	<p>Does MRI undertaken at the following ages:</p> <ul style="list-style-type: none"> <li>• before 1 month (corrected for gestation)</li> <li>• 1 month to 2 years of age</li> <li>• 2-4 years of age</li> </ul> <p>help to predict the prognosis of children and young people with cerebral palsy?</p>
Objective	The aim of this review is to analyse what is the best age to predict the progression of cerebral palsy using MRI findings classified according to the type of brain injury. An early and accurate prognosis allows for planning and initiation of therapies that improve prognostic outcomes.
Language	English
Study design	Systematic reviews of observational studies Observational studies (retrospective or prospective)
Population and directness	<p>Children and young people with cerebral palsy from up to 25 years. Observational studies (prospective and retrospective) with sample size &gt; 50 participants. Treatment duration and dose within standard range If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Confounders	<ul style="list-style-type: none"> <li>• age (1)</li> <li>• treatment received (2)</li> <li>• level of cognition (3)</li> <li>• type of cerebral palsy</li> <li>• type of dysarthria</li> <li>• severity of functional disability</li> </ul>
Stratified, subgroup and	Groups that will be reviewed and analysed separately:

Item	Details
adjusted analyses	<ul style="list-style-type: none"> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Hypoxic ischemic encephalopathy (most likely to have early MRI before hospital discharge)</li> <li>• High risk babies (prematurity, twins/triplets, HIE, IUGR)</li> <li>• Low risk babies (lack of identified risk factors, present with developmental delay)</li> </ul> <p>Only multivariable observational studies and comparative observational studies (including retrospective) which investigate the prognostic role of the MRI indicators below will be considered.</p>
Intervention/test	<p>MRI at different ages:</p> <ul style="list-style-type: none"> <li>• Early scan: before the age of 1 month (corrected for gestation)</li> <li>• 1 month to 2 years of age</li> <li>• 2-4 years of age</li> </ul>
Comparator	<ul style="list-style-type: none"> <li>• No MRI</li> <li>• MRI at different ages</li> </ul>
Outcomes	<p>Binary outcomes:</p> <ul style="list-style-type: none"> <li>• Proportion of children and young people with epilepsy</li> <li>• Proportion of children and young people with feeding problems</li> <li>• Severity of functional disability using -</li> <li>• Gross Motor System Classification</li> <li>• The Manual Ability Classification System</li> <li>• communication problems</li> <li>• cognitive problems</li> <li>• changes in health-related quality of life (e.g. Lifestyle Assessment Questionnaire – Cerebral Palsy [LAQ-CP])</li> </ul> <p>Time to event outcomes: mortality</p>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Mortality</li> <li>• Severity of functional disability</li> </ul>
Setting	<p>All settings in which NHS-commissioned health and social care is provided</p>
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): None</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• the methodological quality of each study should be assessed and the quality of the evidence for an outcome (i.e. across studies) will be assessed using GRADE as per the methods outlined in The Manual (2012).</li> <li>• Synthesis of data:</li> <li>• studies using only univariate analysis will be excluded</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• meta-analysis will not be conducted</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	

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## D.7.2 Prognosis for walking, talking and life expectancy

Item	Details
Review question	<p>In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to:</p> <ul style="list-style-type: none"> <li>• the ability to walk</li> <li>• the ability to talk</li> <li>• life expectancy?</li> </ul>
Objective	The aim of this review is to determine which clinical and developmental indicators are able to predict the future ability of a child with cerebral palsy to talk, walk, and his or hers life expectancy, with the view to providing information for parents and carers and to inform management.
Language	English
Study design	<p>Systematic reviews of observational studies Multivariate observational studies and comparative observational studies (including retrospective) which investigate the prognostic role of the indicators below will be considered.</p> <p>Confounders to be considered in statistical model for walking and talking:</p> <ul style="list-style-type: none"> <li>• Severity of functional disability</li> <li>• Type of motor disorder</li> <li>• Cognition</li> <li>• Age.</li> </ul> <p>Confounders to be considered in statistical model for life expectancy:</p> <ul style="list-style-type: none"> <li>• Severity of functional disability</li> <li>• Type of motor disorder</li> <li>• Cognition</li> <li>• Age</li> <li>• Enteral tube feeding</li> </ul> <p>Observational studies (prospective and retrospective) with sample size &gt; 50 participants. Studies published after 2000 for survival data. Data on natural history of walking and talking will come from older papers.</p>
Population and directness	<p>Infants, children with cerebral palsy aged up to 25 years. If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>

Item	Details
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Prognostic indicators	<p><u>Clinical indicators for walking:</u></p> <ul style="list-style-type: none"> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (measure of severity of brain injury)</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Delayed sitting</li> </ul> <p><u>Clinical indicators for talking:</u></p> <ul style="list-style-type: none"> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (measure of severity of brain injury)</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Uncontrolled epilepsy</li> <li>• Swallowing difficulties/dysphagia including need for enteral tube feeding</li> </ul> <p><u>Clinical indicators for survival:</u></p> <ul style="list-style-type: none"> <li>• Severity of functional disability (GMFCS – 5 levels)</li> <li>• Level of cognition (as a measure of severity of brain injury)</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Comorbidities (epilepsy, scoliosis and chest infections)</li> <li>• Swallowing difficulties/dysphagia including need for enteral tube feeding</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Survival</li> <li>• Ability to walk (including independent community walking/functional walking)</li> <li>• Ability to talk</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Survival</li> <li>• Ability to walk (including independent community walking/functional walking)</li> <li>• Ability to talk</li> </ul>
Setting	Healthcare and community settings.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): None. Date limiting possible for survival data only, not overall search.</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix E for full strategies</p>
Review strategy	<ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed according to the process described in the NICE guidelines manual (2012)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Studies using only univariate analysis will be excluded.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	

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## D.8.2 Information and support

Item	Details
Review question	What information and information types (written or verbal) are perceived as helpful and supportive by children and young people with cerebral palsy and their family members and carers?
Objectives	To identify the content and type of information that is experienced as helpful and supportive or a hindrance by children and young people with cerebral palsy and their parents and carers.
Language	English
Study design	<p>Study designs to be considered:</p> <ul style="list-style-type: none"> <li>• Qualitative studies (for example, interviews, focus groups, observations)</li> <li>• Surveys (which include qualitative data)</li> </ul> <p>Excluded</p> <p>Purely quantitative studies (including surveys with only descriptive quantitative data)</p>
Population and directness	<p>Children and young people with cerebral palsy aged up to 25 years and their families and carers.</p> <p>If no direct evidence of cerebral palsy population is found, mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Age ranges:</p> <ul style="list-style-type: none"> <li>• Infants – 18 months and below</li> <li>• Children – 18 months – 12 years</li> <li>• Adolescents– 12 – 18 years</li> <li>• Young people - 18 - 25 years</li> <li>• Level of cognitive function</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> </ul> <p>Important subgroups:</p> <p>Non-English speakers</p>
Context and likely themes (information)	<p>Context</p> <ul style="list-style-type: none"> <li>• Information content and type with regards to cerebral palsy</li> </ul> <p>Themes</p> <p>Themes will be identified from the literature, but expected themes are:</p>

Item	Details
	<ul style="list-style-type: none"> <li>• Information regarding cerebral palsy</li> <li>• Information regarding identification, cause and prognosis of cerebral palsy</li> <li>• Information about intervention type</li> <li>• Information about feeding and swallowing</li> <li>• Information about pain recognition and management</li> <li>• Information about transition of care</li> <li>• Information about commonly used medications</li> <li>• Information about named individual for point of contact</li> <li>• Information about possible comorbidities and accessing appropriate services/resources for managing them</li> <li>• Information about patient pathway and points of access</li> <li>• Information about education and health care</li> <li>• Information about sexuality and relationships</li> <li>• Information about lifestyle, leisure and social issues</li> <li>• Information about independent living</li> <li>• Information about organisations (support groups and charities, and their contact details)</li> </ul> <p>Methods of information provision</p> <ul style="list-style-type: none"> <li>• Verbal</li> <li>• Written</li> <li>• Online</li> <li>• Apps</li> <li>• Play</li> <li>• Use of jargon and terminology</li> </ul>
Setting	Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, PsycINFO</p> <p>Limits (e.g. date, study design): Apply standard animal/non-English language exclusions</p> <p>Supplementary search techniques: No supplementary search techniques will be used</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using qualitative study quality checklists and the quality of the evidence will be assessed by a modified GRADE approach (CER-QUAL) for each theme.</li> <li>• Data synthesis</li> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
Equalities	<p>Ethnic minorities and people with communication problems</p> <p>Needs to be more emphasis in this area as increasing number of children come from families in which English is not the first language.</p>
Notes/additional information	

## D.9<sub>1</sub> Assessment of eating, drinking and swallowing difficulties

Item	Details
Review question	In infants, children and young people with cerebral palsy, what is the value of videofluoroscopic swallow studies (VF) or fibreoptic endoscopic evaluation of swallowing (FEES) in addition to clinical assessment in assessing difficulties with eating, drinking and swallowing?
Objective	Clinical assessment of infants, children and young people with cerebral palsy with feeding difficulties should be routine practice. Investigations such as VF or FEES might add additional useful information to the assessment. The objective of this review is to determine the nature of any such added value in clarifying why the difficulties are present and informing targeted subsequent interventions.
Study design	Systematic reviews of observational studies Observational studies: <ul style="list-style-type: none"> <li>• Prospective cohorts</li> <li>• Retrospective cohorts</li> </ul> Observational studies (prospective and retrospective) with sample size > 50 participants.
Population size and directness	Infants, children and young people with cerebral palsy up to 25 years of age. If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered. Studies with indirect populations will be considered if no other relevant studies with direct populations are retrieved.
Subgroups and sensitivity analyses	The following groups will be assessed separately: <ul style="list-style-type: none"> <li>• Infants – 0-6 months and 6 to 18 months</li> <li>• Children (18 months to 11 years)</li> <li>• Adolescents and young people (11 to 25 years)</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> </ul> Sensitivity analysis: including and excluding studies with a high risk of bias.
Index test	<ul style="list-style-type: none"> <li>• VF + clinical assessment</li> <li>• FEES + clinical assessment</li> </ul>
Reference tests	<ul style="list-style-type: none"> <li>• Clinical assessment of eating, drinking and swallowing using: <ul style="list-style-type: none"> <li>• VF</li> <li>• FEES</li> </ul> </li> </ul>
Outcomes	The diagnostic accuracy in identifying the oropharyngeal mechanisms underlying difficulties with eating, drinking and swallowing, including: <ul style="list-style-type: none"> <li>• [oral] motor difficulties (tongue movement, chewing, transfer to posterior pharynx, initiation of swallow etc.)</li> <li>• Vocal cord function</li> <li>• aspiration or risk of aspiration</li> <li>• Post-swallow pooling/residue</li> <li>• Nasopharyngeal reflux/regurgitation</li> <li>• oesophageal obstruction/dysmotility</li> <li>• Sensitivity</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Specificity</li> <li>• Positive Likelihood Ratios</li> <li>• Negative Likelihood Ratios</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Identifying the mechanisms underlying difficulties with eating, drinking and swallowing</li> <li>• Identifying risk of aspiration (leading to respiratory pathology)</li> </ul>
Setting	Health care setting
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): Apply standard animal/non-English language exclusions. Limit to RCTs and systematic reviews in first instance but download all results</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Add the groups identified in the scoping phase that need to be considered – see impact assessment form
Notes/additional information	<p>Only tools that are externally validated will be assessed</p> <p>Royal College of Speech and Language therapists: videoflouroscopic evaluation 2007</p>

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## D.10<sub>2</sub> Management of eating, drinking and swallowing difficulties

Item	Details
Review question	In children and young people with cerebral palsy, what interventions are effective in managing difficulties with eating, drinking and swallowing?
Objective	To assess the clinical and cost effectiveness of interventions in managing difficulties with eating, drinking and swallowing in children and young people with cerebral palsy.
Language	English
Study design	<ul style="list-style-type: none"> <li>• Randomised controlled trials (RCTs).</li> <li>• If no RCTs are available we will look for abstracts of RCTs and observational studies.</li> <li>• No restriction to RCT sample size</li> <li>• If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul>
Population size and directness	<ul style="list-style-type: none"> <li>• Infants, children and young people with cerebral palsy up to 25 years of age.</li> </ul>



Item	Details
	<ul style="list-style-type: none"> <li>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</li> </ul>
Subgroups and sensitivity analyses	<p>The following groups will be assessed separately: Stratified analyses:</p> <ul style="list-style-type: none"> <li>Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Intervention	<ul style="list-style-type: none"> <li>Food and fluid thickeners/texture modification</li> <li>Postural management/modifications</li> <li>Feeding techniques including pacing</li> <li>Sensory therapy</li> <li>Oro-motor therapies</li> <li>Pharmacological</li> <li>Feeding equipment</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>intervention versus no intervention</li> <li>intervention versus placebo</li> <li>intervention A versus intervention B</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>physiological function of the oropharyngeal mechanism (determined by clinical evaluation , VF, or FEES)</li> <li>change in diet consistency a child is able to consume (developmentally appropriate oral diet; texture/consistency of foods and fluids must be modified; supplementary feeding required)</li> <li>Respiratory health - presence of a history of confirmed aspiration pneumonia or recurrent chest infection (with or without pneumonia with suspected prandial aspiration aetiology)</li> <li>nutritional status/changes in growth (weight and height percentiles)</li> <li>child's level of participation in mealtime routine/length of meal times(time taken to feed).</li> <li>psychological wellbeing of parents and carers</li> <li>acceptability of programme</li> <li>survival</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>Nutritional status/changes in growth (weight and height percentiles)</li> <li>child's level of participation in mealtime routine/length of meal times (time taken to feed).</li> <li>Respiratory health - presence of a history of confirmed aspiration pneumonia or recurrent chest infection (with or</li> </ul>

Item	Details
	without pneumonia with suspected prandial aspiration aetiology)
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, SpeechBITE, OTseeker, PEDro, CINAHL</p> <p>Limits (e.g. date, study design): Apply standard animal/non-English language exclusions. Limit to RCTs and systematic reviews in first instance but download all results</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012).</li> <li>• Data analysis:</li> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies at high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the included evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	<p>Only tools that are externally validated will be assessed</p> <p>Studies with the following types of populations will not be downgraded for indirectness As the Committee considered it unlikely to influence the relative effectiveness of interventions for swallowing, eating and drinking:</p> <p>Non-progressive neurodisorders</p>

## D.11<sub>1</sub> Optimising nutritional status

Item	Details
Review question	In children and young people with cerebral palsy, what interventions are effective at optimising nutritional status?
Objective	The aim of this review is to identify the interventions for maintaining adequate nutritional status in children and young people with cerebral palsy and to assess their effectiveness.
Language	English
Study design	<ul style="list-style-type: none"> <li>• Randomised controlled trials (RCTs).</li> <li>• If no RCTs are available we will look for abstracts of RCTs and cohort studies</li> <li>• No restriction to RCT sample size</li> <li>• If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul>
Population and directness	<ul style="list-style-type: none"> <li>• Children and young people with cerebral palsy from birth to 25 years.</li> <li>• For enteral feeding interventions, only population from birth to 18 years of age will be examined, as 18 years and over enteral feeding interventions are covered in CG32.</li> <li>• If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</li> <li>• Treatment duration and dose within standard range.</li> <li>• Exclusions: terminally ill patients, patients in ICU, patients who have experienced stroke or are receiving emergency care.</li> </ul>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic) Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Intervention	<p>This review will consider the following interventions:</p> <ul style="list-style-type: none"> <li>• Gastrostomy or jejunostomy tube feeding</li> <li>• Naso-gastric tube feeding</li> <li>• Oral nutrition support: <ul style="list-style-type: none"> <li>○ high calorie feeds</li> </ul> </li> <li>• Lifestyle changes: <ul style="list-style-type: none"> <li>○ physical activity</li> <li>○ dietary changes</li> </ul> </li> <li>• Antiemetics: <ul style="list-style-type: none"> <li>○ Domperidone (trade name: Motilium)</li> <li>○ Metoclopramide (Maxolon, Reglan, Octamide)</li> <li>○ Erythromycin (can be used as an antiemetic if low doses are given)</li> </ul> </li> </ul> <p>Exclusions: Dexamethasone and other steroids as only prescribed if there is indication relating to an additional intercurrent illness.</p>
Comparison	<p>The following possible comparisons will be included:</p> <ul style="list-style-type: none"> <li>• Intervention versus no intervention</li> <li>• Intervention versus placebo</li> <li>• Intervention versus other intervention</li> <li>• Oral feeding vs tube feeding</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Gastrostomy vs oral feeding</li> <li>• Jejunostomy vs oral feeding</li> <li>• Oral feeding vs anti-reflux medication</li> <li>• Other</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Anthropometric measures: <ul style="list-style-type: none"> <li>▪ Weight</li> <li>▪ Growth percentile</li> </ul> </li> <li>• Adverse events: <ul style="list-style-type: none"> <li>▪ complications of feeding tubes</li> <li>▪ complications of antiemetics</li> <li>▪ vomiting frequency</li> </ul> </li> <li>• Dietary intake - food offered and consumed.</li> <li>• Health related quality of life: using Child Health Questionnaire</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ol style="list-style-type: none"> <li>1. Anthropometric measures - weight</li> <li>2. Adverse events</li> <li>3. Dietary intake</li> </ol>
Setting	All settings in which care is provided
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED</p> <p>Limits (e.g. date, study design): Separate results into RCTs/SRs and other designs; both sets to be downloaded.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> <li>• Data analysis</li> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• For continuous data final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies with high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> </ul> <p>Evidence tables and an evidence profile will be used to summarise the evidence</p>
Equalities	<p>Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.</p>

Item	Details
Notes/additional information	<p>Only tools that are externally validated will be assessed</p> <p>Studies with the following types of populations will not be downgraded for indirectness as the Committee considered it unlikely to influence the relative effectiveness of interventions for optimising nutritional status:</p> <p>Participants with non-progressive neurological diseases other than CP</p> <p>Existing Cochrane review on Gastrostomy feeding vs oral feeding</p> <p>Lifestyle changes included in obesity guideline, however there is no clear identification of lifestyle changes in those with disabilities/neurodisabilities including Cerebral Palsy.</p>

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## D.12<sub>2</sub> Improving speech, language and communication: speech intelligibility

Item	Details
Review question	In children and young people with cerebral palsy, what interventions are effective in improving speech intelligibility?
Objective	To assess the clinical and cost effectiveness of interventions in improving speech intelligibility in children and young people with cerebral palsy.
Language	English
Study design	<p>Randomised controlled trials (RCTs).</p> <p>If no RCTs are available we will look for abstracts of RCTs and observational studies.</p> <ul style="list-style-type: none"> <li>• No restriction to RCT sample size</li> <li>• If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul>
Population size and directness	<p>Children and young people with cerebral palsy aged up to 25 years.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Subgroups and sensitivity analyses	<ul style="list-style-type: none"> <li>• Stratified analyses:</li> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Intervention	<p>Therapies given directly to the child with the aim of developing the child's speech skills:</p> <ul style="list-style-type: none"> <li>• Physiological and oro-motor <ul style="list-style-type: none"> <li>○ Facial Oral Tract therapy</li> <li>○ Talk tool</li> <li>○ Beckman</li> </ul> </li> <li>• Articulation, speech sound, phonology, minimal pairs, dyspraxia programme</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Tactile-kinesthetic               <ul style="list-style-type: none"> <li>○ PROMPT</li> </ul> </li> <li>• Sub-systems               <ul style="list-style-type: none"> <li>○ Speech sub-systems</li> <li>○ Lee Silverman</li> </ul> </li> <li>• Intra-oral/orthodontic               <ul style="list-style-type: none"> <li>○ Castillo-Morales appliance</li> <li>○ Innsbruck Sensori Motor Activator and Regulator</li> <li>○ Palatal Training Aid</li> <li>○ electropalatography)</li> </ul> </li> <li>• Medical therapies/tone management               <ul style="list-style-type: none"> <li>○ Muscle relaxants (baclofen, L-dopa, trihexyphenidyl)</li> <li>○ Botox</li> <li>○ Acupuncture</li> <li>○ Postural management</li> <li>○ DBS</li> </ul> </li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• SALT versus no treatment</li> <li>• Intervention A versus intervention B</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Quality of life</li> <li>• Speech intelligibility (for example percentage intelligibility)</li> <li>• Participation (including communication)</li> <li>• Self-confidence</li> <li>• Family stress and coping</li> <li>• Satisfaction of patient and family with treatment</li> </ul>
Importance of outcomes	<ul style="list-style-type: none"> <li>• Critical outcomes:</li> <li>• Participation</li> <li>• Speech intelligibility</li> </ul>
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED, SpeechBITE, OTSeeker</p> <p>Limits (e.g. date, study design): Separate results in to RCTs/SRs and other designs; both sets to be downloaded.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> </ul> <p>Data analysis</p> <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies with high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	<p>Note any data that will or will not be assessed, including data relevant for health economic analyses, e.g.:</p> <ul style="list-style-type: none"> <li>• Only tools that are externally validated will be assessed</li> <li>• Note all individual adverse event frequencies in case needed for health economic model</li> </ul>

1

## D.13<sup>2</sup> Improving speech, language and communication: 3 Communication Systems

Item	Details
Review question	In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?
Objective	To assess what is the clinical and cost effectiveness of communication systems to improve communication.
Language	English
Study design	<p>Randomised controlled trials (RCTs).</p> <p>If no RCTs are available we will look for abstracts of RCTs and observational studies.</p> <p>No restriction to RCT sample size</p> <p>If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</p>
Population and directness	Children and young people with cerebral palsy aged up to 25 years. If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic) Severity of functional disability (GMFCS levels)</li> </ul>

	<ul style="list-style-type: none"> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Intervention	<ul style="list-style-type: none"> <li>• Alternative and Augmentative Communication (AAC):</li> <li>• Pictures or Symbol systems</li> <li>• Signing and gesture systems (for example Makaton)</li> <li>• Tangible symbols/objects of reference (objects used to represent words)</li> <li>• Speech generating devices (SGDs) or voice output communication aids (VOCAs)</li> <li>• Text based (written or computer)</li> <li>• Therapies given to familiar communication partners with the aim of changing the conversation style</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• intervention versus no intervention</li> <li>• intervention A versus intervention B</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Communication production</li> <li>• Change in communication production</li> <li>• Change in sign/symbol production</li> <li>• Impact on family: stress, coping</li> <li>• Parental satisfaction</li> <li>• Participation</li> <li>• Quality of life</li> </ul>
Importance of outcomes	<ul style="list-style-type: none"> <li>• Preliminary classification of the outcomes for decision making:</li> <li>• Participation</li> <li>• Change in communication production</li> </ul>
Setting	Healthcare, community
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED, SpeechBITE, OTSeeker</p> <p>Limits (e.g. date, study design): Separate results in to RCTs/SRs and other designs; both sets to be downloaded.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> <li>• Synthesis of data:</li> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• For continuous data final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> </ul>



	<ul style="list-style-type: none"> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies with high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	Note any data that will or will not be assessed, including data relevant for health economic analyses, e.g.: Only tools that are externally validated will be assessed Note all individual adverse event frequencies in case needed for health economic model

## D.14<sub>1</sub> Managing saliva control

Item	Details
Review question	In children and young people with cerebral palsy, what interventions are effective in optimising saliva control?
Objective	The aim of this review is to investigate which interventions are clinically and cost effective in managing (reducing) drooling in children and young people with cerebral palsy.
Language	English
Study design	Randomised controlled trials (RCTs). If no RCTs are available we will look for abstracts of RCTs and observational studies. <ul style="list-style-type: none"> <li>• No restrictions on RCT sample size</li> <li>• If limited evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> <li>• Treatment duration and dose within standard range</li> </ul>
Population and directness	Children and young people with cerebral palsy from birth to 25 years. If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.
Stratified, subgroup and adjusted analyses	<ul style="list-style-type: none"> <li>• Stratified analyses:</li> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic) Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> <li>• Sensitivity analysis: including and excluding studies with a high risk of bias.</li> </ul>
Intervention	This review will consider the following interventions:

Item	Details
	<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Pharmacologic treatments</li> <li>• Botulinum toxin</li> <li>• Physical/postural, oro-motor and oro-sensory therapies</li> <li>• Behavioural interventions</li> <li>• Intra-oral appliances</li> <li>• Acupuncture</li> </ul>
Comparison	<p>The following possible comparisons will be included:</p> <ul style="list-style-type: none"> <li>• Intervention versus no intervention</li> <li>• Intervention versus placebo</li> <li>• Intervention versus other intervention</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Reduction of frequency and severity of drooling (including specific rating scales and volume)</li> <li>• Health-related quality of life.</li> <li>• Psychological wellbeing (for example, depression or anxiety).</li> <li>• Adverse effects:               <ul style="list-style-type: none"> <li>○ Pharmacological treatment: visual disturbance and constipation.</li> <li>○ Botulinum: swallowing problems and breathing problems.</li> <li>○ Surgery: ranulae and chest infection.</li> </ul> </li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• 1. Drooling severity and frequency</li> <li>• 2. Quality of life</li> <li>• 3. Adverse effects</li> </ul>
Setting	<p>All settings in which care is provided.</p>
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design): Separate results in to RCTs/SRs and other designs; both sets to be downloaded.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012).</li> </ul> <p>Data analysis:</p> <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted wherever possible</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies with high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> <li>• To assess clinical importance for this outcome, the following minimal important difference thresholds were agreed by the Committee: <ul style="list-style-type: none"> <li>• Thomas-Stonell and Greenberg scale: 2-points reduction (1 point for each section of the scale)</li> <li>• Teacher Drooling scale: 3-points reduction difference</li> <li>• Drooling Impact score: 10-points reduction</li> </ul> </li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	

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## D.15<sub>2</sub> Risk factors for low bone mineral density

Item	Details
Review question	In children and young people with cerebral palsy, what are the risk factors for reduced bone mineral density and low-impact fractures?
Objective	The aim of this review is to identify the most important risk factors for reduced bone mineral density and low-impact fractures in cerebral palsy with a view to inform the need for more frequent assessment and early intervention.
Language	English
Study design	<ul style="list-style-type: none"> <li>• Systematic reviews of observational studies</li> <li>• Prospective cohort studies</li> <li>• If insufficient prospective evidence is found: <ul style="list-style-type: none"> <li>• Retrospective comparative cohort studies</li> <li>• Case-control studies will be reviewed if insufficient retrospective comparative cohort studies are found</li> </ul> </li> </ul> <p>Confounders</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> </ul>
Population and directness	<p>Infants, children and young people with cerebral palsy up to 25 years of age and a risk factor listed below (see the risk factors list)</p> <p>Observational studies (prospective and retrospective) with sample size &gt; 50 participants.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> </ul>

Item	Details
adjusted analyses	<ul style="list-style-type: none"> <li>Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> Sensitivity analysis: including and excluding studies with a high risk of bias.
Risk factors to be considered	Risk factors in children and young people with cerebral palsy: <ul style="list-style-type: none"> <li>GMFCS group</li> <li>Type of cerebral palsy (spasticity/dyskinetic)</li> <li>Anticonvulsant therapy</li> <li>Nutritional inadequacy</li> <li>Low Vitamin D status</li> <li>Low weight for age, low weight/height or low BMI SD scores</li> <li>History of metabolic bone disease of pre-mature birth</li> </ul>
Comparison	Risk of reduced bone mineral density and low-impact fractures in children and young people (and if applicable infants) with cerebral palsy and the risk factor compared to risk of reduced bone mineral density and low-impact fractures in children and young people (and if applicable infants) without the risk factor.
Outcomes	<ul style="list-style-type: none"> <li>Risk of low volume bone mineral density- adjusted for the key confounders</li> <li>Risk of low impact fractures- adjusted for the key confounders</li> <li>As adjusted HR/ORs</li> <li>A BMC or BMD z-score of more than 2 SDs below expected (less than -2) should be labelled “low for age.” The diagnosis of osteoporosis in children be made only when both low bone mass (BMC or BMD z-scores of less than -2) and a clinically significant fracture history (defined previously) are present.</li> </ul>
Importance of outcomes	Critical outcomes: <ul style="list-style-type: none"> <li>Risk of low volume bone mineral density- adjusted for the key confounders</li> <li>Risk of low impact fractures- adjusted for the key confounders</li> </ul>
Setting	All settings in which care is provided.
Search strategy	Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase Limits (e.g. date, study design): Publication date 2000+ Supplementary search techniques: No supplementary search techniques were used. See appendix E for full strategies
Review strategy	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> </ul> Data analysis: <ul style="list-style-type: none"> <li>If comparative cohort studies are included, the minimum number of events per covariate to be recorded to ensure accurate multivariate analysis.</li> <li>A list of excluded studies will be provided following weeding</li> <li>Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>

Item	Details
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	Refer to Henderson work in North America. <a href="http://www.ncbi.nlm.nih.gov/pubmed/16261280">http://www.ncbi.nlm.nih.gov/pubmed/16261280</a> For adults: A T score of 0 to -1 is considered normal, a T score of -1 to -2.5 is considered osteopaenic and less than -2.5 is considered osteoporotic. Gold standard is DEXA

## D.16<sub>1</sub> Prevention of reduced bone mineral density

Item	Details
Review question	In children and young people with cerebral palsy, what interventions are effective in preventing reduced bone mineral density and low-impact fractures?
Objective	The aim of this review is assess the clinical and cost effectiveness of interventions to prevent (both primary and secondary prevention) reduced bone mineral density and low-impact fractures in cerebral palsy.
Language	English
Study design	<ul style="list-style-type: none"> <li>• Randomised controlled trials (RCTs).</li> <li>• If no RCTs are available we will look for abstracts of RCTs and observational studies.</li> <li>• No restriction to RCT sample size</li> <li>• If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul> <p>Confounders (for cohort studies):</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> <li>• Weight</li> </ul>
Population and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years at risk of reduced bone mineral density and low-impact fractures</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p> <p>Stratification</p> <ul style="list-style-type: none"> <li>• Primary prevention (those who have, or are at risk of, low bone mineral density but with no prior fractures)</li> <li>• Secondary prevention (those who have had a low impact fracture)</li> </ul>
Interventions	Interventions used for primary and secondary prevention

Item	Details
	<ul style="list-style-type: none"> <li>• Use of standing frame as postural management</li> <li>• Use of vibration therapy as passive exercise</li> <li>• Active exercise programmes:               <ul style="list-style-type: none"> <li>○ rebound therapy</li> <li>○ static bicycle</li> <li>○ treadmill training</li> </ul> </li> <li>• Active physiotherapy programme</li> <li>• Calcium supplementation</li> <li>• Vitamin D supplementation/sunlight</li> <li>• Calcium supplementation with vitamin D</li> <li>• Nutrition support (oral nutrition support, tube feeding, food fortification advice, dietetic advice)</li> </ul> <p>Secondary prevention of reoccurrence of low impact fractures</p> <ul style="list-style-type: none"> <li>• Bisphosphonates</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• Intervention vs no intervention</li> <li>• Intervention versus other intervention</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Alteration on DEXA score (levels of bone mineral density)</li> <li>• Change in frequency of minimally traumatic fractures</li> <li>• Patients satisfaction/acceptability</li> <li>• QoL</li> <li>• Pain</li> <li>• Adverse effects (drugs) for example:               <ul style="list-style-type: none"> <li>○ Bone fragility</li> <li>○ Gastric/oesophageal irritation/ulceration</li> </ul> </li> </ul> <p>Relevant MID: A BMC or BMD z-score of more than 2 SDs below expected (less than -2) should be labelled “low for age.” The diagnosis of osteoporosis in children be made only when both low bone mass (BMC or BMD z-scores of less than -2) and a clinically significant fracture history (defined previously) are present.</p>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Alteration on DEXA score (levels of bone mineral density)</li> <li>• Change in frequency of minimally traumatic fractures</li> <li>• Patients satisfaction/acceptability</li> </ul>
Setting	All settings in which care is provided.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>Limits (e.g. date, study design):</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> <li>• Data analysis:</li> <li>• Meta-analysis will be conducted wherever possible</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews. Relevant MIDs discussed and agreed with the committee: A BMC or BMD z-score of more than 2 SDs below expected (less than -2) should be labelled "low for age." The diagnosis of osteoporosis in children be made only when both low bone mass (BMC or BMD z-scores of less than -2) and a clinically significant fracture history (defined previously) are present.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies with high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	Refer to Henderson work in North America.

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## D.17<sub>2</sub> Causes of pain, discomfort, distress, and sleep disturbance

Item	Details
Review question	In children and young people with cerebral palsy, what are the common causes of pain, discomfort, distress and sleep disturbance?
Objective	The aim of this review is to identify the most common underlying causes of discomfort, pain, distress and sleep disturbance. The review will consider sources directly arising from the condition itself (e.g. spasticity) as well as those caused by secondary issues (e.g. pain from wheelchair use).
Language	English
Study design	<p>Systematic reviews of observational studies</p> <p>Observational studies:</p> <ul style="list-style-type: none"> <li>• Prospective cohort studies</li> <li>• Retrospective cohort studies</li> <li>• Cross sectional studies</li> <li>• Registry data</li> </ul> <p>Only observational studies above sample size of 250 participants will be included.</p>
Population and directness	Children and young people with cerebral palsy up to 25 years of age. If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.

Item	Details
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• age ranges: &lt;5 years; 5-11 years; 11-18; 18-25</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic) Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> <li>• Sensitivity analysis: including and excluding studies with a high risk of bias.</li> </ul>
Clinical manifestations to consider	<p>Causes of pain, discomfort and distress:</p> <ul style="list-style-type: none"> <li>• musculo-skeletal pain/discomfort (including: hip pain, back pain or scoliosis, and spasticity)</li> <li>• gastrointestinal pain/discomfort</li> <li>• surgical pain/discomfort</li> <li>• physical therapy causing pain/discomfort</li> <li>• dysmenorrhea</li> <li>• dental pain</li> <li>• headache</li> </ul> <p>Causes of sleep disturbance:</p> <ul style="list-style-type: none"> <li>• Sleep disordered breathing (including obstructive sleep apnoea and sleep apnoea)</li> <li>• Seizures</li> <li>• Behavioural difficulties (including ADHD)</li> <li>• Pain</li> </ul>
Outcomes	Prevalence of pain, discomfort, distress and sleep disturbance
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Prevalence of pain, discomfort, distress and sleep disturbance</li> </ul>
Setting	All settings in which care is provided
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase</p> <p>There are no limits placed on the dates of the search.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The quality of the evidence will be assessed according to the process described in the NICE guidelines manual (2012)</li> <li>• The quality of the evidence of each study will be assessed using the tool developed and published by Munn et al. 2014 for studies reporting prevalence.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	



## D.18<sup>1</sup> Assessment of pain, distress, discomfort, and sleep 2 disturbances

Item	Details
Review question	What is the validity and reliability of published tools to identify and aid understanding of discomfort, pain and/or distress in children and young people with cerebral palsy?
Objective	<p>The presentation of a child and young person with cerebral palsy who is in discomfort, pain or distress is not uncommon, and can be challenging to recognise due to communication challenges that may be a result of the person's age, cognitive or motor abilities. In addition health care professionals should use tools that are reliable and valid to use in distress in children and young people with cerebral palsy.</p> <p>The aim of this review is to:</p> <ul style="list-style-type: none"> <li>• provide guidance on tools to identify pain in children and young people with cerebral palsy that are reliable and valid.</li> <li>• assist parents, carers and health care professionals in recognising the clinical manifestation of pain, discomfort, distress and sleep disturbance in children and young people with cerebral palsy</li> <li>• assist in the onward specialist referral and management for those children and young people with cerebral palsy</li> </ul>
Language	English
Study design	<p>Systematic reviews of observational studies</p> <p>Observational studies: prospective and retrospective cohorts</p>
Population and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years.</p> <p>Observational studies (prospective and retrospective) with sample size &gt; 50 participants.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• ability to communicate</li> <li>• level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> <li>• age ranges: &lt;5 years; 5-11 years; 11-18; 18-25</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Tools	<p>Tools that are designed to identify the presence of discomfort, pain or distress as reported by the patient or by proxy of the parent/carer:</p> <ul style="list-style-type: none"> <li>• Paediatric pain profile (1)</li> <li>• Non-communicating child's pain checklist – revised/post-operative version</li> <li>• Face, legs, activity, cry, consolability Scale</li> <li>• Wong-Baker FACES® Pain Rating Scale (2)</li> <li>• Individualised Numeric Rating scale (Likert) (3)</li> <li>• Disdat</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• reliability</li> <li>• validity</li> <li>• sensitivity</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• specificity</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• reliability</li> <li>• validity</li> </ul>
Setting	All settings in which care is received
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED</p> <p>There are no limits placed on the dates of the search.</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The quality of the evidence will be assessed according to the process described in the NICE guidelines manual (2012)</li> <li>• The methodological quality of each study will be assessed using the following tool: Jerosch-Herold, C (2005) An evidence-based approach to choosing outcome measures an checklist for the critical appraisal of validity, reliability and responsiveness studies. British Journal of Occupational Therapy, 68 (8). pp. 347-353.</li> </ul> <p>Data analysis:</p> <ul style="list-style-type: none"> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the included evidence</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations
Notes/additional information	<p>A review of pain measures for hospitalised children with cognitive impairment: <a href="http://onlinelibrary.wiley.com/doi/10.1111/jspn.12069/abstract;jsessionid=1726ED392FD9E62AB2FCAD7CB8AD9EAF.f03t01">http://onlinelibrary.wiley.com/doi/10.1111/jspn.12069/abstract;jsessionid=1726ED392FD9E62AB2FCAD7CB8AD9EAF.f03t01</a></p> <p>Pain, discomfort and challenging behaviours: <a href="http://www.birmingham.ac.uk/schools/psychology/centres/cerebra/about/projects/pain-discomfort-challenging-behaviour.aspx">www.birmingham.ac.uk/schools/psychology/centres/cerebra/about/projects/pain-discomfort-challenging-behaviour.aspx</a></p> <p>Massaro, 2014: A comparison of three scales for measuring pain in children with cognitive impairment</p> <p>Non-communicating child's pain checklist: <a href="http://www.aboutkidshealth.ca/En/Documents/AKH_Breau_everyday.pdf">www.aboutkidshealth.ca/En/Documents/AKH_Breau_everyday.pdf</a></p> <p>Royal College of nursing guidelines: <a href="http://www.rcn.org.uk/__data/assets/pdf_file/0004/269185/003542.pdf">http://www.rcn.org.uk/__data/assets/pdf_file/0004/269185/003542.pdf</a></p>

1

## D.19<sub>2</sub> Management of pain, distress and discomfort

Item	Details
Review question	In children and young people with cerebral palsy, which interventions are effective in managing discomfort and/or pain and distress with no identifiable cause?
Objective	The aim of this review is to determine which interventions are more clinically and cost effective for managing discomfort, pain and distress in people with cerebral palsy
Language	English

Item	Details
Study design	<ul style="list-style-type: none"> <li>• Randomised controlled trials (RCTs).</li> <li>• If no RCTs are available we will look for abstracts of RCTs and observational studies.</li> <li>• No restriction to RCT sample size</li> <li>• If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul>
Population and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years who are experiencing discomfort and/or pain and distress that is not due to an apparent cause.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• age ranges: &lt;5 years; 5-11 years; 11-18; 18-25</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)severity of functional disability (GMFCS level)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias</p>
Intervention	<p>Any pharmacological or non-pharmacological intervention that is used to improve pain and/or discomfort, distress that has no apparent cause. For example:</p> <ul style="list-style-type: none"> <li>• Psychological therapy</li> <li>• Cognitive behavioural therapy (CBT)</li> <li>• Physical therapy</li> <li>• Postural management/equipment review/reassessment (seating, wheel chairs, splints)</li> <li>• hydrotherapy</li> </ul> <p><u>Pharmacological</u></p> <ul style="list-style-type: none"> <li>• Analgesics: <ul style="list-style-type: none"> <li>○ Paracetamol</li> <li>○ ibuprofen</li> </ul> </li> <li>• Anticonvulsants: <ul style="list-style-type: none"> <li>○ Gabapentin</li> <li>○ pregabalin</li> <li>○ carbamazepine</li> <li>○ sodium valproate (in CYP with CP but no epilepsy)</li> <li>○ Benzodiazepines</li> <li>○ diazepam</li> <li>○ Opioids</li> <li>○ Fentanyl patches</li> </ul> </li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• Intervention A versus intervention B</li> <li>• placebo</li> <li>• no treatment</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• pain control</li> <li>• distress</li> <li>• physical function (Multidimensional Pain Inventory Interference Scale / Brief Pain Inventory interference items)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• emotional function (for example, depression or anxiety using Beck's depression inventory)</li> <li>• adverse events, including withdrawal</li> <li>• health-related quality of life (for example, Peds-QL, Pediatric QOL-CP module or EQ-5D)</li> <li>• Parent and carer outcomes (e.g. anxiety)</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• pain control</li> <li>• distress</li> <li>• health-related quality of life</li> </ul>
Setting	All settings in which care is provided
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED, PsycINFO</p> <p>There are no limits placed on the dates of the search.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012).</li> <li>• Data analysis:</li> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies at high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the included evidence.</li> </ul>
Equalities	Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	<p>Only externally validated measurement scales will be included for assessment.</p> <p>Reference papers:</p> <p>Cochrane review 2015 Pharmacological interventions for pain in children and young people with a life-limiting condition</p> <p>Measuring pain (Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials: <a href="http://www.immpact.org/">www.immpact.org/</a>)</p> <p>Stinson 2006, Systematic review of the psychometric properties, interpretability and feasibility of self-report pain intensity measures for use in clinical trials in children and adolescents</p>

Item	Details
	Von Bayer 2007 Systematic review of observational (behavioural) measures of pain for children and adolescents aged 3 to 18 years

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## D.20<sub>2</sub> Management of sleep disturbance

Item	Details
Review question	In children and young people with cerebral palsy, which interventions are effective in managing sleep disturbance arising from no identifiable cause?
Objective	Sleep disturbance can lead to a reduction in the quality of life and negative outcomes in children and young people with cerebral palsy and their families. This review aims to determine which interventions are more clinically and cost effective for reducing sleep disturbance.
Language	English
Study design	<ul style="list-style-type: none"> <li>• Randomised controlled trials (RCTs).</li> <li>• If no RCTs are available we will look for abstracts of RCTs and observational studies.</li> <li>• No restriction to RCT sample size</li> <li>• If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul>
Population and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years who are experiencing disturbed sleep (i.e. dyssomnias, parasomnias) that is not due to an apparent cause.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• age ranges: &lt;5 years; 5-11 years; 11-18; 18-25</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)severity of functional disability (GMFCS level)</li> <li>• type of measurement for sleep disturbances (i.e. sleep diaries and actigraphy)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias</p>
Intervention	<p>Any pharmacological or non-pharmacological intervention that is used to reduce sleep disturbance. For example:</p> <ul style="list-style-type: none"> <li>• melatonin</li> <li>• sleep systems/ sleep positioning (postural devices, wedges and supports)</li> <li>• Age appropriate sleep routine (termed as sleep hygiene programmes)</li> </ul> <p>Sedatives:</p> <ul style="list-style-type: none"> <li>• alimemazine</li> <li>• vallergran</li> <li>• chloral hydrate</li> <li>• clonidine</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• any other pharmacological or non-pharmacological intervention that is used to reduce sleep disturbance</li> <li>• placebo</li> <li>• no treatment</li> </ul>

Item	Details
Outcomes	<ul style="list-style-type: none"> <li>• sleep quality, measured for example, by polysomnography (gold standard) or by other methods such as wrist actigraphy, sleep diaries, Sleep Habits Questionnaire</li> <li>• adverse events, including withdrawal</li> <li>• day time emotional wellbeing/labiality</li> <li>• health-related quality of life (for example, Peds-QL, Pediatric QOL-CP module or EQ-5D)</li> </ul>
Importance of outcomes	<p>Preliminary classification of the outcomes for decision making:</p> <p>sleep quality, measured for example, by polysomnography (gold standard) or by other methods such as wrist actigraphy, sleep diaries, Sleep Habits Questionnaire</p> <p>health-related quality of life (for example, Peds-QL, Pediatric QOL-CP module or EQ-5D)</p>
Setting	All settings in which care is provided
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED, PsycINFO</p> <p>There are no limits placed on the dates of the search.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012).</li> <li>• Data analysis:</li> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat analysis (ITT), then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• For continuous data final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If heterogeneity is found, sensitivity analysis will be performed, removing studies at high risk of bias.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the included evidence</li> </ul>
Equalities	Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	Reference papers: Cochrane protocol Sleep positioning

1

## D.21<sub>2</sub> Assessment of mental health problems

Item	Details
Review question	In children and young people with cerebral palsy, what assessments are effective in identifying the presence of mental health problems?
Objectives	Psychological disorders are also often present in present in people with cerebral palsy. For example, the rate of depression is three to four times higher in people

Item	Details
	<p>with disabilities such as cerebral palsy. There is also some evidence that children with neurodevelopmental disorders are more prone to psychiatric disorders in adulthood, some of which can be screened for and treated in childhood.</p> <p>The aim of this review is to determine what assessments are effective in identifying the presence of mental health problems in cerebral palsy.</p>
Language	English
Study design	<ul style="list-style-type: none"> <li>• Systematic reviews of observational studies</li> <li>• Observational studies: <ul style="list-style-type: none"> <li>• Prospective cohorts</li> <li>• Cross-sectional studies</li> <li>• Observational studies (prospective and retrospective) with sample size &gt; 50 participants.</li> </ul> </li> </ul>
Population size and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18 years; 18-25 years</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> <li>• Communication difficulties (verbal/non verbal)</li> </ul> <p>Sensitivity analysis:including and excluding studies with high risk of bias</p>
Index test: Recognition or assessment tool	<ul style="list-style-type: none"> <li>• Self-report Mood and Feelings Questionnaire (MFQ)</li> <li>• Hospital anxiety and depression scale (HADs)</li> <li>• Beck youth inventories</li> <li>• CHQ 50 – child health questionnaire 50</li> <li>• CP Child - quality of life questionnaire</li> <li>• Strengths and difficulties questionnaire</li> <li>• Child behaviour checklist</li> <li>• GHQ – DoH</li> </ul>
Reference standard	Diagnosis statistical manual (DSM) or International Classification of diseases (ICD) diagnosis
Outcomes	<ul style="list-style-type: none"> <li>• Sensitivity</li> <li>• Specificity</li> <li>• Positive predictive value</li> <li>• Negative predictive value</li> <li>• Area under the curve</li> <li>• Reliability/validity</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Sensitivity/specificity</li> <li>• Positive and negative likelihood ratios</li> <li>• Odds ratios</li> </ul>
Setting	Setting of diagnosis (i.e. primary vs secondary)

Item	Details
Search strategy	Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase There are no limits placed on the dates of the search Supplementary search techniques: No supplementary search techniques will be used See appendix E for full strategies
Review strategy	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using NICE checklists and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE guidelines manual (2012)</li> </ul>
Equalities	In some children and young people with communication difficulties functional or mental health problems may not be recognised Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services
Notes/additional information	

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## D.22.2 Management of mental health problems

Item	Details
Review question	What is the clinical and cost effectiveness of interventions to manage mental health problems in children and young people with moderate to severe cerebral palsy (GMFCS III-V)
Objectives	People with cerebral palsy (particularly those of a higher GMFCS level III) are at a higher risk than the general population of developing psychological problems. This often causes more handicap and distress for the child and family than their existing physical or cognitive disabilities and can affect the developmental course of their illness. The aim of this review is to assess the clinical and cost effectiveness of interventions to manage mental health problems in children and young people with moderate to severe cerebral palsy (GMFCS III-V).
Language	English
Study design	<ul style="list-style-type: none"> <li>Randomised controlled trials (RCTs).</li> <li>If no RCTs are available we will look for abstracts of RCTs and observational studies.</li> <li>No restriction to RCT sample size</li> <li>If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</li> </ul>
Population size and directness	Children and young people aged up to 25 years with moderate to severe cerebral palsy (GMFCS III-V) or with other problems likely to impair communication vision, hearing) and understanding.  If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.
Stratified, subgroup and adjusted analyses	Age ranges: <ul style="list-style-type: none"> <li>Children – 18 months to 12 years</li> <li>Adolescents– 12 to 18 years</li> </ul>



Item	Details
	<ul style="list-style-type: none"> <li>• Young people - 18 to 25 years</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>• Ability to communicate</li> </ul> <p>Sensitivity analysis: Sensitivity analysis: including and excluding studies with a high risk of bias</p>
Intervention	<ul style="list-style-type: none"> <li>• Individualised self-help – 16 years and above – will depend on cognitive ability</li> <li>• Behavioral techniques –eg relaxation techniques,mindfulness</li> <li>• Cognitive behavioural therapy</li> <li>• Psychoeducational groups</li> <li>• Psychotherapy (wide term – could cover CBT etc etc etc)</li> <li>• Family therapy</li> </ul> <p>Pharmacological</p> <ul style="list-style-type: none"> <li>• Antidepressants (including SSRIs) <ul style="list-style-type: none"> <li>○ Amitriptylline</li> <li>○ Diazepam</li> <li>○ Fluoxetine</li> <li>○ Citalopram</li> <li>○ Sertraline</li> </ul> </li> <li>• Anxiolytics <ul style="list-style-type: none"> <li>○ Buspirone</li> </ul> </li> <li>• Physical <ul style="list-style-type: none"> <li>○ physical activity</li> </ul> </li> <li>• Counselling and support: <ul style="list-style-type: none"> <li>○ Group based peer support programme</li> <li>○ counselling</li> </ul> </li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• No intervention</li> <li>• Control</li> <li>• placebo group</li> <li>• other interventions</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Health related quality of life of children and young people with CP as well as parents and carers (for example, KIDSCREEN-10, PedsQL, CHQ, European generic HRQOL, CPQOL-child, CPQOL-teen)</li> <li>• Social participation</li> <li>• Emotional health (for example, SDQ)</li> <li>• Improvement in behaviour (for example, Behaviour Problems Inventory/index) Child Behaviour Checklist</li> <li>• Psychological wellbeing (for example, Beck Youth Inventory)</li> <li>• Parent/carer impression of change (for example, Kiddle-SADs (at school starting age))</li> <li>• Adverse effects (side effects of meds – sedation, drowsiness, change in movement, worsening of siezures)</li> <li>• Suicide risk</li> <li>• Sleep quality</li> </ul>
Importance of outcomes	<p>Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Health related quality of life</li> <li>• Emotional Health</li> <li>• Adverse effects</li> </ul>

Item	Details
Setting	Healthcare
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, PsycINFO</p> <p>Limits (e.g. date, study design): Apply standard animal/non-English language exclusions</p> <p>Supplementary search techniques: No supplementary search techniques will be used</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed and the quality of the evidence will be assessed by GRADE for each outcome according to the process described in the NICE manual (2012)</li> <li>• Data analysis:</li> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available care analysis (ACA) and intention to treat (ITT), then ACA will be preferred over ITT</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses. If heterogeneity is found, sensitivity analysis will be performed, removing studies with high risk of bias</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul>
Equalities	<p>Different recommendations may need to be made for CYP with behavioural and psychological problems of differing severities to ensure equality of access to relevant services.</p> <p>Communication difficulties may need to be addressed in some recommendations</p> <p>Should be part of ongoing care, with adequate follow up</p>
Notes/additional information	

## D.23<sup>1</sup> Management of sensory and perceptual difficulties

Item	Details
Review question	In children and young people with cerebral palsy, what interventions are effective for managing difficulties in registering and processing of sensory and perceptual information?
Objectives	<p>To identify interventions that are effective for the management of difficulties in processing sensory and perceptual information in children and young people with cerebral palsy.</p> <p>To target the following sensory domains:</p> <ul style="list-style-type: none"> <li>• Auditory</li> <li>• Gustatory</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Olfactory</li> <li>• Tactile</li> <li>• Vestibular</li> <li>• Proprioception (somatosensory)</li> <li>• Visual</li> </ul> <p>In one or many of the above.</p>
Language	English
Study design	<p>Randomised controlled trials (RCTs). If no RCTs are available we will look for abstracts of RCTs and observational studies.</p> <p>No restriction to RCT sample size If limited RCT evidence is found, observational studies with sample size &gt; 30 participants will be considered.</p>
Population size and directness	<p>Infants, children and young people with cerebral palsy aged up to 25 years of age.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Stratified analyses:</p> <ul style="list-style-type: none"> <li>• Age ranges: &lt;5 years; 5-11 years; 11-18; 18-25.</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Intervention	<ul style="list-style-type: none"> <li>• Sensory integration (traditional method) (sight, sound, taste, smell, touch, balance, body position, tactile, sensory diet, sensory lifestyle)</li> <li>• Goal-directed therapy /Activity focussed and goal directed therapy/Task-orientated therapy</li> <li>• Occupational therapy (Activity analysis, CO-OP approach (cognitive orientation to daily occupational performance)</li> <li>• Computer based programmes (for example, videogame therapy, computer enhanced therapy to improve balance)</li> <li>• Neuro-psychological and educational psychological support (behavioural training)</li> <li>• Regarding assessments of general sensory processing there are various versions of the Sensory Profile that are commonly used and there is also the Sensory Integration Praxis Test (SIPT) developed by Jane Ayres.</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• Control</li> <li>• No treatment</li> <li>• Other interventions</li> <li>• Combinations of interventions</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function, emotional well-being, physical function, socialising and making friends)</li> <li>• Health related quality of life (Child health questionnaire, CPQOL)</li> <li>• Improvement in psychological wellbeing (anxiety and depression) (for example, HADS, Becks Depression Inventory)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Wellbeing of parents and carers (for example, Becks Depression inventory)</li> <li>• Goal attainment scales</li> <li>• Regarding outcome measures for the sensory / perceptual question there are several visual perceptual assessments commonly used by occupational therapists. These include:               <ul style="list-style-type: none"> <li>• The Beery Visual Motor Assessment (VMI) (6 editions)</li> <li>• The Test of Visual Perception Sills (TVPS) (3 editions)</li> <li>• Motor Free Visual Perception Test (MVPT) (4 editions)</li> </ul> </li> </ul>
Importance of outcomes	Critical outcomes: <ul style="list-style-type: none"> <li>• Improved sensory and perceptual function</li> <li>• Health related quality of life</li> <li>• Improved psychological wellbeing</li> </ul>
Setting	Healthcare
Search strategy	Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase Limits (e.g. date, study design): Apply standard animal/non-English language exclusions Supplementary search techniques: No supplementary search techniques will be used See appendix E for full strategies
Review strategy	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>• The methodological quality of each study should be assessed and the quality of the evidence for an outcome (i.e. across studies) will be assessed using GRADE according to NICE guidelines manual (2012).</li> <li>• Synthesis of data:               <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted wherever possible</li> <li>• If studies use available case analysis (ACA) and intention to treat (ITT) then ACA will be preferred over ITT.</li> <li>• To apply NGA process for defining MIDS for intervention evidence reviews.</li> <li>• Final and change scores will be pooled and if any study reports both, change scores will be used in preference over final scores.</li> <li>• If studies only report p-values from parametric analyses, and 95% CIs cannot be calculated from other data provided, this information will be plotted in GRADE tables, but evidence may be downgraded.</li> <li>• If studies only report p-values from non-parametric analyses, this information will be plotted in GRADE tables without downgrading the evidence, as imprecision cannot be assessed for non-parametric analyses. If heterogeneity is found, sensitivity analysis will be performed, removing studies at high risk of bias</li> </ul> </li> </ul> A list of excluded studies will be provided following weeding Evidence tables and an evidence profile will be used to summarise the evidence
Equalities	Different recommendations may need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	

## D.24<sub>1</sub> Other comorbidities in cerebral palsy

Item	Details
Review question	In infants, children and young people with cerebral palsy what is the prevalence of important comorbidities with a view to informing early identification?
Objectives	<p>To determine the prevalence of the most important comorbidities associated with cerebral palsy and relevant subgroups</p> <p>To assist health care professionals in recognising important comorbidities in children and young people with cerebral palsy and identifying subgroups most at risk</p> <p>To improve onward specialist referral and management</p> <p>For parental information and reassurance.</p>
Language	English
Study design	<p>Systematic reviews of observational studies</p> <p>Observational studies:</p> <ul style="list-style-type: none"> <li>• Prospective cohort studies</li> <li>• Retrospective cohort studies</li> <li>• Cross sectional studies</li> <li>• Registry data</li> </ul> <p>Only observational studies above sample size of 250 participants will be included (prevalence review).</p>
Population and directness	<p>Children and young people with cerebral palsy up to 25 years of age.</p> <p>If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Stratified, subgroup and adjusted analyses	<p>Age ranges:</p> <ul style="list-style-type: none"> <li>• Infants – 18 months and below</li> <li>• Children – 18 months – 12 years</li> <li>• Adolescents– 12 – 18 years</li> <li>• Young people - 18 - 25 years</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic))</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Level of cognition (treatments require sustained attention, ability to follow commands and ability to understand the impact of limited intelligibility)</li> <li>• Pre-natal and perinatal cerebral palsy</li> </ul> <p>Sensitivity analysis: including and excluding studies with a high risk of bias.</p>
Clinical markers (comorbidities)	<p>Identification of the following important comorbidities in children and young people with cerebral palsy:</p> <ul style="list-style-type: none"> <li>• Behavioural difficulties</li> <li>• Cognitive and learning disabilities</li> <li>• Hearing difficulties</li> <li>• Visual difficulties</li> <li>• Vomiting, regurgitation and reflux</li> <li>• Constipation</li> <li>• Epilepsy (particularly in specific subgroups)</li> <li>• Communication difficulties</li> </ul>
Outcomes	Percentage/proportion of comorbidities

Item	Details
Importance of outcomes	Critical outcomes: Percentage/proportion of comorbidities
Setting	Healthcare
Search strategy	Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase Limits (e.g. date, study design): Apply standard animal/non-English language exclusions Supplementary search techniques: No supplementary search techniques will be used See appendix E for full strategies
Review strategy	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>• The quality of the evidence has been assessed by using the tool developed and published by Munn et al. 2014 that assesses critical issues of internal and external validity that must be considered when addressing validity of prevalence data.</li> <li>• Synthesis of data: <ul style="list-style-type: none"> <li>• Data from Surveillance for Cerebral Palsy in Europe (SCPE) registry (which includes UK data); the Victorian cerebral palsy register and the CPUP (Scandinavian/ Norwegian database) will be used as key sources of prevalence of comorbidities where possible.</li> <li>• For comorbidities not reported in the key registries: average rates of comorbidities will be presented as ranges.</li> <li>• A list of excluded studies will be provided following weeding</li> <li>• Evidence tables and an evidence profile will be used to summarise the evidence</li> </ul> </li> </ul>
Equalities	[State the groups that need to be considered – see impact assessment form]
Notes/additional information	Key registries: SCPE: <a href="http://www.scpenetwork.eu/en/publications/">http://www.scpenetwork.eu/en/publications/</a> [includes UK data] Australian CP register Swedish, Danish and Icelandic registry: <a href="http://cpup.se/in-english/publications-in-english/">http://cpup.se/in-english/publications-in-english/</a> Other key studies <a href="http://www.neurology.org/content/72/24/2090.abstract">http://www.neurology.org/content/72/24/2090.abstract</a> <a href="http://pediatrics.aappublications.org/content/130/5/e1285.full.pdf+html">http://pediatrics.aappublications.org/content/130/5/e1285.full.pdf+html</a>

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## D.25<sub>2</sub> Social care needs

Item	Details
Review question	What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?
Objectives	To identify the specific social care needs of children and young people with cerebral palsy and their parents and carers.
Language	English
Study design	Study designs to be considered: <ul style="list-style-type: none"> <li>• Qualitative studies (for example, interviews, focus groups, observations)</li> <li>• Surveys (which include qualitative data)</li> </ul>

Item	Details
	<p>Excluded</p> <ul style="list-style-type: none"> <li>• Purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
Population and directness	<p>Children and young people with cerebral palsy aged up to 25 years. If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.</p>
Subgroups	<p>Age ranges:</p> <ul style="list-style-type: none"> <li>• Infants – 18 months and below</li> <li>• Pre-school children – 18 months - 60 months</li> <li>• Primary/ Junior school children – 5 – 11 years</li> <li>• Adolescents– 11 – 18 years</li> <li>• Young adults - 18 - 25 years</li> <li>• Severity of functional disability (GMFCS levels)</li> <li>• Children from ethnic minorities</li> <li>• Children with multiple comorbidities</li> <li>• Children who are undergoing/ recovering from a major intervention (e.g. hip and spine surgery and gastrostomy)</li> <li>• Parents whose specific demographic, geographic, religious or cultural beliefs may affect or restrict their ability to engage or to accept help.</li> <li>• Looked after children/ children who are subject to the safeguarding process</li> </ul>
Context and themes	<p>Examples of contexts and themes that could be found (applicable to both children and young people and family/carer):</p> <ul style="list-style-type: none"> <li>• Independent living</li> <li>• access to transport/adaptable accessible vehicles</li> <li>• Training in independent travel (depending on level of severity of cerebral palsy)</li> <li>• Mentoring support</li> <li>• Access to services</li> <li>• Social care assessments at time of diagnosis to assess the needs of children and young people and family and signposting of available social care options</li> <li>• Access to age appropriate recreation/play/portage opportunities</li> <li>• Access to support groups/activity groups</li> <li>• Access to appropriate educational vocational /work opportunities &gt;16 years of age</li> <li>• Specialist nurse involvement, OT</li> <li>• Attending clinics on the same day or joint clinics</li> <li>• Advice and information provided</li> <li>• Advice on respite care</li> <li>• Information and advice on personal care</li> <li>• Advice, guidance and access to aids, equipment, hoists with adaptations to home/school</li> <li>• Advice and guidance on benefits (DLA/ ESA /carers allowance) and disability allowances</li> </ul>
Setting	<p>All health and social care settings ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence</p>
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, CINAHL, AMED, PsycINFO, HMIC Limits (e.g. date, study design): Apply standard animal/non-English language exclusions</p>

Item	Details
	Supplementary search techniques: No supplementary search techniques will be used See appendix E for full strategies
Review strategy	Appraisal of methodological quality <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using qualitative study quality checklists and the quality of the evidence will be assessed by a modified GRADE approach (CER-QUAL) for each theme.</li> <li>• Data synthesis</li> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
Equalities	Different recommendations would need to be made for children and young people with different levels of functional or cognitive disabilities to ensure equality of access to relevant services. Additionally, communication difficulties might need to be addressed in some recommendations.
Notes/additional information	

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## D.26<sub>2</sub> Transition to adult services

Item	Details
Review question	What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?
Objectives	Transition is considered as timely planned movement of adolescents and young people from child-centred to adult-orientated health care. Transition should be flexible and gradual, and timing of transition should depend on developmental needs. Education and social care transition normally start at 14 years, but in a cerebral palsy population transfer rarely occurs before 18 years.  The aim of this review is to identify elements of the transition process (for example, transition planning involvement) from paediatric to adult services from perspectives of young people with cerebral palsy and their family and carers.
Language	English
Study design	Study designs to be considered: <ul style="list-style-type: none"> <li>• Qualitative studies (for example, interviews, focus groups, observations)</li> <li>• Surveys (which include qualitative data)</li> </ul> Excluded <ul style="list-style-type: none"> <li>• Purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
Population and directness	Children and young people with cerebral palsy aged 12-25 years who are using or receiving health or social care services  Family members and carers of young people undergoing transition from children's to adult services  If no direct evidence of cerebral palsy population is found, a mixed population of children and young people with neurodisabilities will be considered.
Stratified, subgroup and	Age ranges: <ul style="list-style-type: none"> <li>• Adolescents – 12 – 16 years</li> </ul>



Item	Details
adjusted analyses	<ul style="list-style-type: none"> <li>• Young people - 16 – 18 years</li> <li>• Young people - 18 - 25 years</li> <li>• Type and motor distribution of cerebral palsy (spastic unilateral, spastic bilateral, ataxic, and dyskinetic)Severity of functional disability (GMFCS levels)</li> <li>• Severity of cognitive disability</li> <li>• Degree of independence</li> <li>• Level of comorbidities</li> </ul>
Context and themes	<p>MDT:</p> <ul style="list-style-type: none"> <li>• Transition clinic: Transition lead (consultant/social worker) preparation of plan of transition for individual and family/carers, MDT structured approach</li> <li>• Health care professional training in transition to improve practice</li> <li>• Transition programme/preparation period and education programme (for young person to be able to function in the adult clinic, and able to manage illness mostly independently of parents and staff). Use of transition questionnaires.</li> <li>• Involvement of young people and family/carer in planning, implementing and reviewing transition</li> <li>• Communication point of contact information (written, verbal, and email format), and clarity about process (eg, nurse rehabilitation specialist, community paediatrician)</li> <li>• Key transition therapist as part of paediatric and adult service</li> <li>• Involvement of multiagency: health care, social care and education and passing information to adult services (e.g., admin support for records and appointments, transfer checklist, medical and MDT summaries before transfer)</li> <li>• Communication/co-ordination between paediatric and adult services</li> </ul> <p>Services:</p> <ul style="list-style-type: none"> <li>• Timing of transition with education and other agencies (eg social services) to make it as seamless and as flexible as possible (e.g., a joint transition clinic that consists of both paediatric and adult team members)</li> <li>• Information for young people and carers/family about health needs of cerebral palsy as an adult, about treatment centres, available support services and resources and funding, may need to be in different format if they cannot read.</li> <li>• Delivering information to the adult services- for example, booklet or passport for young people carry with them when attending hospital and other appointments.</li> <li>• Timing (age of transition) to take account of individual circumstances and problems.</li> </ul>
Setting	All health and social care settings ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase, PsycINFO, CINAHL</p> <p>Limits (e.g. date, study design): Apply standard animal/non-English language exclusions</p> <p>Supplementary search techniques: No supplementary search techniques will be used</p> <p>See appendix E for full strategies</p>
Review strategy	<p>Appraisal of methodological quality</p> <p>The methodological quality of each study will be assessed using qualitative study quality checklists and the quality of the evidence will be assessed by a modified GRADE approach (CER-QUAL) for each theme.</p>

Item	Details
	Data synthesis Thematic analysis of the data will be conducted and findings presented.
Equalities	Different recommendations would need to be made for children and young people with different levels of cerebral palsy to ensure equality of access to relevant services. Communication difficulties may need to be addressed in some recommendations
Notes/additional information	

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### 3 **Appendix E: Search Strategies**

4 These can be found in a separate document

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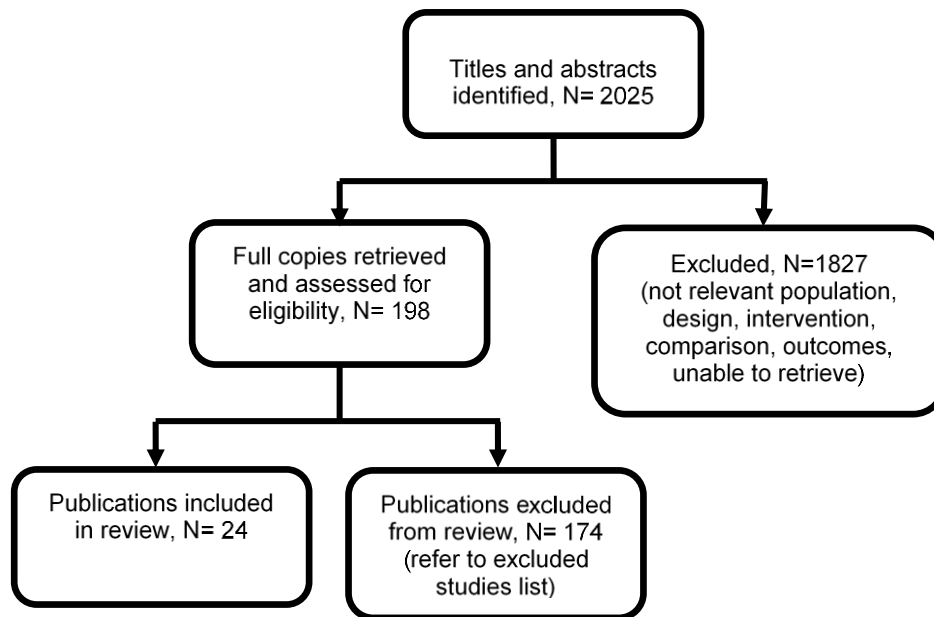
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### 13 **Appendix F: Summary of Identified Studies**

#### **F.14 Risk factors**

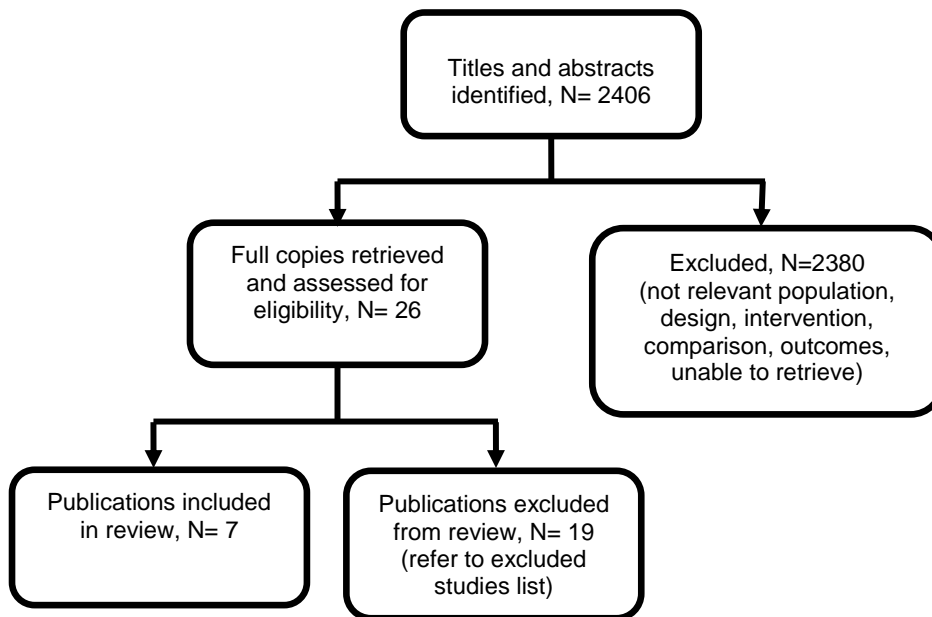
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**Figure 1: Flow diagram of clinical article selection for risk factors review**



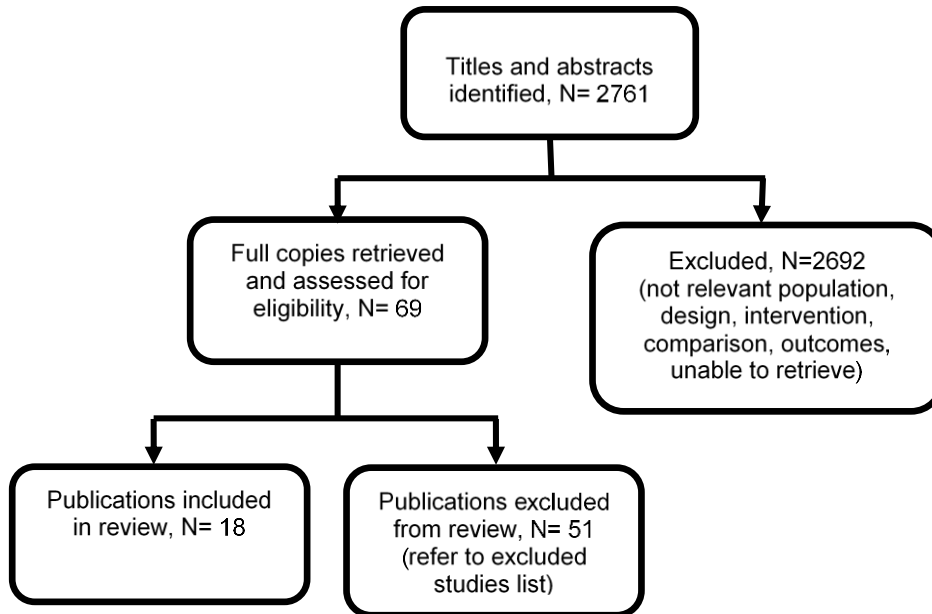
## F.2.1 Causes of cerebral palsy

Figure 2: Flow diagram of clinical article selection for causes of cerebral palsy review



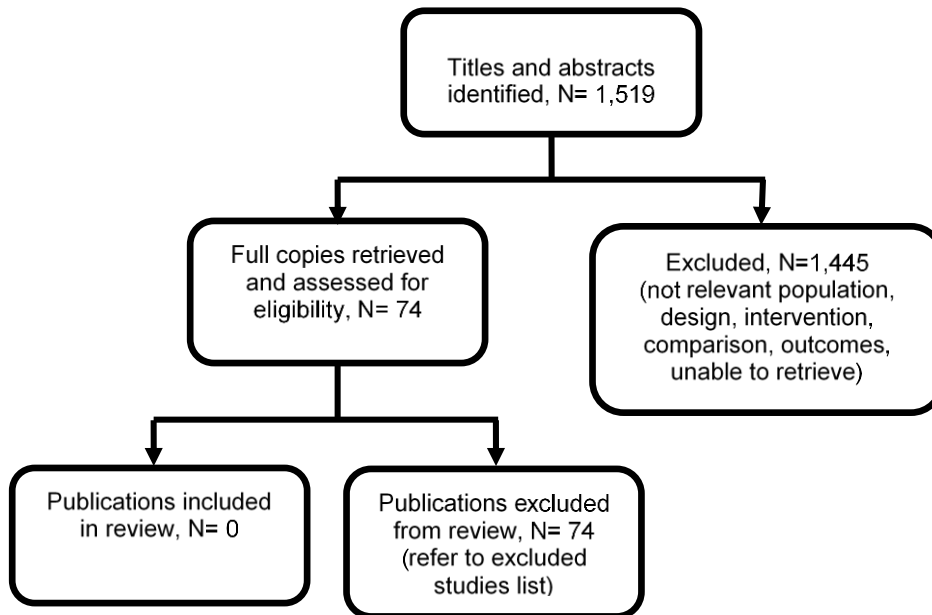
## F.3<sub>1</sub> Clinical and developmental manifestations of cerebral palsy

Figure 3: Flow diagram of clinical article selection for clinical and developmental manifestations review



## F.4.1 Red flags for other neurological disorders

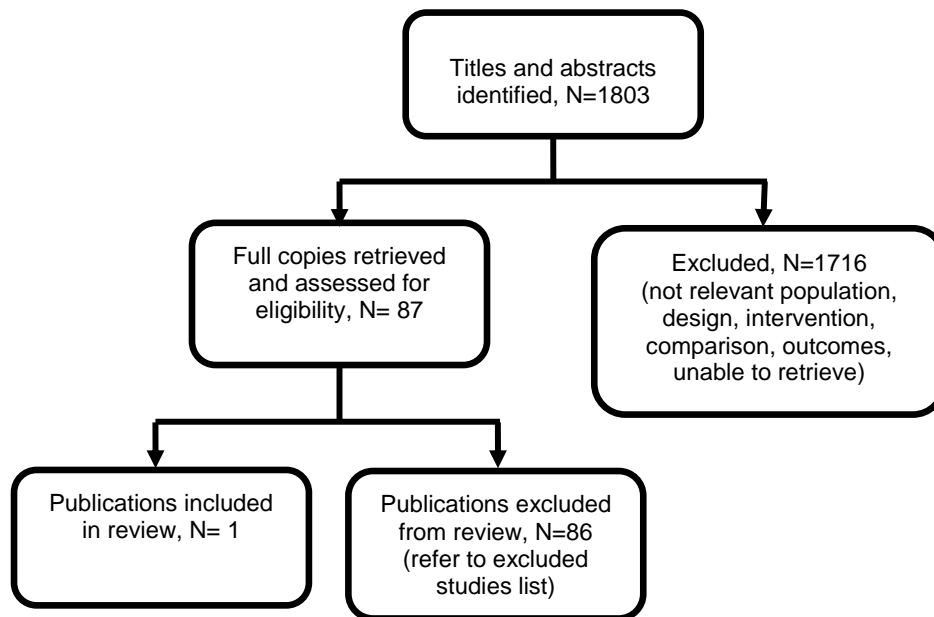
Figure 4: Flow diagram of clinical article selection for red flags review



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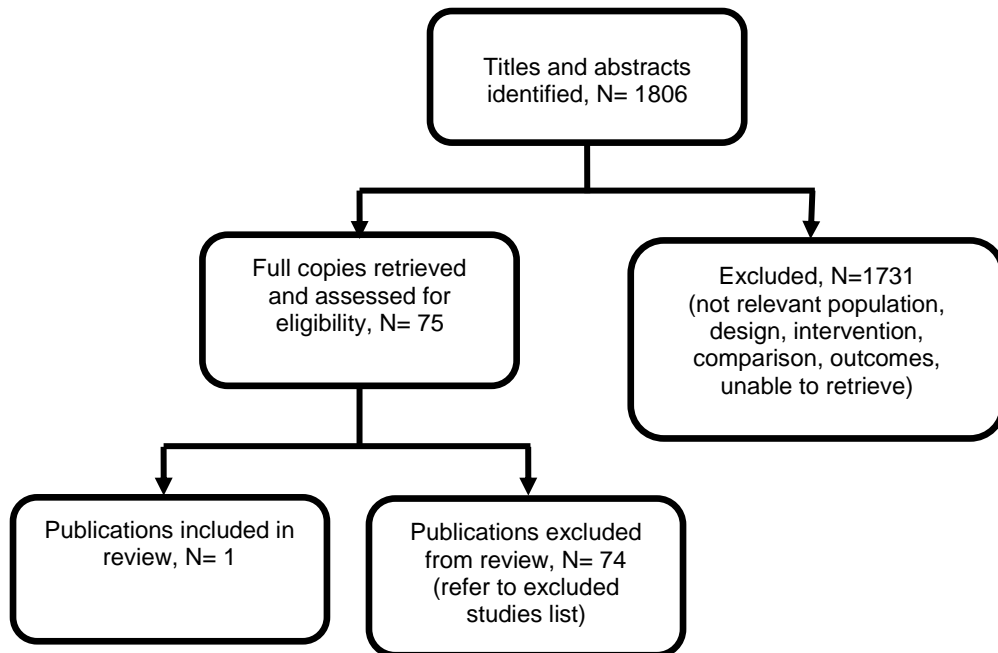
## F.5.3 MRI and identification of causes of cerebral palsy

Figure 5: Flow diagram of clinical article selection for MRI and identification of causes of cerebral palsy review



## F.6<sub>1</sub> MRI and prognosis of cerebral palsy

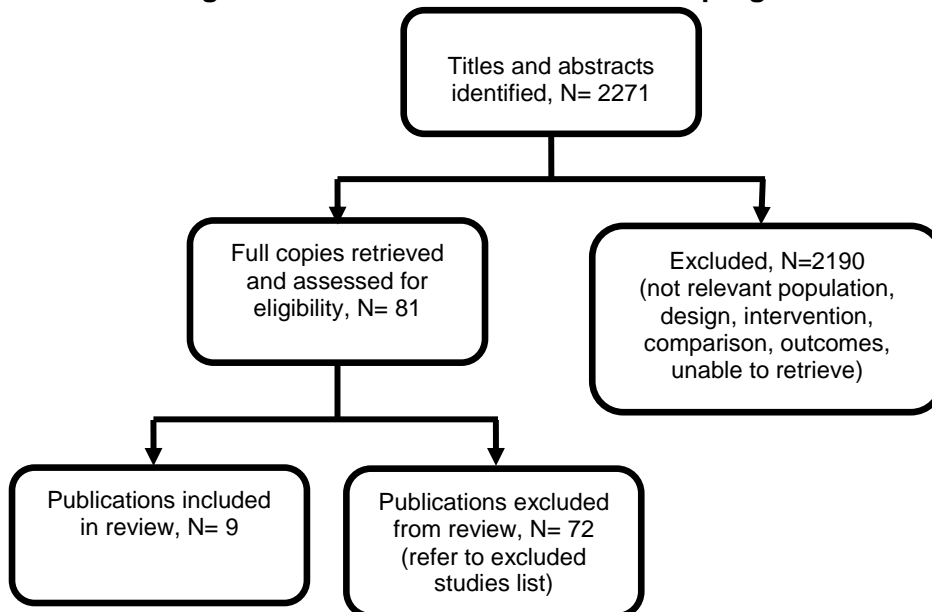
Figure 6: Flow diagram of clinical article selection for MRI and prognosis review





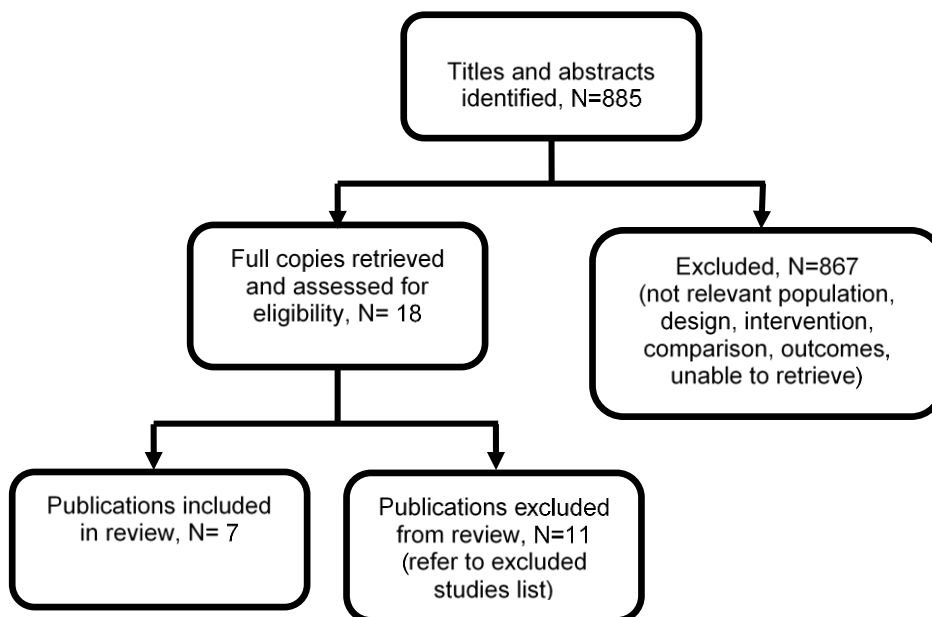
## F.7<sub>1</sub> Prognosis for walking, talking and life expectancy

Figure 7: Flow diagram of clinical article selection for prognostic indicators review



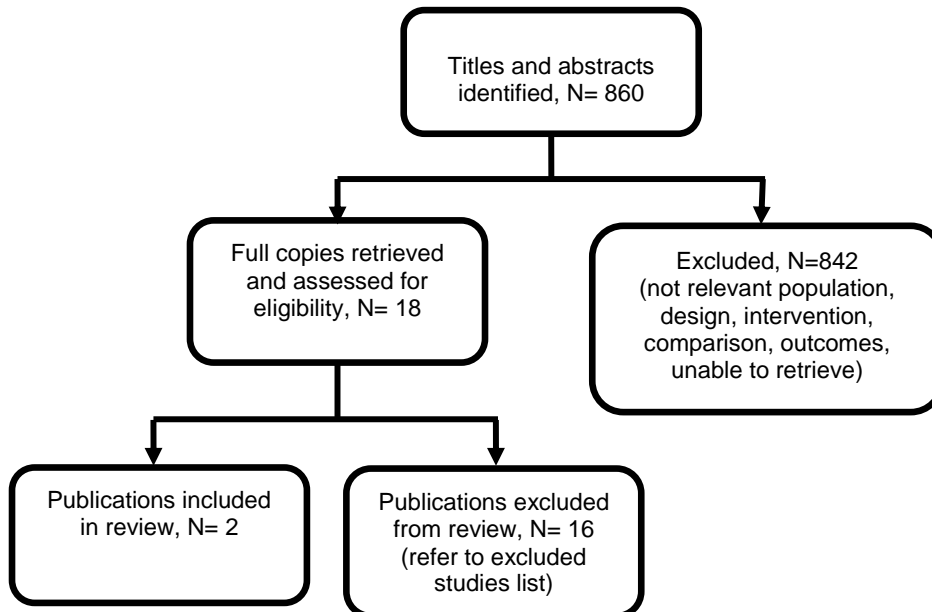
## F.8<sub>1</sub> Information and support

Figure 8: Flow diagram of clinical article selection for information and support review



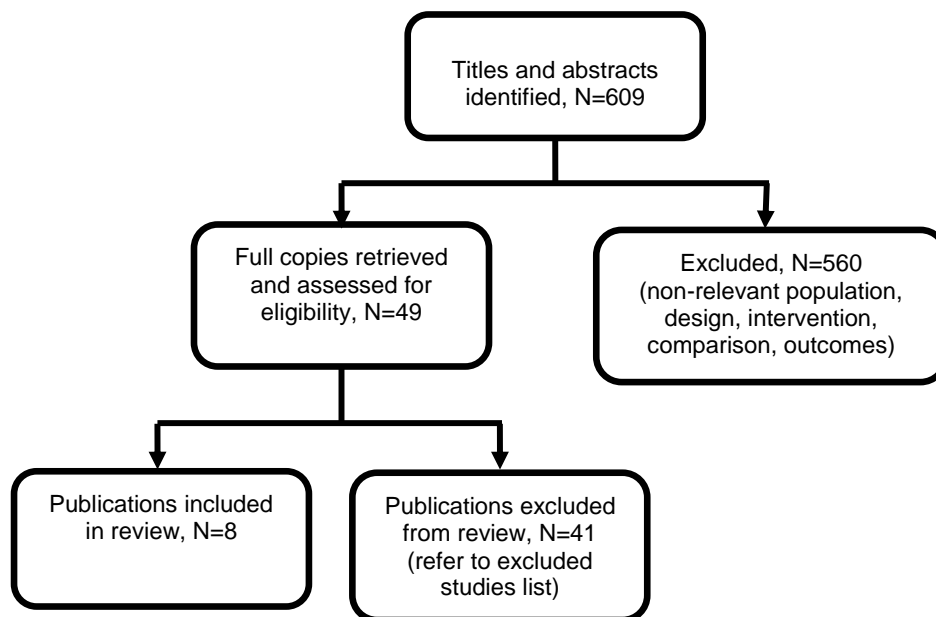
## F.9<sub>1</sub> Assessment of eating, drinking and swallowing difficulties

Figure 9: Flow diagram of clinical article selection or assessment of eating, drinking and swallowing review



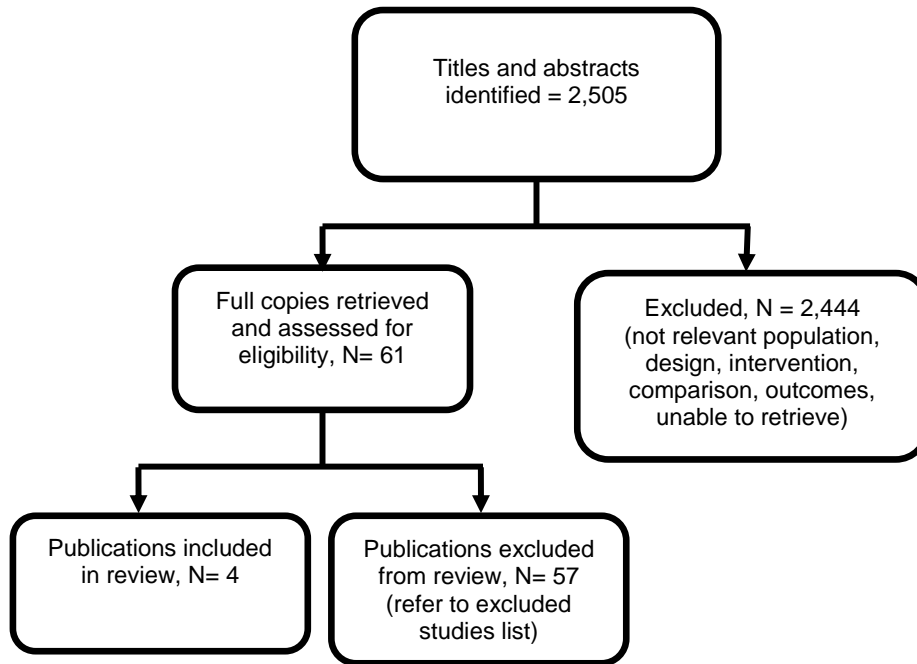
## F.10<sub>1</sub> Management of eating, drinking and swallowing difficulties

Figure 10: Flow diagram of clinical article selection for saliva control review



## F.11<sub>1</sub> Optimising nutritional status

Figure 11: Flow diagram of clinical article selection for optimising nutrition in cerebral palsy



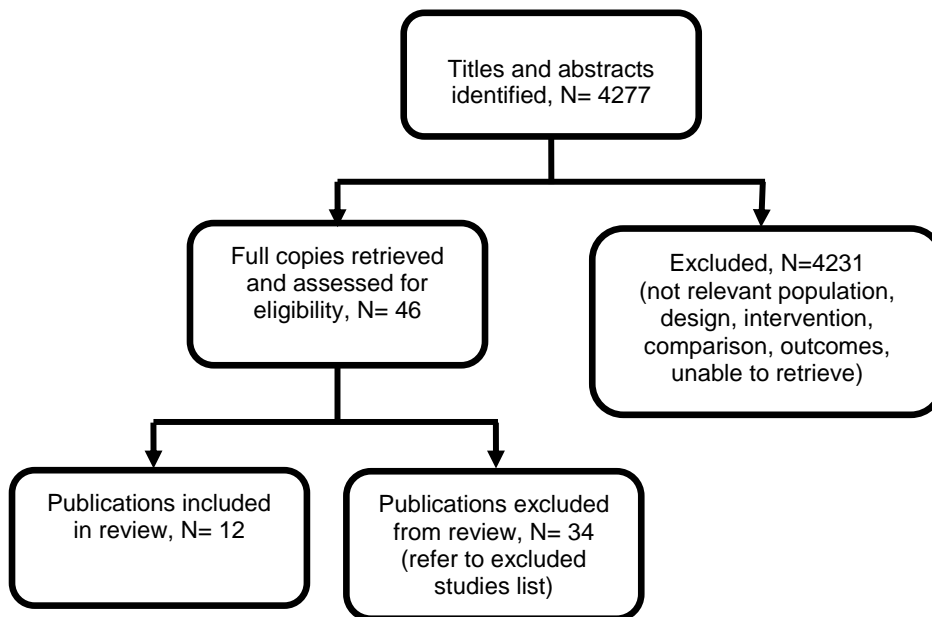
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## F.12<sub>1</sub> Improving speech, language and communication: Speech <sub>2</sub> intelligibility

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<sub>4</sub> **Figure 12:** Flow diagrams of clinical article selection for speech and language  
<sub>5</sub> therapy review

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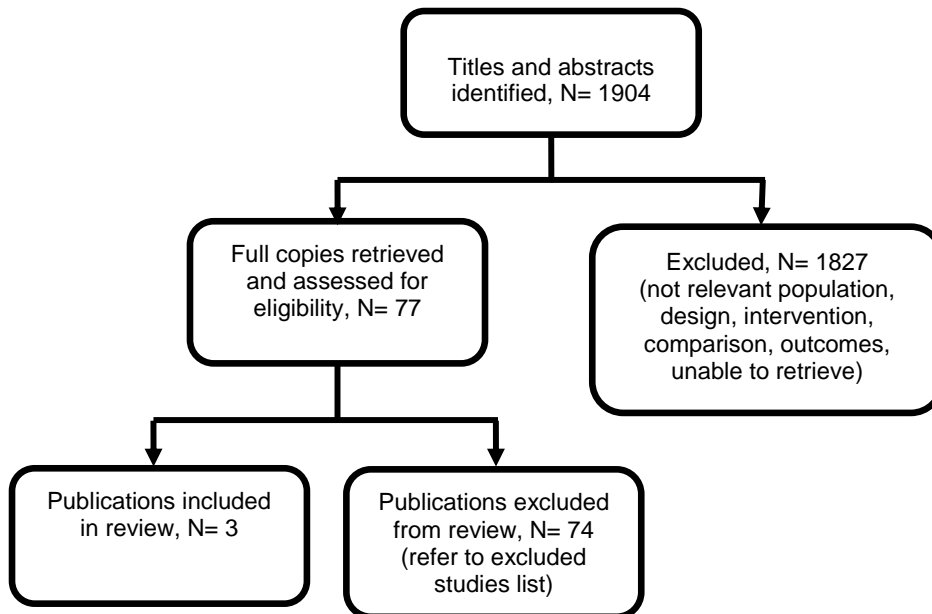
<sub>13</sub>

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## F.13<sup>1</sup> Improving speech, language and communication: 2 Communication systems

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Figure 13: Flow diagram of clinical article selection for communication systems review



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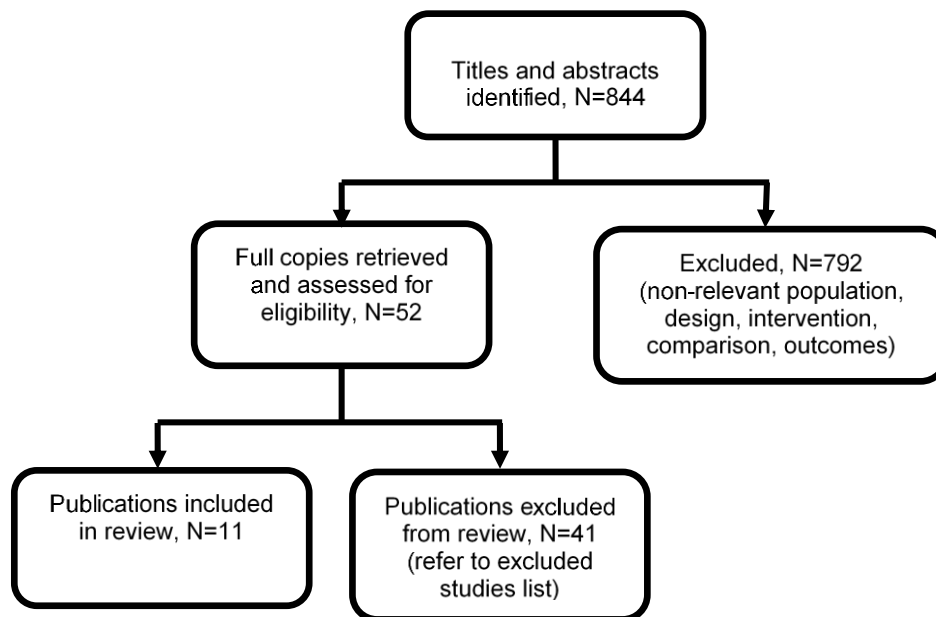
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## F.14<sub>1</sub> Managing saliva control

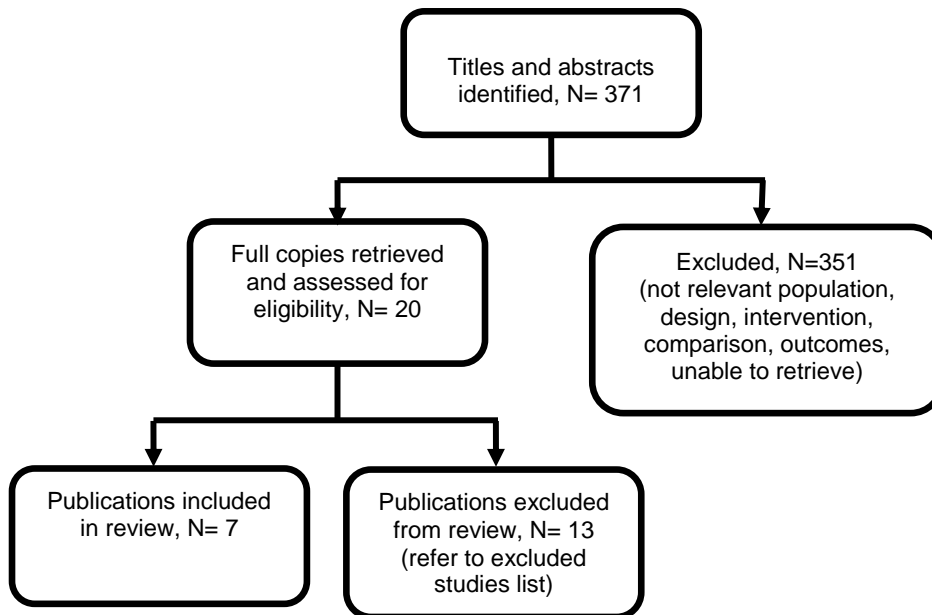
Figure 14: Flow diagram of clinical article selection for saliva control review





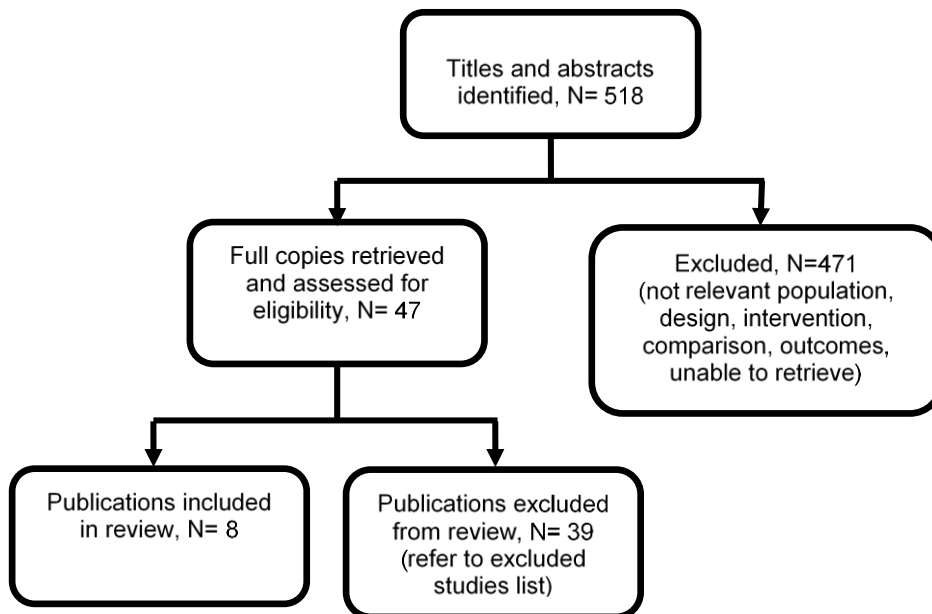
## F.15<sub>1</sub> Risk factors for low bone mineral density

Figure 15: Flow diagram of clinical article selection BMD/fractures risk factors review



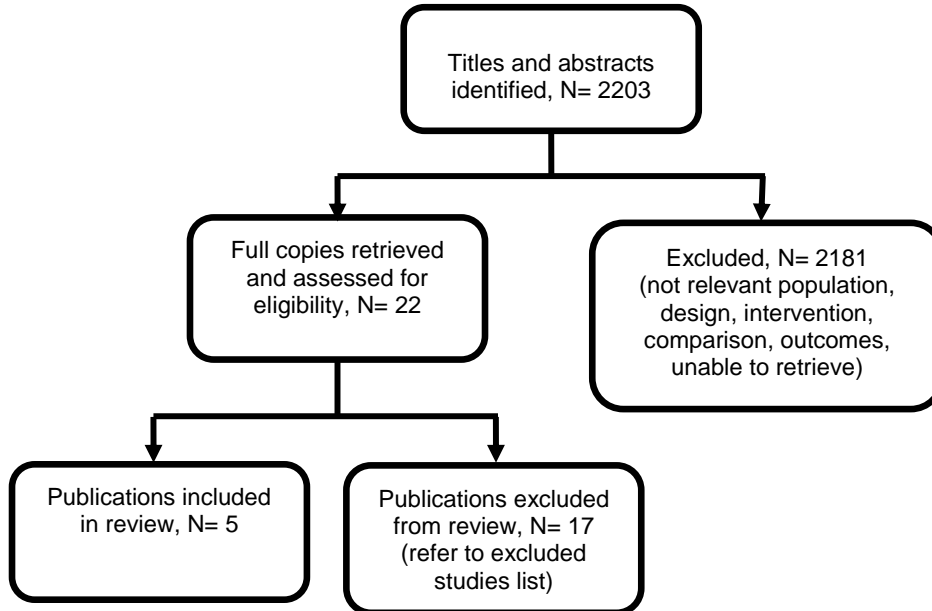
## F.16<sub>1</sub> Prevention of reduced bone mineral density

Figure 16: Flow diagram of clinical article selection for prevention of reduced bone mineral density review



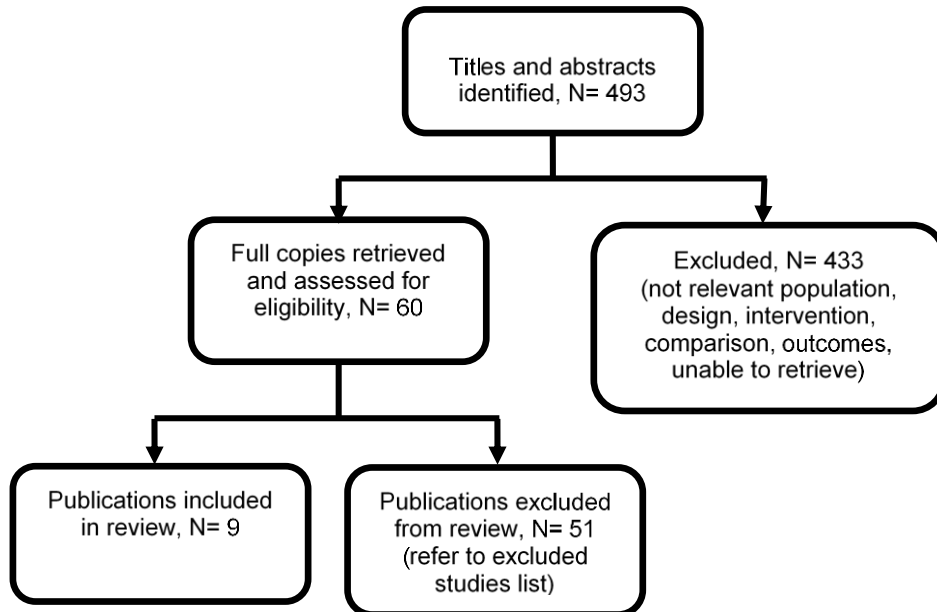
## F.17<sub>1</sub> Assessment of pain, distress and discomfort and sleep 2 disturbance

Figure 17: Flow diagram of clinical article selection for assessment of pain, distress, discomfort and sleep disturbances



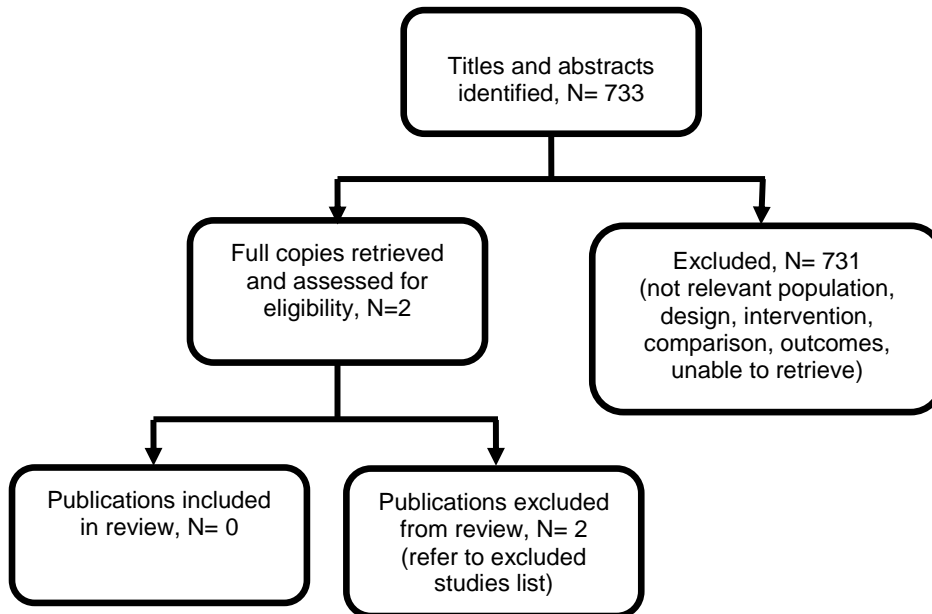
## F.18<sub>1</sub> Causes of pain, discomfort, distress, and sleep disturbance

**Figure 18:** Flow diagram of clinical article selection for pain and sleep causes review



## F.19<sub>1</sub> Management of pain, distress and discomfort

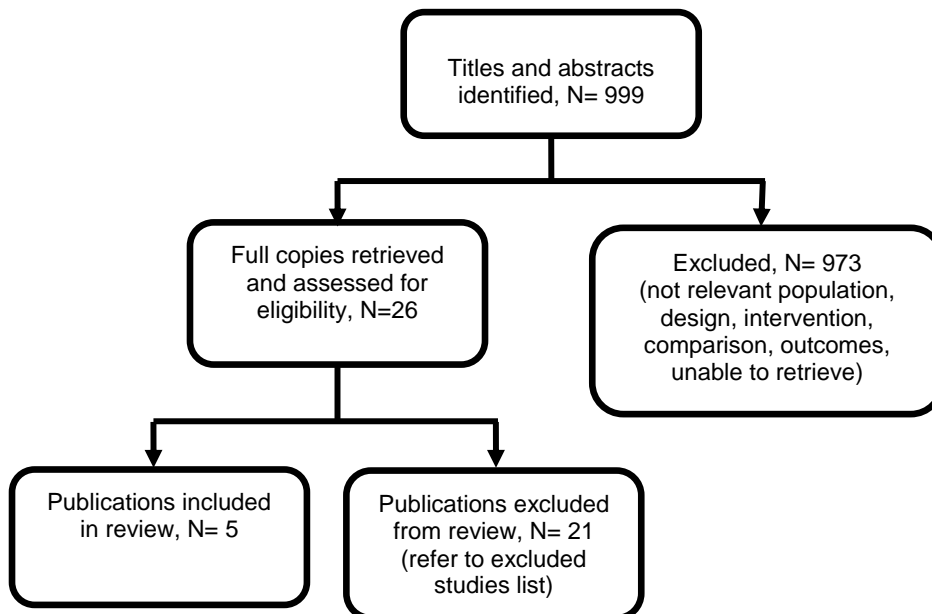
Figure 19: Flow diagram of clinical article selection for managing pain and discomfort review



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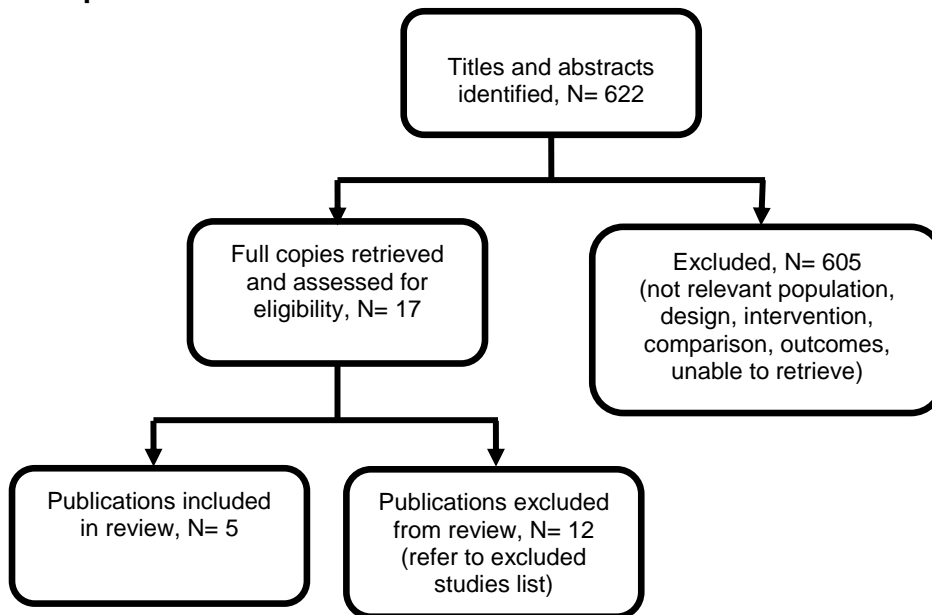
## F.20<sub>1</sub> Management of sleep disturbances

Figure 20: Flow diagram of clinical article selection for managing sleep disturbances evidence review



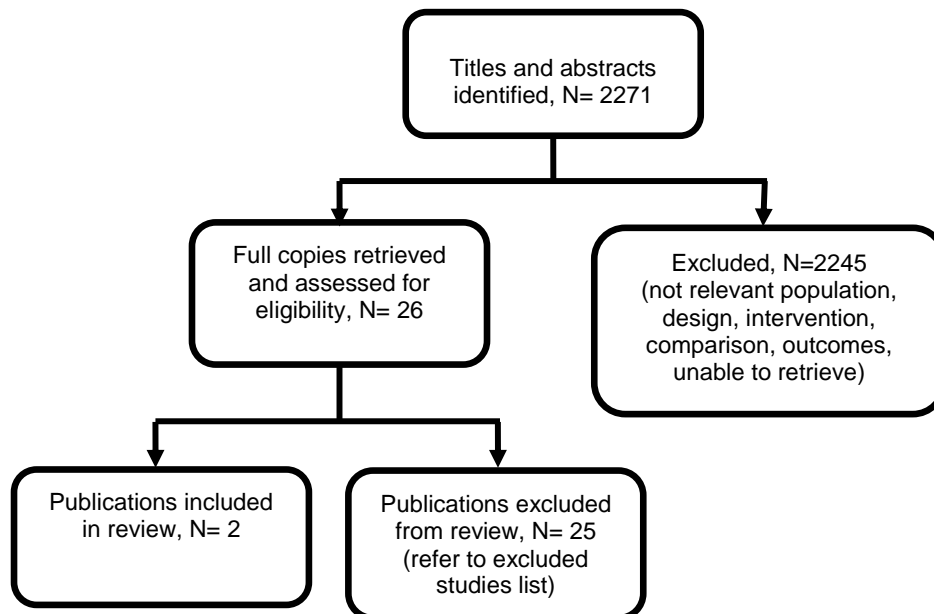
## F.21<sub>1</sub> Assessment of mental health problems

Figure 21: Flow diagram of clinical article selection assessment of mental health problems



## F.22<sub>1</sub> Management of mental health problems

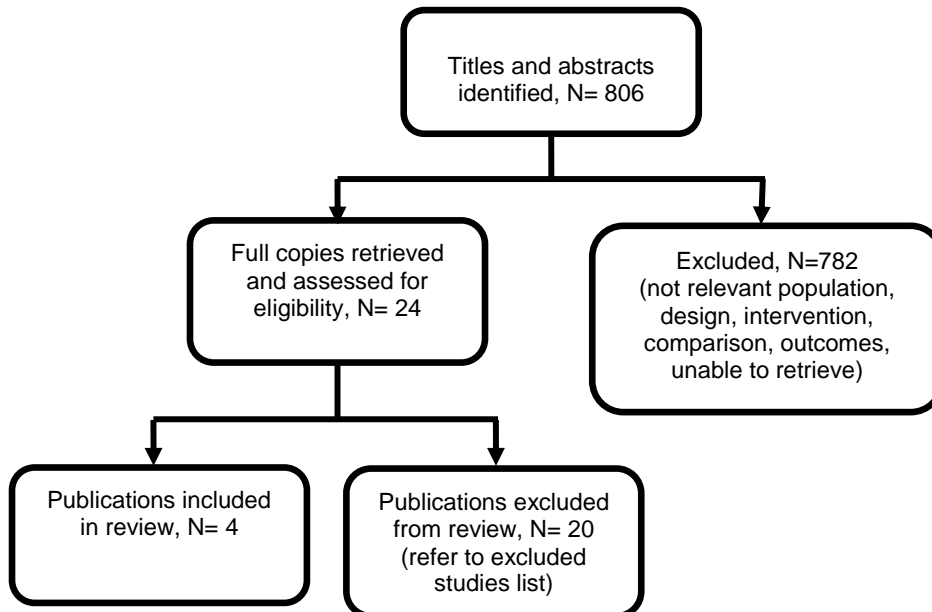
Figure 22: Flow diagram of clinical article selection for management of mental health problems





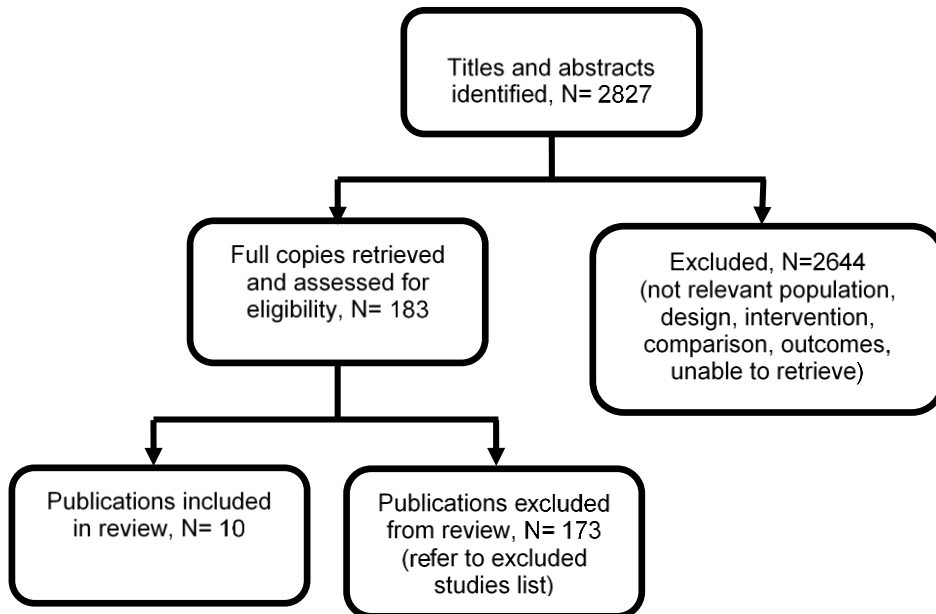
## F.23<sub>1</sub> Management of sensory and perceptual difficulties

Figure 23: Flow diagram of clinical article selection for management of sensory and perceptual difficulties review



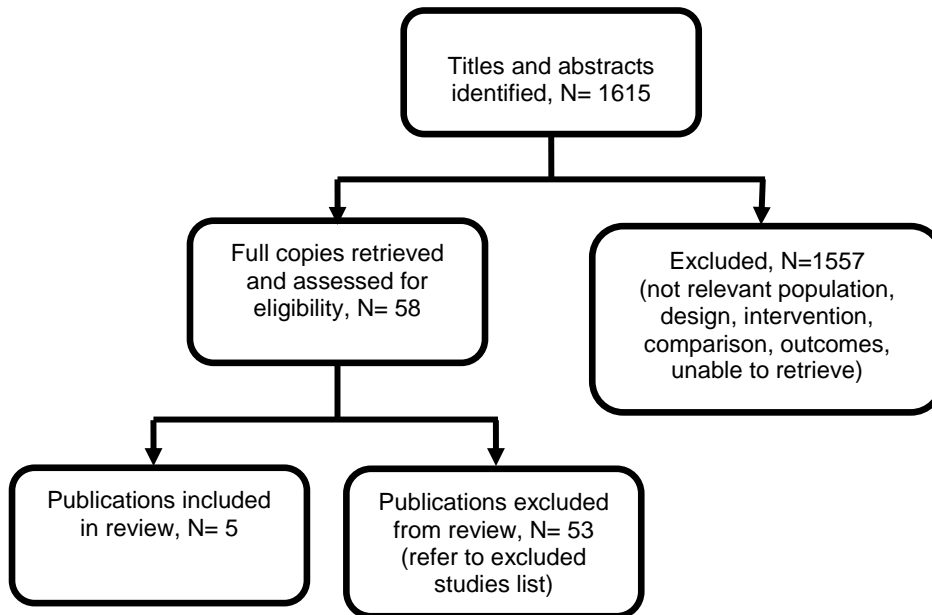
## F.24<sub>1</sub> Other comorbidities in cerebral palsy

Figure 24: Flow diagram of clinical article selection for other comorbidities in cerebral palsy review



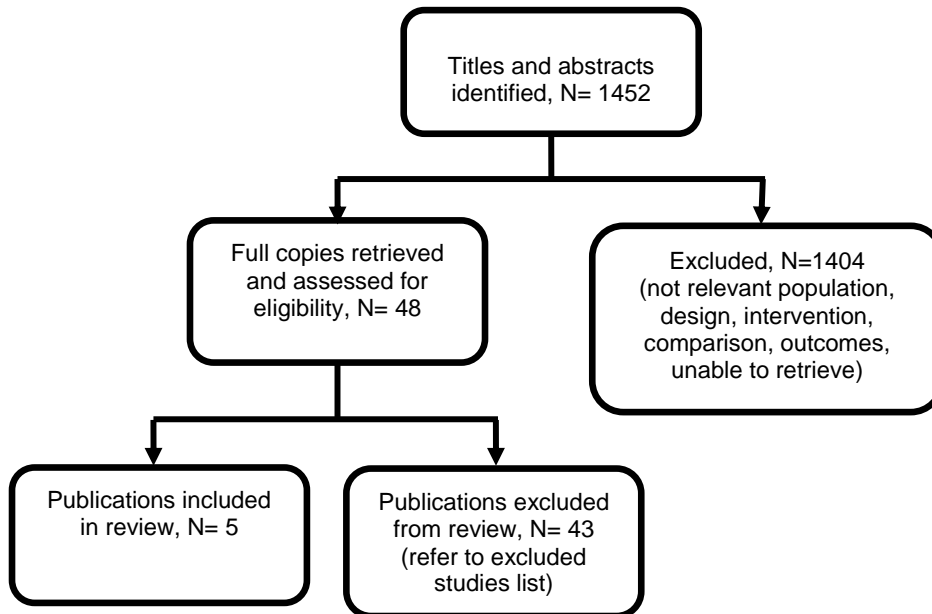
## F.25<sub>1</sub> Social care needs

Figure 25: Flow diagram of clinical article selection for social care needs review



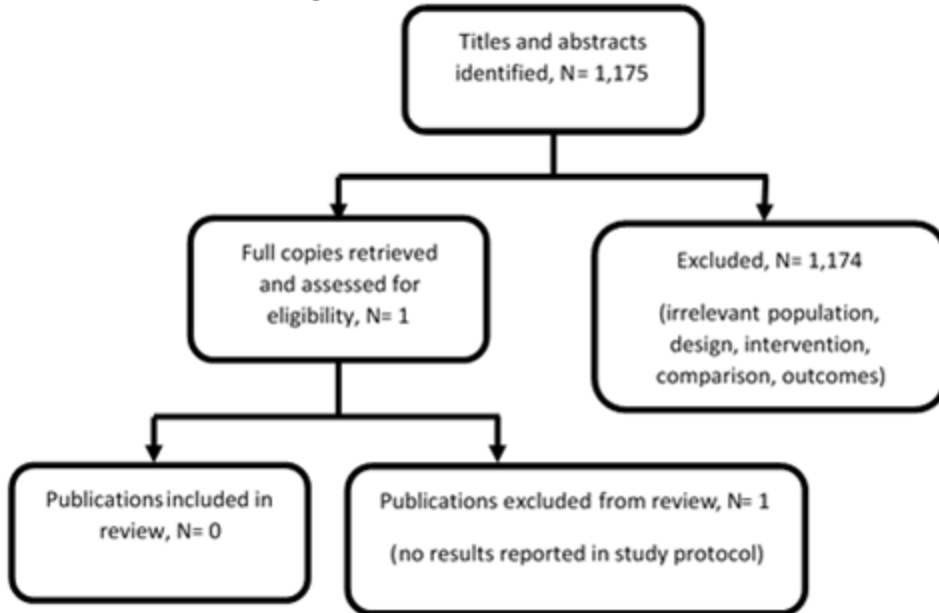
## F.26<sub>1</sub> Transition to adult services

Figure 26: Flow diagram of clinical article selection for transition to adult services review



## F.27<sub>1</sub> Health economics

Figure 27: PRISMA diagram of selection for economic evaluations



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# 1 **Appendix G: Health Economics**

2 These can be found in a separate document.

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## 1 **Appendix H: GRADE Tables**

### **H.1.2 Risk factors**

3 Not applicable for this review

### **H.2.4 Causes of cerebral palsy**

5 Not applicable for this review

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## H.3.1 Clinical and developmental manifestations of cerebral palsy

2 Table 1: Accuracy of clinical and developmental manifestations to predict cerebral palsy in infants under 8 months

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
<b>Abnormality of movement</b>														
<b>Quality of fidgety movement defined according to Prechtl, assessed by General Movement Assessment at 10 – 18 weeks post-term. Reference test: Neurological outcome at 2 years, assessed by MDT (including MRI/CT scans).</b>														
1 (Adde, 2007)	prosp cohort	serious <sup>1</sup>	no serious indirectness	none	n = 25 (n = 17 preterm, n = 8 term) <sup>2</sup>	N = 49	100% (68.9 – 100)	98.3 (95 – 100)	90.9 (58.7 – 98.5)	100 (93.98 – 100)	NR	10/25 high risk diagnosed <sup>3</sup> , 0/49 low risk.	MODERATE	CRITICAL
<b>Infant motor profile (IMP) at 4 months. Reference test: Hempel assessment at 18 months corrected age</b>														
1 (Heinman 2011)	prosp cohort	very serious <sup>4, 5</sup>	no serious indirectness	none	n = 59 preterm	n = 30 term	NR	NR	NR	NR	0.89 (0.80 – 0.98)	8/59 preterm, 0/30 term <sup>6</sup>	LOW	CRITICAL
<b>Infant motor profile (IMP) at 6 months. Reference test: Hempel assessment at 18 months corrected age</b>														
1 (Heinman 2011)	prosp cohort	very serious <sup>4, 5</sup>	no serious indirectness	none	n = 59 preterm	n = 30 term	NR	NR	NR	NR	0.91 (0.75 – 1.00)	8/59 preterm <sup>6</sup>	LOW	CRITICAL
<b>Quality of writhing movements (GMA) at 1 month. Reference test: Neurodevelopmental outcome (Touwen's criteria and Bayley scale) at 2 years</b>														



Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
1 (Brogn a2013)	prosp cohort	very serious <sup>7,8</sup>	no serious indirectness	none	N=574	NA	100%	86%	NR	NR	NR	22/574	LOW	CRITICAL
<b>Quality of fidgety movements (GMA) at 3 months. Reference test: Neurodevelopmental outcome (Touwen's criteria and Bayley scale) at 2 years</b>														
1 (Brogn a2013)	prosp cohort	very serious <sup>7,8</sup>	no serious indirectness	none	N=574	NA	100%	97%	NR	NR	NR	22/574	LOW	CRITICAL
<b>Quality of fidgety movements (GMA) at 12 weeks corrected age. Reference test: Neurological examination at 12 months (in line with Amiel-Tison and Gosselin, Peabody Developmental Motor Scale and Alberta Infant Motor Scale</b>														
1 (Burger 2011)	prosp cohort	very serious <sup>7,9</sup>	no serious indirectness	none	N=110	NA	89% (95% CI 51.75-99.72)	100% (95% CI 96.41-100)	100% (95% CI 63.06-100)	99% (95% CI 94.66-99.98)	NR	9/110	LOW	CRITICAL
<b>Quality of fidgety movements (GMA) at 3 months. Reference test: Neurological examination (Illingworth) at 2 years.</b>														
1 (Semeciglencki 2003)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=120	N=112	94%	92%	81%	98%	NR	High risk 32/120	MODERATE	CRITICAL
<b>Quality of fidgety movements (GMA) at different time points. Reference test: Neurological outcome (Griffiths scale) at 2-3 years</b>														

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
1 (Ferrari 2002)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=93 enrolled	NA <37wks	100	38	63	100	97.4	44/93	MODERATE	CRITICAL
					N=83	38-42wks	100	41	63	100				
					N=79	43-46wks	100	53	55	100				
					N=70	47-60wks	100	82	86	100				
					N=84									
<b>Cramped synchronised character of general movements at different time points. Reference test: Neurological outcome (Griffiths scale) at 2-3 years</b>														
1 (Ferrari 2002)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=93 enrolled	NA <37wks	46	92	87	62	NR	44/93	MODERATE	CRITICAL
					N=83	38-42wks	65	97	96	73				
					N=79	43-46wks	79	100	100	84				
					N=70	47-60wks	77	100	100	80				
					N=84									
<b>Neurological examination at different time points. Reference test: Neurological outcome (Griffiths scale) at 2-3 years</b>														
1 (Ferrari 2002)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=93 enrolled	NA <37wks	58	68	89	95	NR	44/93	MODERATE	CRITICAL
					N=83	38-42wks	45	63	52	70				
					N=79	43-46wks	54	66	67	77				
					N=70	47-60wks	48	65	84	93				
					N=84									
<b>Neurological examination (Amiel-Tison and Grenier) at 3 months. Reference test: Neurological outcomes (Illingworth) at 2 years</b>														
1 (Semeglene)	prosp cohort	serious <sup>7</sup>	no serious	none	N=120	N=112	97%	43%	44%	97%	NR	High risk 32/120 Low risk 35/112	MODERATE	CRITICAL

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
cki (2003)			indirectness											
<b>Abnormal muscle tone at 11-16 weeks assessed by obligatory asymmetric tonic neck (ATN). Reference test: Towne's neurological examination at 7-11 years</b>														
<b>Normal FM's, smooth and variable motor repertoire at 11-16 weeks</b>														
1 (Bruggink 2008/2009)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=21	NA	NA	95.24% (95% CI 76.18% - 99.88%)	0% (95% CI 0-97.5%)	100% (95% CI 83.16-100%)	NR	0/21	MODERATE	CRITICAL
<b>Normal FM's, abnormal motor repertoire at 11-16 weeks</b>														
1 (Bruggink 2008/2009)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=28	NA	100% (95% CI 2.5-100%)	74.07% (95% CI 53.72% - 88.89%)	12.50% (95% CI 0.32-52.65%)	100% (95% CI 83.16-100%)		1/28	MODERATE	CRITICAL
<b>Abnormal FM's, abnormal motor repertoire at 11-16 weeks</b>														
1 (Bruggink 2008/2009)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=11	NA	NA	90.91% (95% CI 58.72% - 99.77%)	0% (95% CI 0-97.5%)	100% (95% CI 69.15-100%)		0/11	MODERATE	CRITICAL

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
<b>Absent FM's, abnormal motor repertoire at 11-16 weeks</b>														
1 (Bruggink 2008/2009)	prosp cohort	serious <sup>7</sup>	no serious indirectness	none	N=73	NA	50% (95% CI 21.09-78.91%)	100% (95% CI 2.5%-100%)	100% (95% CI 54.07-100%)	14.29% (95% CI 0.36-57.87%)		6/13	MODERATE	CRITICAL
<b>Delayed sitting</b>														
<b>Sitting without support (population norms, white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=61 (35%)	NA	93%	71%	52%	NR	NR	NR	VERY LOW	CRITICAL
<b>Sitting without support (population norms, non-white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=121 (65%)	NA	88%	76%	38%	NR	NR	NR	VERY LOW	CRITICAL
<b>Sitting without support (race norms, white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=61 (35%)	NA	93%	75%	56%	NR	NR	NR	VERY LOW	CRITICAL
<b>Sitting without support (race norms, non-white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=121 (65%)	NA	94%	65%	31%	NR	NR	NR	VERY LOW	CRITICAL

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
<b>Sitting without support (delay cut offs, population norms)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=170	N=381 Delay: 12.5% 25% 37.5% 50%	100% 90% 84% 77%	60% 74% 85% 94%	36% 44% 55% 73%	NR NR NR NR	NR NR NR NR	NR NR NR NR	VERY LOW	CRITICAL
<b>Come to a sitting position (population norms, white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=61 (35%)	NA	87%	67%	48%	NR	NR	NR	VERY LOW	CRITICAL
<b>Come to a sitting position (population norms, non-white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=121 (65%)	NA	88%	82%	45%	NR	NR	NR	VERY LOW	CRITICAL
<b>Come to a sitting position (race norms, white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>10</sup>	none	N=61 (35%)	NA	87%	67%	48%	NR	NR	NR	VERY LOW	CRITICAL
<b>Come to a sitting position (race norms, non-white very preterm infants)</b>														
1 (Allen)	case control	serious <sup>7</sup>	serious	none	N=121 (65%)	NA	94%	68%	33%	NR	NR	NR	VERY LOW	CRITICAL

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
1992/1994)			indirectness <sup>10</sup>											
<b>Come to a sitting position (delay cut offs, population norms)</b>														
1 (Allen 1992/1994)	case control	serious <sup>7</sup>	serious indirectness <sup>9</sup>	none	N=167	N=381 Delay: 12.5% 25% 37.5% 50%	97% 87% 87% 87%	55% 77% 83% 87%	33% 47% 54% 61%	NR NR NR NR	NR NR NR NR	NR NR NR NR	VERY LOW	CRITICAL

- 1 1 evidence was downgraded by 1 due to reference test (neurological assessment at 2 years) undertaken with knowledge of index test results, this may lead to bias in interpretation of reference test.
- 2 2 high risk classified as pre-term or if one or more perinatal risk factor present including: perinatal stroke, perinatal asphyxia, intra/peri-ventricular haemorrhage, severe hypoglycaemia and e.coli sepsis, very low birth weight and/or gestational age, bronchopulmonary dysplasia
- 3 3 diagnoses were: 4 with quadriplegia, 4 with right hemiplegia, 1 with left hemiplegia and 1 with unspecified cp.
- 4 4 evidence was downgraded by 1 due to selection bias for term infants: recruited through colleagues and families.
- 5 5 evidence was downgraded by 1 due to unclear if physicians who carried out reference test also carried out index test.
- 6 6 diagnoses were: 3 unilateral spastic cerebral palsy, 5 bilateral spastic cerebral palsy
- 7 7 evidence was downgraded by 1 due to evidence was downgraded by 1 due to attrition bias; 95% ci not reported and/or missing data. These have been calculated where possible.
- 8 8 evidence was downgraded by 1 due to unclear if assessor of the reference test was blinded.
- 9 9 evidence was downgraded by 1 due to 'suspect' infants were removed from analysis which was not described in the methods. Sensitivity analysis was carried out including them in the normal and abnormal groups.
- 10 10 evidence was downgraded by 1 due to controls are from a wider population.

1 Table 5: Accuracy of clinical and developmental manifestations to predict Cerebral Palsy in infants over 8 months

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
<b>Infant motor profile (IMP) at 10 months. Reference test: Hempel assessment at 18 months corrected age</b>														
1 (Heinman 2011)	prosp cohort	very serious <sup>1,2</sup>	no serious indirectness	none	n = 59 preterm	n = 30 term	NR	NR	NR	NR	0.99 (0.96 – 1.00)	8/59 preterm, 0/... term <sup>3</sup>	LOW	CRITICAL
<b>Infant motor profile (IMP) at 12 months. Reference test: Hempel assessment at 18 months corrected age</b>														
1 (Heinman 2011)	prosp cohort	very serious <sup>1,2</sup>	no serious indirectness	none	n = 59 preterm	n = 30 term	NR	NR	NR	NR	0.99 (0.96 – 1.00)	8/59 preterm <sup>3</sup>	LOW	CRITICAL
<b>Walking</b>														
<b>Walking at 18-24 months (population norms, white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>4</sup>	serious indirectness <sup>5</sup>	none	N=61 (35%)	NA	100%	75%	58%	NR	NR	NR	VERY LOW	CRITICAL
<b>Walking at 18-24 months (population norms, non white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>4</sup>	serious indirectness <sup>5</sup>	none	N=121 (65%)	NA	94%	80%	44%	NR	NR	NR	VERY LOW	CRITICAL
<b>Walking at 18-24 months (race norms, non white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>4</sup>	serious indirectness <sup>5</sup>	none	N=61 (35%)	NA	100%	75%	58%	NR	NR	NR	VERY LOW	CRITICAL

Quality assessment					Summary of findings								Quality	Importance
					Number		Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other	High risk	Low/no risk	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
<b>Walking at 18-24 months (race norms, non white very preterm infants)</b>														
1 (Allen 1992/1994)	case control	serious <sup>4</sup>	serious indirectness <sup>5</sup>	none	N=121 (65%)	NA	94%	73%	37%	NR	NR	NR	VERY LOW	CRITICAL
<b>Walking by 18 months (not adjusted for gestational age)</b>														
1 (Johnson 1990)	prosp cohort	serious <sup>4</sup>	no serious indirectness	none	N=4275	NA	86%	92%	16%	NR	NR	77/4275	MODERATE	CRITICAL

- 1 1 evidence was downgraded by 2 due to Selection bias for term infants: recruited through colleagues and families.
- 2 2 evidence was downgraded by 2 due to Reference standard – unclear if interpreted without knowledge of index test results
- 3 3 diagnoses were: 3 unilateral spastic CP, 5 bilateral spastic CP
- 4 4 evidence was downgraded by 1 due to evidence was downgraded by 1 due to Attrition bias; 95% CI not reported and/or missing data. These have been calculated where possible.
- 5 5 controls are from a wider population

7 **Table 6: Accuracy of manifestations in predicting Cerebral Palsy in infants and children in the primary care setting or mixed (low risk and high risk) population.**

Quality assessment					Summary of findings							Quality	Importance	
					Number	Diagnostic accuracy					True positive			
No of studies	Design	Risk of bias	Indirectness	Other		Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %			
<b>Definitely abnormal general movements<sup>1</sup>, assessed by video recording of spontaneous motility in the supine position for at least 5 minutes at corrected age of 3 months  follow up until 3 years 9 months</b>														



Quality assessment					Summary of findings							Quality	Importance
No of studies	Design	Risk of bias	Indirectness	Other	Number	Diagnostic accuracy					True positive		
						Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %		
1 (Bouws tra 2010)	prosp. cohort	no serious risk of bias	no serious indirectness	none	n = 455	67% (13 – 98)	97% (94 – 98)	12% (2 – 38)	100% (99 – 100)	NR	3/455 <sup>2</sup>	HIGH	CRITICAL
<b>Neonatal neurological examination adapted from Prechtl 1977 with added predictors<sup>3</sup> at term or by latest 5 days after birth. Reference test: Bayley Scale of Infant Development (BSID) (Bayley 1969)</b>													
1 (Wolf, 1997)	prosp cohort	no serious risk of bias	serious <sup>4</sup>	none	N = 142	73.9 (51.6 – 89.7)	98.1 (93.3 – 99.7)	89.5 (66.8 – 98.4)	94.5 (88.4 – 97.9)	NR	23/142 <sup>5</sup>	MODERATE	CRITICAL

- 1 1 definitely abnormal general movements characterised by a serious reduction in movement variation and complexity  
 2 2 2 with bilateral spastic CP, 1 with unilateral left-sided spastic CP.  
 3 3 Contains predictors including variation of movement, fixation, fluctuating tone, nasogastric tube feeding, irritability and consolability.  
 4 4 Study conducted in a less resource rich country (Zimbabwe).  
 5 5 16 with quadriplegia, 2 with diplegia, 1 with hemiplegia and 4 with choreoathetosis

6 Table 7: Association between manifestation and cerebral palsy diagnosis

Quality assessment					Summary of findings				Quality	Importance
No of studies	Design	Risk of bias	Indirectness	Other	Number		Proportion of those with CP	Proportion of true positive with manifestation		
					High risk	Low/no risk				
<b>Tone abnormalities, assessed by Amiel-Tison (1986) method at 3, 6, 9 and 12 months</b>										
1 (Chaudhari, 2010)	prosp cohort	serious <sup>2</sup>	serious <sup>1</sup>	none	n = 190 <sup>3</sup>	n = 49 <sup>4</sup>	10/190 high risk	100%, all had tone abnormalities <sup>5</sup>	VERY LOW	CRITICAL

Quality assessment					Summary of findings				Quality	Importance
No of studies	Design	Risk of bias	Indirectness	Other	Number		Proportion of those with CP	Proportion of true positive with manifestation		
					High risk	Low/no risk				
<b>General Movement assessment classification of 'definitely abnormal' with Likert score = 2 at fidgety GM age (8 – 17 weeks post term)</b>										
1 (Groen 2005)	prosp cohort	no serious risk of bias	no serious indirectness	none	n = 24	n = 28	8/24 high risk	3/8	MODERATE	CRITICAL
<b>General Movement assessment classification of 'definitely abnormal' with Likert score = 3 at fidgety GM age (8 – 17 weeks post term)</b>										
1 (Groen 2005)	prosp cohort	no serious risk of bias	no serious indirectness	none	n = 24	n = 28	8/24 high risk	4/8	MODERATE	CRITICAL
<b>General Movement assessment classification of 'mildly abnormal' with Likert score = 5 at fidgety GM age (8 – 17 weeks post term)</b>										
1 (Groen 2005)	prosp cohort	no serious risk of bias	no serious indirectness	none	n = 24	n = 28	8/24 high risk	1/8	MODERATE	CRITICAL
<b>Cramped synchronised general movements at writhing GM age (38 – 47 weeks post term)</b>										
1 (Groen 2005)	prosp cohort	no serious risk of bias	no serious indirectness	none	n = 24	n = 28	8/24 high risk	7/8 (significant association p = 0.001) <sup>6</sup>	MODERATE	CRITICAL
<b>Jerky and stiff movement at writhing GM age (38 – 47 weeks post term)</b>										
1 (Groen 2005)	prosp cohort	no serious risk of bias	no serious indirectness	none	n = 24	n = 28	8/24 high risk	4/8	MODERATE	CRITICAL
<b>Predominantly jerky movement at fidgety GM age (8 – 17 weeks post term)</b>										
1 (Groen 2005)	prosp cohort	no serious risk of bias	no serious indirectness	none	n = 24	n = 28	8/24 high risk	4/8	MODERATE	CRITICAL

- 1 1. study conducted in a less resource rich country (India).
- 2 2. evidence was downgraded by 1 due to controls are not age matched.
- 3 3. high risk: included low birthweight, low gestational age, seizures, apnea, hypoxic ischemic encephalopathy, haemorrhage, hyper bilirubimia, respiratory distress.

- 1 4 normal: full term with normal antenatal, natal and postnatal course enrolled during same period.
- 2 5. 4 had hypertonia, 6 had hypotonia
- 3 6 fisher's test

4 **Table 8: Accuracy of tools to identify clinical and developmental manifestations in predicting Cerebral Palsy in high risk/preterm infants and children**

Quality assessment					Summary of findings							Quality	Importance
					Number	Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other			Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %	
<b>Early Motor Pattern Profile (EMPP) at 6 months. Reference: Motor outcome at 36 months*</b>													
1 (Morgan 1996)	prosp. cohort	serious <sup>1</sup>	no serious indirectness	none	n = 1171	87.13 (81.71-91.42)	97.83 (96.71-98.65)	89.34 (84.17-93.28)	97.33 (96.11-98.25)	NR	176/1171	MODERATE	CRITICAL
<b>Early Motor Pattern Profile (EMPP) at 12 months. Reference: Motor outcome at 36 months*</b>													
1 (Morgan 1996)	prosp. cohort	serious <sup>1</sup>	no serious indirectness	none	n = 942	91.53 (86.41-95.18)	97.91 (96.63-98.80)	91.01 (85.81-94.77)	98.04 (96.78-98.90)	NR	162/942	MODERATE	CRITICAL
<b>Bayley Scales of Infant and Toddler Development (Bayley-III) at 2 years, Cut off of -1SD. Reference: Movement Assessment Battery for Children-second edition (MABC-2) at 4 years</b>													
1 (Spittle 2013)	prosp cohort	no serious risk of bias	no serious indirectness	none	N=120 eligible N =96 with 4 year follow up	83 (36-100)	94 (87-98)	46 (17-77)	99 (94-100)	NR	6/96	HIGH	CRITICAL
<b>Bayley Scales of Infant and Toddler Development (Bayley-III) at 2 years, Cut off of -2SD. Reference: Movement Assessment Battery for Children-second edition (MABC-2) at 4 years</b>													

Quality assessment					Summary of findings							Quality	Importance
					Number	Diagnostic accuracy					True positive		
No of studies	Design	Risk of bias	Indirectness	Other			Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	AUC (95% CI)	Proportion / %	
1 (Spittle 2013)	prosp cohort	no serious risk of bias	no serious indirectness	none	N=120 eligible N =96 with 4 year follow up	67 (22-96)	100 (96-100)	100 (40-100)	98 (93-100)	NR	6/96	HIGH	CRITICAL

1 1 attrition bias; 95% CI not reported. These have been calculated where possible.

2 \* Motor outcome assessed by a variety of tests and classed as normal, abnormal or suspected/minimal impairment.

3

4

#### **H.4<sub>1</sub> Red flags for other neurological disorders**

2 Not applicable for this review

3

#### **H.5<sub>4</sub> MRI and identification of causes of cerebral palsy**

5 Not applicable for this review

#### **H.6<sub>6</sub> MRI and prognosis of cerebral palsy**

7 Not applicable for this review

#### **H.7<sub>8</sub> Prognosis for walking, talking and life expectancy**

9 Not applicable for this review

#### **H.8<sub>0</sub> Information and support**

11 Not applicable for this review

12

13

14

## H.9<sub>1</sub> Assessment of eating, drinking and swallowing difficulties

2 Table 2: GRADE profile for index test (clinical assessment) versus videofluoroscopy

Quality assessment						Summary of findings					Quality	Importance
No of studies	Design	Risk of bias	Indirectness	Inconsistency	Imprecision	Number	Sensitivity (95% CI)	Specificity (95% CI)	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)		
<b>Clinical assessment compared to videofluoroscopy for aspiration of fluids</b>												
1 (DeMatteo 2005)	prosp cohort	no serious risk of bias	serious <sup>1</sup>	n/a	serious <sup>2</sup>	59	92% (95% CI: 73 – 99)	46% (95% CI: 29 – 63)	1.69 (95% CI: 1.22 – 2.34) <sup>3</sup>	0.18 (95% CI: 0.05 – 0.72) <sup>3</sup>	LOW	CRITICAL
<b>Clinical assessment compared to videofluoroscopy for aspiration of solids</b>												
1 (DeMatteo 2005)	prosp cohort	no serious risk of bias	serious <sup>1</sup>	n/a	very serious <sup>4</sup>	32	33% (95% CI: 4.33 – 77.7)	65% (44.3 – 82.8)	0.96 (95% CI: 0.28 – 3.36) <sup>3</sup>	1.02 (0.54 – 1.92) <sup>3</sup>	VERY LOW	CRITICAL
<b>Clinical assessment compared to videofluoroscopy for penetration of fluids</b>												
1 (DeMatteo 2005)	prosp cohort	no serious risk of bias	serious <sup>1</sup>	n/a	serious <sup>2</sup>	68	80% (95% CI: 63.5 – 90.7)	42% (95% CI: 23.5 – 61)	1.36 (95% CI: 0.96 – 1.91) <sup>3</sup>	0.50 (95% CI: 0.23 – 1.05) <sup>3</sup>	LOW	CRITICAL
<b>Clinical assessment compared to videofluoroscopy for penetration of solids</b>												
1 (DeMatteo 2005)	prosp cohort	no serious risk of bias	serious <sup>1</sup>	n/a	very serious <sup>4</sup>	32	70% (95% CI: 35.8 – 93.3)	55% (95% CI: 32.2 – 75.6)	1.54 (95% CI: 0.84 – 2.84) <sup>3</sup>	0.55 (95% CI: 0.20 – 1.53) <sup>3</sup>	VERY LOW	CRITICAL

<sup>3</sup> 1 evidence was downgraded by one due to a mixed population of CP and other conditions. Proportion of children with CP was not reported and evidence was not stratified by

<sup>4</sup> condition.

<sup>5</sup> 2 evidence was downgraded by one due to wide confidence interval for sensitivity (width 20% – 30%)

<sup>6</sup> 3 calculated by the NGA from data available in the study.

<sup>7</sup> 4 evidence was downgraded by two due to very wide confidence interval for sensitivity (width > 30%)

1 Table 3: GRADE profile for index test (clinical assessment) versus fiberoptic endoscopic evaluation of swallowing (FEES)

Quality assessment						Summary of findings					Quality	Importance
No of studies	Design	Risk of bias	Indirectness	Inconsistency	Imprecision	Number	Sensitivity (95% CI)	Specificity (95% CI)	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)		
<b>Clinical assessment compared to FEES for aspiration of saliva</b>												
1 (Beer 2014)	retrospective cohort	no serious risk of bias	no serious indirectness	n/a	very serious <sup>1</sup>	5	67% (95% CI: 9.4 - 99.2)	50% (95% CI: 1.7 - 98.7)	1.33 (95% CI: 1.3 - 98.7) <sup>2</sup>	0.67 (95% CI: 0.1 - 5.5)	LOW	CRITICAL
<b>Clinical assessment compared to FEES for aspiration of puree</b>												
1 (Beer 2014)	retrospective cohort	no serious risk of bias	no serious indirectness	n/a	very serious <sup>1</sup>	2	100% (95% CI: 15.8 - 100)	NC <sup>3</sup>	NC <sup>3</sup>	NC <sup>3</sup>	LOW	CRITICAL
<b>Clinical assessment compared to FEES for aspiration of liquids</b>												
1 (Beer 2014)	retrospective cohort	no serious risk of bias	no serious indirectness	n/a	very serious <sup>1</sup>	2	100% (95% CI: 15.8 - 100)	NC <sup>3</sup>	NC <sup>3</sup>	NC <sup>3</sup>	LOW	CRITICAL

<sup>2</sup> 1 evidence was downgraded by two due to very wide confidence interval for sensitivity (width > 30%)

<sup>3</sup> 2 calculated by the NGA from data available in the study

<sup>4</sup> 3 not calculable due to no false negatives.

## H.10<sub>1</sub> Management of eating, drinking and swallowing difficulties

2 Table 4: GRADE profile for oral sensorimotor therapy versus routine therapy

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor treatment versus routine treatment (randomised trials)	Control	Relative (95% CI)	Absolute		
<b>Anthropometric measure-mean weight kg percentiles for age (final) (follow-up 10 weeks; Better indicated by lower values)</b>												
2 (Gisel 1995 and Gisel 1996)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	very serious <sup>3</sup>	no serious indirectness	serious <sup>4</sup>	none	21	22	-	MD 8.45 lower (11.91 to 5 lower)	VERY LOW	CRITICAL
<b>Anthropometric measure- mean weight (kg) (final) (Better indicated by lower values)</b>												
1 (Gisel 1996)	randomised trials	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	serious <sup>4</sup>	none	11	12	-	MD 2.47 lower (6.79 lower to 1.85 higher)	VERY LOW	CRITICAL
<b>Anthropometric measure-mean weight (pounds, SD) (final at 9 weeks) (Better indicated by lower values)</b>												
1 (Ottensbacher 1981)	randomised trials	very serious	no serious inconsistency	serious <sup>5</sup>	serious <sup>4</sup>	none	10	10	-	MD 9.56 lower (18.65	VERY LOW	CRITICAL



Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor treatment versus routine treatment (randomised trials)	Control	Relative (95% CI)	Absolute		
										to 0.47 lower)		
<b>Duration of mealtime (lunch or snack) - Lunch (follow-up 10 weeks; Better indicated by lower values)</b>												
2 (Gisel 1995 and Gisel 1996)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	serious <sup>6</sup>	no serious indirectness	serious <sup>4</sup>	none	21	22	-	MD 4.2 higher (0.24 lower to 8.16 higher)	VERY LOW	CRITICAL
<b>Duration of mealtime (lunch or snack) - Snack (follow-up 10 weeks; Better indicated by lower values)</b>												
1 (Gisel 1995)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	serious <sup>4</sup>	none	10	10	-	MD 2.5 lower (6.35 lower to 1.35 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD,final) - Puree (Apple sauce) (follow-up 10 weeks; Better indicated by lower values)</b>												
1 (Gisel 1995)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>7</sup>	none	10	10	-	MD 0.4 lower (2.2 lower to 1.4 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD,final) - Viscous (Raisin) (follow-up 10 weeks; Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor treatment versus routine treatment (randomised trials)	Control	Relative (95% CI)	Absolute		
1 (Gisel 1995)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>7</sup>	none	10	10	-	MD 1.3 lower (5.79 lower to 3.19 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD,final) - Viscous (gelatine) (Better indicated by lower values)</b>												
1 (Gisel 1995)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	serious <sup>4</sup>	none	10	10	-	MD 3.2 higher (1.73 lower to 8.13 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD,final) - Solid (Biscuit) (follow-up 10 weeks; Better indicated by lower values)</b>												
1study (Gisel 1995)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	serious <sup>4</sup>	none	10	10	-	MD 2.2 higher (1.53 lower to 5.93 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD,final) - Solid (Cereal ring) (follow-up 10 weeks; Better indicated by lower values)</b>												
1 (Gisel 1995)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>7</sup>	none	10	10	-	MD 9.9 lower (13.27	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor treatment versus routine treatment (randomised trials)	Control	Relative (95% CI)	Absolute		
										to 6.53 lower)		
<b>Eating time of different food textures (mean seconds, SD, change) - Puree (follow-up 10 weeks; Better indicated by lower values)</b>												
1 (Gisel 1996)	randomised trials <sup>1</sup>	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>7</sup>	none	11	12	-	MD 9.79 higher (7.15 to 12.44 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD, change) - Viscous (follow-up 10 weeks; Better indicated by lower values)</b>												
1 (Gisel 1996)	randomised trials	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>7</sup>	none	11	12	-	MD 0.35 lower (4.58 lower to 3.88 higher)	VERY LOW	CRITICAL
<b>Eating time of different food textures (mean seconds, SD, change) - Solid (follow-up 10 weeks; Better indicated by lower values)</b>												
1 (Gisel 1996)	randomised trials	very serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>7</sup>	none	11	12	-	MD 1.1 higher (4.95 lower to 7.14 higher)	VERY LOW	CRITICAL

1 1 open label randomised trial

- 1 2 the evidence was downgraded by 2 due to selection bias and performance bias
- 2 3 the evidence was downgraded by 2 due to very serious heterogeneity (Chi-squared  $p < 0.1$ , I-squared inconsistency statistic of 75%) and no plausible explanation was found with subgroup analysis
- 3 4 evidence was downgraded by one due to 95% confidence interval crossing one default MID (-0.5 to +0.5 SD)
- 4 5 majority of evidence has only 1 indirect aspect of PICO (population)
- 5 6 evidence was downgraded by 1 due to serious heterogeneity (chi-squared  $p < 0.1$ , I-squared inconsistency statistic of 50%-74.99%) and no plausible explanation was found with sensitivity analysis.
- 6 7 the evidence was downgraded by 2 due to 95% confidence interval crossing 2 default MIDs -0.5 and +0.5 SDs
- 7 8 the evidence was downgraded by 1 due to performance bias

10 Table 5: GRADE profile for ISMAR versus no ISMAR treatment

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
<b>Anthropometric measure-weight at 6 months (change) (follow-up 6 months; Better indicated by lower values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	9	8	-	MD 0.87 higher (0.2 to 1.54 higher)	VERY LOW	CRITICAL
<b>Anthropometric measure-weight at 12 months (change) (Better indicated by lower values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	10	7	-	MD 1.44 lower (1.89 to 0.99 lower)	VERY LOW	CRITICAL
<b>Anthropometric measure-height at 6 months (change) (follow-up 6 months; Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	9	8	-	MD 0.15 lower (2.06 lower to 1.76 higher)	VERY LOW	CRITICAL
<b>Anthropometric measure-height at 12 months (change) (follow-up 12 months; Better indicated by lower values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	10	7	-	MD 2.68 higher (1.21 to 4.15 higher)	VERY LOW	CRITICAL
<b>Competency in feeding (percentage) at 12 to 18 months (final) - Spoon feeding (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	no serious risk of bias	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	9	8	-	MD 5.8 lower (16.64 lower to 5.04 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 12 to 18 months (final) - Cup drinking (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	9	8	-	MD 1.9 lower (10.09 lower to	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
										6.29 higher)		
<b>Competency in feeding (percentage) at 12 to 18 months (final) - Swallowing (Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	9	8	-	MD 16 lower (32.08 lower to 0.08 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 12 to 18 months (final) - Clearing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	9	8	-	MD 15.5 lower (31.03 lower to 0.03 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (final) - Spoon feeding (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	10	7	-	MD 2.5 lower (14.97 lower to 9.97 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (final) - Cup drinking (follow-up 6 months; Better indicated by higher values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	10	7	-	MD 2.5 lower (14.97 lower to 9.97 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (final) - Swallowing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	7	-	MD 19 lower (32.66 to 5.34 lower)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (final) - Clearing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	7	-	MD 13.9 lower (24.27 to 3.53 lower)	VERY LOW	
<b>Competency in feeding (percentage) at 12 to 18 months (change) - Spoon feeding (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>2</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	9	8	-	MD 2.7 higher (2.85 lower to 8.25 higher)	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
<b>Competency in feeding (percentage) at 12 to 18 months (change) - Cup drinking (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	9	8	-	MD 3.3 higher (6.26 lower to 12.86 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 12 to 18 months (change) - Swallowing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>4</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	9	9	-	MD 3.5 lower (15.62 lower to 8.62 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 12 to 18 months (change) - Clearing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	9	8	-	MD 4 lower (15.89 lower to 7.89 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (change) - Spoon feeding (follow-up 6 months; Better indicated by higher values)</b>												



Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	10	7	-	MD 0.8 higher (6.96 lower to 8.56 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (change) - Cup drinking (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	7	-	MD 9.6 lower (14.23 to 4.97 lower)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (change) - Swallowing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	10	7	-	MD 2.2 lower (11.43 lower to 7.03 higher)	VERY LOW	IMPORTANT
<b>Competency in feeding (percentage) at 18 to 24 months (change) - Clearing (follow-up 6 months; Better indicated by higher values)</b>												
1 (Gisel 2001)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	10	7	-	MD 3.6 higher (7.96 lower to	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	ISMAR treatment versus no ISMAR treatment (cohort)	Control	Relative (95% CI)	Absolute		
										15.16 higher)		

- 1 1 the evidence was downgraded by 1 due to performance bias
- 2 2 the evidence was downgraded by 1 due to 95% confidence interval crossing 1 default MID (-0.5 to +0.5 SDs)
- 3 3 the evidence was downgraded by 2 due to 95% confidence intervals crossing 2 default MIDs (-0.5 to +0.5 SDs)

**4 Table 6: Multi-component intervention versus routine physiotherapy**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Multi-component intervention	Routine physiotherapy	Relative (95% CI)	Absolute		
<b>Physical function - Spoon feeding (follow-up 6 months; measured with: mFFA ; Better indicated by lower values)</b>												
1 (Sign 2013)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	41	40	-	MD 8.85 higher (1.55 to 16.15 higher)	LOW	IMPORTANT
<b>Physical function - Swallowing (follow-up 6 months; measured with: mFFA; Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Multi-component intervention	Routine physiotherapy	Relative (95% CI)	Absolute		
1 (Sign 2013)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	41	40	-	MD 8.4 higher (1.54 to 15.26 higher)	LOW	IMPORTANT
<b>Physical function - Drinking (follow-up 6 months; measured with: mFFA; Better indicated by lower values)</b>												
1 (Sign 2013)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	41	40	-	MD 4.13 higher (1.12 to 7.14 higher)	LOW	IMPORTANT

1 1 the evidence was downgraded by 1 due to performance bias

2 2 evidence was downgraded by one due to 95% confidence interval crossing one default MID (-0.5 to +0.5 SD)

**3 Table 7: GRADE profile for oral sensorimotor stimulations**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor therapy	Control	Relative (95% CI)	Absolute		
<b>Mouth closure (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor or therapy	Control	Relative (95% CI)	Absolute		
1 (Baghbadorani 2014)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 1.33 (SD 1.15)	VERY LOW	IMPORTANT
<b>Lip closure onto utensil (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												
1 (Baghbadorani 2014)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 0.66 (SD 0.77)	VERY LOW	IMPORTANT
<b>Lip closure during deglutition (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												
1 (Baghbadorani 2014)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 0.5 (SD 0.67)	VERY LOW	CRITICAL
<b>Control of food during deglutition (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												
1 (Baghbadorani)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 1 (SD 0.73)	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Oral sensorimotor or therapy	Control	Relative (95% CI)	Absolute		
2014)												
<b>Straw suction (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												
1 (Baghbadorani 2014)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 0.41 (SD 0.51)	VERY LOW	CRITICAL
<b>Control of liquid during deglutition (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												
1 (Baghbadorani 2014)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 0.75 (SD 0.45)	VERY LOW	CRITICAL
<b>Mastication (follow-up 2 months; measured with: Oral motor assessment scale (change score); range of scores: 0-10; Better indicated by higher values)</b>												
1 (Baghbadorani 2014)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	12	-	-	mean 1 (SD 0.85)	VERY LOW	CRITICAL

1 1 the evidence was downgraded by 1 due to performance and detection bias  
2 2 not calculable

1 **Table 8: GRADE profile for the multi-component intervention (including Beckman oral exercise training, behavioural intervention and parenting training)**  
 2

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Multi-component intervention	Control	Relative (95% CI)	Absolute		
<b>Height (follow-up 1 years; measured with: Percentile ; Better indicated by higher values)</b>												
1 (Clawson 2007)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	8	-	-	mean (SD) 16.13 higher (17.08)	VERY LOW	CRITICAL
<b>Weight (follow-up 1 years; measured with: Percentile; Better indicated by higher values)</b>												
1 (Clawson 2007)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	0	-	-	mean (SD) 10.28 higher (15.41)	VERY LOW	CRITICAL
<b>Length of food time/time taken to feed (follow-up 5.8 weeks; measured with: Minutes; Better indicated by lower values)</b>												
1 (Clawson 2007)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	8	-	-	mean (SD) 17.83 higher (2.06)	VERY LOW	CRITICAL

3 1 the evidence was downgraded by 1 due to performance bias

4 2 not calculable

1 Table 9: GRADE Profile for the six session training programme

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Six training sessions	Control	Relative (95% CI)	Absolute		
<b>Weight for age (follow-up 4-6 months; measured with: waz score; range of scores: -3-0; Better indicated by higher values)</b>												
1 (Adams 2011)	observational studies	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	no serious imprecision <sup>3</sup>	none	22	-	-	mean 4.07 (SD 4.25)	VERY LOW	CRITICAL
<b>Chest related illness at least once every 3 months (follow-up 4-6 months; assessed with: Frequency)</b>												
1 (Adams 2011)	observational studies	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	no serious imprecision <sup>3</sup>	none	6/22 P 0.005	-	-	-	VERY LOW	CRITICAL

- 2 1 the evidence was downgraded by 2 due to performance, attrition and detection bias
- 3 2 the evidence was downgraded by 1 due to study setting in Bangladesh
- 4 3 not calculable
- 5 4 the absolute risk could not be calculated as there was no comparator group in the study

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## H.11<sub>1</sub> Optimising nutritional status

2 Table 10: Immediate high energy feeding versus control

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	High energy feeding	Control	Relative (95% CI)	Absolute		
<b>Weight (measured with: kg; Better indicated by lower values)</b>												
1 (Patrick 1986)	randomised trials	very serious <sup>1</sup>	N/A	no serious indirectness	serious <sup>2</sup>	none	5	5	-	mean 6.1 higher (95% CI not calculable) <sup>3</sup>	VERY LOW	CRITICAL

- 3 1 evidence was downgraded by 2 due to no information on randomisation process, blinding or allocation concealment given. Attrition bias due to missing data.  
 4 2 Imprecision not calculable: standard deviation for intervention group not reported.  
 5 3 Unable to calculate 95% CI as standard deviation for intervention group not available.

6 Table 11: Tube fed versus orally fed

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Tube fed	Orally fed	Relative (95% CI)	Absolute		
<b>Weight (follow-up 12 months; measured with: z-score; Better indicated by lower values)</b>												
1 (Sullivan 2006)	observational studies	serious <sup>1</sup>	N/A	no serious indirectness	very serious <sup>2</sup>	none	22	17	-	MD 0.002 higher (0.64 lower to 0.65 higher)	VERY LOW	CRITICAL



Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Tube fed	Orally fed	Relative (95% CI)	Absolute		
<b>Weight (measured with: z-score; Better indicated by lower values)</b>												
1 (Fung 2002)	observational studies	no serious risk of bias	N/A	no serious indirectness	serious <sup>4</sup>	none	49	70	-	MD 0.62 higher (0.24 lower to 1.48 higher)	VERY LOW	CRITICAL
<b>Weight (measured with: kg; Better indicated by lower values)</b>												
1 (Kong and Heung 2005)	observational studies	no serious risk of bias	no serious inconsistency	no serious indirectness	no serious imprecision	none	48	62	-	MD 0.51 higher (1.79 lower to 2.8 higher)	LOW	CRITICAL
<b>Health related quality of life (CHQ) (measured with: CHQ: Global Health Score; Better indicated by lower values)</b>												
1 (Fung 2002)	observational studies	no serious risk of bias	N/A	no serious indirectness	no serious imprecision	none	49	70	-	MD 1.38 lower (1.79 to 0.97 lower)	LOW	IMPORTANT
<b>Health related quality of life (CHQ) (measured with: CHQ: Physical Summary Score; Better indicated by lower values)</b>												
1 (Fung 2002)	observational studies	no serious risk of bias	N/A	no serious indirectness	no serious imprecision	none	49	70	-	MD 14.5 lower (19.35 to 9.65 lower)	LOW	IMPORTANT
<b>Health related quality of life (CHQ) - Impact on Parent-Time: z-score (Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Tube fed	Orally fed	Relative (95% CI)	Absolute		
1 (Fung 2002)	observational studies	no serious risk of bias	N/A	no serious indirectness	serious <sup>4</sup>	none	49	70	-	MD 0.47 lower (1.11 lower to 0.17 higher)	VERY LOW	IMPORTANT

- 1 1 evidence was downgraded by 1 due to attrition bias: Drop out rate at follow-up not given.
- 2 2 evidence was downgraded by 2 due to very serious imprecision as 95%CI crossed two default MID
- 3 3 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID
- 4 4 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

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**H.12<sup>1</sup> Improving speech, language and communication: Speech  
2 intelligibility**

3 Not applicable for this review

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## H.13<sub>1</sub> Improving speech, language and communication: Communication systems

2 Table 12: GRADE profile for Blissymbols intervention

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Blissymbol	Control	Relative (95% CI)	Absolute		
<b>Number of symbols/signs understood (follow-up 10.5 months; Better indicated by higher values)</b>												
1 (Udwin and Yule 1990)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	20	-	-	mean (SD) 54.0 higher (47.3)	VERY LOW	CRITICAL
<b>Number of symbol/sign understood (follow-up 1.5 years; Better indicated by higher values)</b>												
1 (Udwin and Yule 1990)	observational studies	very serious <sup>1,3</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	20	-	-	mean (SD) 113.7 higher (70.5)	VERY LOW	CRITICAL
<b>Number of symbols/signs produced (follow-up 10.5 months; Better indicated by lower values)</b>												
1 (Udwin and Yule 1990)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	20	-	-	mean (SD) 50.6 higher (42.9)	VERY LOW	CRITICAL
<b>Number of symbols/signs produced (follow-up 1.5; Better indicated by lower values)</b>												
1 (Udwin and	observational studies	very serious <sup>3</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	20	-	-	mean (SD) 109	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Blissymbol	Control	Relative (95% CI)	Absolute		
Yule 1990)										higher (69.9)		

- 1 1 evidence was downgraded by 1 due to participants not comparable at baseline for: 'measures of physical handicap, non-verbal IQ and language comprehension and expression'.
- 2 2 not calculable.
- 3 3 evidence was downgraded by 2 due to attrition bias - groups not comparable for availability of outcome data

**5 Table 13: GRADE profile for Makaton intervention**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Makaton	Control	Relative (95% CI)	Absolute		
<b>Number of symbols/signs understood (follow-up 10.5 months; Better indicated by higher values)</b>												
1 (Udwin and Yule 1990)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	20	-	-	mean 34.4 (27.9) higher (0 to 0 higher)	VERY LOW	CRITICAL
<b>Number of symbols/signs understood (follow-up 1.5 years; Better indicated by higher values)</b>												
1 (Udwin and Yule 1990)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	14	-	-	mean 72.1 (46.1) higher (0 to 0 higher)	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Makaton	Control	Relative (95% CI)	Absolute		
<b>Number of symbols/signs produced (follow-up 10.5 months; Better indicated by higher values)</b>												
1 (Udwin and Yule 1990)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	20	-	-	mean 28.2 (25.6) higher (0 to 0 higher)	VERY LOW	CRITICAL
<b>Number of symbols/signs produced (follow-up 1.5 years; Better indicated by higher values)</b>												
1 (Udwin and Yule 1990)	observational studies	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	14	-	-	mean 65.1 (46.2) higher (0 to 0 higher)	VERY LOW	CRITICAL

1 1 evidence downgraded by 1 due to participants not comparable at baseline for: 'measures of physical handicap, non-verbal IQ and language comprehension and expression'.  
 2 2 not calculable.  
 3 3 2 not calculable.

**4 Table 14: GRADE profile for 'My Turn to Speak' training vs no training for teachers/assistants**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	'My Turn to Speak' training (workshops)	No training	Relative (95% CI)	Absolute		
<b>Change in quality of facilitation of children's communication by adults (teachers and assistants) (follow-up 1 months; Better indicated by lower values)<sup>1</sup></b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	'My Turn to Speak' training (workshops)	No training	Relative (95% CI)	Absolute		
1 (McConachie and Pennington, 1997)	observational study	no serious risk of bias	N/A	no serious indirectness	NC <sup>2</sup>	none	19	10	-	NC <sup>3</sup>	VERY LOW	CRITICAL
<b>Change in quality of facilitation of children's communication by adults (teachers and assistants) (follow-up 4 months; Better indicated by lower values)<sup>1</sup></b>												
1 (McConachie and Pennington, 1997)	observational study	serious <sup>4</sup>	N/A	no serious indirectness	NC <sup>2</sup>	none	9	4	-	NC <sup>5</sup>	VERY LOW	CRITICAL

- 1 1 facilitation of communication by n = 34 teachers and assistants with n = 9 students who had CP and used AAC (2 used VOCAs)
- 2 2 raw data was not available for both groups to calculate mean difference and imprecision.
- 3 3 raw data was not available for both groups to calculate mean difference. No significant difference in quality of facilitation of children's communication in participant group reported (Chi squared = 1.62, not significant).
- 4 4 evidence was downgraded by 1 due to attrition bias - loss of follow-up in comparison group and unavailability of data in intervention group.
- 5 5 raw data was not available for both groups to calculate mean difference. Significant improvement in quality of facilitation of children's communication in participant group reported but no significant difference in comparison group.

**8 Table 15: GRADE profile for Dynavox2c vs Alphatalker**

Quality assessment							Error rate in 7 participants		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Dynavox2c (dual level display)	Alphatalker (single level display)	Relative (95% CI)	Absolute		
<b>Error rate in test 1 among 7 CP participants<sup>1</sup> (measured with: errors ÷ number of possible correct responses; Better indicated by lower values)</b>												

Quality assessment							Error rate in 7 participants		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Dynavox2c (dual level display)	Alphatalker (single level display)	Relative (95% CI)	Absolute		
1 (Hochstein 2003)	observational study <sup>2</sup>	no serious risk of bias	N/A	no serious indirectness	NC	none	Median 0.59 (range 0.22 to 0.78)	Median 0.19 (range 0.09 to 0.44)	-	NC <sup>2</sup>	LOW	IMPORTANT
<b>Error rate in test 2 among 7 CP participants<sup>1</sup> (measured with: errors ÷ number of possible correct responses; Better indicated by lower values)</b>												
1 (Hochstein 2003)	observational study <sup>2</sup>	no serious risk of bias	N/A	no serious indirectness	NC	none	Median 0.50 (range 0.13 to 0.72)	Median 0.19 (range 0.06 to 0.38)	-	NC <sup>2</sup>	LOW	IMPORTANT

1 1 case-control (controls were non-CP participants, results not reported here). 7 CP participants used both Dynavox2c and Alphatalker.

2 2 absolute effect not calculable.

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## H.145 Managing saliva control

6 Table 16: GRADE profile for comparison of Botulinum versus Placebo for drooling

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Botulinum toxin A	Placebo	Relative (95% CI)	Absolute		
<b>Reduction of frequency and severity of drooling (measured with: Total TSG scale at 4 weeks; Better indicated by lower values)</b>												



Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Botulinum toxin A	Placebo	Relative (95% CI)	Absolute		
1 (Lin 2008)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=6 Mean=5.17	N=7 Mean=6.71	-	MD=1.54 lower P<0.01	VERY LOW	CRITICAL
<b>Frequency of drooling (measured with: Frequency section only of TSG scale at 4 weeks; Better indicated by lower values)</b>												
1 (Alrefai 2009)	randomised trials	serious <sup>3</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=11 Median=3	N=13 Median=4	-	MD=N C P<0.05	LOW	CRITICAL
<b>Severity of drooling (measured with: Severity section of TSG scale at 4 weeks; Better indicated by lower values)</b>												
1 (Alrefai 2009)	randomised trials	serious <sup>3</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=11 Median=4	N=13 Median=5	-	MD=N C P<0.05	LOW	CRITICAL
<b>Reduction of frequency and severity of drooling (measured with: Subjective drooling scale at 4 weeks; Better indicated by lower values)</b>												
1 (Wu 2011)	randomised trials	serious <sup>4</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=10 Mean=N R	N=10 Mean=N R	-	MD=N C P>0.05	LOW	CRITICAL
<b>Reduction of frequency and severity of drooling (measured with: Salivary flow, mL/min at 4 weeks; Better indicated by lower values)</b>												
1 (Wu 2011)	randomised trials	serious <sup>4</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=10 Mean=N R	N=10 Mean=N R	-	MD=N C P=0.037	LOW	CRITICAL
<b>Adverse effects: swallowing problems (assessed with: Reported by parents or carers)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Botulinum toxin A	Placebo	Relative (95% CI)	Absolute		
2 (Alfred et al 2009; Wu et al 2011)	randomised trials	very serious <sup>4,5</sup>	no serious inconsistency	no serious indirectness	NA	none	2/21 (9.5%)	0/23 (0%)	NC	NC	LOW	CRITICAL
<b>Adverse effects: breathing problems - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		CRITICAL
<b>Health-related quality of life - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		CRITICAL
<b>Psychological wellbeing - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		IMPORTANT

1 MD mean difference; NA not applicable; NC not calculable; NR non reported; P p-value  
2 1 evidence was downgraded by 2 due to selection bias: authors state 'randomly assigned' but insufficient information to permit judgement; concealment of allocation unclear.  
3 Performance bias: states 'double-blind' but the blinding of the person delivering treatment to group is unknown; Unclear if children were blinded to treatment as well. Attrition  
4 bias: no information on whether there were withdrawals from treatment, and no adverse effects were reported. Detection bias: unclear from the paper if investigators taking  
5 outcome measures are blinded to treatment allocation. It was not possible to calculate imprecision due to lack of information reported in the paper (no 95% CI and SD).  
6 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded.  
7 3 evidence was downgraded by 1 due to selection bias: 'each patient was given a number and a registered nurse, independent from the investigator assigned the patients to  
8 the treatment or placebo group' unclear if the numbers given had a non-random component; unclear allocation concealment because of lack of information. Performance bias:  
9 low risk. Attrition bias: data on 16 people only provided although 24 received the first injection. No data provided for outcomes at 4 months. Detection bias: unclear if parents  
10 and carers taking outcome measures were blinded to allocation as well. It was not possible to calculate imprecision due to lack of information reported in the paper (no 95%  
11 CI and ranges).  
12 4 evidence was downgraded by 1 due to selection bias: unclear as the sequence generation is unspecified as well as concealment of allocation is unspecified. Performance  
13 bias: low risk. Attrition bias: low risk. Detection bias: low risk. It was not possible to calculate imprecision due to lack of information reported in the paper (no 95% CI, means  
14 and SD).  
15 5 evidence was downgraded by 2 due to selection bias: 'each patient was given a number and a registered nurse, independent from the investigator assigned the patients to  
16 the treatment or placebo group' unclear if the numbers given had a non-random component; unclear allocation concealment because of lack of information. Performance bias:

- 1 person delivering the treatment and patients were blinded to treatment allocation. Attrition bias: data on 16 people only provided although 24 received the first injection. No
- 2 data provided for outcomes at 4 months. Detection bias: unclear if parents and carers taking outcome measures were blinded to allocation as well.
- 3 4 evidence was downgraded by 1 due to selection bias: unclear as the sequence generation is unspecified as well as concealment of allocation is unspecified. Performance
- 4 bias: low risk. Attrition bias: low risk. Detection bias: low risk. It was not possible to calculate imprecision due to lack of information reported in the paper (no 95% CI, means
- 5 and SD).
- 6 5 evidence was downgraded by 2 due to selection bias: 'each patient was given a number and a registered nurse, independent from the investigator assigned the patients to
- 7 the treatment or placebo group' unclear if the numbers given had a non-random component; unclear allocation concealment because of lack of information. Performance bias:
- 8 person delivering the treatment and patients were blinded to treatment allocation. Attrition bias: data on 16 people only provided although 24 received the first injection. No
- 9 data provided for outcomes at 4 months. Detection bias: unclear if parents and carers taking outcome measures were blinded to allocation as well.

10 Table 17: GRADE profile for comparison of Botulinum versus no treatment for drooling

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Botulinum	No treatment	Relative (95% CI)	Absolute		
<b>Reduction of frequency and severity of drooling (measured with: Total TSG scale at 4 weeks - medium dose; Better indicated by lower values)</b>												
1 (Basciani 2011)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=7 (BoNT-B)	N=7	-	MD=5.143 lower P<0.001	VERY LOW	CRITICAL
<b>Reduction of frequency and severity of drooling (measured with: Total TSG scale at 4 weeks - high dose; Better indicated by lower values)</b>												
1 (Basciani 2011)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=7 (BoNT-B)	N=7	-	MD=5.714 lower P<0.001	VERY LOW	CRITICAL
<b>Reduction of frequency and severity of drooling (measured with: Drooling impact scale at 4 weeks; Better indicated by lower values)</b>												
1 (Reid 2008)	randomised trials	serious <sup>3</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	N=13 Mean(SD)=34.29(14.96)	N=18 Mean(SD)=61.74(12.35)	-	MD=27.38 lower (-)	MODERATE	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Botulinum	No treatment	Relative (95% CI)	Absolute		
							(Botulinum toxin A)			17.44 to -37.31)		
<b>Adverse effects: swallowing problems (assessed with: Diary reports and communication from the parents)</b>												
1 (Basciani 2011)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	NA	none	2/7 (28.6%) in the high dose group only	0/7 (0%)	NC	NC	LOW	CRITICAL
								0%		-		
<b>Adverse effects: breathing problems - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		
<b>Health-related quality of life - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		CRITICAL
<b>Psychological wellbeing - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		IMPORTANT

- 1 MD mean difference; NA not applicable; NC not calculable; NR non reported; p-value
- 2 1 evidence downgraded by 2 due to selection bias: concealment of allocation not reported; groups haven't been compared at baseline; Performance bias: this is a trial comparing treatment against no treatment and no information is reported on other types of care provided; the study is not blinded; Attrition bias: low dose group had 1 lost at follow-up, medium dose group had 1, control group had 1. No intention to treat analysis reported; Detection bias: the study is not blinded. It was not possible to calculate imprecision due to lack of information reported (No. of participants in each arm not reported).
- 3 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded.
- 4 3 evidence was downgraded by 1 due to selection bias: low risk; Performance bias: person delivering treatment was not blinded. Also, children, carers and parents were not blinded to intervention; Attrition bias: outcome measures for baseline and 1 month post baseline for CP group only available to review authors. No outcomes available at 2-6 months and at 1 year for CP group; Detection bias: investigators taken outcomes measures were not blinded to intervention.

1 Table 18: GRADE profile for comparison of Anticholinergic drug versus Placebo for drooling

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Anticholinergic drug	Placebo	Relative (95% CI)	Absolute		
<b>Reduction of frequency and severity of drooling (measured with: Total TSG scale at 8 weeks; Better indicated by lower values)</b>												
1 (Mier 2000)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	NC <sup>2</sup>	none	N=NR Mean=1.85 (glycopyrrolate)	N=NR Mean=6.83	-	MD=4.98 lower P<0.001	VERY LOW	CRITICAL
<b>Reduction of frequency and severity of drooling (measured with: Improvement in the mTDS scale at 8 weeks; Better indicated by higher values)</b>												
1 (Zeller 2012)	randomised trials	very serious <sup>3</sup>	no serious inconsistency	no serious indirectness	serious imprecision <sup>7</sup>	none	N=19 Mean (SD)=3.94 (1.95) (glycopyrrolate)	N=17 Mean (SD)=0.71 (2.14)	-	MD=3.23 higher (1.89 to 4.57) P<0.0001	VERY LOW	CRITICAL
<b>Reduction of frequency and severity of drooling (measured with: TDS scale at 2 weeks; Better indicated by lower values)</b>												
1 (Camp-Bruno 1989)	randomised trials	very serious <sup>4</sup>	no serious inconsistency	no serious indirectness <sup>5,6</sup>	NC <sup>2</sup>	none	N=10 Mean=2.38 (benztropine)	N=10 Mean=3.53	-	MD=1.15 lower P≤0.001	VERY LOW	CRITICAL
<b>Adverse effects: visual problems - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		CRITICAL
<b>Adverse effects: constipation</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Anticholinergic drug	Placebo	Relative (95% CI)	Absolute		
1 (Zeller 2012)	randomised trials	very serious <sup>3</sup>	no serious inconsistency	no serious indirectness <sup>5, 6</sup>	very serious <sup>8</sup>	none	6/20 (30%)	4/18 (22.2%)	RR 1.35 (0.45 to 4.03)	78 more per 1000 (from 122 fewer to 673 more)	VERY LOW	CRITICAL
								0%		-		
<b>Health-related quality of life - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		CRITICAL
<b>Psychological wellbeing - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		IMPORTANT

1 MD mean difference; NA not applicable; NC not calculable; NR non reported; P p-value

2 1 evidence was downgraded by 2 due to selection bias: authors do not specify how many participants have been randomised in each group; concealment of allocation not

3 reported; groups haven't been compared at baseline; Performance bias: blinding of person delivering the treatment and patients receiving the treatment. However, parents

4 reported to know when their child was receiving the intervention because of the dramatic improvement in drooling; Attrition bias: data from 12 children who commenced the

5 study (and have been randomised) were not included in the final analysis. No outcome measures reported for those 12 children. Therefore, authors reported outcomes only

6 on the children who completed the study; Detection bias: Not clear whether the person doing the physical examination for side effects was blind to the intervention. It was not

7 possible to calculate imprecision due to lack of information reported (the study doesn't report No. of participants in each arm).

8 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded.

9 3 evidence was downgraded by 2 due to selection bias: unclear as the sequence generation is unspecified as well as concealment of allocation is unspecified; Performance

10 bias: the study is reported to be double-blind but it is also said that 'as patients receiving placebo would be expected to continue drooling chronically, caregivers of this group

11 were encouraged to keep patients in the study until at least the end of 4-week titration period'; Attrition bias: safety and efficacy populations are different (2 participants not

12 included in the efficacy analysis); Detection bias: study reported to be double-blind but lack of information on this.

13 4 evidence was downgraded by 2 due to selection bias: unclear risk as no information provided on the sequence generation process, nor on the allocation concealment;

14 Performance and Detection bias: unclear risk, as the study is reported to be "double-blind" but unclear if all staff involved in taking outcome measures were blinded to

15 intervention; Attrition bias: high risk as 7 children were eliminated from the study but no details were given regarding the point at which they were excluded. Three patients

- 1 developed side effects to drug and were excluded on that basis. No data provided for these participants. . It was not possible to calculate imprecision due to lack of
- 2 information reported (the study doesn't report SD).
- 3 5 population considered in the study: children with CP and other neurological disorders (study hasn't been downgraded for Indirectness).
- 4 6 study was carried out in a school setting.
- 5 7 evidence was downgraded by 1 due to serious imprecision as 95% CI crossed one default MID.
- 6 8 evidence was downgraded by 2 due to very serious imprecision as 95% CI crossed two default MID.

7 **Table 19: GRADE profile for comparison of Behaviour therapy and usual care for drooling**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Behavioural therapy	Usual care	Relative (95% CI)	Absolute		
<b>Frequency of drooling (measured with: Each drooling episode over a period of 20 minute was recorded.; Better indicated by lower values)</b>												
1 (Sethy 2011)	randomised trials	serious <sup>1</sup>	NA	no serious indirectness	no serious imprecision	none	N=12 Mean(SD)=5.67(3.17)	N=13 Mean(SD)=21.38(2.60)	-	MD=15.71 lower (-17.99 to -13.43)	MODERATE	CRITICAL
<b>Health-related quality of life - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		CRITICAL
<b>Psychological wellbeing - not reported</b>												
0	-	-	-	-	-	none	-	-	-	-		IMPORTANT

- 8 MD mean difference; NA not applicable; NC not calculable; NR non reported; p-value; SD standard deviation.
- 9 1 evidence was downgraded by 1 due to selection bias: low risk; Performance bias: patients and carers are not blind to study allocation; Attrition bias: low risk; Detection bias: low risk.
- 10 low risk.

1 Table 20: GRADE Profile for Botulinum versus surgery

Quality assessment							No of patients = 19		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Pre-	Post-	Relative (95% CI)	Absolute		
<b>Drooling quotient after botulinum (follow-up 8 weeks; measured with: the percentage of time a person drools and was measured by a speech and language therapist; Better indicated by lower values)</b>												
1 (Scheffer 2010)	observational studies	Very serious <sup>1</sup>	NA	no serious indirectness	no serious imprecision	none	-	-	-	MD 11.8 lower (2.6 to 21.0 higher)	VERY LOW	CRITICAL
<b>Drooling quotient after botulinum (follow-up 32 weeks; measured with: the percentage of time a person drools and was measured by a speech and language therapist; Better indicated by lower values)</b>												
1 (Scheffer 2010)	observational studies	Very serious <sup>1</sup>	NA	no serious indirectness	serious <sup>2</sup>	none	-	-	-	MD 7.5 lower (0.1 to 14.8 higher)	VERY LOW	CRITICAL
<b>Drooling quotient after surgery (follow-up 8 weeks; measured with: the percentage of time a person drools and was measured by a speech and language therapist; Better indicated by lower values)</b>												
1 (Scheffer 2010)	observational studies	Very serious <sup>1</sup>	NA	no serious indirectness	no serious imprecision	none	-	-	-	MD 18.0 lower (10.5 to 25.6 higher)	VERY LOW	CRITICAL
<b>Drooling quotient after surgery (follow-up 32 weeks; measured with: the percentage of time a person drools and was measured by a speech and language therapist; Better indicated by lower values)</b>												
1 (Scheffer 2010)	observational studies	Very serious <sup>1</sup>	NA	no serious indirectness	no serious imprecision	none	-	-	-	MD 23.4 lower (14.2 to 32.6 higher)	VERY LOW	CRITICAL

2 MD mean difference; NA not applicable; NC not calculable; NR non reported; P p-value; SD standard deviation.

3 1 evidence was downgraded by 2 due to selection bias: only children who initially underwent botulinum treatment were selected for surgical treatment; attrition bias: n=3, n=2,

4 and n=5 observations lost at follow-up; Confounding was not reported; small sample size. In addition, the authors state that a 6 months 'at least' washout period was



- 1 observed in order to avoid a carry-over effect, however with 6 months there is an overlap between the two interventions of 2 months (therefore a carry-over effect is possible from BoNT-A to surgery).
- 2 evidence was downgraded by 1 due to serious imprecision as 95% CI crossed one default MID.

**4 Table 21: GRADE profile for transdermal hyoscine hydrobromide compared to glycopyrrolate**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Transdermal hyoscine hydrobromide	glycopyrrolate	Relative (95% CI)	Absolute		
<b>Reduction of frequency and severity of drooling (follow-up 4 weeks; measured with: Drooling impact score (DIS); range of scores: 0-100; Better indicated by lower values)</b>												
1 (Parr 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	41	29	-	MD 6.80 higher (1.05 lower to 14.65 higher)	LOW	CRITICAL
<b>reduction of frequency and severity of drooling (follow-up 12 weeks; measured with: DIS; range of scores: 0-100; Better indicated by lower values)</b>												
1 (Parr 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	38	33	-	MD 7.20 higher (1.36 lower to 15.76 higher)	LOW	CRITICAL
<b>reduction of frequency and severity of drooling (follow-up 4 weeks; measured with: DSFS; Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Transdermal hyoscine hydrobromide	glycopyrrolate	Relative (95% CI)	Absolute		
1 (Parr 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>3</sup>	none	0	-	-	MD 0.4 higher (0 to 0 higher)	LOW	CRITICAL
<b>reduction of frequency and severity of drooling (Copy) (follow-up 12 weeks; measured with: DSFS; Better indicated by lower values)</b>												
1 (Parr 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>3</sup>	none	0	-	-	MD 0 higher (0 to 0 higher)	LOW	CRITICAL
<b>adverse effect - constipation</b>												
1 (Parr 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	5/47 (10.6%)	12/38 (31.6%)	RR 0.33 (0.130 to 0.8725)	212 fewer per 1000 (from 40 fewer to 275 fewer)	LOW	CRITICAL
								0%		-		

1 1 evidence was downgraded by 1 due to high risk of performance bias (participants, families, and trial clinicians not blind to treatment allocation).  
 2 2 evidence was downgraded by 1 due to serious imprecision as the 95% CI crossed one MID.  
 3 3 imprecision could not be calculated due to lack of information reported. Evidence downgraded by 1.

## **H.15<sub>1</sub> Risk factors for low bone mineral density**

2 Not applicable for this review

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## H.16<sup>1</sup> Prevention of reduced bone mineral density

2 Table 11: GRADE profile for increased time spent on standing frame versus usual time

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Increased time spent on standing frame	Usual time on standing frame	Relative (95% CI)	Absolute		
<b>Change in the vertebral vTBMD (follow-up 9 months; measured with: DEXA scan (mg/cm<sup>3</sup>); Better indicated by higher values)</b>												
1 (Caulton 2004)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	13	13	-	mean 8.91 higher (2.4 to 15.41 higher)	LOW	CRITICAL
<b>Change in the proximal tibial TBMD (follow-up 9 months; measured with: DEXA scan (mg/cm<sup>3</sup>); Better indicated by higher values)</b>												
1 (Caulton 2004)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	13	13	-	mean 0.85 lower (16.83 lower to 15.13 higher)	MODERATE	CRITICAL

3 1 evidence was downgraded by 1 due to lack of blinding.

4 2 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

1 Table 12: GRADE profile for whole-body vibration versus usual physiotherapy

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Whole-body vibration + usual physiotherapy	Usual physiotherapy	Relative (95% CI)	Absolute		
<b>Lumbar spine areal BMD (mg/cm<sup>3</sup>) (follow-up 6 months; measured with: DEXA scan; Better indicated by lower values)</b>												
1 (Ruck 2010)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQ range) = 0.013 (0.005 to 0.022)	Median (IQ range) = 0.010 (0.001 to 0.055)	-	P value = 0.89	LOW	CRITICAL
<b>Distal femur region 1 areal BMD (mg/cm<sup>3</sup>) (follow-up 6 months; measured with: DEXA scan ; Better indicated by lower values)</b>												
1 (Ruck 2010)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQ range) = 0.032 (0.003 to 0.099)	Median (IQ range) = -0.046 (-0.107 to 0.003)	-	P value = 0.11	LOW	CRITICAL
<b>Distal femur region 2 (mg/cm<sup>3</sup>) (follow-up 6 months; measured with: DEXA scan; Better indicated by lower values)</b>												
1 (Ruck 2010)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQ range) = -0.002 (-0.041 to 0.024)	Median (IQ range) = 0.020 (-0.107 to 0.042)	-	P value = 0.41	LOW	CRITICAL
<b>Distal femur region 3 areal BMD (mg/cm<sup>3</sup>) (follow-up 6 months; measured with: DEXA scan; Better indicated by lower values)</b>												
1 (Ruck 2010)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQ range) = -0.026 (-0.076 to -0.015)	Median (IQ range) = 0.034 (-0.019 to 0.041)	-	P value = 0.03	LOW	CRITICAL

2 1 evidence was downgraded by 1 due to high performance bias.

3 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded by 1.

1 Table 13: GRADE profile for home-based virtual cycling versus usual physical activity

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Home-based virtual cycling training	Usual and general physical activity at home	Relative (95% CI)	Absolute		
<b>Lumbar areal BMD (g/cm<sup>3</sup>) (follow-up 12 weeks; measured with: DEXA scan ; Better indicated by lower values)</b>												
1 (Chen 2013)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Mean±SD = 0.583±0.136	Mean±SD = 0.583±0.140	-	P value = 0.357	VERY LOW	CRITICAL
<b>Femur areal BMD (g/cm<sup>3</sup>) (follow-up 12 weeks; measured with: DEXA scan; Better indicated by lower values)</b>												
1 (Chen 2013)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Mean±SD = 0.744±0.097	Mean±SD = 0.73±0.124	-	P value = 0.022	VERY LOW	CRITICAL

- 2 1 evidence was downgraded by 2 due to high selection bias and high performance bias.  
 3 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded.

4 Table 14: GRADE profile for physical activity program versus usual life style habits

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Physical activity program (weight bearing)	Usual life style habits	Relative (95% CI)	Absolute		
<b>% change in proximal femur BMC (g) (follow-up 8 months; measured with: DEXA scan; Better indicated by lower values)</b>												
1 (Chad 1999)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	11.5%	3.5%	-	P = 0.08	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Physical activity program (weight bearing)	Usual life style habits	Relative (95% CI)	Absolute		
<b>% change in femoral neck BMC (g) (follow-up 8 months; measured with: DEXA scan ; Better indicated by lower values)</b>												
1 (Chad 1999)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	9.6%	-5.8%	-	P = 0.03	VERY LOW	CRITICAL
<b>% change in femoral neck vBMD (g/cm<sup>3</sup>) (follow-up 8 months; measured with: DEXA scan ; Better indicated by lower values)</b>												
1 (Chad 1999)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	5.6%	-6.3%	-	P = 0.02	VERY LOW	CRITICAL

- 1 1 evidence was downgraded by 2 due to high selection bias and high performance bias.  
 2 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded.

3 Table 15: GRADE profile for vitamin D only versus vitamin D + biphosphonates

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Vitam in D	Vitamin D + biphosphonates	Relative (95% CI)	Absolute		
<b>BMD pre versus post treatment in Monotherapy group (follow-up 6 months; measured with: DEXA scans; Better indicated by higher values)</b>												
1 (Iwasaki 2008)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	-	-	-	P value = 0.003	VERY LOW	CRITICAL
<b>BMD pre versus post treatment in Polytherapy group (follow-up 6 months; measured with: DEXA scans; Better indicated by higher values)</b>												
1 (Iwasaki 2008)	randomised trials	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	-	-	-	P value = 0.0035	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Vitamin D	Vitamin D + biphosphonates	Relative (95% CI)	Absolute		
aki 2008)												

- 1 1 evidence was downgraded by 2 due to high selection bias and high detection bias.  
 2 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded by 1.

3 Table 16: GRADE profile for calcium + vitamin D versus observation only

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Pre-treatment	Post-treatment	Relative (95% CI)	Absolute		
<b>BMD in intervention group, g/cm<sup>2</sup> (follow-up 9 months; measured with: DEXA scan; Better indicated by higher values)</b>												
1 (Jekovec-Vrhovsek 2000)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Mean±SD = 0.383±0.175	Mean±SD = 0.476±0.199	-	P <0.001	VERY LOW	CRITICAL
<b>BMD in control group, g/cm<sup>2</sup> (follow-up 9 months; measured with: DEXA scan; Better indicated by lower values)</b>												
1 (Jekovec-Vrhovsek 2000)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Mean±SD = 0.393±0.077	Mean±SD = 0.315±0.109	-	P value = 0.013	VERY LOW	CRITICAL

- 4 1 evidence was downgraded by 2 due to moderate selection bias, weak study design, confounders not included in analysis, no blinding.  
 5 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded by 1.



1 Table 17: GRADE profile for pamidronate versus placebo

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Biphosphonates	Placebo	Relative (95% CI)	Absolute		
<b>% change in distal femur region 1 (follow-up 1 years; measured with: DEXA scan ; Better indicated by higher values)</b>												
1 (Henderson 2002)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	7	7	-	MD 80.0 higher (37.19 to 122.28 higher)	LOW	
<b>% change in distal femur region 2 (follow-up 1 years; measured with: DEXA scan ; Better indicated by higher values)</b>												
1 (Henderson 2002)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	7	7	-	MD 27.0 higher (8.93 to 45.07 higher)	LOW	CRITICAL
<b>% change in distal femur region 3 (follow-up 1 years; measured with: DEXA scan ; Better indicated by higher values)</b>												
1 (Henderson 2002)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	7	6	-	MD 12.0 higher (1.85 lower to 25.85 higher)	LOW	CRITICAL
<b>% change in lumbar spine (follow-up 1 years; measured with: DEXA scan ; Better indicated by higher values)</b>												
1 (Henderson)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	7	7	-	MD 18.0 higher (6.57 to	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Biphosphonates	Placebo	Relative (95% CI)	Absolute		
n 2002)										29.42 higher)		

- 1 1 evidence was downgraded by 1 due to high selection bias.  
 2 2 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

3 Table 18: GRADE profile for gastrostomy pre- and after intervention

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Pre-intervention	Post-intervention	Relative (95% CI)	Absolute		
<b>BMC, g (measured with: DEXA scan; Better indicated by higher values)</b>												
1 (Arrowsmith 2010)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQ range) = 469 (374 to 632)	Median (IQ range) = 626 (509 to 736)	-	P<0.05	VERY LOW	CRITICAL
<b>BMC for age, SDS (measured with: DEXA scan; Better indicated by higher values)</b>												
1 (Arrowsmith 2010)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQ range) = -2.3 (-3.3 to -1.7)	Median (IQ range) = -2.5 (-	-	P ns	VERY LOW	

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Pre-intervention	Post-intervention	Relative (95% CI)	Absolute		
								3.6 to -1.7)				
<b>BMC for height SDS (measured with: DEXA scan; Better indicated by higher values)</b>												
1 (Arrowsmith 2010)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	Median (IQR) = -0.6 (-1.0 to -0.1)	Median (IQR) = -1.1 (-1.5 to -0.3)	-	P ns	VERY LOW	

1 1 evidence was downgraded by 2 due to weak selection bias, weak study design, confounders not fully assessed in analysis, no blinding.

2 2 imprecision could not be calculated due to lack of information reported in the paper. Study has been downgraded by 1.

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**H.17<sup>2</sup> Causes of pain, distress, discomfort and sleep disturbance**

3 Not applicable for this review

**H.18<sup>4</sup> Assessment of pain, distress, discomfort and sleep  
5 disturbances**

6 Not applicable for this review

**H.19<sup>7</sup> Management of pain, distress and discomfort**

8 Not applicable for this review

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## H.20<sub>1</sub> Management of sleep disturbances

2 Table 22: GRADE profile for clinical evidence profile: melatonin versus placebo

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Melatonin	Placebo	Relative (95% CI)	Absolute		
<b>total night time sleep (measured with: sleep diaries; Better indicated by higher values)</b>												
4 (Coppola 2004; Dodge 2001; Wasdell 2008; Appleton 2012)	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	no serious imprecision	none	146	154	-	MD 30.01 higher (12.29 to 47.72 higher)	HIGH	CRITICAL
<b>total night time sleep (measured with: actigraphy; Better indicated by higher values)</b>												
2 (Wasdell 2008; Appleton 2012);	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious <sup>1</sup>	none	80	79	-	MD 14.51 higher (7.69 lower to 36.72 higher)	MODERATE	CRITICAL
<b>sleep latency (measured with: sleep diaries; Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Melatonin	Placebo	Relative (95% CI)	Absolute		
4 (Coppola 2004; Dodge 2001; Wasdell 2008; Appleton 2012)	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious <sup>1</sup>	none	146	151	-	MD 32.73 lower (43.37 to 22.09 lower)	MODERATE	CRITICAL
<b>sleep latency (measured with: actigraphy; Better indicated by lower values)</b>												
2 (Wasdell 2008; Appleton 2012);	randomised trials	no serious risk of bias	serious <sup>2</sup>	no serious indirectness	serious <sup>1</sup>	none	74	75	-	MD 29.91 lower (42.16 to 17.66 lower)	LOW	CRITICAL
<b>night wakes (measured with: sleep diaries; Better indicated by lower values)</b>												
3 (Coppola 2004; Dodge)	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	no serious imprecision	none	95	95	-	MD 0.01 higher (0.28 lower to	HIGH	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Melatonin	Placebo	Relative (95% CI)	Absolute		
2001; Wasdell 2008; Appleton 2012)										0.3 higher)		
<b>night wakes (measured with: actigraphy; Better indicated by lower values)</b>												
1 (Wasdell 2008)	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious <sup>1</sup>	none	50	50	-	MD 0.45 higher (1.56 lower to 2.46 higher)	MODERATE	CRITICAL
<b>night wakes (measured with: CSDI score; range of scores: 0-12; Better indicated by lower values)</b>												
1 (Appleton 2012)	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious <sup>1</sup>	none	60	65	-	MD 1.00 lower (1.83 to 0.16 lower)	MODERATE	CRITICAL
<b>quality of life of the parent (measured with: Family Impact Module of the PedsQL; range of scores: 0-100; Better indicated by lower values)</b>												
1 (Appleton 2012)	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	no serious imprecision	none	64	69	-	MD 3.57 higher (0.86 lower to	HIGH	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Melatonin	Placebo	Relative (95% CI)	Absolute		
										8 higher)		

- 1 1 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID
- 2 2 evidence was downgraded by 1 due to serious heterogeneity (chi-squared  $p < 0.1$ , I-squared inconsistency statistic of 50%-74.99%) and no plausible explanation was found
- 3 with sensitivity or subgroup analysis

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## **H.21** <sup>1</sup> **Assessment of mental health problems**

2 Not applicable for this review

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1 <Start typing text here>

## H.22 Management of mental health problems

3 Table 23: GRADE profile for SSTP compared to WL for mental health problems in cerebral palsy

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP	WL	Relative (95% CI)	Absolute		
<b>ECBI intensity (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 15.43 higher (0.78 to 30.08 higher)	LOW	CRITICAL
<b>ECBI problem (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 6.04 higher (2.20 to 9.89 higher)	LOW	CRITICAL
<b>SDQ emotional symptoms (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 1.33 higher (0.45 to 2.21 higher)	LOW	CRITICAL
<b>SDQ conduct problems (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 0.85 higher (0.23 to 1.47 higher)	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP	WL	Relative (95% CI)	Absolute		
Whittingham 2014)										lower to 1.72 higher)		
<b>SDQ hyperactivity (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 0.73 higher (0.40 lower to 1.86 higher)	LOW	CRITICAL
<b>SDQ peer problems (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 0.77 higher (0.10 lower to 1.65 higher)	LOW	CRITICAL
<b>SDQ prosocial (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 0.44 lower (1.68 lower to 0.78 higher)	LOW	CRITICAL
<b>SDQ impact (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	20	22	-	MD 0.67 higher (1.14 lower to 2.50 higher)	LOW	CRITICAL

- 1 SDQ Strengths and Difficulties Questionnaire; ECBI Eyberg Child Behaviour Inventory; WL waiting list; SSTP Stepping Stones Triple P; ACT parent Acceptance and Commitment Therapy; MD mean difference; NC not calculable.
- 2 Commitment Therapy; MD mean difference; NC not calculable.
- 3 1 evidence was downgraded by 1 due to unclear blinding of participants and investigators
- 4 2 majority of evidence has only 1 indirect aspect of PICO (intervention not clearly specified in the protocol)

1 Table 24: GRADE profile for SSTP + ACT versus WL for mental health problems in cerebral palsy

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	WL	Relative (95% CI)	Absolute		
<b>DASS depression (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 5.33 higher (0 to 0 higher)	LOW	CRITICAL
<b>DASS stress (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 5.50 higher (0 to 0 higher)	LOW	CRITICAL
<b>CP-QOL acceptance (Better indicated by lower values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 9.01 lower (0 to 0 higher)	LOW	CRITICAL
<b>CP-QOL functioning (Better indicated by lower values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 8.72 lower (0 to 0 higher)	LOW	CRITICAL
<b>ECBI intensity (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 24.12 higher (10.22 to 38.03 higher)	LOW	CRITICAL
<b>ECBI problem (Better indicated by higher values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	WL	Relative (95% CI)	Absolute		
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 8.30 higher (4.63 to 11.97 higher)	LOW	CRITICAL
<b>SDQ emotional symptoms (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 0.37 higher (0.46 lower to 1.21 higher)	LOW	CRITICAL
<b>SDQ conduct problems (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 0.43 higher (0.41 lower to 1.26 higher)	LOW	CRITICAL
<b>SDQ hyperactivity (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 1.66 higher (0.55 to 2.77 higher)	LOW	CRITICAL
<b>SDQ peer problems (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 0.64 higher (0.18 lower to 1.46 higher)	LOW	CRITICAL
<b>SDQ prosocial (Better indicated by higher values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	WL	Relative (95% CI)	Absolute		
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 0.16 lower (1.33 lower to 0.78 higher)	LOW	CRITICAL
<b>SDQ impact (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	2/2	-	MD 1.00 higher (0.66 lower to 2.67 higher)	LOW	CRITICAL

- 1 SDQ Strengths and Difficulties Questionnaire; ECBI Eyberg Child Behaviour Inventory; WL waiting list; SSTP Stepping Stones Triple P; ACT parent Acceptance and Commitment Therapy; MD mean difference; NC not calculable.
- 2 1 evidence was downgraded by 1 due to unclear blinding of participants and investigators
- 3 2 majority of evidence has only 1 indirect aspect of PICO (intervention not clearly specified in the protocol)

**5 Table 25: GRADE profile for SSTP + ACT compared to SSTP only for mental health problems in cerebral palsy**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	SSTP only	Relative (95% CI)	Absolute		
<b>ECBI intensity (Better indicated by lower values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 8.69 higher (5.65 lower to 23.04 higher)	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SST P + ACT	SST P only	Relative (95% CI)	Absolute		
<b>ECBI problem (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 2.26 higher (1.61 lower to 6.12 higher)	LOW	CRITICAL
<b>SDQ emotional symptoms (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.95 lower (1.81 to 0.09 lower)	LOW	CRITICAL
<b>SDQ conduct problems (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.42 lower (1.28 lower to 0.44 higher)	LOW	CRITICAL
<b>SDQ hyperactivity (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.93 higher (0.17 lower to 2.04 higher)	LOW	CRITICAL
<b>SDQ peer problems (Better indicated by higher values)</b>												
1 (Whittingham)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.13 lower (0.98	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	SSTP only	Relative (95% CI)	Absolute		
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.29 higher (0.91 lower to 1.49 higher)	LOW	CRITICAL
<b>SDQ prosocial (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.33 higher (1.42 lower to 2.07 higher)	LOW	CRITICAL
<b>SDQ impact (Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	NC	none	23	20	-	MD 0.33 higher (1.42 lower to 2.07 higher)	LOW	CRITICAL

1 SDQ Strengths and Difficulties Questionnaire; ECBI Eyberg Child Behaviour Inventory; WL waiting list; SSTP Stepping Stones Triple P; ACT parent Acceptance and

2 Commitment Therapy; MD mean difference; NC not calculable.

3 1 evidence was downgraded by 1 due to unclear blinding of participants and investigators

4 2 majority of evidence has only 1 indirect aspect of PICO (intervention not clearly specified in the protocol)

5 Table 26: GRADE profile for SSTP + ACT compared to SSTP only at 6 months follow up for mental health problems in cerebral palsy

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	SSTP only	Relative (95% CI)	Absolute		
<b>ECBI intensity (follow-up 6 months; Better indicated by higher values)</b>												



Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SST P + ACT	SST P only	Relative (95% CI)	Absolute		
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	12	16	-	MD 15.3 lower (36.74 lower to 6.14 higher)	VERY LOW	CRITICAL
<b>ECBI problem (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	serious <sup>1</sup>	no serious indirectness	serious <sup>2</sup>	none	12	16	-	MD 2.61 lower (7.32 lower to 2.1 higher)	VERY LOW	CRITICAL
<b>SDQ emotional symptoms (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	very serious <sup>4</sup>	none	12	16	-	MD 0.08 higher (1.04 lower to 1.2 higher)	VERY LOW	CRITICAL
<b>SDQ conduct problems (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	12	16	-	MD 0.31 higher (0.46 lower to 1.08 higher)	VERY LOW	CRITICAL
<b>SDQ hyperactivity (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	12	16	-	MD 0.36 lower (2.17 lower to 1.45 higher)	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	SSTP + ACT	SSTP only	Relative (95% CI)	Absolute		
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	12	16	-	MD 0.78 lower (2.14 lower to 0.58 higher)	VERY LOW	CRITICAL
<b>SDQ peer problems (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	very serious <sup>4</sup>	none	12	16	-	MD 0.26 lower (2.26 lower to 1.74 higher)	VERY LOW	CRITICAL
<b>SDQ prosocial (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	12	16	-	MD 0.67 lower (1.67 lower to 0.33 higher)	VERY LOW	CRITICAL
<b>SDQ impact (follow-up 6 months; Better indicated by higher values)</b>												
1 (Whittingham 2014)	randomised trials	serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	12	16	-	MD 0.67 lower (1.67 lower to 0.33 higher)	VERY LOW	CRITICAL

1 SDQ Strengths and Difficulties Questionnaire; ECBI Eyberg Child Behaviour Inventory; WL waiting list; SSTP Stepping Stones Triple P; ACT parent Acceptance and

2 Commitment Therapy; MD mean difference; NC not calculable.

3 1 evidence was downgraded by 1 due to unclear blinding of participants and investigators

4 2 majority of evidence has only 1 indirect aspect of PICO (intervention not clearly specified in the protocol)

5 3 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

6 4 evidence was downgraded by 2 due to very serious imprecision as 95%CI crossed two default MIDs

## H.23<sup>1</sup> Management of sensory and perceptual difficulties

2 Table 27: GRADE profile for sensory-perceptual motor training vs home-based programme

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Sensory-perceptual motor training	Home-based programme	Relative (95% CI)	Absolute		
<b>Individual versus group - double tactile stimuli perception DTS (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 1 lower (2.99 lower to 0.99 higher)	VERY LOW	CRITICAL
<b>Individual versus group - localization of tactile stimuli LTS (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 1.29 higher (2.49 lower to 5.07 higher)	VERY LOW	CRITICAL
<b>Individual versus group - graphesthesia GRA (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	16	16	-	MD 0.25 lower (1.49 lower to	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Sensory-perceptual motor training	Home-based programme	Relative (95% CI)	Absolute		
										0.99 higher)		
<b>Individual versus group - kinaesthesia KIN (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 11.68 lower (20.51 to 2.85 lower)	VERY LOW	CRITICAL
<b>Individual versus group - finger identification FI (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 1.44 higher (0.42 lower to 3.3 higher)	VERY LOW	CRITICAL
<b>Individual versus group - manual form perception MFP (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	16	16	-	MD 0.06 higher (0.3 lower to 0.42 higher)	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Sensory-perceptual motor training	Home-based programme	Relative (95% CI)	Absolute		
<b>Individual versus group - design copying DC (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	16	16	-	MD 0.06 higher (1.27 lower to 1.39 higher)	VERY LOW	CRITICAL
<b>Individual versus group - position in space PS (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 0.38 higher (1.16 lower to 1.92 higher)	VERY LOW	CRITICAL
<b>Individual versus group - imitation of posture IP (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 0.62 higher (0.62 lower to 1.86 higher)	VERY LOW	CRITICAL
<b>Individual versus group - motor accuracy MAC (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Sensory-perceptual motor training	Home-based programme	Relative (95% CI)	Absolute		
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 4.48 lower (15.77 lower to 6.81 higher)	VERY LOW	CRITICAL
<b>Individual versus group - right-left discrimination RLD (measured with: The Ayres Southern California Sensory Integration Test (SCSIT); Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	16	16	-	MD 1.25 lower (3.14 lower to 0.64 higher)	VERY LOW	CRITICAL
<b>Individual versus group - physical activity test PA (Better indicated by lower values)</b>												
1 (Bum in 2001)	observational studies	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	16	16	-	MD 7.31 lower (19.34 lower to 4.72 higher)	VERY LOW	CRITICAL

- 1 1 evidence was downgraded by 2 due to moderate selection bias, weak study design, unclear blinding, weak data collection methods, moderate attrition bias, unclear intervention integrity.
- 2 2 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID
- 3 3 evidence was downgraded by 2 due to very serious imprecision as 95%CI crossed two default MIDs

1 Table 28: GRADE profile for child-focused vs context-focused approach

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
<b>paediatric evaluation of disability inventory (PEDI) - Self-care (functional skill scale) at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	71	57	-	MD 2.49 higher (3.25 lower to 8.23 higher)	LOW	CRITICAL
<b>paediatric evaluation of disability inventory (PEDI) - Self-care (functional skill scale) at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision <sup>2</sup>	none	71	57	-	MD 0.11 higher (6.22 lower to 6.44 higher)	MODERATE	CRITICAL
<b>paediatric evaluation of disability inventory (PEDI) - Self-care (caregiver assistance scale) at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.58 lower (9.2 lower)	MODERATE	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
										to 8.04 higher)		
<b>paediatric evaluation of disability inventory (PEDI) - Self-care (caregiver assistance scale) at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 1.28 higher (7.78 lower to 10.34 higher)	MODERATE	CRITICAL
<b>paediatric evaluation of disability inventory (PEDI) - Mobility (functional skill scale) at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 1.17 higher (7.27 lower to 9.61 higher)	MODERATE	CRITICAL
<b>paediatric evaluation of disability inventory (PEDI) - Mobility (functional skill scale) at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 1.52 higher (7.26	MODERATE	CRITICAL



Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
										lower to 10.3 higher)		
<b>paediatric evaluation of disability inventory (PEDI) - Mobility (caregiver assistance scale) at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.42 higher (9.64 lower to 10.48 higher)	MODERATE	CRITICAL
<b>paediatric evaluation of disability inventory (PEDI) - Mobility (caregiver assistance scale) at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 3.18 higher (7.25 lower to 13.61 higher)	MODERATE	CRITICAL
<b>Gross Motor Function Measure (GMFM) (Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 1.44 lower	MODERATE	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
2011)										(16.63 lower to 13.75 higher)		
<b>Gross Motor Function Measure (GMFM) - at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	71	57	-	MD 2.73 higher (2.33 lower to 7.79 higher)	LOW	CRITICAL
<b>family empowerment scale (FES) - at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	71	57	-	MD 0.07 higher (0.1 lower to 0.24 higher)	LOW	CRITICAL
<b>family empowerment scale (FES) - at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	71	57	-	MD 0.15 higher (0.01 lower)	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
										to 0.31 higher)		
<b>assessment of preschool children's participation - ACPC play at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.08 higher (0.45 lower to 0.61 higher)	MODERATE	CRITICAL
<b>assessment of preschool children's participation - ACPC play at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.18 lower (0.7 lower to 0.34 higher)	MODERATE	CRITICAL
<b>assessment of preschool children's participation - ACPC skill development at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.05 lower (0.45 lower to 0.35 higher)	MODERATE	CRITICAL
<b>assessment of preschool children's participation - ACPC skill development at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.02 higher (0.36 lower to 0.4 higher)	MODERATE	CRITICAL
<b>assessment of preschool children's participation - ACPC social activities at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0 higher (0.36 lower to 0.36 higher)	MODERATE	CRITICAL
<b>assessment of preschool children's participation - ACPC social activities at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.02 higher (0.33 lower to 0.37 higher)	MODERATE	CRITICAL
<b>assessment of preschool children's participation - ACPC active physical activities at 6 mo (follow-up 6 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.07 higher (0.35	MODERATE	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Child-focused	context-focused approach	Relative (95% CI)	Absolute		
										lower to 0.49 higher)		
<b>assessment of preschool children's participation - ACPC active physical activities at 9 mo (follow-up 9 months; Better indicated by lower values)</b>												
1 (Law 2011)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	no serious imprecision	none	71	57	-	MD 0.09 higher (0.39 lower to 0.57 higher)	MODERATE	CRITICAL

- 1 1 evidence was downgraded by 1 due to high level of performance bias and moderate level of detection bias.  
 2 2 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

3 Table 29: GRADE profile for web-based multimodal therapy vs standard care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-based multimodal therapy	standard care	Relative (95% CI)	Absolute		
<b>Assessment of Motor and Process Skills (AMPS) - motor skills (follow-up 3 months; Better indicated by lower values)</b>												
1 (James 2015)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	51	51	-	MD 0.27 higher (0.02 to	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-based multimodal therapy	standard care	Relative (95% CI)	Absolute		
										0.52 higher)		
<b>Assessment of Motor and Process Skills (AMPS) - processing skills (follow-up 3 months; Better indicated by lower values)</b>												
1 (Janes 2015)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	51	51	-	MD 0.31 higher (0.14 to 0.48 higher)	LOW	CRITICAL
<b>Canadian Occupational Performance Measure (COPM) (follow-up 3 months; Better indicated by lower values)</b>												
1 (Janes 2015)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	51	51	-	MD 1.28 higher (0.68 to 1.88 higher)	LOW	CRITICAL
<b>Test of Visual Perceptual Skill (non-motor) 3rd edition (TVPS-3) (follow-up 3 months; Better indicated by lower values)</b>												
1 (Janes 2015)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	51	51	-	MD 8.83 higher (1.83 to 15.83 higher)	LOW	CRITICAL

1 1 evidence was downgraded by 1 due to unclear/unknown performance bias and detection bias.  
 2 2 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

1 Table 30: GRADE profile for hand-arm intensive manual therapy vs hand-arm intensive manual therapy + tactile training

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Hand-arm intensive manual therapy	hand-arm intensive manual therapy + tactile training	Relative (95% CI)	Absolute		
<b>Grating Orientation Task (GOT) (Better indicated by lower values)</b>												
1 (Kuo 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	10	-	MD 0.46 higher (0.06 to 0.86 higher)	LOW	CRITICAL
<b>Sterognosis (Better indicated by lower values)</b>												
1 (Kuo 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	10	-	MD 1.17 lower (2.41 lower to 0.07 higher)	LOW	CRITICAL
<b>Two-point discrimination thumb, mm (TPD) (Better indicated by lower values)</b>												
1 (Kuo 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	10	-	MD 0.03 higher (0.04 lower to 0.1 higher)	LOW	CRITICAL
<b>Semmes-Weinstein monofilaments (SWM) (Better indicated by lower values)</b>												
1 (Kuo 2016)	randomised trials	serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	10	10	-	MD 1.1 lower (2.98)	LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Hand-arm intensive manual therapy	hand-arm intensive manual therapy + tactile training	Relative (95% CI)	Absolute		
										lower to 0.78 higher)		

- 1 1 evidence was downgraded by 1 due to unclear/unknown performance bias, attrition bias, and detection bias.
- 2 2 evidence was downgraded by 1 due to serious imprecision as 95%CI crossed one default MID

3  
4  
5  
6



## **H.24<sup>1</sup> Other comorbidities in cerebral palsy**

2 Not applicable for this review

## **H.25<sup>3</sup> Social care needs**

4 Not applicable for this review

## **H.26<sup>5</sup> Transition to adult services**

6 Not applicable for this review

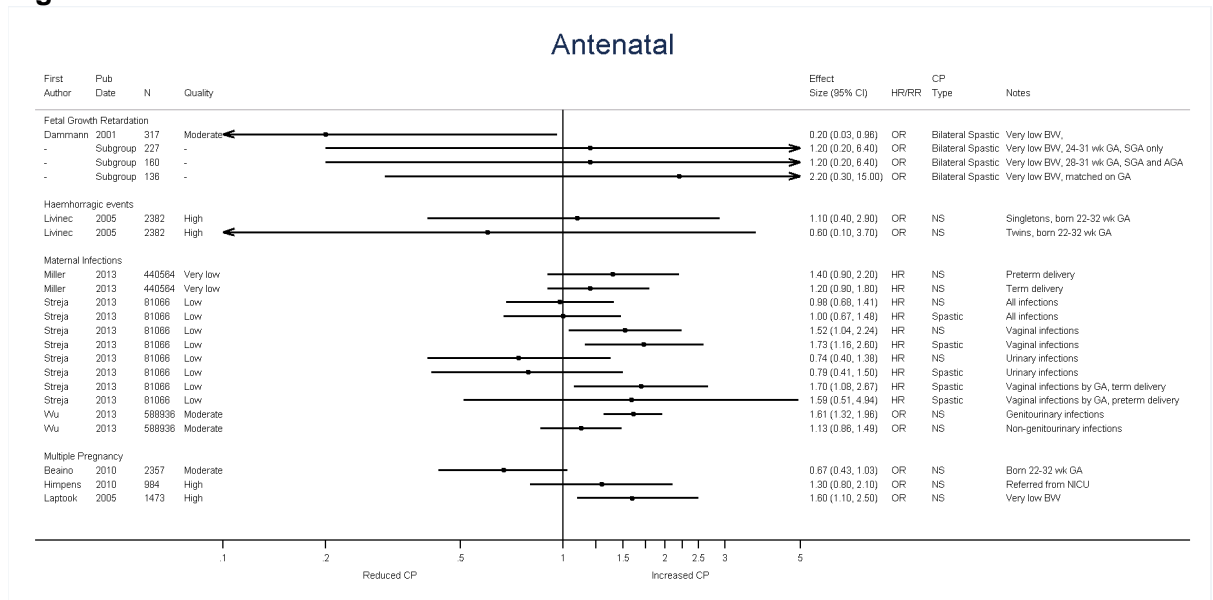
7

# 1 Appendix I: Forest Plots

## I.1.2 Risk factors

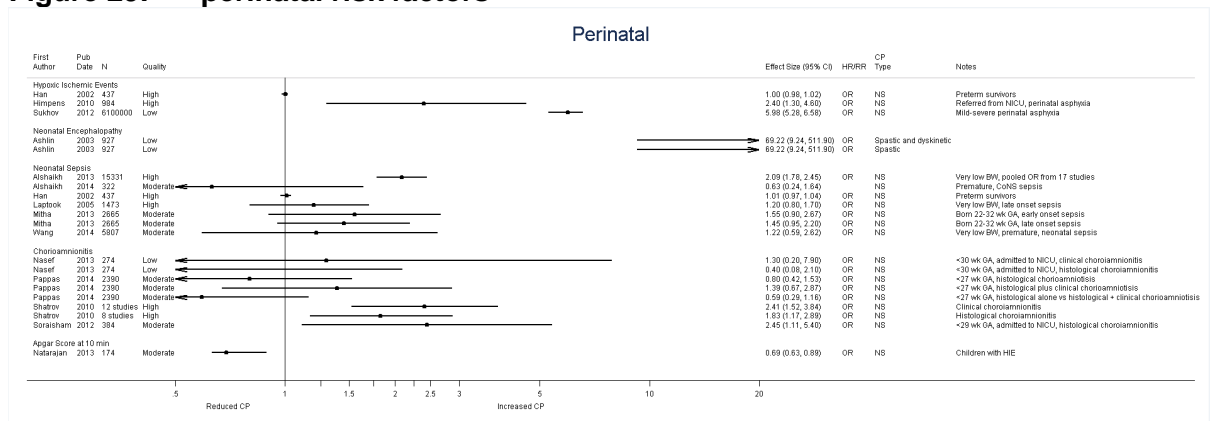
### 3 Antenatal, perinatal and postnatal risk factors

Figure 28: antenatal risk factors



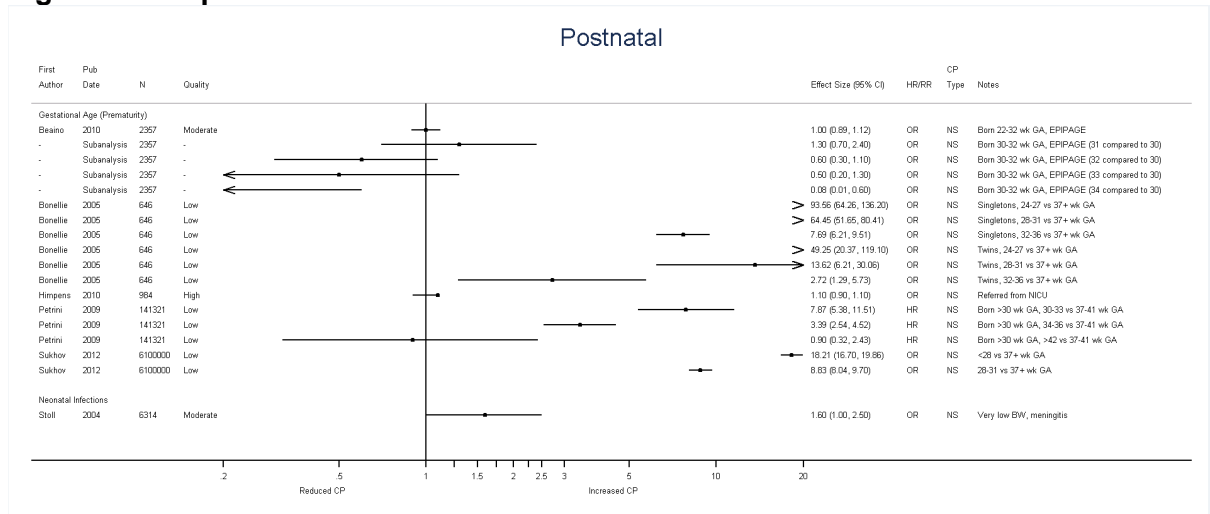
4

Figure 29: perinatal risk factors



5

**Figure 30: postnatal risk factors**



## I.2.1 Causes of cerebral palsy

2 Not applicable for this review

## I.3.3 Clinical and developmental manifestations of cerebral palsy

4 Not applicable for this review

## I.4.6 Red flags for other neurological disorders

7 Not applicable for this review

## I.5.8 MRI and identification of causes of cerebral palsy

9 Not applicable for this review

## I.6.0 MRI and prognosis of cerebral palsy

11 Not applicable for this review

## I.7.2 Prognosis for walking, talking and life expectancy

13 Not applicable for this review

## I.8.4 Information and support

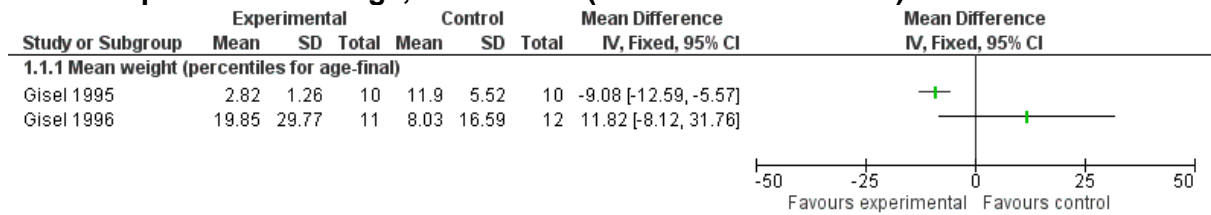
15 Not applicable for this review

## I.9.6 Assessment of eating, drinking and swallowing difficulties

17 Not applicable for this review

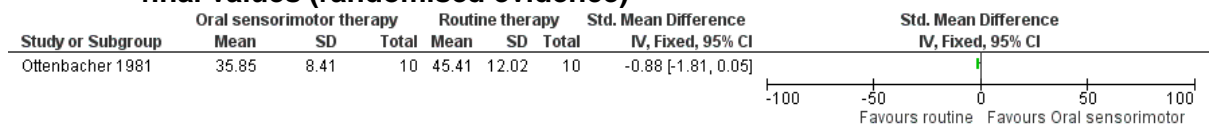
## I.10<sub>1</sub> Management of eating, drinking and swallowing difficulties

**Figure 31: Oral sensorimotor treatment versus routine treatment-weight percentiles for age, final values (randomised evidence)**



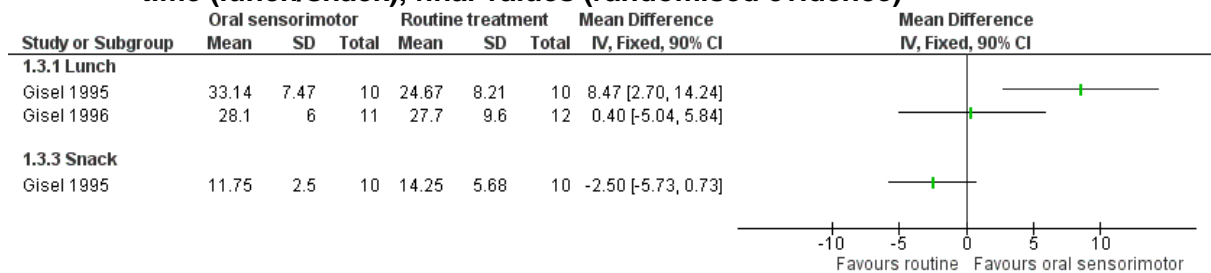
2

**Figure 32: Oral sensorimotor treatment versus routine treatment-weight (pounds) final values (randomised evidence)**



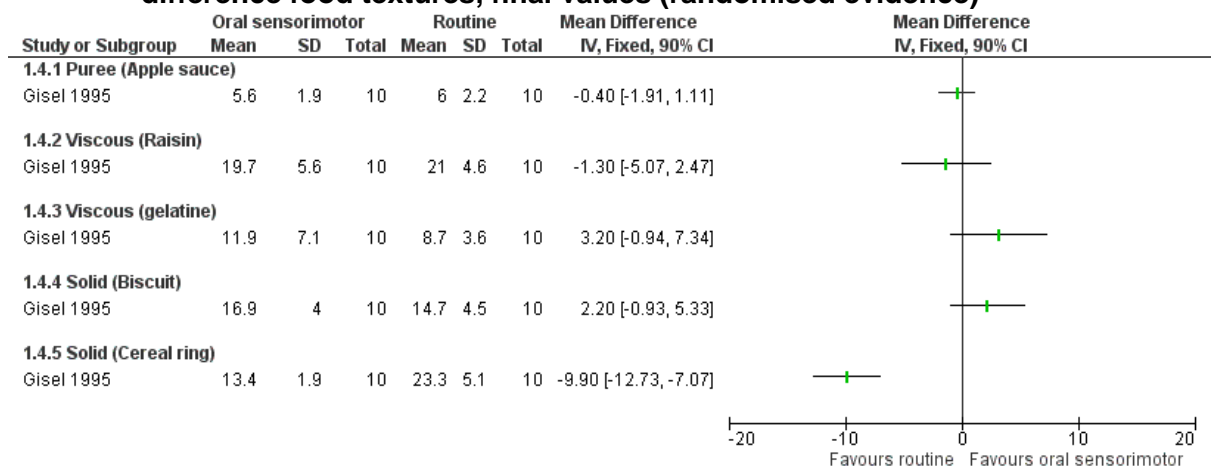
3

**Figure 33: Oral sensorimotor treatment versus routine treatment- duration of meal time (lunch/snack), final values (randomised evidence)**



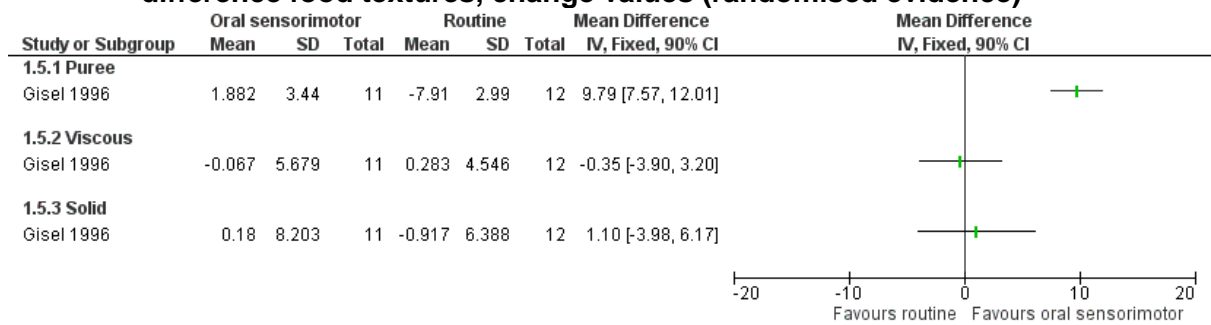
4

**Figure 34: Oral sensorimotor treatment versus routine treatment-eating time of difference food textures, final values (randomised evidence)**



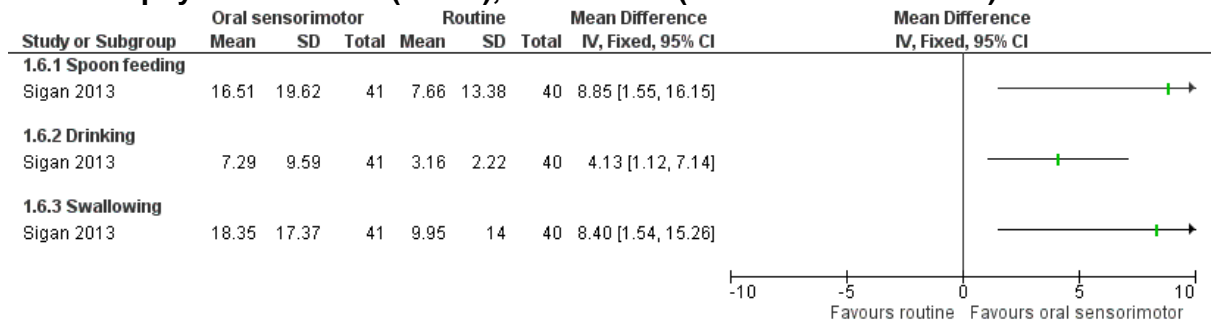
5

**Figure 35: Oral sensorimotor treatment versus routine treatment-eating time of difference food textures, change values (randomised evidence)**



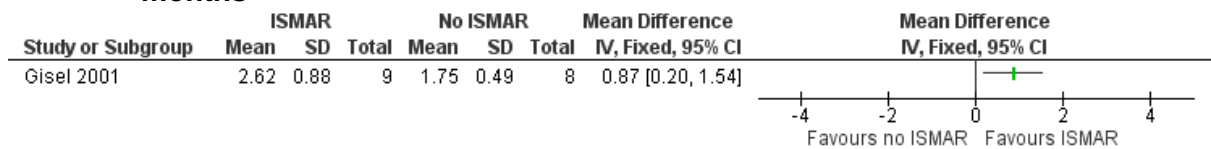
1

**Figure 36: Multi-component intervention versus routine treatment physiotherapy - physical function (mFFA), final values (randomised evidence)**



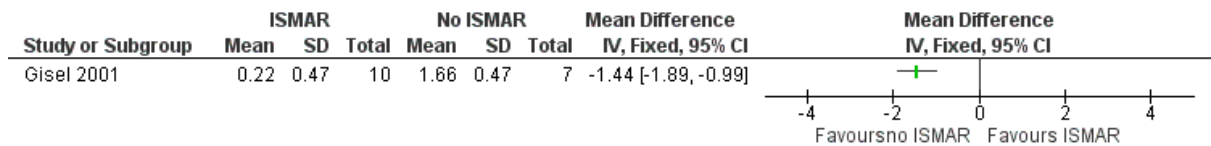
2

**Figure 37: ISMAR versus no ISMAR –weight kg, change values(cohort study) at 6 months**



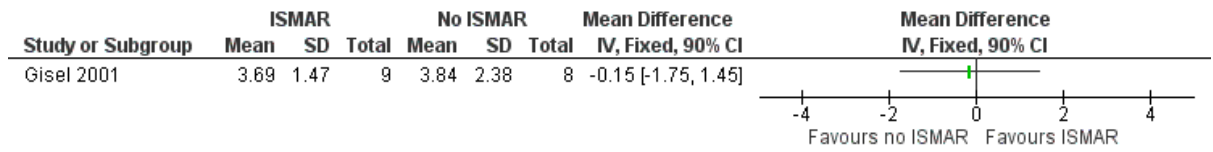
3

**Figure 38: ISMAR versus no ISMAR –weight kg, change values(cohort study) at 12months**



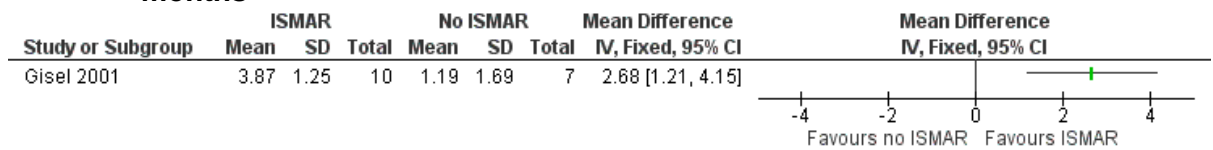
4

**Figure 39: ISMAR versus no ISMAR –height (cm), change values(cohort study) at 6 months**



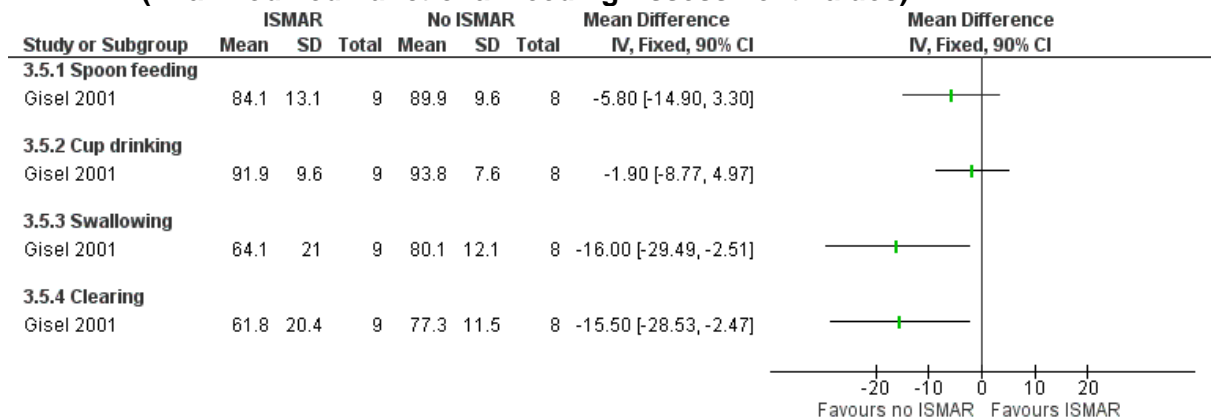
1

**Figure 40: ISMAR versus no ISMAR –height (cm), change values(cohort study) at 6 months**



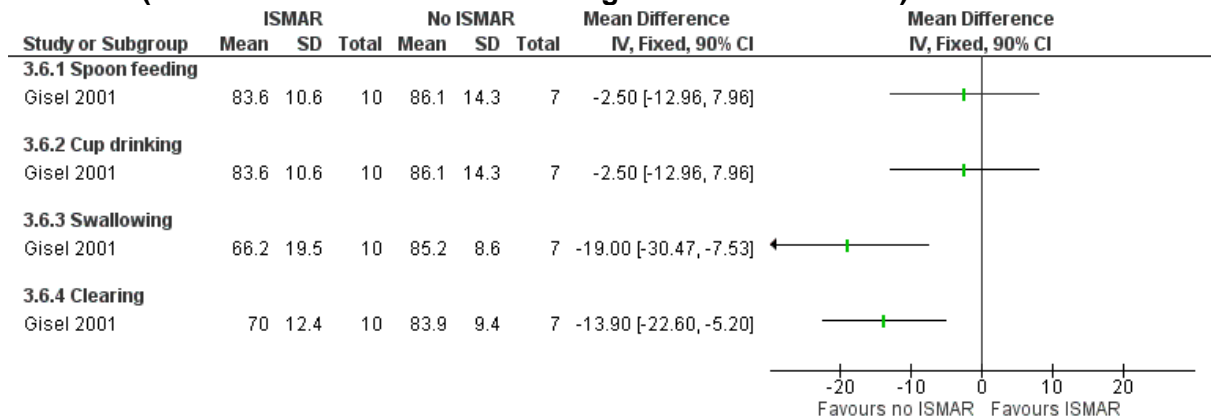
2

**Figure 41: ISMAR versus no ISMAR-competency in feeding (%) at 12-18 months (final modified Functional Feeding Assessment values)**



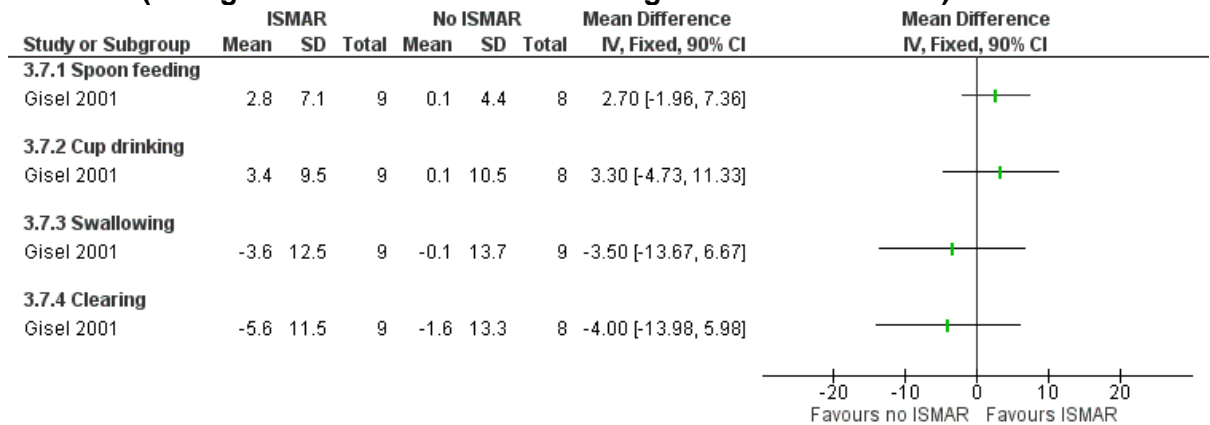
3

**Figure 42: ISMAR versus no ISMAR-competency in feeding (%) at 18-24 months (final modified Functional Feeding Assessment values)**



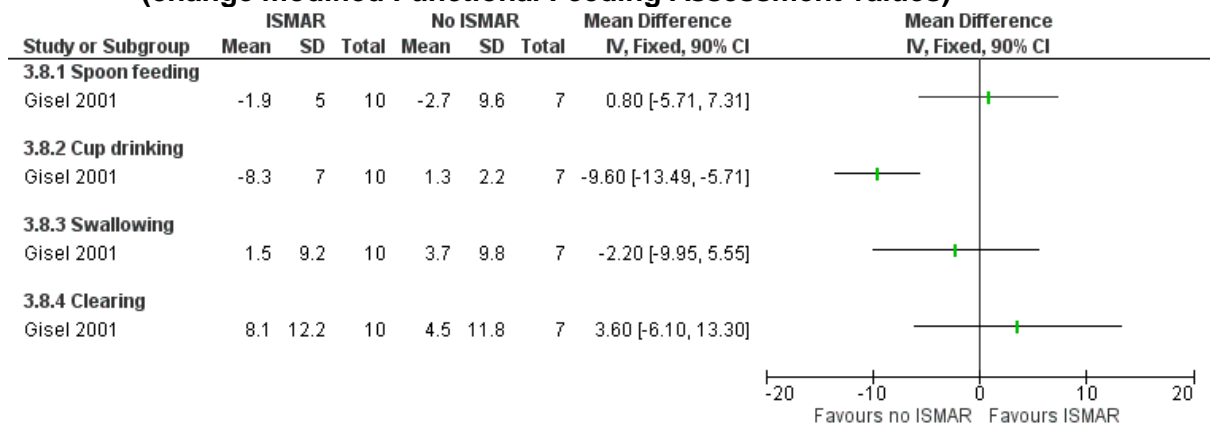
4

**Figure 43: ISMAR versus no ISMAR-competency in feeding (%) at 12-18 months (change modified Functional Feeding Assessment values)**



1

**Figure 44: ISMAR versus no ISMAR-competency in feeding (%) at 18-24 months (change modified Functional Feeding Assessment values)**

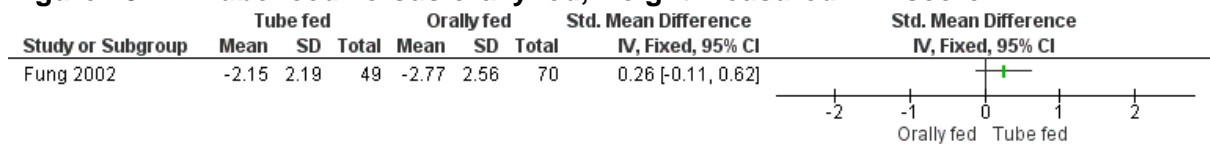


2

3

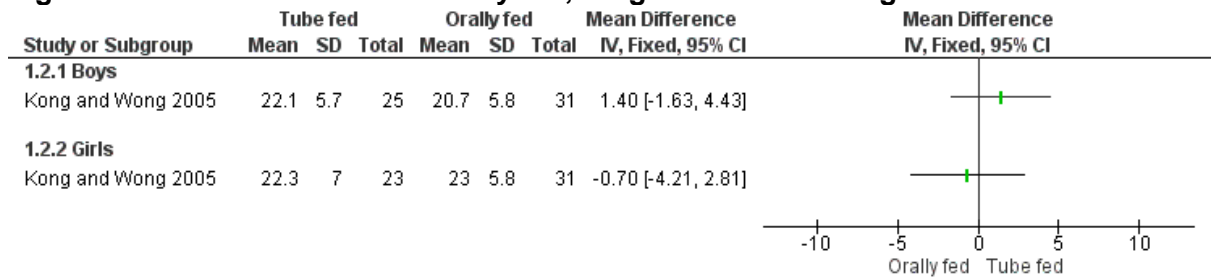
## I.11 4 Optimising nutritional status

**Figure 45: Tube feed versus orally fed, weight measured in z-score**



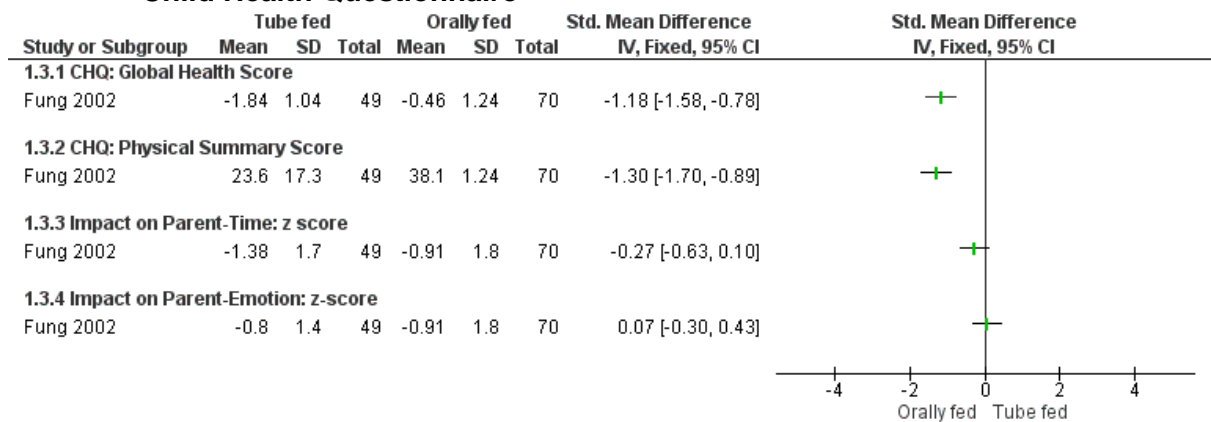
5

**Figure 46: Tube fed versus orally fed, weight measured in kg**



1

**Figure 47: Tube fed versus orally fed, health related quality of life measured by Child Health Questionnaire**



2

### I.12<sup>3</sup> Improving speech language and communication: Speech 4 intelligibility

5 Not applicable for this review

### I.13<sup>6</sup> Improving speech, language and communication: 7 Communciation systems

### I.14<sup>8</sup> Managing saliva control

9 Not applicable for this review

### I.15<sup>0</sup> Risk factors for low bone mineral density

11 Not applicable for this review

### I.16<sup>2</sup> Prevention of reduced bone mineral density

13 Not applicable for this review



**I.17<sup>1</sup> Causes of pain, distress, discomfort and sleep disturbances**

3 Not applicable for this review

**I.18<sup>4</sup> Assessment of pain, distress, discomfort and sleep disturbances**

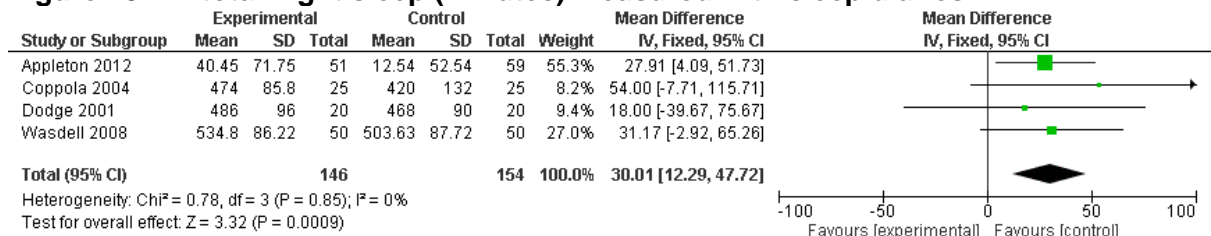
6 Not applicable for this review

**I.19<sup>7</sup> Management of pain, distress and discomfort**

8 Not applicable for this review

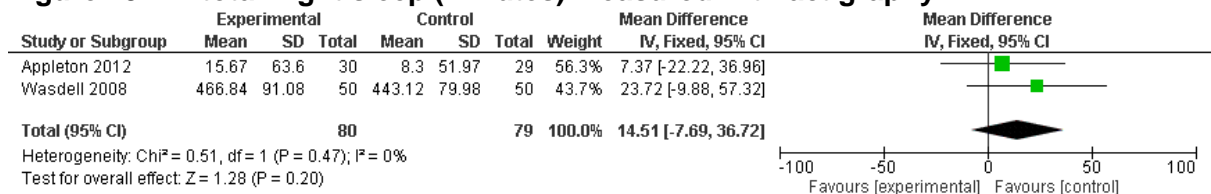
**I.20<sup>9</sup> Management of sleep disturbances**

**Figure 48: total night sleep (minutes) measured with sleep diaries**



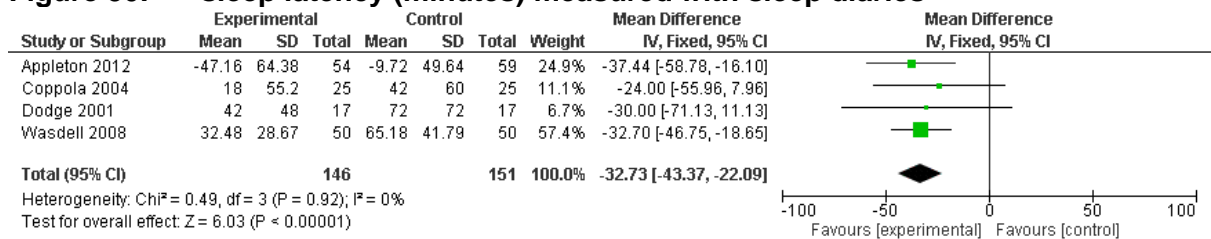
10

**Figure 49: total night sleep (minutes) measured with actigraphy**



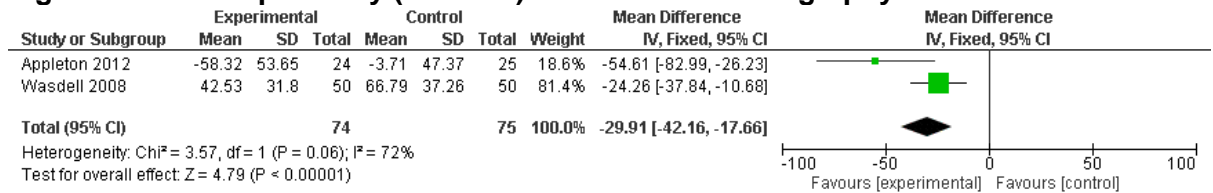
11

**Figure 50: sleep latency (minutes) measured with sleep diaries**



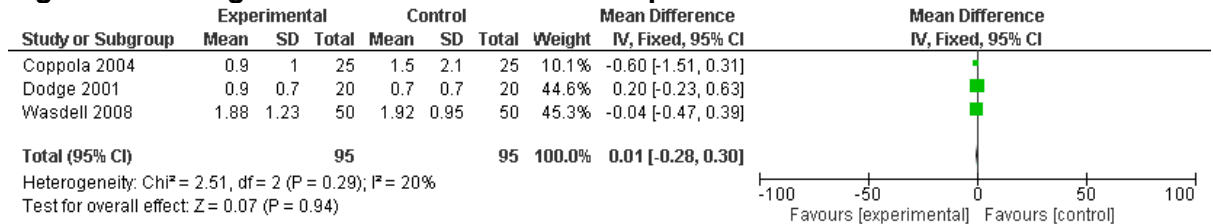
12

**Figure 51: sleep latency (minutes) measured with actigraphy**



1

**Figure 52: night wakes measured with sleep diaries**



2

### I.213 Assessment of mental health problems

4 Not applicable for this review

### I.225 Management of mental health problems

6 Not applicable for this review

### I.237 Management of sensory and perceptual difficulties

8 Not applicable for this review

### I.249 Other comorbidities in cerebral palsy

10 Not applicable for this review

### I.251 Social care needs

12 Not applicable for this review

### I.263 Transition to adult services

14 Not applicable for this review

15

16

17

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# 1 **Appendix J: Evidence Tables**

2 These can be found in a separate document.

# 1 Appendix K: Excluded Studies

## K.1.2 Risk factors

Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?	
Study	Reason for Exclusion
Abdullahi,H., Satti,M., Rayis,D.A., Imam,A.M., Adam,I., Intra-partum fever and cerebral palsy in Khartoum, Sudan, BMC Research Notes, 6, 163-, 2013	Case-control design.
Ahlin, K., Himmelmann, K., Hagberg, G., Kacerovsky, M., Cobo, T., Wennerholm, U. B., Jacobsson, B., Cerebral palsy and perinatal infection in children born at term, Obstetrics & Gynecology, 122, 41-9, 2013	Case-control design.
Allen, M. C., Neurodevelopmental outcomes of preterm infants, Current Opinion in Neurology, 21, 123-8, 2008	Non-systematic review
Al-Macki,N., Miller,S.P., Hall,N., Shevell,M., The spectrum of abnormal neurologic outcomes subsequent to term intrapartum asphyxia, Pediatric Neurology, 41, 399-405, 2009	All children had the risk factor (no comparison).
Al-Marzooq,R., Prognostic indicators of developmental outcome in preterm infants, Bahrain Medical Bulletin, 32, -, 2010	Not CP specific.
American Collge of, Obstetricians, GynecologistsGDG Neonatal encephalopathy and cerebral palsy: executive summary, Obstetrics & Gynecology, 103, 780-1, 2004	Non-systematic review.
Andersen,G.L., Irgens,L.M., Skranes,J., Salvesen,K.A., Meberg,A., Vik,T., Is breech presentation a risk factor for cerebral palsy? A Norwegian birth cohort study, Developmental Medicine and Child Neurology, 51, 860-865, 2009	Risk factor analysed not relevant to protocol.
Andrews, W. W., Cliver, S. P., Biasini, F., Peralta-Carcelen, A. M., Rector, R., Alriksson-Schmidt, A. I., Faye-Petersen, O., Carlo, W., Goldenberg, R., Hauth, J. C., Early preterm birth: association between in utero exposure to acute inflammation and severe neurodevelopmental disability at 6 years of age, American Journal of Obstetrics & Gynecology, 198, 466.e1-466.e11, 2008	This paper will be considered for the 'causes of CP' review as it reports on seizures.
Asakura, H., Ichikawa, H., Nakabayashi, M., Ando, K., Kaneko, K., Kawabata, M., Tani, A., Satoh, M., Takahashi, K., Sakamoto, S., Perinatal risk factors related to neurologic outcomes of term newborns with asphyxia at birth: A prospective study, Journal of Obstetrics and Gynaecology Research, 26, 313-324, 2000	Not CP specific.
Ayyavoo, A., Derraik, J. G., Hofman, P. L., Cutfield, W. S., Postterm births: are prolonged	Non systematic review.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
pregnancies too long?, Journal of Pediatrics, 164, 647-51, 2014	
Badawi,N., Felix,J.F., Kurinczuk,J.J., Dixon,G., Watson,L., Keogh,J.M., Valentine,J., Stanley,F.J., Cerebral palsy following term newborn encephalopathy: a population-based study, Developmental Medicine and Child Neurology, 47, 293-298, 2005	Case-control design.
Ballot,D.E., Potterton,J., Chirwa,T., Hilburn,N., Cooper,P.A., Developmental outcome of very low birth weight infants in a developing country, BMC Pediatrics, 12, 11-, 2012	Scores not risk factors.
Bangash,A.S., Hanafi,M.Z., Idrees,R., Zehra,N., Risk factors and types of cerebral palsy, JPMA - Journal of the Pakistan Medical Association, 64, 103-107, 2014	Cross-sectional design no risk factors analysis.
Bashiri,A., Burstein,E., Mazor,M., Cerebral palsy and fetal inflammatory response syndrome: A review, Journal of Perinatal Medicine, 34, 5-12, 2006	Non-systematic review.
Bax,M., Tydeman,C., Flodmark,O., Clinical and MRI correlates of cerebral palsy: the European Cerebral Palsy Study, JAMA, 296, 1602-1608, 2006	The paper reports on causes of CP rather than risk factors.
Beqaj-Zheqj, V., Etiological factors in cerebral palsy in Prishtina region, Medicinski Arhiv, 62, 20-4, 2008	No comparison group without risk factor.
Blair, E. M., Nelson, K. B., Fetal growth restriction and risk of cerebral palsy in singletons born after at least 35 weeks' gestation, American Journal of Obstetrics & Gynecology, 212, 520.e1-7, 2015	Case-control design.
Blickstein,I., Do multiple gestations raise the risk of cerebral palsy?, Clinics in Perinatology, 31, 395-408, 2004	Non-systematic review.
Brouwer,A.J., Groenendaal,F., Koopman,C., Nievelstein,R.J., Han,S.K., de Vries,L.S., Intracranial hemorrhage in full-term newborns: a hospital-based cohort study, Neuroradiology, 52, 567-576, 2010	All children had the risk factor.
Cans, C., McManus, V., Crowley, M., Guillem, P., Platt, M. J., Johnson, A., Arnaud, C., Surveillance of Cerebral Palsy in Europe Collaborative, Group, Cerebral palsy of post-neonatal origin: characteristics and risk factors, Paediatric and Perinatal Epidemiology, 18, 214-20, 2004	Wrong comparison.
Chau, V., McFadden, D. E., Poskitt, K. J., Miller, S. P., Chorioamnionitis in the pathogenesis of brain injury in preterm infants, Clinics in Perinatology, 41, 83-103, 2014	Non-systematic review.
Clark, S. M., Ghulmiyyah, L. M., Hankins, G. D., Antenatal antecedents and the impact of obstetric care in the etiology of cerebral palsy,	Non-systematic review.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Clinical Obstetrics & Gynecology, 51, 775-86, 2008	
Costantine,M.M., How,H.Y., Coppage,K., Maxwell,R.A., Sibai,B.M., Does peripartum infection increase the incidence of cerebral palsy in extremely low birthweight infants?, American Journal of Obstetrics and Gynecology, #196, e6-e8, 2007	Case-control design.
Crnkovic, M., Matijevic-Mikelic, V., Demarin, V., Kosicek, T., Morovic, S., Grazio, S., Risk factors for gross motor dysfunction of lower limbs in children, Acta Clinica Croatica, 50, 361-6, 2011	Not CP specific.
Croen, L. A., Grether, J. K., Curry, C. J., Nelson, K. B., Congenital abnormalities among children with cerebral palsy: More evidence for prenatal antecedents, Journal of Pediatrics, 138, 804-10, 2001	Case-control design.
Daher, S., El-Khair, L., Association of cerebral palsy with consanguineous parents and other risk factors in a Palestinian population, Eastern Mediterranean Health Journal, 20, 459-68, 2014	Case-control design.
Dahlseng,M.O., Andersen,G.L., Irgens,L.M., Skranes,J., Vik,T., Risk of cerebral palsy in term-born singletons according to growth status at birth, Developmental Medicine and Child Neurology, 56, 53-58, 2014	Risk factor analysed not relevant to protocol.
Davis, A. S., Hintz, S. R., Van Meurs, K. P., Li, L., Das, A., Stoll, B. J., Walsh, M. C., Pappas, A., Bell, E. F., Lupton, A. R., Higgins, R. D., Eunice Kennedy Shriver National Institute of Child, Health, Human Development Neonatal Research, Network, Seizures in extremely low birth weight infants are associated with adverse outcome, Journal of Pediatrics, 157, 720-5.e1-2, 2010	This paper will be considered for the 'causes of CP' review as it reports on seizures.
Doctor,B.A., Newman,N., Minich,N.M., Taylor,H.G., Fanaroff,A.A., Hack,M., Clinical outcomes of neonatal meningitis in very-low birth-weight infants, Clinical Pediatrics, 40, 473-480, 2001	All children had CP - no comparison.
Drougia,A., Giapros,V., Krallis,N., Theocharis,P., Nikaki,A., Tzoufi,M., Andronikou,S., Incidence and risk factors for cerebral palsy in infants with perinatal problems: a 15-year review, Early Human Development, 83, 541-547, 2007	Case-control design.
Drummond,P.M., Colver,A.F., Analysis by gestational age of cerebral palsy in singleton births in north-east England 1970-94, Paediatric and Perinatal Epidemiology, 16, 172-180, 2002	Comparison between two cohorts.
Erkin, G., Delialioglu, S. U., Ozel, S., Culha, C., Sirzai, H., Risk factors and clinical profiles in Turkish children with cerebral palsy: analysis of 625 cases, International Journal of Rehabilitation Research, 31, 89-91, 2008	No comparison made.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Eunson, P., Aetiology and epidemiology of cerebral palsy, Paediatrics and Child Health (United Kingdom), 22, 361-366, 2012	Used for references - non-systematic review.
Evans, K., Rigby, A. S., Hamilton, P., Titchiner, N., Hall, D. M. B., The relationships between neonatal encephalopathy and cerebral palsy: A cohort study, Journal of Obstetrics and Gynaecology, 21, 114-120, 2001	All children had risk factor.
Felix, J.F., Badawi, N., Kurinczuk, J.J., Bower, C., Keogh, J.M., Pemberton, P.J., Birth defects in children with newborn encephalopathy, Developmental Medicine and Child Neurology, 42, 803-808, 2000	Case-control design.
Fukuda, S., Mizuno, K., Kawai, S., Kakita, H., Goto, T., Hussein, M. H., Daoud, G. A., Ito, T., Kato, I., Suzuki, S., Togari, H., Reduction in cerebral blood flow volume in infants complicated with hypoxic ischemic encephalopathy resulting in cerebral palsy, Brain & Development, 30, 246-53, 2008	Risk factor analysed not relevant to protocol.
Fung, G., Bawden, K., Chow, P., Yu, V., Chorioamnionitis and outcome in extremely preterm infants, Annals of the Academy of Medicine Singapore, 32, 305-310, 2003	This papers has been included in a meta-analysis.
Garfinkle, J., Shevell, M.I., Cerebral palsy, developmental delay, and epilepsy after neonatal seizures, Pediatric Neurology, 44, 88-96, 2011	All children had the risk factor (no comparison).
Ghi, T., Giunchi, S., Pilu, G., Youssef, A., Morselli-Labate, A.M., Arcangeli, T., Meriggiola, M.C., Pelusi, C., Ancora, G., Cocchi, G., Faldella, G., Pelusi, G., Neonatal hypoxic-ischemic encephalopathy in apparently low risk pregnancies: retrospective analysis of the last five years at the University of Bologna, Journal of Maternal-Fetal and Neonatal Medicine, 23, 516-521, 2010	Not CP specific.
Gibson, C. S., MacLennan, A. H., Goldwater, P. N., Haan, E. A., Priest, K., Dekker, G. A., Neurotropic viruses and cerebral palsy: Population based case-control study, British Medical Journal, 332, 76-79, 2006	Incomplete study.
Gilbert, W. M., Jacoby, B. N., Xing, G., Danielsen, B., Smith, L. H., Adverse obstetric events are associated with significant risk of cerebral palsy, American Journal of Obstetrics & Gynecology, 203, 328.e1-5, 2010	OR not reported.
Glinianaia, S. V., Jarvis, S., Topp, M., Guillem, P., Platt, M. J., Pearce, M. S., Parker, L., Scape Collaboration of European Cerebral Palsy Registers, Intrauterine growth and cerebral palsy in twins: a European multicenter study, Twin Research & Human Genetics: the Official Journal of the International Society for Twin Studies, 9, 460-6, 2006	Not a cohort design and unadjusted analysis.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Glinianaia, S. V., Pharoah, P. O., Wright, C., Rankin, J. M., Northern Region Perinatal Mortality Survey Steering, Group, Fetal or infant death in twin pregnancy: neurodevelopmental consequence for the survivor, Archives of Disease in Childhood Fetal & Neonatal Edition, 86, F9-15, 2002	Risk factor analysed not relevant to protocol.
Glinianaia, S. V., Rankin, J., Colver, A., North of England Collaborative Cerebral Palsy, Survey, Cerebral palsy rates by birth weight, gestation and severity in North of England, 1991-2000 singleton births, Archives of Disease in Childhood, 96, 180-5, 2011	Comparisons between decades.
Goelz,R., Meisner,C., Bevot,A., Hamprecht,K., Kraegeloh-Mann,I., Poets,C.F., Long-term cognitive and neurological outcome of preterm infants with postnatally acquired CMV infection through breast milk, Archives of Disease in Childhood Fetal and Neonatal Edition, 98, F430-F433, 2013	Case-control design.
Goldstein, R. F., Cotten, C. M., Shankaran, S., Gantz, M. G., Poole, W. K., Influence of gestational age on death and neurodevelopmental outcome in premature infants with severe intracranial hemorrhage, Journal of Perinatology, 33, 25-32, 2013	Not specific to CP.
Golomb,M.R., Garg,B.P., Saha,C., Azzouz,F., Williams,L.S., Cerebral palsy after perinatal arterial ischemic stroke, Journal of Child Neurology, 23, 279-286, 2008	Risk factor analysed not relevant to protocol.
Gray,P.H., Jones,P., O'Callaghan,M.J., Maternal antecedents for cerebral palsy in extremely preterm babies: a case-control study, Developmental Medicine and Child Neurology, 43, 580-585, 2001	Case-control design.
Greenwood,C., Yudkin,P., Sellers,S., Impey,L., Doyle,P., Why is there a modifying effect of gestational age on risk factors for cerebral palsy?, Archives of Disease in Childhood Fetal and Neonatal Edition, 90, F141-F146, 2005	Case-control design.
Grobman, W. A., Lai, Y., Rouse, D. J., Spong, C. Y., Varner, M. W., Mercer, B. M., Leveno, K. J., Iams, J. D., Wapner, R. J., Sorokin, Y., Thorp, J. M., Jr., Ramin, S. M., Malone, F. D., O'Sullivan, M. J., Hankins, G. D., Caritis, S. N., Eunice Kennedy Shriver National Institute of Child, Health, Human Development Maternal-Fetal Medicine Units, Network, The association of cerebral palsy and death with small-for-gestational-age birthweight in preterm neonates by individualised and population-based percentiles, American Journal of Obstetrics & Gynecology, 209, 340.e1-5, 2013	No relevant comparison.
Guellec, I., Lapillonne, A., Renolleau, S., Charlaluk, M. L., Roze, J. C., Marret, S., Vieux, R., Monique, K., Ancel, P. Y., Epipage Study	Risk factor analysed not relevant to protocol.



<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Group, Neurologic outcomes at school age in very preterm infants born with severe or mild growth restriction, <i>Pediatrics</i> , 127, e883-91, 2011	
Gurbuz,A., Karateke,A., Yilmaz,U., Kabaca,C., The role of perinatal and intrapartum risk factors in the etiology of cerebral palsy in term deliveries in a Turkish population, <i>Journal of Maternal-Fetal and Neonatal Medicine</i> , #19, 147-Fetal, 2006	Case-control design risk factor not relevant to review protocol.
Hagberg, B., Hagberg, G., Beckung, E., Uvebrant, P., Changing panorama of cerebral palsy in Sweden. VIII. Prevalence and origin in the birth year period 1991-94, <i>Acta Paediatrica</i> , 90, 271-7, 2001	Description of trend of prevalence of CP.
Hemming,K., Hutton,J.L., Bonellie,S., Kurinczuk,J.J., Intrauterine growth and survival in cerebral palsy, <i>Archives of Disease in Childhood Fetal and Neonatal Edition</i> , 93, F121-F126, 2008	Outcome = survival.
Himmelmann, K., Hagberg, G., Beckung, E., Hagberg, B., Uvebrant, P., The changing panorama of cerebral palsy in Sweden. IX. Prevalence and origin in the birth-year period 1995-1998, <i>Acta Paediatrica, International Journal of Paediatrics</i> , 94, 287-294, 2005	Trends in prevalence of CP reported.
Himmelmann,K., Ahlin,K., Jacobsson,B., Cans,C., Thorsen,P., Risk factors for cerebral palsy in children born at term, <i>Acta Obstetrica et Gynecologica Scandinavica</i> , 90, 1070-1081, 2011	No quality appraisal of studies.
Himpens, E., Oostra, A., Franki, I., Van Maele, G., Vanhaesebrouck, P., Van Den Broeck, C., Predictability of cerebral palsy and its characteristics through neonatal cranial ultrasound in a high-risk NICU population, <i>European Journal of Pediatrics</i> , 169, 1213-1219, 2010	Reports on causes of CP rather than risk factors.
Himpens, E., Van den Broeck, C., Oostra, A., Calders, P., Vanhaesebrouck, P., Prevalence, type, distribution, and severity of cerebral palsy in relation to gestational age: a meta-analytic review, <i>Developmental Medicine &amp; Child Neurology</i> , 50, 334-40, 2008	This meta-analysis includes old studies a more recent one has been considered.
Hintz, S. R., Kendrick, D. E., Vohr, B. R., Poole, W. K., Higgins, R. D., National Institute of Child, Health, Human Development Neonatal Research, Network, Changes in neurodevelopmental outcomes at 18 to 22 months' corrected age among infants of less than 25 weeks' gestational age born in 1993-1999, <i>Pediatrics</i> , 115, 1645-51, 2005	Comparisons between decades are presented.
Hirvonen, M., Ojala, R., Korhonen, P., Haataja, P., Eriksson, K., Gissler, M., Luukkaala, T., Tammela, O., Cerebral palsy among children	This paper reports incidence of CP in different gestational age groups, but not risk factor analysis.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
born moderately and late preterm, <i>Pediatrics</i> , 134, e1584-93, 2014	
Horvath,B., Grasselly,M., Bodecs,T., Boncz,I., Bodis,J., Histological chorioamnionitis is associated with cerebral palsy in preterm neonates, <i>European Journal of Obstetrics Gynecology and Reproductive Biology</i> , 163, 160-164, 2012	Unadjusted analysis only.
Jacobs, S. E., O'Brien, K., Inwood, S., Kelly, E. N., Whyte, H. E., Outcome of infants 23-26 weeks' gestation pre and post surfactant, <i>Acta Paediatrica, International Journal of Paediatrics</i> , 89, 959-965, 2000	Comparison between pre- and post-intervention reported.
Jacobsson,B., Ahlin,K., Francis,A., Hagberg,G., Hagberg,H., Gardosi,J., Cerebral palsy and restricted growth status at birth: population-based case-control study, <i>BJOG: An International Journal of Obstetrics and Gynaecology</i> , 115, 1250-1255, 2008	Case-control design.
Jacobsson,B., Hagberg,G., Hagberg,B., Ladfors,L., Niklasson,A., Hagberg,H., Cerebral palsy in preterm infants: a population-based case-control study of antenatal and intrapartum risk factors, <i>Acta Paediatrica</i> , 91, 946-951, 2002	Case-control design
Jarjour, I. T., Neurodevelopmental outcome after extreme prematurity: A review of the literature, <i>Pediatric Neurology</i> , 52, 143-152, 2015	Non-systematic review.
Jarvis, S., Glinianaia, S. V., Arnaud, C., Fauconnier, J., Johnson, A., McManus, V., Topp, M., Uvebrant, P., Cans, C., Krageloh-Mann, I., Scape collaboration of European Cerebral Palsy Registers, Case gender and severity in cerebral palsy varies with intrauterine growth, <i>Archives of Disease in Childhood</i> , 90, 474-9, 2005	All children had CP - no comparison.
Jensen, L. V., Mathiasen, R., Molholm, B., Greisen, G., Low 5-min Apgar score in moderately preterm infants; association with subsequent death and cerebral palsy: a register based Danish national study, <i>Acta Paediatrica</i> , 101, e80-2, 2012	Risk factor not relevant to review protocol.
Johnson,S., Fawke,J., Hennessy,E., Rowell,V., Thomas,S., Wolke,D., Marlow,N., Neurodevelopmental disability through 11 years of age in children born before 26 weeks of gestation, <i>Pediatrics</i> , 124, e249-e257, 2009	Case-control study design.
Kaneko,M., Sameshima,H., Ikeda,T., Ikenoue,T., Minematsu,T., Intrapartum fetal heart rate monitoring in cases of cytomegalovirus infection, <i>American Journal of Obstetrics and Gynecology</i> , 191, 1257-1262, 2004	Case-control design no relevant risk factors presented.
Kipiani,T., Tatishvili,N., Sirbiladze,Ts, Long-term neurological development of the preterm newborns, <i>Georgian Medical News</i> , 42-45, 2007	Case-control design.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Klebermass-Schrehof, K., Czaba, C., Olischar, M., Fuiko, R., Waldhoer, T., Rona, Z., Pollak, A., Weninger, M., Impact of low-grade intraventricular hemorrhage on long-term neurodevelopmental outcome in preterm infants, <i>Childs Nervous System</i> , 28, 2085-92, 2012	Cause rather than risk factor.
Kosuge, S., Ohkuchi, A., Minakami, H., Matsubara, S., Uchida, A., Eguchi, Y., Honma, Y., Sato, I., Influence of chorioamnionitis on survival and morbidity in singletons live-born at < 32 weeks of gestation, <i>Acta Obstetrica et Gynecologica Scandinavica</i> , 79, 861-865, 2000	Not CP specific.
Krebs, L., Langhoff-Roos, J., Thorngren-Jerneck, K., Long-term outcome in term breech infants with low Apgar score--a population-based follow-up, <i>European Journal of Obstetrics, Gynecology, &amp; Reproductive Biology</i> , 100, 5-8, 2001	Not CP specific.
Kuban, K. C., O'Shea, T. M., Allred, E. N., Fichorova, R. N., Heeren, T., Paneth, N., Hirtz, D., Dammann, O., Leviton, A., Elgan Study Investigators, The breadth and type of systemic inflammation and the risk of adverse neurological outcomes in extremely low gestation newborns, <i>Pediatric Neurology</i> , 52, 42-8, 2015	The paper reports on cause rather than risk factor for CP.
Kuban, K. C., O'Shea, T. M., Allred, E. N., Paneth, N., Hirtz, D., Fichorova, R. N., Leviton, A., Elgan Study Investigators, Systemic inflammation and cerebral palsy risk in extremely preterm infants, <i>Journal of Child Neurology</i> , 29, 1692-8, 2014	No relevant risk factors.
Lee, J., Croen, L.A., Lindan, C., Nash, K.B., Yoshida, C.K., Ferriero, D.M., Barkovich, A.J., Wu, Y.W., Predictors of outcome in perinatal arterial stroke: a population-based study, <i>Annals of Neurology</i> , 58, 303-308, 2005	Risk factor analysed not relevant to protocol.
Lehman, L. L., Rivkin, M. J., Perinatal arterial ischemic stroke: presentation, risk factors, evaluation, and outcome, <i>Pediatric Neurology</i> , 51, 760-8, 2014	Risk factor for perinatal arterial ischemic stroke included, not risk factor for development of CP.
Lie, K.K., Groholt, E.K., Eskild, A., Association of cerebral palsy with Apgar score in low and normal birthweight infants: population based cohort study, <i>BMJ</i> , 341, c4990-, 2010	Risk factor analysed not relevant to protocol.
Lindstrom, K., Hallberg, B., Blennow, M., Wolff, K., Fernell, E., Westgren, M., Moderate neonatal encephalopathy: pre- and perinatal risk factors and long-term outcome, <i>Acta Obstetrica et Gynecologica Scandinavica</i> , 87, 503-509, 2008	Risk factor analysed not relevant to protocol.
Liu, J., Li, Z., Lin, Q., Zhao, P., Zhao, F., Hong, S., Li, S., Cerebral palsy and multiple births in China, <i>International Journal of Epidemiology</i> , 29, 292-9, 2000	Results are unadjusted.
Lodha, A., Sauve, R., Chen, S., Tang, S., Christianson, H., Clinical Risk Index for Babies	Not CP specific.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
score for the prediction of neurodevelopmental outcomes at 3 years of age in infants of very low birthweight, <i>Developmental Medicine and Child Neurology</i> , 51, 895-900, 2009	
Luciano, R., Baranello, G., Masini, L., Ricci, D., Gallini, F., Ciotti, S., Leone, D., Serrao, F., De Santis, M., Zecca, E., Zuppa, A., Romagnoli, C., Di Rocco, C., Guzzetta, F., Mercuri, E., Antenatal post-hemorrhagic ventriculomegaly: a prospective follow-up study, <i>Neuropediatrics</i> , 38, 137-42, 2007	Not included as risk factor in protocol.
Mann, J. R., McDermott, S., Griffith, M. I., Hardin, J., Gregg, A., Uncovering the complex relationship between pre-eclampsia, preterm birth and cerebral palsy, <i>Paediatric and Perinatal Epidemiology</i> , 25, 100-10, 2011	Risk factor not relevant to review protocol.
Manuck, T.A., Sheng, X., Yoder, B.A., Varner, M.W., Correlation between initial neonatal and early childhood outcomes following preterm birth, <i>American Journal of Obstetrics and Gynecology</i> , 210, 426-429, 2014	This paper will be considered for the 'causes of CP' review as it reports on seizures.
Marlow, N., Pike, K., Bower, E., Brocklehurst, P., Jones, D., Kenyon, S., Kurinczuk, J.J., Taylor, D., Salt, A., Characteristics of children with cerebral palsy in the ORACLE children study, <i>Developmental Medicine and Child Neurology</i> , 54, 640-646, 2012	Risk factor analysed not relevant to protocol.
Marret, S., Ancel, P. Y., Marpeau, L., Marchand, L., Pierrat, V., Larroque, B., Foix-L'Hélias, L., Thiriez, G., Fresson, J., Alberge, C., Roze, J. C., Matis, J., Breart, G., Kaminski, M., Epipage Study, Neonatal and 5-year outcomes after birth at 30-34 weeks of gestation, <i>Obstetrics &amp; Gynecology</i> , 110, 72-80, 2007	This paper has been included in a recent meta-analysis which is part of the review.
Matsuda, Y., Maeda, T., Kouno, S., Comparison of neonatal outcome including cerebral palsy between abruptio placentae and placenta previa, <i>European Journal of Obstetrics Gynecology and Reproductive Biology</i> , 106, 125-129, 2003	Not included as risk factor in protocol.
Matsuda, Y., Kouno, S., Hiroyama, Y., Kuraya, K., Kamitomo, M., Ibara, S., Hatae, M., Intrauterine infection, magnesium sulfate exposure and cerebral palsy in infants born between 26 and 30 weeks of gestation, <i>European Journal of Obstetrics Gynecology and Reproductive Biology</i> , 91, 159-164, 2000	Case-control design.
McIntyre, S., Badawi, N., Brown, C., Blair, E., Population case-control study of cerebral palsy: neonatal predictors for low-risk term singletons, <i>Pediatrics</i> , 127, e667-e673, 2011	Case-control design.
McIntyre, S., Taitz, D., Keogh, J., Goldsmith, S., Badawi, N., Blair, E., A systematic review of risk factors for cerebral palsy in children born at term in developed countries, <i>Developmental Medicine and Child Neurology</i> , 55, 499-508, 2013	Included studies have been published before 2000 risk of bias analysis not presented.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
McMichael, G., MacLennan, A., Gibson, C., Alvino, E., Goldwater, P., Haan, E., Dekker, G., Australian Collaborative Cerebral Palsy Research, Group, Cytomegalovirus and Epstein-Barr virus may be associated with some cases of cerebral palsy, <i>Journal of Maternal-Fetal &amp; Neonatal Medicine</i> , 25, 2078-81, 2012	Case-control design.
Mendez-Figueroa, H., Dahlke, J.D., Viteri, O.A., Chauhan, S.P., Rouse, D.J., Sibai, B.M., Blackwell, S.C., Neonatal and infant outcomes in twin gestations with preterm premature rupture of membranes at 24-31 weeks of gestation, <i>Obstetrics and Gynecology</i> , 124, 323-331, 2014	All children had the risk factors, no comparison made.
Menticoglou, S.M., How often do perinatal events at full term cause cerebral palsy?, <i>Journal of Obstetrics and Gynaecology Canada: JOGC</i> , 30, 396-403, 2008	Risk factor not listed in protocol.
Moore, G. P., Lemyre, B., Barrowman, N., Daboval, T., Neurodevelopmental outcomes at 4 to 8 years of children born at 22 to 25 weeks' gestational age: A meta-analysis, <i>JAMA Pediatrics</i> , 167, 967-974, 2013	Not CP specific.
Moore, T., Hennessy, E.M., Myles, J., Johnson, S.J., Draper, E.S., Costeloe, K.L., Marlow, N., Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies, <i>BMJ</i> , 345, e7961-, 2012	All children had the risk factor.
Mukhopadhyay, K., Malhi, P., Mahajan, R., Narang, A., Neurodevelopmental and behavioral outcome of very low birth weight babies at corrected age of 2 years, <i>Indian Journal of Pediatrics</i> , 77, 963-967, 2010	Not relevant risk factor.
Mwaniki, M.K., Atieno, M., Lawn, J.E., Newton, C.R., Long-term neurodevelopmental outcomes after intrauterine and neonatal insults: a systematic review, <i>Lancet</i> , 379, 445-452, 2012	Not specific to CP it includes old studies.
Nelson, K.B., Grether, J.K., Dambrosia, J.M., Walsh, E., Kohler, S., Satyanarayana, G., Nelson, P.G., Dickens, B.F., Phillips, T.M., Neonatal cytokines and cerebral palsy in very preterm infants, <i>Pediatric Research</i> , 53, 600-607, 2003	Not included as risk factor in protocol.
Neufeld, M.D., Frigon, C., Graham, A.S., Mueller, B.A., Maternal infection and risk of cerebral palsy in term and preterm infants, <i>Journal of Perinatology</i> , 25, 108-113, 2005	Case-control design.
Nordmark, E., Hagglund, G., Lagergren, J., Cerebral palsy in southern Sweden I. Prevalence and clinical features, <i>Acta Paediatrica</i> , 90, 1271-1276, 2001	Distribution of CP only reported, no risk factors analysis presented.
O'Shea, T. M., Allred, E. N., Dammann, O., Hirtz, D., Kuban, K. C., Paneth, N., Leviton, A., Elgan study Investigators, The ELGAN study of the brain and related disorders in extremely low	This paper studies causes rather than risk factors.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
gestational age newborns, Early Human Development, 85, 719-25, 2009	
O'Shea, T. M., Allred, E. N., Kuban, K. C., Hirtz, D., Specter, B., Durfee, S., Paneth, N., Leviton, A., Elgan Study Investigators, Intraventricular hemorrhage and developmental outcomes at 24 months of age in extremely preterm infants, Journal of Child Neurology, 27, 22-9, 2012	The paper reports on causes rather than risk factors.
Ozturk,A., Demirci,F., Yavuz,T., Yildiz,S., Degirmenci,Y., Dosoglu,M., Avsar,Y., Antenatal and delivery risk factors and prevalence of cerebral palsy in Duzce (Turkey), Brain and Development, 29, 39-42, 2007	Cross-sectional design unadjusted.
Patrick, L. A., Smith, G. N., Proinflammatory cytokines: a link between chorioamnionitis and fetal brain injury, Journal of Obstetrics & Gynaecology Canada: JOGC, 24, 705-9, 2002	Non systematic review.
Payne, A. H., Hintz, S. R., Hibbs, A. M., Walsh, M. C., Vohr, B. R., Bann, C. M., Wilson-Costello, D. E., Eunice Kennedy Shriver National Institute of Child, Health, Human Development Neonatal Research, Network, Neurodevelopmental outcomes of extremely low-gestational-age neonates with low-grade periventricular-intraventricular hemorrhage, JAMA Pediatrics, 167, 451-9, 2013	The paper reports on causes of CP rather than on risk factors.
Pharoah, P. O., Risk of cerebral palsy in multiple pregnancies, Obstetrics & Gynecology Clinics of North America, 32, 55-67, viii, 2005	Non systematic review.
Pharoah,P.O.D., Risk of Cerebral Palsy in Multiple Pregnancies, Clinics in Perinatology, 33, 301-313, 2006	Non-systematic review.
Pinborg,A., Loft,A., Schmidt,L., Greisen,G., Rasmussen,S., Andersen,A.N., Neurological sequelae in twins born after assisted conception: controlled national cohort study, BMJ, 329, 311-, 2004	Risk factor analysed not relevant to protocol.
Platt,M.J., Cans,C., Johnson,A., Surman,G., Topp,M., Torrioli,M.G., Krageloh-Mann,I., Trends in cerebral palsy among infants of very low birthweight (<1500 g) or born prematurely (<32 weeks) in 16 European centres: a database study, Lancet, 369, 43-50, 2007	The papers reports on trends of CP.
Pritchard,M.A., Colditz,P.B., Cartwright,D., Gray,P.H., Tudehope,D., Beller,E., Risk determinants in early intervention use during the first postnatal year in children born very preterm, BMC Pediatrics, 13, 201-, 2013	Risk determinants of early interventions.
Qiu,H., Paneth,N., Lorenz,J.M., Collins,M., Labor and delivery factors in brain damage, disabling cerebral palsy, and neonatal death in low-birth-weight infants, American Journal of Obstetrics and Gynecology, 189, 1143-1149, 2003	Results are unadjusted.
Qiu,H.B., Wang,Z.G., Li,X.J., Wang,B.Y., Jiang,Z.M., Multi-factor logistic regression	Case-control design.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
analysis on risk factors of prenatal infantile cerebral palsy, Chinese Journal of Clinical Rehabilitation, 9, 158-161, 2005	
Ramaswamy,V., Miller,S.P., Barkovich,A.J., Partridge,J.C., Ferriero,D.M., Perinatal stroke in term infants with neonatal encephalopathy, Neurology, 62, 2088-2091, 2004	Risk factor not relevant to review protocol.
Redline, R. W., O'Riordan, M. A., Placental lesions associated with cerebral palsy and neurologic impairment following term birth, Archives of Pathology & Laboratory Medicine, 124, 1785-91, 2000	Not CP specific
Redline,R.W., Severe fetal placental vascular lesions in term infants with neurologic impairment, American Journal of Obstetrics and Gynecology, 192, 452-457, 2005	Case-control design.
Redline,R.W., Minich,N., Taylor,H.G., Hack,M., Placental lesions as predictors of cerebral palsy and abnormal neurocognitive function at school age in extremely low birth weight infants (<1 kg), Pediatric and Developmental Pathology, 10, 282-292, 2007	No relevant risk factors.
Reid, S. M., Lanigan, A., Reddihough, D. S., Post-neonatally acquired cerebral palsy in Victoria, Australia, 1970-1999, Journal of Paediatrics & Child Health, 42, 606-11, 2006	Comparison of decades - not a risk factors study.
Roze,E., Kerstjens,J.M., Maathuis,C.G., Ter Horst,H.J., Bos,A.F., Risk factors for adverse outcome in preterm infants with periventricular hemorrhagic infarction, Pediatrics, 122, e46-e52, 2008	Risk factor not relevant to review protocol unadjusted results.
Sameshima,H., Ikenoue,T., Developmental effects on neonatal mortality and subsequent cerebral palsy in infants exposed to intrauterine infection, Early Human Development, 83, 517-519, 2007	Results are not adjusted.
Schendel, D. E., Infection in pregnancy and cerebral palsy, Journal of the American Medical Womens Association, 56, 105-8, 2001	Non systematic review.
Scher,A.I., Petterson,B., Blair,E., Ellenberg,J.H., Grether,J.K., Haan,E., Reddihough,D.S., Yeargin-Allsopp,M., Nelson,K.B., The risk of mortality or cerebral palsy in twins: a collaborative population-based study, Pediatric Research, 52, 671-681, 2002	Risk of mortality in CP.
Schlapbach, L. J., Adams, M., Proietti, E., Aebischer, M., Grunt, S., Borradori-Tolsa, C., Bickle-Graz, M., Bucher, H. U., Latal, B., Natalucci, G., Swiss Neonatal, Network, Follow-up, Group, Outcome at two years of age in a Swiss national cohort of extremely preterm infants born between 2000 and 2008, BMC Pediatrics, 12, 198, 2012	Not CP specific.
Schlapbach, L. J., Aebischer, M., Adams, M., Natalucci, G., Bonhoeffer, J., Latzin, P., Nelle, M., Bucher, H. U., Latal, B., Swiss Neonatal,	This study has been included in a recent meta-analysis.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Network, Follow-Up, Group, Impact of sepsis on neurodevelopmental outcome in a Swiss National Cohort of extremely premature infants, <i>Pediatrics</i> , 128, e348-57, 2011	
Schlapbach, L. J., Ersch, J., Adams, M., Bernet, V., Bucher, H. U., Latal, B., Impact of chorioamnionitis and preeclampsia on neurodevelopmental outcome in preterm infants below 32 weeks gestational age, <i>Acta Paediatrica</i> , 99, 1504-9, 2010	Case-control study design.
Shankaran,S., Johnson,Y., Langer,J.C., Vohr,B.R., Fanaroff,A.A., Wright,L.L., Poole,W.K., Outcome of extremely-low-birth-weight infants at highest risk: gestational age < or =24 weeks, birth weight < or =750 g, and 1-minute Apgar < or =3, <i>American Journal of Obstetrics and Gynecology</i> , 191, 1084-1091, 2004	Not relevant risk factor.
Shevell, A., Wintermark, P., Benini, R., Shevell, M., Oskoui, M., Chorioamnionitis and cerebral palsy: lessons from a patient registry, <i>European Journal of Paediatric Neurology</i> , 18, 301-7, 2014	Unavailable paper.
Skrablin, S., Kuvacic, I., Simunic, V., Bosnjak-Nadj, K., Kalafatic, D., Banovic, V., Long-term neurodevelopmental outcome of triplets, <i>European Journal of Obstetrics, Gynecology, &amp; Reproductive Biology</i> , 132, 76-82, 2007	Incidence of ND in triplets - no comparison.
Soleimani, F., Vameghi, R., Biglarian, A., Antenatal and intrapartum risk factors for cerebral palsy in term and near-term newborns, <i>Archives of Iranian Medicine</i> , 16, 213-6, 2013	Unavailable paper.
Soleimani,F., Vameghi,R., Biglarian,A., Daneshmandan,N., Risk factors associated with cerebral palsy in children born in eastern and northern districts of Tehran, <i>Iranian Red Crescent Medical Journal</i> , 12, 428-433, 2010	Case-control design.
Spinillo,A., Montanari,L., Sanpaolo,P., Bergante,C., Chiara,A., Fazzi,E., Fetal growth and infant neurodevelopmental outcome after preterm premature rupture of membranes, <i>Obstetrics and Gynecology</i> , 103, 1286-1293, 2004	Results are unadjusted.
Sreenan,C., Bhargava,R., Robertson,C.M., Cerebral infarction in the term newborn: clinical presentation and long-term outcome, <i>Journal of Pediatrics</i> , 137, 351-355, 2000	Not CP specific.
Stelmach, T., Pisarev, H., Talvik, T., Ante- and perinatal factors for cerebral palsy: case-control study in Estonia, <i>Journal of Child Neurology</i> , 20, 654-60, 2005	Case-control design.
Stelmach,T., Kallas,E., Pisarev,H., Talvik,T., Antenatal risk factors associated with unfavorable neurologic status in newborns and at 2 years of age, <i>Journal of Child Neurology</i> , 19, 116-122, 2004	Not CP specific.



<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Stoinska,B., Gadzinowski,J., Neurological and developmental disabilities in ELBW and VLBW: follow-up at 2 years of age, Journal of Perinatology, 31, 137-142, 2011	Not relevant risk factors.
Stoknes,M., Andersen,G.L., Dahlseng,M.O., Skranes,J., Salvesen,K.A., Irgens,L.M., Kurinczuk,J.J., Vik,T., Cerebral palsy and neonatal death in term singletons born small for gestational age, Pediatrics, 130, e1629-e1635, 2012	Risk factor analysed not relevant to protocol.
Stoknes,M., Andersen,G.L., Elkamil,A.I., Irgens,L.M., Skranes,J., Salvesen,K.A., Vik,T., The effects of multiple pre- and perinatal risk factors on the occurrence of cerebral palsy. A Norwegian register based study, European Journal of Paediatric Neurology, 16, 56-63, 2012	Unavailable paper.
Strand,K.M., Heimstad,R., Iversen,A.C., Austgulen,R., Lydersen,S., Andersen,G.L., Irgens,L.M., Vik,T., Mediators of the association between pre-eclampsia and cerebral palsy: population based cohort study, BMJ, 347, f4089-, 2013	Risk factor analysed not relevant to protocol.
Streja, E., Wu, C., Uldall, P., Grove, J., Arah, O., Olsen, J., Congenital cerebral palsy, child sex and parent cardiovascular risk, PLoS ONE [Electronic Resource], 8, e79071, 2013	Risk factor not relevant to review protocol.
Sun, Y., Vestergaard, M., Pedersen, C. B., Christensen, J., Olsen, J., Apgar scores and long-term risk of epilepsy, Epidemiology, 17, 296-301, 2006	Risk factor analysed not relevant to protocol.
Suzuki, J., Ito, M., Incidence patterns of cerebral palsy in Shiga Prefecture, Japan, 1977-1991, Brain & Development, 24, 39-48, 2002	Incidence patterns compared in different decades.
Takahashi,R., Yamada,M., Takahashi,T., Ito,T., Nakae,S., Kobayashi,Y., Onuma,A., Risk factors for cerebral palsy in preterm infants, Early Human Development, 81, 545-553, 2005	Case-control design.
Taylor, C. L., de Groot, J., Blair, E. M., Stanley, F. J., The risk of cerebral palsy in survivors of multiple pregnancies with cofetal loss or death, American Journal of Obstetrics & Gynecology, 201, 41.e1-6, 2009	Results are unadjusted.
Thorngren-Jerneck,K., Herbst,A., Low 5-minute Apgar score: a population-based register study of 1 million term births, Obstetrics and Gynecology, 98, 65-70, 2001	Not relevant risk factor.
Thorngren-Jerneck,K., Herbst,A., Perinatal factors associated with cerebral palsy in children born in Sweden, Obstetrics and Gynecology, 108, 1499-1505, 2006	Case-control design.
Toome,L., Varendi,H., Mannamaa,M., Vals,M.A., Tanavsuu,T., Kolk,A., Follow-up study of 2-year-olds born at very low gestational age in Estonia, Acta Paediatrica, 102, 300-307, 2013	Risk factor analysed not relevant to protocol.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Topp, M., Huusom, L. D., Langhoff-Roos, J., Delhumeau, C., Hutton, J. L., Dolk, H., Scape Collaborative Group, Multiple birth and cerebral palsy in Europe: a multicenter study, <i>Acta Obstetrica et Gynecologica Scandinavica</i> , 83, 548-53, 2004	Results are unadjusted wrong outcome (type of CP rather than CP yes/no)
Topp, M., Uldall, P., Greisen, G., Cerebral palsy births in eastern Denmark, 1987--90: implications for neonatal care, <i>Paediatric and Perinatal Epidemiology</i> , 15, 271-7, 2001	Changes in rate of CP - no relevant comparison.
Torres, V. M., Saddi, V. A., Systematic review: Hereditary thrombophilia associated to pediatric strokes and cerebral palsy, <i>Jornal de Pediatria</i> , 91, 22-29, 2015	Thrombophilia not included protocol.
Tran, U., Gray, P. H., O'Callaghan, M. J., Neonatal antecedents for cerebral palsy in extremely preterm babies and interaction with maternal factors, <i>Early Human Development</i> , 81, 555-61, 2005	Case-control design.
Van den Broeck, C., Himpens, E., Vanhaesebrouck, P., Calders, P., Oostra, A., Influence of gestational age on the type of brain injury and neuromotor outcome in high-risk neonates, <i>European Journal of Pediatrics</i> , 167, 1005-9, 2008	Results are not adjusted.
van Iersel, P.A., Bakker, S.C., Jonker, A.J., Hadders-Algra, M., Does perinatal asphyxia contribute to neurological dysfunction in preterm infants?, <i>Early Human Development</i> , 86, 457-461, 2010	Risk factor analysed not relevant to protocol.
Vermeulen, G.M., Bruinse, H.W., de Vries, L.S., Perinatal risk factors for adverse neurodevelopmental outcome after spontaneous preterm birth, <i>European Journal of Obstetrics, Gynecology, and Reproductive Biology</i> , 99, 207-212, 2001	Results are not adjusted.
Vigneswaran, R., Aitchison, S. J., McDonald, H. M., Khong, T. Y., Hiller, J. E., Cerebral palsy and placental infection: A case-cohort study, <i>BMC Pregnancy and Childbirth</i> , 4, 2004	Case-control design.
Vohr, B.R., Wright, L.L., Poole, W.K., McDonald, S.A., Neurodevelopmental outcomes of extremely low birth weight infants <32 weeks' gestation between 1993 and 1998, <i>Pediatrics</i> , 116, 635-643, 2005	Comparisons between decades are presented.
Vukojevic, M., Soldo, I., Granic, D., Risk factors associated with cerebral palsy in newborns, <i>Collegium Antropologicum</i> , 33 Suppl 2, 199-201, 2009	Case-control design.
Wadhawan, R., Oh, W., Perritt, R.L., McDonald, S.A., Das, A., Poole, W.K., Vohr, B.R., Higgins, R.D., Twin gestation and neurodevelopmental outcome in extremely low birth weight infants, <i>Pediatrics</i> , 123, e220-e227, 2009	Unavailable paper.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
Walstab,J., Bell,R., Reddihough,D., Brennecke,S., Bessell,C., Beischer,N., Antenatal and intrapartum antecedents of cerebral palsy: a case-control study, Australian and New Zealand Journal of Obstetrics and Gynaecology, 42, 138-146, 2002	Case-control design.
Walstab,J.E., Bell,R.J., Reddihough,D.S., Brennecke,S.P., Bessell,C.K., Beischer,N.A., Factors identified during the neonatal period associated with risk of cerebral palsy, Australian and New Zealand Journal of Obstetrics and Gynaecology, 44, 342-346, 2004	Case-control design.
Were,F.N., Bwibo,N.O., Two year neurological outcomes of Very Low Birth Weight infants, East African Medical Journal, 83, 243-249, 2006	All children had the risk factor - no comparison.
Wheater,M., Rennie,J.M., Perinatal infection is an important risk factor for cerebral palsy in very-low-birthweight infants, Developmental Medicine and Child Neurology, 42, 364-367, 2000	No comparison (all babies had CP).
Willoughby, R. E., Jr., Nelson, K. B., Chorioamnionitis and brain injury, Clinics in Perinatology, 29, 603-21, 2002	Non-systematic review.
Wilson-Costello, D., Risk factors for neurologic impairment among very low-birth-weight infants, Seminars in Pediatric Neurology, 8, 120-6, 2001	Non systematic review.
Wu, C. S., Nohr, E. A., Bech, B. H., Vestergaard, M., Catov, J. M., Olsen, J., Health of children born to mothers who had preeclampsia: a population-based cohort study, American Journal of Obstetrics and Gynecology, 201, 269.e1-269.e10, 2009	Risk factor analysed not relevant to protocol.
Wu, L., Yu, J., Wu, W., Geng, X., Shang, Q., Ma, C., Song, L., Related factors analysis on cerebral palsy of pediatrics and intrauterine infection, Chinese Journal of Clinical Rehabilitation, 7, 1545-1546, 2003	All children had CP - no comparison.
Wu, Y. W., Systematic review of chorioamnionitis and cerebral palsy, Mental Retardation & Developmental Disabilities Research Reviews, 8, 25-9, 2002	Old studies (1966-2000)
Wu, Y. W., Colford, J. M., Jr., Chorioamnionitis as a risk factor for cerebral palsy: A meta-analysis, JAMA, 284, 1417-24, 2000	Included studies have been published before 2000 a more recent meta-analysis has been considered.
Wu,Y.W., Escobar,G.J., Grether,J.K., Croen,L.A., Greene,J.D., Newman,T.B., Chorioamnionitis and cerebral palsy in term and near-term infants, JAMA, 290, 2677-2684, 2003	Case-control design.
Xiong,T., Gonzalez,F., Mu,D.Z., An overview of risk factors for poor neurodevelopmental outcome associated with prematurity, World Journal of Pediatrics, 8, 293-300, 2012	Non-systematic review
Xiong,X., Saunders,L.D., Wang,F.L., Davidge,S.T., Buekens,P., Preeclampsia and cerebral palsy in low-birth-weight and preterm	Risk factor analysed not relevant to protocol.

<b>Excluded studies - What are the most important risk factors for developing cerebral palsy with a view to informing more frequent assessment and early intervention?</b>	
infants: implications for the current "ischemic model" of preeclampsia, Hypertension in Pregnancy, 20, 1-13, 2001	
Yamada, T., Akaishi, R., Yamada, T., Morikawa, M., Kaneuchi, M., Minakami, H., Risk of cerebral palsy associated with neonatal encephalopathy in macrosomic neonates, Journal of Obstetrics & Gynaecology Research, 40, 1611-7, 2014	Not included as risk factor in protocol.
Yee, W.H., Hicks, M., Chen, S., Christianson, H., Sauve, R., Triplet infants with birthweight < or = 1250 grams: how well do they compare with twin and singleton infants at 36 to 48 months of age?, American Journal of Perinatology, 25, 373-380, 2008	Results are unadjusted.
Yoon, B. H., Romero, R., Park, J. S., Kim, C. J., Kim, S. H., Choi, J. H., Han, T. R., Fetal exposure to an intra-amniotic inflammation and the development of cerebral palsy at the age of three years, American Journal of Obstetrics & Gynecology, 182, 675-81, 2000	Risk factor analysed is not relevant to review protocol.
Yu, T., Rong, L., Wang, Q., You, Y., Fu, J. X., Kang, L. M., Wu, Y. Q., [Influence of neonatal diseases and treatments on the development of cerebral palsy in preterm infant], Sichuan da Xue Xue Bao. Yi Xue Ban/Journal of Sichuan University. Medical Science Edition, 44, 270-3, 2013	Unavailable paper.
Zhou, X. J., Qiu, H. B., Xu, H., Zhu, L. L., [Risk factors related to infantile spastic cerebral palsy among 145 cases], Chung-Hua Liu Hsing Ping Hsueh Tsa Chih Chinese Journal of Epidemiology, 34, 389-92, 2013	Paper in Chinese.

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## K.2.3 Causes of cerebral palsy

<b>Excluded studies - What are the most common causes of cerebral palsy in resource-rich countries with a view to informing relevant investigation and change in management?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Blair, E., Al Asedy, F., Badawi, N., Bower, C., Is cerebral palsy associated with birth defects other than cerebral defects?, Developmental Medicine & Child Neurology, 49, 252-8, 2007	The paper reports on 'birth defects associations'.
Costeff, H., Estimated frequency of genetic and nongenetic causes of congenital idiopathic cerebral palsy in west Sweden, Annals of Human Genetics, 68, 515-20, 2004	Unclear where they collected the data from.
Freire, G., Shevell, M., Oskoui, M., Cerebral palsy: Phenotypes and risk factors in term singletons born small for gestational age, European Journal of Paediatric Neurology, 19, 218-225, 2015	Unavailable.

<b>Excluded studies - What are the most common causes of cerebral palsy in resource-rich countries with a view to informing relevant investigation and change in management?</b>	
Gilbert, W. M., Jacoby, B. N., Xing, G., Danielsen, B., Smith, L. H., Adverse obstetric events are associated with significant risk of cerebral palsy, <i>American Journal of Obstetrics &amp; Gynecology</i> , 203, 328.e1-5, 2010	No causes relevant to the review protocol were investigated.
Himmelmann, K., Ahlin, K., Jacobsson, B., Cans, C., Thorsen, P., Risk factors for cerebral palsy in children born at term, <i>Acta Obstetrica et Gynecologica Scandinavica</i> , 90, 1070-1081, 2011	Overview of current evidence without any quality appraisal of the studies.
Himpens, E., Oostra, A., Franki, I., Vansteelandt, S., Vanhaesebrouck, P., den Broeck, C.V., Predictability of cerebral palsy in a high-risk NICU population, <i>Early Human Development</i> , 86, 413-417, 2010	Included in the risk factors review. Reports on a predictive model.
Jacobsson, B., Infectious and inflammatory mechanisms in preterm birth and cerebral palsy, <i>European Journal of Obstetrics, Gynecology, and Reproductive Biology</i> , 115, 159-160, 2004	Preterm labor women.
Leviton, A., Allred, E. N., Kuban, K. C., Hecht, J. L., Onderdonk, A. B., O'Shea T, M., Paneth, N., Microbiologic and histologic characteristics of the extremely preterm infant's placenta predict white matter damage and later cerebral palsy. the ELGAN study, <i>Pediatric Research</i> , 67, 95-101, 2010	The papers focuses on prediction of white matter damage.
Mann, J.R., McDermott, S., Bao, H., Bersabe, A., Maternal genitourinary infection and risk of cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 51, 282-288, 2009	Not a prevalence study.
McIntyre, S., Taitz, D., Keogh, J., Goldsmith, S., Badawi, N., Blair, E., A systematic review of risk factors for cerebral palsy in children born at term in developed countries, <i>Developmental Medicine and Child Neurology</i> , 55, 499-508, 2013	The paper presents univariate analysis - no prevalence study.
Miller, J. E., Pedersen, L. H., Streja, E., Bech, B. H., Yeargin-Allsopp, M., Van Naarden Braun, K., Schendel, D. E., Christensen, D., Uldall, P., Olsen, J., Maternal infections during pregnancy and cerebral palsy: A population-based cohort study, <i>Paediatric and Perinatal Epidemiology</i> , 27, 542-552, 2013	No relevant infections reported.
Minciu, I., Clinical and etiological correlations in cerebral palsy, <i>Romanian Journal of Neurology/ Revista Romana de Neurologie</i> , 11, 178-183, 2012	Deprioritised at it considered a hospital based cohort (retrospective trial)
Odding, E., Roebroek, M. E., Stam, H. J., The epidemiology of cerebral palsy: Incidence, impairments and risk factors, <i>Disability and Rehabilitation</i> , 28, 183-191, 2006	The paper reported on % of associated impairments (no causes).
Ravn, S.H., Flachs, E.M., Uldall, P., Cerebral palsy in eastern Denmark: declining birth prevalence but increasing numbers of unilateral cerebral palsy in birth year period 1986-1998, <i>European Journal of Paediatric Neurology</i> , 14, 214-218, 2010	The paper does not report on prevalence of causes of CP cases.

<b>Excluded studies - What are the most common causes of cerebral palsy in resource-rich countries with a view to informing relevant investigation and change in management?</b>	
Reid,S.M., Dagia,C.D., Ditchfield,M.R., Carlin,J.B., Meehan,E.M., Reddihough,D.S., An Australian population study of factors associated with MRI patterns in cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 56, 178-184, 2014	Included in Reid 2014 review.
Self, L., Shevell, M. I., Repacq Consortium, A registry-based assessment of cerebral palsy and cerebral malformations, <i>Journal of Child Neurology</i> , 25, 1313-8, 2010	The analysis is conducted on a sub-sample of 24 cases.
Shevell, A., Wintermark, P., Benini, R., Shevell, M., Oskoui, M., Chorioamnionitis and cerebral palsy: lessons from a patient registry, <i>European Journal of Paediatric Neurology</i> , 18, 301-7, 2014	Unavailable.
van Haastert, I. C., Groenendaal, F., Uiterwaal, C. S., Termote, J. U., van der Heide-Jalving, M., Eijsermans, M. J., Gorter, J. W., Helders, P. J., Jongmans, M. J., de Vries, L. S., Decreasing incidence and severity of cerebral palsy in prematurely born children, <i>Journal of Pediatrics</i> , 159, 86-91.e1, 2011	deprioritised at it considered a hospital based cohort (retrospective trial)
Wu,Y.W., Croen,L.A., Shah,S.J., Newman,T.B., Najjar,D.V., Cerebral palsy in a term population: risk factors and neuroimaging findings, <i>Pediatrics</i> , 118, 690-697, 2006	Deprioritised as it considers retrospective cohort from a medical care program.

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### K.3.4 Clinical and developmental manifestations of cerebral palsy

<b>Excluded studies - What are the key clinical and developmental manifestations of cerebral palsy at first presentation?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Adde,L., Helbostad,J., Jensenius,A.R., Langaas,M., Stoen,R., Identification of fidgety movements and prediction of CP by the use of computer-based video analysis is more accurate when based on two video recordings, <i>Physiotherapy Theory and Practice</i> , 29, 469-475, 2013	No comparative group (all children included have risk including preterm, NICU, stroke).
Adebami, O. J., Onigbinde, O. M., Joel-Medewase, V., Oyedeji, A. G., Afolabi, A. A., Neurological disorders among children in Osogbo, southwestern Nigeria, <i>Journal of Pediatric Neurology</i> , 9, 341-345, 2011	Clinical manifestations not reported.
Allen,M.C., Capute,A.J., Neonatal neurodevelopmental examination as a predictor of neuromotor outcome in premature infants, <i>Pediatrics</i> , 83, 498-506, 1989	No comparison group (all premature).
Ballot,D.E., Potterton,J., Chirwa,T., Hilburn,N., Cooper,P.A., Developmental outcome of very	No comparison group (all very low birth weight).

<b>Excluded studies - What are the key clinical and developmental manifestations of cerebral palsy at first presentation?</b>	
low birth weight infants in a developing country, BMC Pediatrics, 12, 11-, 2012	
Burns, Y.R., O'Callaghan, M., Tudehope, D.I., Early identification of cerebral palsy in high risk infants, Australian Paediatric Journal, 25, 215-219, 1989	No comparison group (all at risk: preterm or requiring ventilators).
Centre for Reviews and Dissemination, The predictive validity of general movements: a systematic review (Structured abstract), Database of Abstracts of Reviews of Effects, 2014	Only structured abstract. Full version found online: no relevant references - all have no comparison group or below sample size requirement.
Doyle, L.W., Betheras, F.R., Ford, G.W., Davis, N.M., Callanan, C., Survival, cranial ultrasound and cerebral palsy in very low birthweight infants: 1980s versus 1990s, Journal of Paediatrics and Child Health, 36, 7-12, 2000	No comparison group (all very low birth weight).
Dubowitz, L.M., Dubowitz, V., Palmer, P.G., Miller, G., Fawer, C.L., Levene, M.I., Correlation of neurologic assessment in the preterm newborn infant with outcome at 1 year, Journal of Pediatrics, 105, 452-456, 1984	No comparison group (all preterm).
Einspieler, C., Cioni, G., Paolicelli, P. B., Bos, A. F., Dressler, A., Ferrari, F., Roversi, M. F., Prechtel, H. F. R., The early markers for later dyskinetic cerebral palsy are different from those for spastic cerebral palsy, Neuropediatrics, 33, 73-78, 2002	Below specified sample size of n = 50.
Einspieler, C., Marschik, P. B., Bos, A. F., Ferrari, F., Cioni, G., Prechtel, H. F. R., Early markers for cerebral palsy: Insights from the assessment of general movements, Future Neurology, 7, 709-717, 2012	Review: references assessed and 1 included (Adders et al 2007). Rest of references assessed have no comparison group.
Elliman, A.M., Bryan, E.M., Elliman, A.D., Palmer, P., Dubowitz, L., Denver developmental screening test and preterm infants, Archives of Disease in Childhood, 60, 20-24, 1985	No comparison group (all preterm).
Farber, J.M., Shapiro, B.K., Palmer, F.B., Capute, A.J., The diagnostic value of the neurodevelopmental examination, Clinical Pediatrics, 24, 367-372, 1985	Below sample size requirement of n = 50.
Fily, A., Pierrat, V., Delporte, V., Breart, G., Truffert, P., Epipage Nord-Pas-de-Calais Study Group, Factors associated with neurodevelopmental outcome at 2 years after very preterm birth: the population-based Nord-Pas-de-Calais EPIPAGE cohort, Pediatrics, 117, 357-66, 2006	No comparison group (all very preterm).
Hallam, P., Weindling, A. M., Klenka, H., Gregg, J., Rosenbloom, L., A comparison of three procedures to assess the motor ability of 12-month-old infants with cerebral palsy, Developmental Medicine & Child Neurology, 35, 602-7, 1993	No comparison group (all preterm).
Hamer, E.G., Bos, A.F., Hadders-Algra, M., Assessment of specific characteristics of abnormal general movements: does it enhance	Below sample size requirement of n = 50.

<b>Excluded studies - What are the key clinical and developmental manifestations of cerebral palsy at first presentation?</b>	
the prediction of cerebral palsy?, <i>Developmental Medicine and Child Neurology</i> , 53, 751-756, 2011	
Hayashi-Kurahashi,N., Kidokoro,H., Kubota,T., Maruyama,K., Kato,Y., Kato,T., Natsume,J., Hayakawa,F., Watanabe,K., Okumura,A., EEG for predicting early neurodevelopment in preterm infants: an observational cohort study, <i>Pediatrics</i> , 130, e891-e897, 2012	Index test not in protocol (EEG). Reserved for prognostic indicators review.
Himpens,E., Oostra,A., Franki,I., Vansteelandt,S., Vanhaesebrouck,P., den Broeck,C.V., Predictability of cerebral palsy in a high-risk NICU population, <i>Early Human Development</i> , 86, 413-417, 2010	No comparison group (all NICU).
Hintz, S. R., Kendrick, D. E., Wilson-Costello, D. E., Das, A., Bell, E. F., Vohr, B. R., Higgins, R. D., Early-childhood neurodevelopmental outcomes are not improving for infants born at <25 weeks' gestational age, <i>Pediatrics</i> , 127, 62-70, 2011	No comparison group (all preterm).
Imamura,S., Sakuma,K., Takahashi,T., Follow-up study of children with cerebral coordination disturbance (CCD, Vojta), <i>Brain and Development</i> , 5, 311-314, 1983	Clinical manifestations used for diagnosis not reported.
Jongmans, M., Mercuri, E., de Vries, L., Dubowitz, L., Henderson, S. E., Minor neurological signs and perceptual-motor difficulties in prematurely born children, <i>Archives of Disease in Childhood Fetal &amp; Neonatal Edition</i> , 76, F9-14, 1997	No comparison group (all preterm).
Kitchen,W.H., Ford,G.W., Murton,L.J., Rickards,A.L., Ryan,M.M., Lissenden,J.V., De Crespigny,L.C., Fortune,D.W., Mortality and two year outcome of infants of birthweight 500-1500 g: relationship with neonatal cerebral ultrasound data, <i>Australian Paediatric Journal</i> , 21, 253-259, 1985	Index test not in protocol (ultrasounds). Reserved for prognostic indicators review.
Kuban, K. C., Allred, E. N., O'Shea, T. M., Paneth, N., Pagano, M., Dammann, O., Leviton, A., Du Plessis, A., Westra, S. J., Miller, C. R., Bassan, H., Krishnamoorthy, K., Junewick, J., Olomu, N., Romano, E., Seibert, J., Engelke, S., Karna, P., Batton, D., O'Connor, S. E., Keller, C. E., Elgan study investigators, Cranial ultrasound lesions in the NICU predict cerebral palsy at age 2 years in children born at extremely low gestational age, <i>Journal of Child Neurology</i> , 24, 63-72, 2009	Index test not in protocol (ultrasounds). Reserved for causes of CP review.
Kuban,K.C., Allred,E.N., O'Shea,T.M., Paneth,N., Westra,S., Miller,C., Rosman,N.P., Leviton,A., Developmental correlates of head circumference at birth and two years in a cohort of extremely low gestational age newborns, <i>Journal of Pediatrics</i> , 155, 344-349, 2009	No comparison group (all preterm).
Lacey, J. L., Henderson-Smart, D., Edwards, D., Storey, B., Neurological assessment of the	No comparison group (all preterm).



<b>Excluded studies - What are the key clinical and developmental manifestations of cerebral palsy at first presentation?</b>	
preterm infant in the special care nursery and the diagnostic significance of the asymmetrical tonic neck reflex, Australian Journal of Physiotherapy, 33, 135-142, 1987	
Lacey,J.L., Henderson-Smart,D.J., Assessment of preterm infants in the intensive-care unit to predict cerebral palsy and motor outcome at 6 years, Developmental Medicine and Child Neurology, 40, 310-318, 1998	No comparison group (all preterm and NICU).
Lacey,J.L., Rudge,S., Rieger,I., Osborn,D.A., Assessment of neurological status in preterm infants in neonatal intensive care and prediction of cerebral palsy, Australian Journal of Physiotherapy, 50, 137-144, 2004	Study design not appropriate: cohort of one group (preterm) and case-control at follow-up.
Larroque, B., Ancel, P. Y., Marret, S., Marchand, L., Andre, M., Arnaud, C., Pierrat, V., Roze, J. C., Messer, J., Thiriez, G., Burguet, A., Picaud, J. C., Breart, G., Kaminski, M., Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the EPIPAGE study): a longitudinal cohort study, The Lancet, 371, 813-820, 2008	Clinical manifestations used for diagnosis unclear.
Lee,J., Croen,L.A., Lindan,C., Nash,K.B., Yoshida,C.K., Ferriero,D.M., Barkovich,A.J., Wu,Y.W., Predictors of outcome in perinatal arterial stroke: a population-based study, Annals of Neurology, 58, 303-308, 2005	Index test not in protocol (MRI and ST scan). Reserved for prognostic indicators and MRI review.
Lee,Y.K., Daito,Y., Katayama,Y., Minami,H., Negishi,H., The significance of measurement of serum unbound bilirubin concentrations in high-risk infants, Pediatrics International, 51, 795-799, 2009	Index test not in protocol (serum bilirubin).
Lejarraga, H., Menendez, A. M., Menzano, E., Guerra, L., Biancato, S., Pianelli, P., Del Pino, M., Fattore, M. J., Contreras, M. M., Screening for developmental problems at primary care level: a field programme in San Isidro, Argentina, Paediatric and Perinatal Epidemiology, 22, 180-7, 2008	No Cerebral Palsy included.
Leveresen, K. T., Sommerfelt, K., Ronnestad, A., Kaaresen, P. I., Farstad, T., Skranes, J., Stoen, R., Elgen, I. B., Rettedal, S., Eide, G. E., Irgens, L. M., Markestad, T., Prediction of neurodevelopmental and sensory outcome at 5 years in norwegian children born extremely preterm, Pediatrics, 127, e630-e638, 2011	No comparison group (all very preterm).
Leveresen,K.T., Sommerfelt,K., Elgen,I.B., Eide,G.E., Irgens,L.M., Juliusson,P.B., Markestad,T., Prediction of outcome at 5 years from assessments at 2 years among extremely preterm children: a Norwegian national cohort study, Acta Paediatrica, 101, 264-270, 2012	No comparison group (all NICU).
Lian, W. B., Ho, S. K. Y., Choo, S. H. T., Shah, V. A., Chan, D. K. L., Yeo, C. L., Ho, L. Y., Children with developmental and behavioural	Clinical manifestations unclear.

<b>Excluded studies - What are the key clinical and developmental manifestations of cerebral palsy at first presentation?</b>	
concerns in Singapore, Singapore Medical Journal, 53, 439-445, 2012	
Liao,W., Wen,E.Y., Li,C., Chang,Q., Lv,K.L., Yang,W., He,Z.M., Zhao,C.M., Predicting neurodevelopmental outcomes for at-risk infants: reliability and predictive validity using a Chinese version of the INFANIB at 3, 7 and 10 months, BMC Pediatrics, 12, 72-, 2012	Cerebral Palsy not defined, study only has 'abnormal' group.
Lindstrom,K., Lagerroos,P., Gillberg,C., Fernell,E., Teenage outcome after being born at term with moderate neonatal encephalopathy, Pediatric Neurology, 35, 268-274, 2006	Clinical manifestation (encephalopathy) not stated in protocol. Reserved for prognostic indicators review.
Logan, J. W., O'Shea, T. M., Allred, E. N., Laughon, M. M., Bose, C. L., Dammann, O., Batton, D. G., Kuban, K. C., Paneth, N., Leviton, A., Early postnatal hypotension is not associated with indicators of white matter damage or cerebral palsy in extremely low gestational age newborns, Journal of Perinatology, 31, 524-534, 2011	No comparison group (all preterm). Reserved for prognostic indicators review.
Losch, H., Dammann, O., Impact of motor skills on cognitive test results in very-low-birthweight children, Journal of Child Neurology, 19, 318-322, 2004	No comparison group (all very low birth weight). Reserved for prognostic indicators review.
Maitre,N.L., Slaughter,J.C., Aschner,J.L., Early prediction of cerebral palsy after neonatal intensive care using motor development trajectories in infancy, Early Human Development, 89, 781-786, 2013	No comparison group (all NICU).
Martinez-Biarge, M., Diez-Sebastian, J., Kapellou, O., Gindner, D., Allsop, J. M., Rutherford, M. A., Cowan, F. M., Predicting motor outcome and death in term hypoxic-ischemic encephalopathy, Neurology, 76, 2055-61, 2011	No comparison (all high risk: encephalopathy). Reserved for causes and MRI reviews.
Maruyama, K., Okumura, A., Hayakawa, F., Kato, T., Kuno, K., Watanabe, K., Prognostic value of EEG depression in preterm infants for later development of cerebral palsy, Neuropediatrics, 33, 133-137, 2002	Index test not in protocol (EEG). Reserved for prognostic indicators review.
Mazor-Aronovitch, K., Gillis, D., Lobel, D., Hirsch, H. J., Pinhas-Hamiel, O., Modan-Moses, D., Glaser, B., Landau, H., Long-term neurodevelopmental outcome in conservatively treated congenital hyperinsulinism, European Journal of Endocrinology, 157, 491-497, 2007	Below sample size of n = 50.
Nwaesei, C. G., Allen, A. C., Vicner, M. J., Brown St, J., Stinson, D. A., Evans, J. R., Byrne, J. M., Effect of timing of cerebral ultrasonography on the prediction of later neurodevelopmental outcome high-risk in preterm infants, Journal of Pediatrics, 112, 970-975, 1988	Index test not in protocol (ultrasounds). Reserved for prognostic indicators review.
Ozelli, L., Demographic and diagnostic characteristics of pediatric neurology	Clinical manifestations not reported.

<b>Excluded studies - What are the key clinical and developmental manifestations of cerebral palsy at first presentation?</b>	
outpatients, Turkish Journal of Pediatrics, 19, 16-30, 1977	
Palfrey,J.S., Singer,J.D., Walker,D.K., Butler,J.A., Early identification of children's special needs: a study in five metropolitan communities, Journal of Pediatrics, 111, 651-659, 1987	Clinical manifestations used for diagnosis not reported.
Picciolini,O., Gianni,M.L., Vegni,C., Fumagalli,M., Mosca,F., Usefulness of an early neurofunctional assessment in predicting neurodevelopmental outcome in very low birthweight infants, Archives of Disease in Childhood Fetal and Neonatal Edition, 91, F111-F117, 2006	No comparison group (all very low birth weight).
Spagnoli, C., De Sousa, C., Retrospective study of the investigations of children presenting with lower limbs spasticity in a single institution, Neuropediatrics, 45, 109-116, 2014	Sample size below requirement of n = 50.
Spinillo,A., Gardella,B., Preti,E., Zanchi,S., Stronati,M., Fazzi,E., Rates of neonatal death and cerebral palsy associated with fetal growth restriction among very low birthweight infants. A temporal analysis, BJOG: An International Journal of Obstetrics and Gynaecology, 113, 775-780, 2006	No comparison group (all very low birth weight).
Spittle,A.J., Spencer-Smith,M.M., Cheong,J.L., Eeles,A.L., Lee,K.J., Anderson,P.J., Doyle,L.W., General movements in very preterm children and neurodevelopment at 2 and 4 years, Pediatrics, 132, e452-e458, 2013	No comparison group (all very preterm).
Weisglas-Kuperus, N., Baerts, W., Fetter, W. P., Sauer, P. J., Neonatal cerebral ultrasound, neonatal neurology and perinatal conditions as predictors of neurodevelopmental outcome in very low birthweight infants, Early Human Development, 31, 131-48, 1992	Does not include CP specific results.
Wolf,M.J., Beunen,G., Casaer,P., Wolf,B., Neonatal neurological examination as a predictor of neuromotor outcome at 4 months in term low-Apgar-score babies in Zimbabwe, Early Human Development, 51, 179-186, 1998	Cerebral palsy not defined, study only has 'abnormal' group.
Zafeiriou,D.I., Tsikoulas,I.G., Kremnopoulos,G.M., Prospective follow-up of primitive reflex profiles in high-risk infants: clues to an early diagnosis of cerebral palsy, Pediatric Neurology, 13, 148-152, 1995	No comparison group (all high risk).

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### K.4.3 Red flags for other neurological disorders

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
Study	Reason for Exclusion

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
Andersson, S., Persson, E. K., Aring, E., Lindquist, B., Dutton, G. N., Hellstrom, A., Vision in children with hydrocephalus, <i>Developmental Medicine and Child Neurology</i> , 48, 836-841, 2006	No data on differential diagnosis.
Anonymous, Diagnostic criteria for Rett syndrome. The Rett Syndrome Diagnostic Criteria Work Group, <i>Annals of Neurology</i> , 23, 425-8, 1988	Descriptive on criteria and classification RS.
Ashwal, S., Michelson, D., Plawner, L., Dobyns, W. B., Practice parameter: Evaluation of the child with microcephaly (an evidence-based review): Report of the quality standards subcommittee of the American academy of neurology and the practice committee of the child neurology society, <i>Neurology</i> , 73, 887-897, 2009	No data on differential diagnosis.
Ashwal, S., Russman, B. S., Blasco, P. A., Miller, G., Sandler, A., Shevell, M., Stevenson, R., Quality Standards Subcommittee of the American Academy of Neurology, Practice Committee of the Child Neurology Society, Practice parameter: diagnostic assessment of the child with cerebral palsy: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society, <i>Neurology</i> , 62, 851-63, 2004	No data on differential diagnosis.
Babb, A., Carlson, W. O., Idiopathic toe-walking, <i>South Dakota Medicine: The Journal of the South Dakota State Medical Association</i> , 61, 53-57, 2008	Descriptive review.
Barabas, G., Taft, L. T., The early signs and differential diagnosis of cerebral palsy, <i>Pediatric Annals</i> , 15, 203-214, 1986	No analysis of red flags for progressive disorder presented.
Barnett, A., Mercuri, E., Rutherford, M., Haataja, L., Frisone, M. F., Henderson, S., Cowan, F., Dubowitz, L., Neurological and perceptual-motor outcome at 5 - 6 years of age in children with neonatal encephalopathy: relationship with neonatal brain MRI, <i>Neuropediatrics</i> , 33, 242-248, 2002	No data on differential diagnosis reported. MRI used as an index test.
Bass, N., Cerebral palsy and neurodegenerative disease, <i>Current Opinion in Pediatrics</i> , 11, 504-7, 1999	Case study; descriptive.
Blair, M. A., Riddle, M. E., Wells, J. F., Breviu, B. A., Hedera, P., Infantile onset of hereditary spastic paraplegia poorly predicts the genotype, <i>Pediatric Neurology</i> , 36, 382-386, 2007	Genetic study. No data on evolution of motor signs or differential diagnosis presented.
Bodensteiner, J. B., Schaefer, G. B., Evaluation of the patient with idiopathic mental retardation, <i>Journal of Neuropsychiatry and Clinical Neurosciences</i> , 7, 361-370, 1995	Descriptive review.
Bonnefoy-Mazure, A., Turcot, K., Kaelin, A., De Coulon, G., Armand, S., Full body gait analysis may improve diagnostic discrimination between	HSP versus SD (the latter not confirmed as due to CP).

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
hereditary spastic paraplegia and spastic diplegia: a preliminary study, <i>Research in Developmental Disabilities</i> , 34, 495-504, 2013	
Boyd,K., Patterson,V., Dopa responsive dystonia: a treatable condition misdiagnosed as cerebral palsy, <i>BMJ</i> , 298, 1019-1020, 1989	2 cases. Final diagnosis made on Levodopa response.
Carvalho,D.R., Brum,J.M., Speck-Martins,C.E., Ventura,F.D., Navarro,M.M., Coelho,K.E., Portugal,D., Pratesi,R., Clinical features and neurologic progression of hyperargininemia, <i>Pediatric Neurology</i> , 46, 369-374, 2012	Small sample size (n=16), non-comparative retrospective study, no analysis presented.
Centre for Reviews and Dissemination, A systematic review of tests to predict cerebral palsy in young children (Provisional abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2014	No data on differential diagnosis.
Chambers, H. G., Update on neuromuscular disorders in pediatric orthopaedics: Duchenne muscular dystrophy, myelomeningocele, and cerebral palsy, <i>Journal of Pediatric Orthopaedics</i> , 34, S44-S48, 2014	Descriptive review.
Cimolin,V., Piccinini,L., D'Angelo,M.G., Turconi,A.C., Berti,M., Crivellini,M., Albertini,G., Galli,M., Are patients with hereditary spastic paraplegia different from patients with spastic diplegia during walking? Gait evaluation using 3D gait analysis, <i>Functional Neurology</i> , 22, 23-28, 2007	No relevant red flags to the protocol not clear if SD is secondary to CP.
Dekair, L. H., Kamel, H., El-Bashir, H. O., Joubert syndrome labeled as hypotonic cerebral palsy, <i>Neurosciences</i> , 19, 233-5, 2014	Unavailable.
Dennis,S.C., Green,N.E., Hereditary spastic paraplegia, <i>Journal of Pediatric Orthopedics</i> , 8, 413-417, 1988	No relevant red flags considered.
Deonna,T.W., Ziegler,A.L., Nielsen,J., Transient idiopathic dystonia in infancy, <i>Neuropediatrics</i> , 22, 220-224, 1991	Case series (n=8), doesn't report who was initially diagnosed with CP.
Devadathan, K., Sreedharan, M., Sarasam, S., Colah, R. B., Kunju, P. A., Neurometabolic disorder with microcephaly, dystonia, and central cyanosis masquerading as cerebral palsy, <i>Journal of Child Neurology</i> , 29, NP139-42, 2014	Case series (n=3). Final diagnosis based on imaging.
El-Mallakh, R. S., Rao, K., Barwick, M., Cervical myelopathy secondary to movement disorders: Case report, <i>Neurosurgery</i> , 24, 902-905, 1989	Small sample size not relevant population (2 cases of 48 and 68 years of age).
Fayyazi, A., Khezrian, L., Kheradmand, Z., Damadi, S., Khajeh, A., Evaluation of the young children with neurodevelopmental disability: A prospective study at Hamadan University of medical sciences clinics, <i>Iranian Journal of Child Neurology</i> , 7, 29-33, 2013	No data presented on red flags for differential diagnosis.
Forsyth, R. J., Neurological and cognitive decline in adolescence, <i>Journal of Neurology, Neurosurgery and Psychiatry</i> , 74, i9-i16, 2003	No data on red flags relevant to the review protocol.

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
Gupta, R., Appleton, R. E., Cerebral palsy: not always what it seems, Archives of Disease in Childhood, 85, 356-60, 2001	Descriptive review.
Hankins, G. D., Speer, M., Defining the pathogenesis and pathophysiology of neonatal encephalopathy and cerebral palsy, Obstetrics & Gynecology, 102, 628-36, 2003	No data on differential diagnosis (data on aetiology only).
Haslam, R.H., 'Progressive cerebral palsy' or spinal cord tumor? Two cases of mistaken identity, Developmental Medicine and Child Neurology, 17, 232-237, 1975	2 cases presented.
Hoon, A. H., Jr., Reinhardt, E. M., Kelley, R. I., Breiter, S. N., Morton, D. H., Naidu, S., Johnston, M. V., Brain magnetic resonance imaging in suspected extrapyramidal cerebral palsy: Observations in distinguishing genetic-metabolic from acquired causes, Journal of Pediatrics, 131, 240-245, 1997	Small sample size (n=6) the authors used MRI to identify cases.
Jones, M. W., Morgan, E., Shelton, J. E., Thorogood, C., Cerebral palsy: introduction and diagnosis (part I), Journal of Pediatric Health Care, 21, 146-52, 2007	Descriptive review.
Jung, S.H., Bang, M.S., A case of congenital kyphosis misdiagnosed as cerebral palsy, Childs Nervous System, 23, 1205-1208, 2007	Case study.
Kehrer, C., Blumenstock, G., Raabe, C., Krageloh-Mann, I., Development and reliability of a classification system for gross motor function in children with metachromatic leucodystrophy, Developmental Medicine and Child Neurology, 53, 156-160, 2011	GMF Classification in MLD patients.
Kikuchi, K., Hamano, S., Mochizuki, H., Ichida, K., Ida, H., Molybdenum cofactor deficiency mimics cerebral palsy: differentiating factors for diagnosis, Pediatric Neurology, 47, 147-149, 2012	One patient examined.
Kilinc, Y., Cetik, F., Tanyeli, A., Ozsahinoglu, C., Kumi, M., Extramedullary leukemia with central facial palsy originated from poorly differentiated abdominal lymphoma, International Journal of Pediatric Otorhinolaryngology, 17, 281-286, 1989	One patient examined.
Kota, S.K., Meher, L.K., Jammula, S., Kota, S.K., Modi, K.D., Clinical profile of coexisting conditions in type 1 diabetes mellitus patients, Diabetes and Metabolic Syndrome, 6, 70-76, 2012	Clinical profile of coexisting conditions, red flags for differential diagnosis reported.
Krigger, K.W., Cerebral palsy: An overview, American Family Physician, 73, 91-100, 2006	Descriptive review.
Kumar, S., Alexander, M., Gnanamuthu, C., Recent experience with Rett syndrome at a tertiary care center, Neurology India, 52, 494-495, 2004	RS only, no data on differential diagnosis. Sample size = 4 cases.
Kurian, M. A., Li, Y., Zhen, J., Meyer, E., Hai, N., Christen, H. J., Hoffmann, G. F., Jardine, P., von	Small sample size (n=11), no relevant index tests performed.

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
Moers, A., Mordekar, S. R., O'Callaghan, F., Wassmer, E., Wraige, E., Dietrich, C., Lewis, T., Hyland, K., Heales, S. J. R., Sanger, T., Gissen, P., Assmann, B. E., Reith, M. E. A., Maher, E. R., Clinical and molecular characterisation of hereditary dopamine transporter deficiency syndrome: An observational cohort and experimental study, <i>The Lancet Neurology</i> , 10, 54-62, 2011	
Kyvelidou, A., Harbourne, R. T., Stergiou, N., Severity and characteristics of developmental delay can be assessed using variability measures of sitting posture, <i>Pediatric Physical Therapy</i> , 22, 259-266, 2010	No red flags used for differential diagnosis.
Lademann, A., Postneonatally acquired cerebral palsy. A study of the aetiology, clinical findings and prognosis in 170 cases, <i>Acta Neurologica Scandinavica. Supplementum</i> , 65, 3-148, 1978	No differential diagnosis presented.
Lee, J. H., Ki, C. S., Kim, D. S., Cho, J. W., Park, K. P., Kim, S., Dopa-responsive dystonia with a novel initiation codon mutation in the GCH1 gene misdiagnosed as cerebral palsy, <i>Journal of Korean Medical Science</i> , 26, 1244-6, 2011	Case study.
Lee, T. K. M., McTaggart, K. E., Sieving, P. A., Heckenlively, J. R., Levin, A. V., Greenberg, J., Weleber, R. G., Tong, P. Y., Anhalt, E. F., Powell, B. R., MacDonald, I. M., Clinical diagnoses that overlap with choroideremia, <i>Canadian Journal of Ophthalmology</i> , 38, 364-372, 2003	Case series of 13 patients (not clear if one of them had CP).
Liaw, S. B., Shen, E. Y., Hsu, C. H., Hong, H. Y., Kao, H. A., Ho, M. Y., Huang, F. Y., Periventricular leukomalacia in infancy: ultrasonic diagnosis and neurological outcome, <i>Chung-Hua Min Kuo Hsiao Erh Ko i Hsueh Hui Tsa Chih</i> , 31, 288-298, 1990	Unavailable.
Lin, J. P., The cerebral palsies: a physiological approach, <i>Journal of Neurology, Neurosurgery &amp; Psychiatry</i> , 74 Suppl 1, i23-9, 2003	Descriptive review.
Lindquist, B., Carlsson, G., Persson, E. K., Uvebrant, P., Learning disabilities in a population-based group of children with hydrocephalus, <i>Acta Paediatrica</i> , 94, 878-83, 2005	No differential diagnosis with CP.
Linthicum, F. H., Jr., Symposium on sensorineural hearing loss in children: early detection and intervention. Evaluation of the child with sensorineural hearing impairment, <i>Otolaryngologic Clinics of North America</i> , 8, 69-75, 1975	No data analysis provided; descriptive review.
Lorente Hurtado, I., Cerebral palsy. Updating the concept, diagnosis and treatment, <i>Pediatría Integral</i> , 15, 776-787, 2011	Spanish only.
Lotan, M., Ben-Zeev, B., Rett syndrome. A review with emphasis on clinical characteristics	Characteristics of RS presented.

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
and intervention, TheScientificWorldJournal, 6, 1517-1541, 2006	
Madan, S. S., Fernandes, J. A., Paralytic conditions in childhood, Surgery, 25, 166-170, 2007	Descriptive review.
Mahant,S., Feigenbaum,A., A child with an underrecognised form of developmental delay: a congenital disorder of glycosylation, CMAJ Canadian Medical Association Journal, 175, 1369-, 2006	Case study.
Marks, W., Bailey, L., Reed, M., Pomykal, A., Mercer, M., Macomber, D., Acosta, F., Jr., Honeycutt, J., Pallidal stimulation in children: comparison between cerebral palsy and DYT1 dystonia, Journal of Child Neurology, 28, 840-8, 2013	The study examines the effect on DBS on patients with dystonia or CP.
Marques, J. S., Garrido, A., Real, M. V., Santos, H., Alvares, S., Index of suspicion: Case 3. Presentation, Pediatrics in Review, 27, 271+275-277, 2006	3 cases reported.
Meilahn,J.R., Identifying loss of function caused by cervical spondylotic myelopathy in young adults with nonathetoid spastic cerebral palsy, Pm and R, 4, 783-786, 2012	2 cases reported.
Mitchell, G., McInness, R. R., Differential diagnosis of cerebral palsy: Lesch-Nyhan syndrome without self-mutilation, Canadian Medical Association Journal, 130, 1323-1324, 1984	Case study.
Molnar,G.E., Cerebral palsy: prognosis and how to judge it, Pediatric Annals, 8, 596-605, 1979	Descriptive, no differential diagnosis presented.
Mordekar,S.R., Baxter,P.S., 'Cerebral palsy' due to mitochondrial cytopathy, Journal of Paediatrics and Child Health, 40, 714-715, 2004	Two cases presented.
Ng, J., Zhen, J., Meyer, E., Erreger, K., Li, Y., Kakar, N., Ahmad, J., Thiele, H., Kubisch, C., Rider, N. L., Morton, D. H., Strauss, K. A., Puffenberger, E. G., D'Agnano, D., Anikster, Y., Carducci, C., Hyland, K., Rotstein, M., Leuzzi, V., Borck, G., Reith, M. E., Kurian, M. A., Dopamine transporter deficiency syndrome: phenotypic spectrum from infancy to adulthood, Brain, 137, 1107-19, 2014	Small sample size (n=8) the paper examines dopamine transporter deficiency syndrome with no data on differential diagnosis.
Noritz, G. H., Murphy, N. A., Motor delays: Early identification and evaluation, Pediatrics, 131, e2016-e2027, 2013	Motor delays identification, no differential diagnosis.
norman,r.m., kay,j.m., cerebello-thalamo-spinal degeneration in infancy: an unusual variant of werdnig-hoffmann disease, Archives of Disease in Childhood, 40, 302-308, 1965	Paper on 2 cases.
Novacheck,T.F., Walker,K.R., Progress in neuromuscular disorders, Current Opinion in Orthopaedics, 11, 454-460, 2000	No differential diagnosis presented.



<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
Nygaard, T.G., Waran, S.P., Levine, R.A., Naini, A.B., Chutorian, A.M., Dopa-responsive dystonia simulating cerebral palsy, <i>Pediatric Neurology</i> , 11, 236-240, 1994	Small sample size (n=5), non-comparative study, no analysis presented, index test used: CSF.
Paneth, N., Establishing the diagnosis of cerebral palsy, <i>Clinical Obstetrics &amp; Gynecology</i> , 51, 742-8, 2008	Descriptive review article.
Powell, K. K., Van Naarden Braun, K., Singh, R. H., Shapira, S. K., Olney, R. S., Yeargin-Allsopp, M., Long-term speech and language developmental issues among children with Duarte galactosemia, <i>Genetics in Medicine</i> , 11, 874-9, 2009	Population: children with Duarte galactosemia already diagnosed.
Schaefer, G. B., Bodensteiner, J. B., Evaluation of the child with idiopathic mental retardation, <i>Pediatric Clinics of North America</i> , 39, 929-943, 1992	No data analysis provided. Description of CP only.
Schain, R.J., Neurological evaluation of children with learning disorders, <i>Neuropadiatrie</i> , 1, 307-317, 1970	Index signs used do not apply to the review protocol.
Semmler, A., Urbach, H., Klockgether, T., Linnebank, M., Progressive multifocal leukoencephalopathy with selective involvement of the pyramidal tracts, <i>Neurology</i> , 68, 871, 2007	Case study.
Smyth, E., Kaliaperumal, C., Leonard, J., Caird, J., Acute functional deterioration in a child with cerebral palsy, <i>BMJ Case Reports</i> , 2012	Unavailable.
Sobrado, P., Suarez, J., Garcia-Sanchez, F. A., Uson, E., Refractive errors in children with cerebral palsy, psychomotor retardation, and other non-cerebral palsy neuromotor disabilities, <i>Developmental Medicine and Child Neurology</i> , 41, 396-403, 1999	The paper presents proportions on visual problems in children with various neurological signs, but no data on deterioration of vision or on differential diagnosis.
Stamelou, M., Lai, S. C., Aggarwal, A., Schneider, S. A., Houlden, H., Yeh, T. H., Batla, A., Lu, C. S., Bhatt, M., Bhatia, K. P., Dystonic opisthotonus: A "red flag" for neurodegeneration with brain iron accumulation syndromes?, <i>Movement Disorders</i> , 28, 1325-1329, 2013	Descriptive review.
Trevathan, E., Moser, H. W., Diagnostic criteria for Rett syndrome, <i>Annals of Neurology</i> , 23, 425-428, 1988	Diagnostic criteria for RS, no differential diagnosis presented.
Videnovic, A., Shannon, K. M., Huntington disease and other choreas, <i>Hyperkinetic Movement Disorders, Current Clinical Neurology</i> . 16, 23-54, 2012	Unavailable.
Wang, P. J., Recent developments in genetic leukodystrophies, <i>Tzu Chi Medical Journal</i> , 14, 63-67, 2002	Descriptive, no differential diagnosis.
Williams, C. A., Lossie, A., Driscoll, D., R. C. Phillips Unit, Angelman syndrome: mimicking conditions and phenotypes, <i>American Journal of Medical Genetics</i> , 101, 59-64, 2001	Population: Angelman syndrome, no differential diagnosis with CP.

<b>Excluded studies - What clinical manifestations should be recognised as 'red flags' that suggest a progressive neurological or neuromuscular disorder rather than cerebral palsy?</b>	
Wilson, J., Investigation of degenerative disease of the central nervous system, Archives of Disease in Childhood, 47, 163-70, 1972	Descriptive review article.
Woods, G.E., Visual problems in the handicapped child, Child: Care, Health and Development, 5, 303-322, 1979	Erratum.
Zarrinkalam, R., Russo, R. N., Gibson, C. S., van Essen, P., Peek, A. K., Haan, E. A., CP or not CP? A review of diagnoses in a cerebral palsy register, Pediatric Neurology, 42, 177-80, 2010	Descriptive, no useful data provided.

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### K.5.3 MRI and identification of causes of cerebral palsy

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Accardo, J., Kammann, H., Hoon, A. H., Jr., Neuroimaging in cerebral palsy, Journal of Pediatrics, 145, S19-27, 2004	Descriptive review.
Aggarwal, A., Mittal, H., Kr Debnath, S., Rai, A., Neuroimaging in cerebral palsy - Report from North India, Iranian Journal of Child Neurology, 7, 41-46, 2013	No comparison with other test for aetiological findings
Aida, N., Nishimura, G., Hachiya, Y., Matsui, K., Takeuchi, M., Itani, Y., MR imaging of perinatal brain damage: comparison of clinical outcome with initial and follow-up MR findings, Ajnr: American Journal of Neuroradiology, 19, 1909-1921, 1998	Indirect population (term and preterm infants). No comparison test.
Al Ajlouni, S. F., Aqrabawi, M., Oweis, N., Daoud, A. S., Clinical spectrum of cerebral palsy in Jordanian children: An analysis of 200 cases, Journal of Pediatric Neurology, 4, 251-255, 2006	Aetiology found in MRI not compared to another test (clinical examination).
Andersen, G. L., Skranes, J., Hollung, S. J., Vik, T., Cerebral mri findings in children with cerebral palsy (CP) in Norway, Archives of Disease in Childhood, 99, A202, 2014	No comparison with other test for aetiological findings. Abstract only.
Anderson, P., Tich, S. N. T., Shimony, J., Hunt, R., Doyle, L., Inder, T., Brain metrics at term equivalent age predicts early cognitive and motor development in very preterm children, Developmental medicine and child neurology, 51, 33, 2009	Diagnostic accuracy not reported. Conference abstract.
Arnfield, E., Guzzetta, A., Boyd, R., Relationship between brain structure on magnetic resonance imaging and motor outcomes in children with cerebral palsy: a systematic review, Research in Developmental Disabilities, 34, 2234-2250, 2013	No comparison with reference test.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
Arzoumanian, Y., Mirmiran, M., Barnes, P.D., Woolley, K., Ariagno, R.L., Moseley, M.E., Fleisher, B.E., Atlas, S.W., Diffusion tensor brain imaging findings at term-equivalent age may predict neurologic abnormalities in low birth weight preterm infants, <i>Ajnr: American Journal of Neuroradiology</i> , 24, 1646-1653, 2003	Indirect population (low birth weight infants).
Barnett, A., Mercuri, E., Rutherford, M., Haataja, L., Frisone, M.F., Henderson, S., Cowan, F., Dubowitz, L., Neurological and perceptual-motor outcome at 5 - 6 years of age in children with neonatal encephalopathy: relationship with neonatal brain MRI, <i>Neuropediatrics</i> , 33, 242-248, 2002	Indirect population (children with encephalopathy).
Baud, O., D'Allest, A. M., Lacaze-Masmonteil, T., Zupan, V., Nedelcoux, H., Boithias, C., Delaveaucoupet, J., Dehan, M., The early diagnosis of periventricular leukomalacia in premature infants with positive rolandic sharp waves on serial electroencephalography, <i>Journal of Pediatrics</i> , 132, 813-817, 1998	Indirect population (periventricular leukomalacia). No comparison test.
Bax, M., Tydeman, C., Flodmark, O., Clinical and MRI correlates of cerebral palsy: the European Cerebral Palsy Study, <i>JAMA</i> , 296, 1602-1608, 2006	Comparisons between tests not made and diagnostic accuracy could not be calculated.
Benini, R., Dagenais, L., Shevell, M., Does the absence of an abnormal imaging study define a specific cerebral palsy subtype?, <i>Annals of Neurology</i> , 70, S120-S121, 2011	Conference abstract.
Bosanquet, M., Copeland, L., Ware, R., Boyd, R., A systematic review of tests to predict cerebral palsy in young children, <i>Developmental Medicine and Child Neurology</i> , 55, 418-426, 2013	No comparison with other test for aetiological findings.
Boudokhane, S., Nouira, A., Migaou, H., Salah, S., Elmay, W., Jellad, A., Ben Salah Frih, Z., Function and neuroimaging in cerebral palsy, <i>Annals of Physical and Rehabilitation Medicine</i> , 57, e348, 2014	No comparison with other test for aetiological findings. Abstract only.
Bouza, H., Dubowitz, L. M., Rutherford, M., Cowan, F., Pennock, J. M., Late magnetic resonance imaging and clinical findings in neonates with unilateral lesions on cranial ultrasound, <i>Developmental Medicine &amp; Child Neurology</i> , 36, 951-64, 1994	Aetiology of cerebral palsy identified on tests not compared.
Bouza, H., Rutherford, M., Acolet, D., Pennock, J.M., Dubowitz, L.M., Evolution of early hemiplegic signs in full-term infants with unilateral brain lesions in the neonatal period: a prospective study, <i>Neuropediatrics</i> , 25, 201-207, 1994	No direct comparison of cerebral palsy aetiology between tests.
Boyd, R. N., Rose, S., Guzzetta, A., Tournier, D., Burke, S., Sakzewski, L., Jackson, G., Relationship between brain micro structure and upper limb motor and sensory function in	Diagnostic accuracy not reported and could not be calculated. Conference abstract.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
congenital hemiplegia, <i>Developmental medicine and child neurology</i> , 52, 62-63, 2010	
Burke, S., Clarke, D., Sinclair, K., Boyd, R. N., Pathogenesis of congenital hemiplegia- based on MR imaging: A systematic review, <i>Developmental medicine and child neurology</i> , 52, 38-39, 2010	Conference abstract.
Burton, H., Dixit, S., Litkowski, P., Wingert, J.R., Functional connectivity for somatosensory and motor cortex in spastic diplegia, <i>Somatosensory and Motor Research</i> , 26, 90-104, 2009	No comparison with other test for aetiological findings.
Candy, E.J., Hoon, A.H., Capute, A.J., Bryan, R.N., MRI in motor delay: important adjunct to classification of cerebral palsy, <i>Pediatric Neurology</i> , 9, 421-429, 1993	Comparison test (CT scan) not included in evidence review.
Chinier, E., N'Guyen, S., Lignon, G., Ter Minassian, A., Richard, I., Dinomais, M., Effect of motor imagery in children with unilateral cerebral palsy: fMRI study, <i>PLoS ONE [Electronic Resource]</i> , 9, e93378, 2014	Aetiology of cerebral palsy not identified and no comparison test.
Cho, H.K., Jang, S.H., Lee, E., Kim, S.Y., Kim, S., Kwon, Y.H., Son, S.M., Diffusion tensor imaging- demonstrated differences between hemiplegic and diplegic cerebral palsy with symmetric periventricular leukomalacia, <i>Ajnr: American Journal of Neuroradiology</i> , 34, 650-654, 2013	MRI outcome not directly compared with clinical assessment.
Cioni, G., Bartalena, L., Biagioni, E., Boldrini, A., Canapicchi, R., Neuroimaging and functional outcome of neonatal leukomalacia, <i>Behavioural Brain Research</i> , 49, 7-19, 1992	Indirect population (infants with PVL).
Cioni, G., Di Paco, M.C., Bertuccelli, B., Paolicelli, P.B., Canapicchi, R., MRI findings and sensorimotor development in infants with bilateral spastic cerebral palsy, <i>Brain and Development</i> , 19, 245-253, 1997	No comparison with other test for aetiological findings.
Cioni, G., Sales, B., Paolicelli, P.B., Petacchi, E., Scusa, M.F., Canapicchi, R., MRI and clinical characteristics of children with hemiplegic cerebral palsy, <i>Neuropediatrics</i> , 30, 249-255, 1999	No comparison with other test for aetiological findings.
Constantinou, J. C., Adamson-Macedo, E. N., Mirmiran, M., Fleisher, B. E., Movement, imaging and neurobehavioral assessment as predictors of cerebral palsy in preterm infants, <i>Journal of Perinatology</i> , 27, 225-9, 2007	Indirect population (infants with low birth weight). Outcome is prediction of future CP and not diagnostic accuracy of aetiology findings.
Dyet, L. E., Kennea, N., Counsell, S. J., Maalouf, E. F., Ajayi-Obe, M., Duggan, P. J., Harrison, M., Allsop, J. M., Hajnal, J., Herlihy, A. H., Edwards, B., Laroche, S., Cowan, F. M., Rutherford, M. A., Edwards, A. D., Natural history of brain lesions in extremely preterm infants studied with serial magnetic resonance imaging from birth and neurodevelopmental assessment, <i>Pediatrics</i> , 118, 536-48, 2006	Aetiology identified through MRI not compared with another test.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
Elliott, C. M., Currie, G., Reid, S. L., Valentine, J., Bynevelt, M., Robins, E., Licari, M. K., The relationship between white matter integrity and motor function in spastic diplegic cerebral palsy with and without periventricular leukomalacia, <i>Developmental medicine and child neurology</i> , 54, 5-6, 2012	Case-control study. Diagnostic accuracy not reported. Conference abstract.
Englander, Z. A., Pizoli, C. E., Batrachenko, A., Sun, J., Worley, G., Mikati, M. A., Kurtzberg, J., Song, A. W., Diffuse reduction of white matter connectivity in cerebral palsy with specific vulnerability of long range fiber tracts, <i>NeuroImage: Clinical</i> , 2, 440-447, 2013	Comparison of abnormalities identified using each test not reported.
Fedrizzi, E., Inverno, M., Bruzzone, M. G., Botteon, G., Saletti, V., Farinotti, M., MRI features of cerebral lesions and cognitive functions in preterm spastic diplegic children, <i>Pediatric Neurology</i> , 15, 207-212, 1996	Aetiology findings not compared between tests and no diagnostic accuracy.
Feys, H., Eyssen, M., Jaspers, E., Klingels, K., Desloovere, K., Molenaers, G., De Cock, P., Relation between neuroradiological findings and upper limb function in hemiplegic cerebral palsy, <i>European Journal of Paediatric Neurology</i> , 14, 169-77, 2010	No comparison with other test for aetiological findings.
Fiori, S., Mayberry, C. R., Ross, S. A., Whittingham, K., Guzzetta, A., Cioni, G., Boyd, R. N., Brain lesion severity and relationship to executive function in children with congenital hemiplegia, <i>Developmental medicine and child neurology</i> , 56, 7-8, 2014	No comparison with other test for aetiological findings. Abstract only.
Fujimoto, S., Togari, H., Banno, T., Takashima, S., Funato, M., Yoshioka, H., Ibara, S., Tatsuno, M., Hashimoto, K., Correlation between magnetic resonance imaging and clinical profiles of periventricular leukomalacia, <i>Tohoku Journal of Experimental Medicine</i> , 188, 143-151, 1999	Indirect population: children with PVL. No comparison test.
Fujimoto, S., Togari, H., Takashima, S., Funato, M., Yoshioka, H., Ibara, S., Tatsuno, M., National survey of periventricular leukomalacia in Japan, <i>Acta Paediatrica Japonica</i> , 40, 239-243, 1998	Indirect population: children with PVL. No comparison test.
Fukamachi, M., Akiyama, T., Tsuru, A., Morikawa, M., Kawaguchi, Y., Moriuchi, H., Neuropsychological and MRI assessment of young adults with hemiplegic cerebral palsy, <i>Acta Medica Nagasakiensia</i> , 49, 81-85, 2004	No comparison with other test for aetiological findings.
Geytenbeek, J. J., Harlaar, L., Ostrom, K., Barkhof, F., Becher, J., Vermeulen, J., MRI pattern is related to level of spoken language comprehension in children with severe cerebral palsy, <i>Developmental medicine and child neurology</i> , 54, 63-64, 2012	No comparison with other test for aetiological findings. Abstract only.
Gika, A. D., Siddiqui, A., Hulse, A. J., Edward, S., Fallon, P., McEntagart, M. E., Jan, W., Josifova, D., Lerman-Sagie, T., Drummond, J., Thompson, E.,	No comparison with other test for aetiological findings.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
Refetoff,S., Bonnemann,C.G., Jungbluth,H., White matter abnormalities and dystonic motor disorder associated with mutations in the SLC16A2 gene, <i>Developmental Medicine and Child Neurology</i> , 52, 475-482, 2010	
Gkoltsiou,K., Tzoufi,M., Counsell,S., Rutherford,M., Cowan,F., Serial brain MRI and ultrasound findings: relation to gestational age, bilirubin level, neonatal neurologic status and neurodevelopmental outcome in infants at risk of kernicterus, <i>Early Human Development</i> , 84, 829-838, 2008	Indirect population (neonates with ecephalopathy). Tests (cUS and MRI) carried out prior to CP diagnosis. Tests not compared for aetiology at diagnosis stage.
Goto, M., Ota, R., Iai, M., Sugita, K., Tanabe, Y., MRI changes and deficits of higher brain functions in preterm diplegia, <i>Acta Paediatrica</i> , 83, 506-11, 1994	No comparison test for aetiology of cerebral palsy.
Govindshenoy, M., Hennigan, S., Ahmed, R., Magnetic resonance imaging (MRI) scans in children with neurodevelopmental disabilities: Should a paediatric neuroradiologist's opinion be sought?, <i>Archives of Disease in Childhood</i> , 100, A83-A84, 2015	No comparison with other test for aetiological findings. Abstract only.
Griffiths,P.D., Radon,M.R., Crossman,A.R., Zurakowski,D., Connolly,D.J., Anatomic localization of dyskinesia in children with "profound" perinatal hypoxic-ischemic injury, <i>Ajnr: American Journal of Neuroradiology</i> , 31, 436-441, 2010	No comparison with other test for aetiological findings.
Hart, A. R., Alladi, S., Swilkinson, Whitby, E. H., Paley, M. N., Smith, M. F., Griffiths, P. D., Can magnetic resonance imaging, proton spectroscopy, and diffusion-weighted imaging identify preterm infants at risk of neurodevelopmental difficulties?, <i>Developmental medicine and child neurology</i> , 53, 5, 2011	Comparison test (MRS) not included in evidence review. Conference abstract.
Hart, A. R., Whitby, E. W., Griffiths, P. D., Smith, M. F., Magnetic resonance imaging and developmental outcome following preterm birth: review of current evidence, <i>Developmental Medicine &amp; Child Neurology</i> , 50, 655-63, 2008	Review. Studies included do not provide diagnostic accuracy of MRI compared to other tests for aetiological findings.
Hashimoto,K., Hasegawa,H., Kida,Y., Takeuchi,Y., Correlation between neuroimaging and neurological outcome in periventricular leukomalacia: diagnostic criteria, <i>Pediatrics International</i> , 43, 240-245, 2001	Aetiology for cerebral palsy not reported, study only reports outcomes for infants who were admitted to NICU.
Hayes,B., Ryan,S., Stephenson,J.B., King,M.D., Cerebral palsy after maternal trauma in pregnancy, <i>Developmental Medicine and Child Neurology</i> , 49, 700-706, 2007	Case series.
Himmelman,K., Uvebrant,P., Function and neuroimaging in cerebral palsy: a population-based study, <i>Developmental Medicine and Child Neurology</i> , 53, 516-521, 2011	Comparison test (CT scan) not included in protocol.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
Hnatyszyn,G., Cyrylowski,L., Czeszynska,M.B., Walecka,A., Konefal,H., Szmigiel,O., Gizewska,M., Dawid,G., The role of magnetic resonance imaging in early prediction of cerebral palsy, Turkish Journal of Pediatrics, 52, 278-284, 2010	Indirect population (neonates with asphyxia). Outcome is prediction of future CP and not diagnostic accuracy of aetiology findings.
Hoon, A. H., Jr., Reinhardt, E. M., Kelley, R. I., Breiter, S. N., Morton, D. H., Naidu, S. B., Johnston, M. V., Brain magnetic resonance imaging in suspected extrapyramidal cerebral palsy: observations in distinguishing genetic-metabolic from acquired causes, Journal of Pediatrics, 131, 240-5, 1997	Case series. No comparison to MRI.
Humphreys,P., Whiting,S., Pham,B., Hemiparetic cerebral palsy: clinical pattern and imaging in prediction of outcome, Canadian Journal of Neurological Sciences, 27, 210-219, 2000	Comparison test (CT scan) not included in evidence review.
Jain, K. K., Paliwal, V. K., Yadav, A., Roy, B., Goel, P., Chaturvedi, S., Chaurasia, A., Garg, R. K., Rathore, R. K. S., Gupta, R. K., Cerebral blood flow and DTI metrics changes in children with cerebral palsy following therapy, Journal of Pediatric Neuroradiology, 3, 63-73, 2014	No comparison with other test for aetiological findings.
Jaw,T.S., Jong,Y.J., Sheu,R.S., Liu,G.C., Chou,M.S., Yang,R.C., Etiology, timing of insult, and neuropathology of cerebral palsy evaluated with magnetic resonance imaging, Journal of the Formosan Medical Association, 97, 239-246, 1998	MRI not compared to another test for aetiological findings.
Jeon,T.Y., Kim,J.H., Yoo,S.Y., Eo,H., Kwon,J.Y., Lee,J., Lee,M., Chang,Y.S., Park,W.S., Neurodevelopmental outcomes in preterm infants: comparison of infants with and without diffuse excessive high signal intensity on MR images at near-term-equivalent age, Radiology, 263, 518-526, 2012	No comparison with other test for aetiological findings.
Johnsen,S.D., Bodensteiner,J.B., Lotze,T.E., Frequency and nature of cerebellar injury in the extremely premature survivor with cerebral palsy, Journal of Child Neurology, 20, 60-64, 2005	No comparison with other test for aetiological findings.
Koeda, T., Takeshita, K., Visuo-perceptual impairment and cerebral lesions in spastic diplegia with preterm birth, Brain and Development, 14, 239-244, 1992	No comparison with other test for aetiological findings.
Koeda,T., Takeshita,K., Electroencephalographic coherence abnormalities in preterm diplegia, Pediatric Neurology, 18, 51-56, 1998	Tests used are not included in the review protocol.
Koroglu, M., Turedi, A., Kisioglu, N., Ilhan Ergurhan, I., MRI findings in patients with hemiparetic cerebral palsy, Neuroradiology Journal, 19, 589-96, 2006	Comparison test (CT scan) not included in review protocol.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
Korzeniewski, S. J., Birbeck, G., DeLano, M. C., Potchen, M. J., Paneth, N., A systematic review of neuroimaging for cerebral palsy, <i>Journal of Child Neurology</i> , 23, 216-227, 2008	Literature review, aetiological findings from MRI not compared to reference tests in protocol.
Krageloh-Mann, I., Horber, V., The role of magnetic resonance imaging in elucidating the pathogenesis of cerebral palsy: A systematic review, <i>Developmental Medicine and Child Neurology</i> , 49, 144-151, 2007	Systematic review includes no studies which compared MRI with another test, therefore no comparative diagnostic accuracy results reported.
Krageloh-Mann, I., Petersen, D., Hagberg, G., Vollmer, B., Hagberg, B., Michaelis, R., Bilateral spastic cerebral palsy--MRI pathology and origin. Analysis from a representative series of 56 cases, <i>Developmental Medicine &amp; Child Neurology</i> , 37, 379-97, 1995	Studies included for MRI examination were not compared to other tests for aetiological findings.
Krageloh-Mann, I., Hagberg, B., Petersen, D., Riethmuller, J., Gut, E., Michaelis, R., Bilateral spastic cerebral palsy--pathogenetic aspects from MRI, <i>Neuropediatrics</i> , 23, 46-48, 1992	MRI not compared to another test for aetiological findings.
Kulak, W., Okurowska-Zawada, B., Sienkiewicz, D., Paszko-Patej, G., Goscik, E., The clinical signs and risk factors of non-ambulatory children with cerebral palsy, <i>Journal of Pediatric Neurology</i> , 9, 447-454, 2011	Aetiological findings from MRI not compared to another test.
Kulak, W., Okurowska-Zawada, B., Goscik, E., Sienkiewicz, D., Paszko-Patej, G., Kubas, B., Schizencephaly as a cause of spastic cerebral palsy, <i>Advances in Medical Sciences</i> , 56, 64-70, 2011	No comparison with other test for aetiological findings.
Kulak, W., Sobaniec, W., Kubas, B., Walecki, J., Smigielska-Kuzia, J., Bockowski, L., Artemowicz, B., Sendrowski, K., Spastic cerebral palsy: clinical magnetic resonance imaging correlation of 129 children, <i>Journal of Child Neurology</i> , 22, 8-14, 2007	No comparison of aetiology findings with clinical assessment, only test correlations provided.
Leonard, J.M., Cozens, A.L., Reid, S.M., Fahey, M.C., Ditchfield, M.R., Reddihough, D.S., Should children with cerebral palsy and normal imaging undergo testing for inherited metabolic disorders?, <i>Developmental Medicine and Child Neurology</i> , 53, 226-232, 2011	No outcomes in protocol: no alternative diagnosis made or confirmation/ruling out of genetic or progressive disease (these children were excluded from the study). Only children with normal MRI had further investigations.
Menkes, J.H., Curran, J., Clinical and MR correlates in children with extrapyramidal cerebral palsy, <i>Ajnr: American Journal of Neuroradiology</i> , 15, 451-457, 1994	No comparison with other test for aetiological findings.
Minagawa, K., Tsuji, Y., Ueda, H., Koyama, K., Tanizawa, K., Okamura, H., Hashimoto-Tamaoki, T., Possible correlation between high levels of IL-18 in the cord blood of pre-term infants and neonatal development of periventricular leukomalacia and cerebral palsy, <i>Cytokine</i> , 17, 164-170, 2002	Indirect population whom some consequently developed CP. Outcomes includes the prediction of future CP and aetiological findings not compared to MRI.
Mirmiran, M., Barnes, P.D., Keller, K., Constantinou, J.C., Fleisher, B.E., Hintz, S.R., Ariagno, R.L., Neonatal brain magnetic	Outcome reported is the prediction of future CP. No diagnostic accuracy for comparison of aetiological findings between tests.



<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
resonance imaging before discharge is better than serial cranial ultrasound in predicting cerebral palsy in very low birth weight preterm infants, <i>Pediatrics</i> , 114, 992-998, 2004	
Numata,Y., Onuma,A., Kobayashi,Y., Sato-Shirai,I., Tanaka,S., Kobayashi,S., Wakusawa,K., Inui,T., Kure,S., Haginoya,K., Brain magnetic resonance imaging and motor and intellectual functioning in 86 patients born at term with spastic diplegia, <i>Developmental Medicine and Child Neurology</i> , 55, 167-172, 2013	No comparison test.
Oishi, K., Faria, A. V., Yoshida, S., Chang, L., Mori, S., Reprint of "Quantitative evaluation of brain development using anatomical MRI and diffusion tensor imaging".[Reprint of <i>Int J Dev Neurosci</i> . 2013 Nov;31(7):512-24; PMID: 23796902], <i>International Journal of Developmental Neuroscience</i> , 32, 28-40, 2014	No comparison with other test for aetiological findings. Abstract only.
Okumura,A., Hayakawa,F., Kato,T., Kuno,K., Watanabe,K., MRI findings in patients with spastic cerebral palsy. I: Correlation with gestational age at birth, <i>Developmental Medicine and Child Neurology</i> , 39, 363-368, 1997	No comparison with other test for aetiological findings.
Pagliano, E., Fedrizzi, E., Erbetta, A., Bulgheroni, S., Solari, A., Bono, R., Fazzi, E., Andreucci, E., Riva, D., Cognitive profiles and visuoperceptual abilities in preterm and term spastic diplegic children with periventricular leukomalacia, <i>Journal of Child Neurology</i> , 22, 282-8, 2007	Only correlations between clinical assessment and MRI made, no comparison of aetiology findings.
Panigrahy,A., Barnes,P.D., Robertson,R.L., Sleeper,L.A., Sayre,J.W., Quantitative analysis of the corpus callosum in children with cerebral palsy and developmental delay: correlation with cerebral white matter volume, <i>Pediatric Radiology</i> , 35, 1199-1207, 2005	No comparison with other test for aetiological findings.
Pannek, K., Boyd, R. N., Fiori, S., Guzzetta, A., Rose, S. E., Assessment of the structural brain network reveals altered connectivity in children with unilateral cerebral palsy due to periventricular white matter lesions, <i>NeuroImage Clinical</i> , 5, 84-92, 2014	No comparison with other test for aetiological findings.
Park,E.S., Park,C.I., Choi,K.S., Choi,I.H., Shin,J.S., Over-expression of S100B protein in children with cerebral palsy or delayed development, <i>Brain and Development</i> , 26, 190-196, 2004	Aetiological findings not compared between tests.
Robinson,M.N., Peake,L.J., Ditchfield,M.R., Reid,S.M., Lanigan,A., Reddihough,D.S., Magnetic resonance imaging findings in a population-based cohort of children with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 51, 39-45, 2009	No comparison with other test for aetiological findings.

<b>Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?</b>	
Setanen, S., Lahti, K., Lehtonen, L., Parkkola, R., Maunu, J., Saarinen, K., Haataja, L., Neurological examination combined with brain MRI or cranial US improves prediction of neurological outcome in preterm infants, <i>Early Human Development</i> , 90, 851-856, 2014	Indirect population (very low birthweight). Aetiology of CP not compared with other test.
Shiran, S. I., Weinstein, M., Sirota-Cohen, C., Myers, V., Ben Bashat, D., Fattal-Valevski, A., Green, D., Schertz, M., MRI-based radiologic scoring system for extent of brain injury in children with hemiplegia, <i>American Journal of Neuroradiology</i> , 35, 2388-2396, 2014	No outcomes stated in protocol (only correlation between tests provided). Aetiology not compared with different tests.
Spagnoli, C., De Sousa, C., Retrospective study of the investigations of children presenting with lower limbs spasticity in a single institution, <i>Neuropediatrics</i> , 45, 109-116, 2014	Aetiology of CP not reported.
Spittle, A. J., Boyd, R. N., Inder, T. E., Doyle, L. W., Predicting motor development in very preterm infants at 12 months' corrected age: the role of qualitative magnetic resonance imaging and general movements assessments, <i>Pediatrics</i> , 123, 512-7, 2009	Outcome reported is the prediction of future CP. No diagnostic accuracy for comparison of aetiological findings between tests.
Spittle, A. J., Cheong, J., Doyle, L. W., Roberts, G., Lee, K. J., Lim, J., Hunt, R. W., Inder, T. E., Anderson, P. J., Neonatal white matter abnormality predicts childhood motor impairment in very preterm children, <i>Developmental Medicine and Child Neurology</i> , 53, 1000-1006, 2011	No comparison of aetiology findings in examinations.
Taufika, S., Macfarlane, S., Edwards, P., Guzzetta, A., Boyd, R., Relationship between brain structure and gait patterns in children with diplegia, <i>Developmental medicine and child neurology</i> , 53, 25-26, 2011	No comparison with other test for aetiological findings. Abstract only.
Valkama, A. M., Paakko, E. L., Vainionpaa, L. K., Lanning, F. P., Ilkko, E. A., Koivisto, M. E., Magnetic resonance imaging at term and neuromotor outcome in preterm infants, <i>Acta Paediatrica</i> , 89, 348-355, 2000	Indirect population (very low birth weight). Outcome reported is the prediction of future CP. No diagnostic accuracy for comparison of aetiological findings between tests.
Van Schie, P. E. M., Schijns, J., Becher, J. G., Barkhof, F., Van Weissenbruch, M. M., Vermeulen, R. J., Long-term motor and behavioral outcome after perinatal hypoxic-ischemic encephalopathy, <i>European Journal of Paediatric Neurology</i> , 19, 354-359, 2015	Indirect population (children with HIE). Aetiological findings not compared between tests.
Van't Hooft, J., van der Lee, J. H., Opmeer, B. C., Aarnoudse-Moens, C. S., Leenders, A. G., Mol, B. W., de Haan, T. R., Predicting developmental outcomes in premature infants by term equivalent MRI: systematic review and meta-analysis, <i>Systems Review</i> , 4, 71, 2015	Outcome is prediction of future CP and not diagnostic accuracy of aetiology findings.
Virella, D., Gouveia, R., Andrada, M. G., Folha, T., Conceicao, C., Cadete, A., Alvarelhao, J. J., Calado, E., MRI in 5-year-old children born in 2001-2003, from the Portuguese Surveillance of	No comparison with other test for aetiological findings. Abstract only.

**Excluded studies - Does MRI in addition to routine clinical assessment (including neonatal ultrasound) help determine the aetiology in children and young people with suspected or confirmed CP and if so in which subgroups is it most important?**

cerebral palsy, <i>Developmental medicine and child neurology</i> , 56, 29, 2014	
Williams,K., Alberman,E., The impact of diagnostic labelling in population-based research into cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 40, 182-185, 1998	Descriptive study, aetiology in MRI not compared to an additional test.

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### K.6.3 MRI and prognosis of cerebral palsy

**Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?**

Study	Reason for Exclusion
Aida,N., Nishimura,G., Hachiya,Y., Matsui,K., Takeuchi,M., Itani,Y., MR imaging of perinatal brain damage: comparison of clinical outcome with initial and follow-up MR findings, <i>Ajnr: American Journal of Neuroradiology</i> , 19, 1909-1921, 1998	The paper reports on development of CP in premature babies related to MRI findings.
Al Ajlouni, S. F., Aqrabawi, M., Oweis, N., Daoud, A. S., Clinical spectrum of cerebral palsy in Jordanian children: An analysis of 200 cases, <i>Journal of Pediatric Neurology</i> , 4, 251-255, 2006	Prevalence of causes MRI findings.
Andersen, G. L., Skranes, J., Hollung, S. J., Vik, T., Cerebral mri findings in children with cerebral palsy (CP) in Norway, <i>Archives of Disease in Childhood</i> , 99, A202, 2014	Prevalence study.
Anderson, P., Tich, S. N. T., Shimony, J., Hunt, R., Doyle, L., Inder, T., Brain metrics at term equivalent age predicts early cognitive and motor development in very preterm children, <i>Developmental medicine and child neurology</i> , 51, 33, 2009	Brain metric measurements not relevant to review protocol children did not have CP.
Anslow, P., <i>Neuroradiology - The use of magnetic resonance imaging scans in cerebral palsy cases</i> , <i>Clinical Risk</i> , 8, 197-199, 2002	Commentary/narrative review.
Arnfield,E., Guzzetta,A., Boyd,R., Relationship between brain structure on magnetic resonance imaging and motor outcomes in children with cerebral palsy: a systematic review, <i>Research in Developmental Disabilities</i> , 34, 2234-2250, 2013	The paper reports on prevalence of MRI findings by CP type and severity. No data on prognosis.
Barkovich, A. J., Hajnal, B. L., Vigneron, D., Sola, A., Partridge, J. C., Allen, F., Ferriero, D. M., Prediction of neuromotor outcome in perinatal asphyxia: evaluation of MR scoring systems, <i>Ajnr: American Journal of Neuroradiology</i> , 19, 143-9, 1998	Not CP specific; studying scoring systems on MRI; no data on prognosis of CP.
Barnett,A., Mercuri,E., Rutherford,M., Haataja,L., Frisone,M.F., Henderson,S., Cowan,F., Dubowitz,L., Neurological and perceptual-motor outcome at 5 - 6 years of age	outcome = development of CP (not relevant to review protocol); all children had MRI so virtually there's no comparison.

<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
in children with neonatal encephalopathy: relationship with neonatal brain MRI, <i>Neuropediatrics</i> , 33, 242-248, 2002	
Benini, R., Dagenais, L., Shevell, M. I., <i>Registre de la Paralysie Cerebrale au Quebec, Consortium, Normal imaging in patients with cerebral palsy: what does it tell us?</i> , <i>Journal of Pediatrics</i> , 162, 369-74.e1, 2013	Comparison = normal versus abnormal MRI findings (not relevant to review protocol); no multivariate analysis presented; unclear WHEN MRI was performed.
Bouza, H., Dubowitz, L. M., Rutherford, M., Cowan, F., Pennock, J. M., <i>Late magnetic resonance imaging and clinical findings in neonates with unilateral lesions on cranial ultrasound</i> , <i>Developmental Medicine &amp; Child Neurology</i> , 36, 951-64, 1994	No neurodevelopmental outcome considered for prognosis.
Byrne, P., Welch, R., Johnson, M.A., Darrah, J., Piper, M., <i>Serial magnetic resonance imaging in neonatal hypoxic-ischemic encephalopathy</i> , <i>Journal of Pediatrics</i> , 117, 694-700, 1990	Full text unavailable.
Candy, E.J., Hoon, A.H., Capute, A.J., Bryan, R.N., <i>MRI in motor delay: important adjunct to classification of cerebral palsy</i> , <i>Pediatric Neurology</i> , 9, 421-429, 1993	To evaluate the ability of MRI to determine aetiology factors (not relevant).
Cheong, J. L. Y., Coleman, L., Hunt, R. W., Lee, K. J., Doyle, L. W., Inder, T. E., Jacobs, S. E., <i>Prognostic utility of magnetic resonance imaging in neonatal hypoxic-ischemic encephalopathy: Substudy of a randomised trial</i> , <i>Archives of Pediatrics and Adolescent Medicine</i> , 166, 634-640, 2012	No relevant comparison for MRI as indicated in the review protocol the study outcome is prediction of death or major disability.
Cioni, G., Bartalena, L., Biagioni, E., Boldrini, A., Canapicchi, R., <i>Neuroimaging and functional outcome of neonatal leukomalacia</i> , <i>Behavioural Brain Research</i> , 49, 7-19, 1992	No analysis of association.
Constantinou, J. C., Adamson-Macedo, E. N., Mirmiran, M., Fleisher, B. E., <i>Movement, imaging and neurobehavioral assessment as predictors of cerebral palsy in preterm infants</i> , <i>Journal of Perinatology</i> , 27, 225-9, 2007	Only outcome considered is cases of CP (not relevant to review protocol).
de Bruine, F. T., van den Berg-Huysmans, A. A., Leijser, L. M., Rijken, M., Steggerda, S. J., van der Grond, J., van Wezel-Meijler, G., <i>Clinical implications of MR imaging findings in the white matter in very preterm infants: a 2-year follow-up study</i> , <i>Radiology</i> , 261, 899-906, 2011	No relevant comparison for MRI as indicated in the review protocol association between MRI findings and neurodevelopmental outcome. .
De Vries, L. S., Groenendaal, F., Van Haastert, I. C., Eken, P., Rademaker, K. J., Meiners, L. C., <i>Asymmetrical myelination of the posterior limb of the internal capsule in infants with periventricular haemorrhagic infarction: An early predictor of hemiplegia</i> , <i>Neuropediatrics</i> , 30, 314-319, 1999	correlation between MRI findings and hemiplegia - no results on timing of MRI and no multivariate analysis considered.
Dyet, L. E., Kennea, N., Counsell, S. J., Maalouf, E. F., Ajayi-Obe, M., Duggan, P. J., Harrison, M., Allsop, J. M., Hajnal, J., Herlihy, A. H., Edwards, B., Laroche, S., Cowan, F. M., Rutherford, M. A., Edwards, A. D., <i>Natural history of brain lesions in extremely preterm</i>	No relevant comparison for MRI as indicated in the review protocol the study is not CP specific.

<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
infants studied with serial magnetic resonance imaging from birth and neurodevelopmental assessment, <i>Pediatrics</i> , 118, 536-48, 2006	
Feldman,H.M., Scher,M.S., Kemp,S.S., Neurodevelopmental outcome of children with evidence of periventricular leukomalacia on late MRI, <i>Pediatric Neurology</i> , 6, 296-302, 1990	Association between extent of MRI abnormality and cognitive functioning (not relevant to review protocol); no multivariate analysis performed.
Fujimoto,S., Togari,H., Banno,T., Takashima,S., Funato,M., Yoshioka,H., Ibara,S., Tatsuno,M., Hashimoto,K., Correlation between magnetic resonance imaging and clinical profiles of periventricular leukomalacia, <i>Tohoku Journal of Experimental Medicine</i> , 188, 143-151, 1999	No relevant comparison for MRI as indicated in the review protocol.
Gkoltsiou,K., Tzoufi,M., Counsell,S., Rutherford,M., Cowan,F., Serial brain MRI and ultrasound findings: relation to gestational age, bilirubin level, neonatal neurologic status and neurodevelopmental outcome in infants at risk of kernicterus, <i>Early Human Development</i> , 84, 829-838, 2008	the paper does not report on prognosis of CP.
Gururaj,A., Sztrihla,L., Dawodu,A., Nath,K.R., Varady,E., Nork,M., Haas,D., CT and MR patterns of hypoxic ischemic brain damage following perinatal asphyxia, <i>Journal of Tropical Pediatrics</i> , 48, 5-9, 2002	Reports on association between risk factors and neurological findings and type of CP. No relevant MRI comparison considered.
Himmelman,K., Hagberg,G., Wiklund,L.M., Eek,M.N., Uvebrant,P., Dyskinetic cerebral palsy: a population-based study of children born between 1991 and 1998, <i>Developmental Medicine and Child Neurology</i> , 49, 246-251, 2007	Reports on prevalence of outcomes but no MRI comparison.
Hintz, S. R., Barnes, P. D., Bulas, D., Slovis, T. L., Finer, N. N., Wrage, L. A., Das, A., Tyson, J. E., Stevenson, D. K., Carlo, W. A., Walsh, M. C., Laptook, A. R., Yoder, B. A., Van Meurs, K. P., Faix, R. G., Rich, W., Newman, N. S., Cheng, H., Heyne, R. J., Vohr, B. R., Acarregui, M. J., Vaucher, Y. E., Pappas, A., Peralta-Carcelen, M., Wilson-Costello, D. E., Evans, P. W., Goldstein, R. F., Myers, G. J., Poindexter, B. B., McGowan, E. C., Adams-Chapman, I., Fuller, J., Higgins, R. D., Neuroimaging and neurodevelopmental outcome in extremely preterm infants, <i>Pediatrics</i> , 135, e32-e42, 2015	No relevant comparison for MRI as indicated in the review protocol the study outcome is prediction of CP.
Hnatyszyn,G., Cyrylowski,L., Czeszyska,M.B., Walecka,A., Konefal,H., Szmigiel,O., Gizewska,M., Dawid,G., The role of magnetic resonance imaging in early prediction of cerebral palsy, <i>Turkish Journal of Pediatrics</i> , 52, 278-284, 2010	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
Holmefur,M., Kits,A., Bergstrom,J., Krumlinde-Sundholm,L., Flodmark,O., Forssberg,H., Eliasson,A.C., Neuroradiology can predict the development of hand function in children with unilateral cerebral palsy, <i>Neurorehabilitation and Neural Repair</i> , 27, 72-78, 2013	Correlation between imaging abnormality and hand function. No relevant comparison for MRI as indicated in the review protocol.

<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
Iwata,S., Nakamura,T., Hizume,E., Kihara,H., Takashima,S., Matsuishi,T., Iwata,O., Qualitative brain MRI at term and cognitive outcomes at 9 years after very preterm birth, <i>Pediatrics</i> , 129, e1138-e1147, 2012	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
Jeon,T.Y., Kim,J.H., Yoo,S.Y., Eo,H., Kwon,J.Y., Lee,J., Lee,M., Chang,Y.S., Park,W.S., Neurodevelopmental outcomes in preterm infants: comparison of infants with and without diffuse excessive high signal intensity on MR images at near-term-equivalent age, <i>Radiology</i> , 263, 518-526, 2012	No relevant comparison for MRI as indicated in the review protocol.
Jyoti,R., O'Neil,R., Hurrion,E., Predicting outcome in term neonates with hypoxic-ischaemic encephalopathy using simplified MR criteria.[Erratum appears in <i>Pediatr Radiol.</i> 2007 Feb;37(2):243 Note: Hurrion, Elizabeth [added]], <i>Pediatric Radiology</i> , 36, 38-42, 2006	No relevant comparison for MRI as indicated in the review protocol.
Kidokoro, H., Anderson, P. J., Doyle, L. W., Woodward, L. J., Neil, J. J., Inder, T. E., Brain injury and altered brain growth in preterm infants: predictors and prognosis, <i>Pediatrics</i> , 134, e444-53, 2014	No relevant comparison for MRI as indicated in the review protocol the study outcome is prediction of CP.
Korzeniewski, S. J., Birbeck, G., DeLano, M. C., Potchen, M. J., Paneth, N., A systematic review of neuroimaging for cerebral palsy, <i>Journal of Child Neurology</i> , 23, 216-227, 2008	Duplicate.
Krageloh-Mann, I., Imaging of early brain injury and cortical plasticity, <i>Experimental Neurology</i> , 190 Suppl 1, S84-90, 2004	Descriptive paper on brain development – not CP specific.
Krageloh-Mann, I., Horber, V., The role of magnetic resonance imaging in elucidating the pathogenesis of cerebral palsy: A systematic review, <i>Developmental Medicine and Child Neurology</i> , 49, 144-151, 2007	The paper reports on the role of MRI on elucidating the aetiology of CP - no data for prognosis.
Krageloh-Mann,I., Helber,A., Mader,I., Staudt,M., Wolff,M., Groenendaal,F., DeVries,L., Bilateral lesions of thalamus and basal ganglia: origin and outcome, <i>Developmental Medicine and Child Neurology</i> , 44, 477-484, 2002	reports on prevalence of outcomes but no MRI comparison.
Kuenzle, C., Baenziger, O., Martin, E., Thun-Hohenstein, L., Steinlin, M., Good, M., Fanconi, S., Boltshauser, E., Largo, R. H., Prognostic value of early MR imaging in term infants with severe perinatal asphyxia, <i>Neuropediatrics</i> , 25, 191-200, 1994	Population = perinatal asphyxia; MRI at 1-14 days; Outcome at 18.9 months (measured as abnormal/normal) – no data on CP prognosis (for example cognition, epilepsy)
Kwon, S. H., Vasung, L., Ment, L. R., Huppi, P. S., The Role of Neuroimaging in Predicting Neurodevelopmental Outcomes of Preterm Neonates, <i>Clinics in Perinatology</i> , 41, 257-283, 2014	Narrative review.
Legault, G., Shevell, M. I., Dagenais, L., Quebec Cerebral Palsy Registry, Consortium, Predicting comorbidities with neuroimaging in children with cerebral palsy, <i>Pediatric Neurology</i> , 45, 229-32, 2011	Frequency of comorbidities by MRI findings (not relevant); no multivariate analysis.

<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
Lind, A., Parkkola, R., Lehtonen, L., Munck, P., Maunu, J., Lapinleimu, H., Haataja, L., Pipari Study Group, Associations between regional brain volumes at term-equivalent age and development at 2 years of age in preterm children, <i>Pediatric Radiology</i> , 41, 953-61, 2011	Not specific to CP it is comparing NDI vs no-NDI.
Logitharajah, P., Rutherford, M. A., Cowan, F. M., Hypoxic-ischemic encephalopathy in preterm infants: antecedent factors, brain imaging, and outcome, <i>Pediatric Research</i> , 66, 222-229, 2009	No relevant comparison for MRI as indicated in the review protocol the study is not specific to CP.
Martinez-Biarge, M., Diez-Sebastian, J., Kapellou, O., Gindner, D., Allsop, J. M., Rutherford, M. A., Cowan, F. M., Predicting motor outcome and death in term hypoxic-ischemic encephalopathy, <i>Neurology</i> , 76, 2055-61, 2011	No relevant comparison for MRI as indicated in the review protocol wrong population of interest.
Maunu, J., Lehtonen, L., Lapinleimu, H., Matomaki, J., Munck, P., Rikalainen, H., Parkkola, R., Haataja, L., Pipari Study Group, Ventricular dilatation in relation to outcome at 2 years of age in very preterm infants: a prospective Finnish cohort study, <i>Developmental Medicine &amp; Child Neurology</i> , 53, 48-54, 2011	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
Melhem, E. R., Hoon, A. H., Jr., Ferrucci, J. T., Jr., Quinn, C. B., Reinhardt, E. M., Demetrides, S. W., Freeman, B. M., Johnston, M. V., Periventricular leukomalacia: relationship between lateral ventricular volume on brain MR images and severity of cognitive and motor impairment, <i>Radiology</i> , 214, 199-204, 2000	Reports on association between moderate/severe CP and ventricular volumes. No relevant comparison for MRI.
Mercuri, E., Barnett, A., Rutherford, M., Guzzetta, A., Haataja, L., Cioni, G., Cowan, F., Dubowitz, L., Neonatal Cerebral Infarction and Neuromotor Outcome at School Age, <i>Pediatrics</i> , 113, 95-100, 2004	No relevant comparison for MRI as indicated in the review protocol the study does not report on prognosis in CP.
Mercuri, E., Rutherford, M., Cowan, F., Pennock, J., Counsell, S., Papadimitriou, M., Azzopardi, D., Bydder, G., Dubowitz, L., Early prognostic indicators of outcome in infants with neonatal cerebral infarction: a clinical, electroencephalogram, and magnetic resonance imaging study, <i>Pediatrics</i> , 103, 39-46, 1999	No relevant comparison for MRI as indicated in the review protocol the study outcome is not prognosis in CP.
Millet, V., Bartoli, J. M., Lacroze, V., Raybaud, C., Unal, D., Girard, N., Predictive significance of magnetic resonance imaging at 4 months of adjusted age in infants after a perinatal neurologic insult, <i>Biology of the Neonate</i> , 73, 207-219, 1998	Full text unavailable.
Mirmiran, M., Barnes, P. D., Keller, K., Constantinou, J. C., Fleisher, B. E., Hintz, S. R., Ariagno, R. L., Neonatal brain magnetic resonance imaging before discharge is better than serial cranial ultrasound in predicting cerebral palsy in very low birth weight preterm infants, <i>Pediatrics</i> , 114, 992-998, 2004	No relevant comparison for MRI as indicated in the review protocol the study outcome is prediction of CP.

<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
Mulkey,S.B., Yap,V.L., Swearingen,C.J., Riggins,M.S., Kaiser,J.R., Schaefer,G.B., Quantitative cranial magnetic resonance imaging in neonatal hypoxic-ischemic encephalopathy, <i>Pediatric Neurology</i> , 47, 101-108, 2012	Outcome = brain volume/volume of acute injury (not relevant to protocol).
Nanba,Y., Matsui,K., Aida,N., Sato,Y., Toyoshima,K., Kawataki,M., Hoshino,R., Ohyama,M., Itani,Y., Goto,A., Oka,A., Magnetic resonance imaging regional T1 abnormalities at term accurately predict motor outcome in preterm infants, <i>Pediatrics</i> , 120, e10-e19, 2007	No relevant comparison for MRI as indicated in the review protocol.
Okereafor,A., Allsop,J., Counsell,S.J., Fitzpatrick,J., Azzopardi,D., Rutherford,M.A., Cowan,F.M., Patterns of brain injury in neonates exposed to perinatal sentinel events, <i>Pediatrics</i> , 121, 906-914, 2008	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
Otapowicz,D., Sobaniec,W., Kulak,W., Sendrowski,K., Severity of dysarthric speech in children with infantile cerebral palsy in correlation with the brain CT and MRI, <i>Advances in Medical Sciences</i> , 52 Suppl 1, 188-190, 2007	Full text unavailable.
Reid, S. M., Dagia, C., Ditchfield, M. R., Carlin, J. B., Reddihough, D., Systematic review of population-based studies of brain imaging patterns in cerebral palsy, <i>Developmental medicine and child neurology</i> , 55, 35-36, 2013	The paper comments on standardization of MRI findings, no data on CP prognosis.
Robinson,M.N., Peake,L.J., Ditchfield,M.R., Reid,S.M., Lanigan,A., Reddihough,D.S., Magnetic resonance imaging findings in a population-based cohort of children with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 51, 39-45, 2009	Reports on prevalence of outcomes but no MRI comparison.
Roelants-van Rijn, A. M., Groenendaal, F., Beek, F. J., Eken, P., van Haastert, I. C., de Vries, L. S., Parenchymal brain injury in the preterm infant: comparison of cranial ultrasound, MRI and neurodevelopmental outcome, <i>Neuropediatrics</i> , 32, 80-9, 2001	The paper does not study prognosis of CP.
Rutherford,M.A., Supramaniam,V., Ederies,A., Chew,A., Bassi,L., Groppo,M., Anjari,M., Counsell,S., Ramenghi,L.A., Magnetic resonance imaging of white matter diseases of prematurity, <i>Neuroradiology</i> , 52, 505-521, 2010	Not CP specific, no MRI comparison, no data on CP prognosis.
Serdaroglu,G., Tekgul,H., Kitis,O., Serdaroglu,E., Gokben,S., Correlative value of magnetic resonance imaging for neurodevelopmental outcome in periventricular leukomalacia, <i>Developmental Medicine and Child Neurology</i> , 46, 733-739, 2004	Prognosis of CP presence.
Setanen, S., Lahti, K., Lehtonen, L., Parkkola, R., Maunu, J., Saarinen, K., Haataja, L., Neurological examination combined with brain MRI or cranial US improves prediction of neurological outcome in preterm infants, <i>Early Human Development</i> , 90, 851-856, 2014	No prediction of relevant outcomes presented.



<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
Setanen,S., Haataja,L., Parkkola,R., Lind,A., Lehtonen,L., Predictive value of neonatal brain MRI on the neurodevelopmental outcome of preterm infants by 5 years of age, <i>Acta Paediatrica</i> , 102, 492-497, 2013	All children received MRI - no comparison.
Shang, Q., Ma, C. Y., Lv, N., Lv, Z. L., Yan, Y. B., Wu, Z. R., Li, J. J., Duan, J. L., Zhu, C. L., Clinical study of cerebral palsy in 408 children with periventricular leukomalacia, <i>Experimental and Therapeutic Medicine</i> , 9, 1336-1344, 2015	Full text unavailable.
Sie, L. T., Hart, A. A., van Hof, J., de Groot, L., Lems, W., Lafeber, H. N., Valk, J., van der Knaap, M. S., Predictive value of neonatal MRI with respect to late MRI findings and clinical outcome. A study in infants with periventricular densities on neonatal ultrasound, <i>Neuropediatrics</i> , 36, 78-89, 2005	No relevant comparison for MRI as indicated in the review protocol the study outcome is prediction of CP.
Skiold,B., Vollmer,B., Bohm,B., Hallberg,B., Horsch,S., Mosskin,M., Lagercrantz,H., Aden,U., Blennow,M., Neonatal magnetic resonance imaging and outcome at age 30 months in extremely preterm infants, <i>Journal of Pediatrics</i> , 160, 559-566, 2012	Comparison at term versus preterm babies OR normal versus abnormal MRI findings; outcomes not relevant to review protocol.
Skranes,J.S., Vik,T., Nilsen,G., Smevik,O., Andersson,H.W., Rinck,P., Brubakk,A.M., Cerebral magnetic resonance imaging (MRI) and mental and motor function of very low birth weight infants at one year of corrected age, <i>Neuropediatrics</i> , 24, 256-262, 1993	Correlation between MRI abnormal finding and presence of Cp - no prognostic evaluation of neurodevelopment.
Spittle,A.J., Cheong,J., Doyle,L.W., Roberts,G., Lee,K.J., Lim,J., Hunt,R.W., Inder,T.E., Anderson,P.J., Neonatal white matter abnormality predicts childhood motor impairment in very preterm children, <i>Developmental Medicine and Child Neurology</i> , 53, 1000-1006, 2011	No relevant comparison for MRI as indicated in the review protocol.
Steinlin,M., Dirr,R., Martin,E., Boesch,C., Largo,R.H., Fanconi,S., Boltshauser,E., MRI following severe perinatal asphyxia: preliminary experience, <i>Pediatric Neurology</i> , 7, 164-170, 1991	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
Towsley, K., Shevell, M. I., Dagenais, L., Repacq Consortium, Population-based study of neuroimaging findings in children with cerebral palsy, <i>European Journal of Paediatric Neurology</i> , 15, 29-35, 2011	Reports on prevalence only of MRI findings.
Tsai, A. J., Lasky, R. E., John, S. D., Evans, P. W., Kennedy, K. A., Predictors of neurodevelopmental outcomes in preterm infants with intraparenchymal hemorrhage, <i>Journal of Perinatology</i> , 34, 399-404, 2014	Primary outcome = CP presence; no comparison made between imaging versus no imaging or imaging at different age; no multivariate analysis presented; for outcome 'cognition' MRI has not been considerate as predictor.
Twomey,E., Twomey,A., Ryan,S., Murphy,J., Donoghue,V.B., MR imaging of term infants with hypoxic-ischaemic encephalopathy as a predictor of neurodevelopmental outcome and	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.

<b>Excluded studies - What is the best age to perform an MRI to help provide information regarding prognosis in cerebral palsy?</b>	
late MRI appearances, <i>Pediatric Radiology</i> , 40, 1526-1535, 2010	
Valkama,A.M., Paakko,E.L., Vainionpaa,L.K., Lanning,F.P., Ilkko,E.A., Koivisto,M.E., Magnetic resonance imaging at term and neuromotor outcome in preterm infants, <i>Acta Paediatrica</i> , 89, 348-355, 2000	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
van der Aa, N. E., Verhage, C. H., Groenendaal, F., Vermeulen, R. J., de Bode, S., van Nieuwenhuizen, O., de Vries, L. S., Neonatal neuroimaging predicts recruitment of contralesional corticospinal tracts following perinatal brain injury, <i>Developmental Medicine &amp; Child Neurology</i> , 55, 707-12, 2013	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of USCP.
Van't Hooft, J., van der Lee, J. H., Opmeer, B. C., Aarnoudse-Moens, C. S., Leenders, A. G., Mol, B. W., de Haan, T. R., Predicting developmental outcomes in premature infants by term equivalent MRI: systematic review and meta-analysis, <i>Systems Review</i> , 4, 71, 2015	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP.
Weierink,L., Vermeulen,R.J., Boyd,R.N., Brain structure and executive functions in children with cerebral palsy: a systematic review, <i>Research in Developmental Disabilities</i> , 34, 1678-1688, 2013	No relevant comparison for MRI as indicated in the review protocol.
Woodward,L.J., Anderson,P.J., Austin,N.C., Howard,K., Inder,T.E., Neonatal MRI to predict neurodevelopmental outcomes in preterm infants, <i>New England Journal of Medicine</i> , 355, 685-694, 2006	Correlation etween MRI specific findings and developmental outcome in preterm babies (not relevant to review protocol).
Wu,Y.W., Lindan,C.E., Henning,L.H., Yoshida,C.K., Fullerton,H.J., Ferriero,D.M., Barkovich,A.J., Croen,L.A., Neuroimaging abnormalities in infants with congenital hemiparesis, <i>Pediatric Neurology</i> , 35, 191-196, 2006	All children received MRI (those who didn't have been excluded) - not relevant to review protocol in terms of comparison.
Yokochi,K., Fujimoto,S., Magnetic resonance imaging in children with neonatal asphyxia: correlation with developmental sequelae, <i>Acta Paediatrica</i> , 85, 88-95, 1996	No relevant comparison for MRI as indicated in the review protocol one of the study outcomes is prediction of CP/type of CP.
Zelnik, N., Konopnicki, M., Bennett-Back, O., Castel-Deutsch, T., Tirosh, E., Risk factors for epilepsy in children with cerebral palsy, <i>European Journal of Paediatric Neurology</i> , 14, 67-72, 2010	Comparison = CP vs CP epilepsy, and not MRI specific.

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### K.7.3 Prognosis for walking, talking and life expectancy

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Study	Reason for Exclusion

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Badawi,N., Felix,J.F., Kurinczuk,J.J., Dixon,G., Watson,L., Keogh,J.M., Valentine,J., Stanley,F.J., Cerebral palsy following term newborn encephalopathy: a population-based study, <i>Developmental Medicine and Child Neurology</i> , 47, 293-298, 2005	Case-control study design.
Badell-Ribera, A., Cerebral palsy: postural-locomotor prognosis in spastic diplegia, <i>Archives of Physical Medicine &amp; Rehabilitation</i> , 66, 614-9, 1985	No comparison for severity.
Baird,G., Allen,E., Scrutton,D., Knight,A., McNee,A., Will,E., Elbourne,D., Mortality from 1 to 16-18 years in bilateral cerebral palsy, <i>Archives of Disease in Childhood</i> , 96, 1077-1081, 2011	Incomplete reporting: results for prognostic indicators of survival not provided.
Barnes,D., Linton,J.L., Sullivan,E., Bagley,A., Oeffinger,D., Abel,M., Damiano,D., Gorton,G., Nicholson,D., Romness,M., Rogers,S., Tylkowski,C., Pediatric outcomes data collection instrument scores in ambulatory children with cerebral palsy: an analysis by age groups and severity level, <i>Journal of Pediatric Orthopedics</i> , 28, 97-102, 2008	No prognostic indicators for walking, talking or life expectancy.
Barnhart, R. C., Liemohn, W. P., Ambulatory status of children with cerebral palsy: a retrospective study, <i>Perceptual &amp; Motor Skills</i> , 81, 571-4, 1995	No statistical analysis undertaken.
Bassler, D., Stoll, B. J., Schmidt, B., Asztalos, E. V., Roberts, R. S., Robertson, C. M. T., Sauve, R. S., Using a count of neonatal morbidities to predict poor outcome in extremely low birth weight infants: Added role of neonatal infection, <i>Pediatrics</i> , 123, 313-318, 2009	Prognosis of extremely low birth weight infants. No prognosis of CP.
Beaino, G., Khoshnood, B., Kaminski, M., Pierrat, V., Marret, S., Matis, J., Ledesert, B., Thiriez, G., Fresson, J., Roze, J. C., Zupan-Simunek, V., Arnaud, C., Burguet, A., Larroque, B., Breart, G., Ancel, P. Y., Epipage Study Group, Predictors of cerebral palsy in very preterm infants: the EPIPAGE prospective population-based cohort study, <i>Developmental Medicine &amp; Child Neurology</i> , 52, e119-25, 2010	No prognostic indicators of walking, talking or life expectancy.
Begnoche, D. M., Chiarello, L. A., Palisano, R. J., Gracely, E. J., McCoy, S. W., Orlin, M. N., Predictors of Independent Walking in Young Children With Cerebral Palsy, <i>Physical Therapy</i> , 96, 183-92, 2016	Predictors of walking not relevant to the review protocol.
Benfer,K.A., Weir,K.A., Bell,K.L., Ware,R.S., Davies,P.S., Boyd,R.N., Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy, <i>Pediatrics</i> , 131, e1553-e1562, 2013	Cross-sectional study design. Prognosis of talking not included.
Benfer,K.A., Weir,K.A., Bell,K.L., Ware,R.S., Davies,P.S.W., Boyd,R.N., Longitudinal cohort protocol study of oropharyngeal dysphagia:	Protocol study, no results.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Relationships to gross motor attainment, growth and nutritional status in preschool children with cerebral palsy, <i>BMJ Open</i> , 2, -, 2012	
Bjornson,K.F., Zhou,C., Stevenson,R.D., Christakis,D., Relation of stride activity and participation in mobility-based life habits among children with cerebral palsy, <i>Archives of Physical Medicine and Rehabilitation</i> , 95, 360-368, 2014	Cross-sectional design.
Bleck,E.E., Locomotor prognosis in cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 17, 18-25, 1975	Prognosis of walking not assessed using multivariate analysis.
Bodeau-Livinec, F., Zeitlin, J., Blondel, B., Arnaud, C., Fresson, J., Burguet, A., Subtil, D., Marret, S., Roze, J. C., Marchand-Martin, L., Ancel, P. Y., Kaminski, M., Etude Epidémiologique sur les Petits Ages Gestationnels, group, Do very preterm twins and singletons differ in their neurodevelopment at 5 years of age?, <i>Archives of Disease in Childhood Fetal &amp; Neonatal Edition</i> , 98, F480-7, 2013	Comparison of twins vs singletons. No prognostic indicators.
Bottos,M., Puato,M.L., Vianello,A., Facchin,P., Locomotion patterns in cerebral palsy syndromes, <i>Developmental Medicine and Child Neurology</i> , 37, 883-899, 1995	No prognosis of walking, talking or life expectancy.
Bowen,J.R., Starte,D.R., Arnold,J.D., Simmons,J.L., Ma,P.J., Leslie,G.I., Extremely low birthweight infants at 3 years: a developmental profile, <i>Journal of Paediatrics and Child Health</i> , 29, 276-281, 1993	No prognosis of walking, talking or life expectancy.
Brooks,J.C., Strauss,D.J., Shavelle,R.M., Tran,L.M., Rosenbloom,L., Wu,Y.W., Recent trends in cerebral palsy survival. Part I: period and cohort effects, <i>Developmental Medicine and Child Neurology</i> , 56, 1059-1064, 2014	Incomplete reporting.Life expectancy not provided separately per prognostic indicator listed in protocol (feeding tube).
Bruck,I., Antoniuk,S.A., Spessatto,A., Bem,R.S., Hausberger,R., Pacheco,C.G., Epilepsy in children with cerebral palsy, <i>Arquivos de Neuro-Psiquiatria</i> , 59, 35-39, 2001	No prognosis of walking, talking or life expectancy.
Bruggink,J.L., Cioni,G., Einspieler,C., Maathuis,C.G., Pascale,R., Bos,A.F., Early motor repertoire is related to level of self-mobility in children with cerebral palsy at school age, <i>Developmental Medicine and Child Neurology</i> , 51, 878-885, 2009	No prognosis of walking, talking or life expectancy.
Brunquell, P. J., Glennon, C. M., DiMario, F. J., Jr., Lerer, T., Eisenfeld, L., Prediction of outcome based on clinical seizure type in newborn infants.[Erratum appears in <i>J Pediatr</i> 2002 Sep;141(3):452], <i>Journal of Pediatrics</i> , 140, 707-12, 2002	No prognostic indicators for walking, talking or life expectancy.
Burja,S., Seme-Ciglencecki,P., Gajsek-Marchetti,M., Hajdinjak,D., Levanic,A., Kodelic,B., Epidemiological study of cerebral palsy in the Maribor region, <i>Wiener Klinische Wochenschrift</i> , 116 Suppl 2, 39-43, 2004	No prognosis (incidence of CP).

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Calis,E.A., Veugelers,R., Sheppard,J.J., Tibboel,D., Evenhuis,H.M., Penning,C., Dysphagia in children with severe generalised cerebral palsy and intellectual disability, <i>Developmental Medicine and Child Neurology</i> , 50, 625-630, 2008	Prognosis of survival or talking not reported.
Carli,G., Reiger,I., Evans,N., One-year neurodevelopmental outcome after moderate newborn hypoxic ischaemic encephalopathy, <i>Journal of Paediatrics and Child Health</i> , 40, 217-220, 2004	Univariate analysis of risk factor. No prognosis included.
Carlsson,M., Olsson,I., Hagberg,G., Beckung,E., Behaviour in children with cerebral palsy with and without epilepsy, <i>Developmental Medicine and Child Neurology</i> , 50, 784-789, 2008	Case-control study design.
Chen,C.L., Chen,C.Y., Chen,H.C., Liu,W.Y., Shen,I.H., Lin,K.C., Potential predictors of changes in gross motor function during various tasks for children with cerebral palsy: a follow-up study, <i>Research in Developmental Disabilities</i> , 34, 721-728, 2013	Prognosis of walking not included.
Cohen,P., Kohn,J.G., Follow-up study of patients with cerebral palsy, <i>Western Journal of Medicine</i> , 130, 6-11, 1979	No statistical analysis.
Czochanska,J., Langner-Tyszka,B., Losiowski,Z., Schmidt-Sidor,B., Children who develop epilepsy in the first year of life: a prospective study, <i>Developmental Medicine and Child Neurology</i> , 36, 345-350, 1994	No survival or talking for CP and epilepsy.
da Paz Junior,A.C., Burnett,S.M., Braga,L.W., Walking prognosis in cerebral palsy: a 22-year retrospective analysis, <i>Developmental Medicine and Child Neurology</i> , 36, 130-134, 1994	No multivariate analysis.
Day, S. M., Wu, Y. W., Strauss, D. J., Shavelle, R. M., Reynolds, R. J., Change in ambulatory ability of adolescents and young adults with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 49, 647-653, 2007	No multivariate analysis.
Day,S.M., Wu,Y.W., Strauss,D.J., Shavelle,R.M., Reynolds,R.J., Causes of death in remote symptomatic epilepsy, <i>Neurology</i> , 65, 216-222, 2005	No multivariate analysis. Survival for cerebral palsy below 25 years not reported.
Doyle,L.W., Betheras,F.R., Ford,G.W., Davis,N.M., Callanan,C., Survival, cranial ultrasound and cerebral palsy in very low birthweight infants: 1980s versus 1990s, <i>Journal of Paediatrics and Child Health</i> , 36, 7-12, 2000	No prognosis of walking, talking or life expectancy.
Escobar, G. J., Littenberg, B., Petitti, D. B., Outcome among surviving very low birthweight infants: a meta-analysis, <i>Archives of Disease in Childhood</i> , 66, 204-11, 1991	Survival prior 2000.
Farmer,S.E., Key factors in the development of lower limb co-ordination: implications for the acquisition of walking in children with cerebral	Narrative review. References have been checked.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
palsy, Disability and Rehabilitation, 25, 807-816, 2003	
Fedrizzi, E., Facchin, P., Marzaroli, M., Pagliano, E., Botteon, G., Percivalle, L., Fazzi, E., Predictors of independent walking in children with spastic diplegia, Journal of Child Neurology, 15, 228-234, 2000	Incomplete data reporting (confidence intervals not provided).
Fedrizzi, E., Zuccarino, M.L., Vizziello, P., Clinical problems in neurodevelopmental diagnosis: a 7-year neurological and psychological follow-up study of low risk preterm infants, Italian Journal of Neurological Sciences, Suppl 5, 117-126, 1986	No prognostic indicators after diagnosis of CP.
Froslev-Friis, C., Dunkhase-Heinl, U., Andersen, J. D., Stausbol-Gron, B., Hansen, A. V., Garne, E., Epidemiology of cerebral palsy in Southern Denmark, Danish Medical Journal, 62, A4990, 2015	No prognosis of walking, talking or life expectancy.
Geytenbeek, J. J., Vermeulen, R. J., Becher, J. G., Oostrom, K. J., Comprehension of spoken language in non-speaking children with severe cerebral palsy: an explorative study on associations with motor type and disabilities, Developmental Medicine & Child Neurology, 57, 294-300, 2015	Cross-sectional study design.
Gosselin, J., Amiel-Tison, C., Infante-Rivard, C., Fouron, C., Fouron, J. C., Minor neurological signs and developmental performance in high risk children at preschool age, Developmental Medicine & Child Neurology, 44, 323-8, 2002	No prognosis of walking, talking or life expectancy
Grimmer, I., Metze, B.C., Walch, E., Scholz, T., Buhner, C., Predicting neurodevelopmental impairment in preterm infants by standardised neurological assessments at 6 and 12 months corrected age, Acta Paediatrica, 99, 526-530, 2010	No prognosis of walking, talking or life expectancy.
Gururaj, A. K., Sztrihai, L., Bener, A., Dawodu, A., Eapen, V., Epilepsy in children with cerebral palsy, Seizure, 12, 110-114, 2003	Case-control study design.
Haak, P., Lenski, M., Hidecker, M. J. C., Li, M., Paneth, N., Cerebral palsy and aging, Developmental Medicine and Child Neurology, 51, 16-23, 2009	Narrative review.
Hausler, M., Merz, U., Van Tuil, C., Ramaekers, V. T., Long-term outcome after neonatal parenchymatous brain lesions, Klinische Padiatrie, 216, 244-51, 2004	No prognosis of walking, talking or life expectancy.
Hemming, K., Hutton, J. L., Pharoah, P. O., Long-term survival for a cohort of adults with cerebral palsy, Developmental Medicine & Child Neurology, 48, 90-5, 2006	No adjustments in statistical model (univariate).
Hemming, K., Hutton, J.L., Bonellie, S., Kurinczuk, J.J., Intrauterine growth and survival in cerebral palsy, Archives of Disease in	Univariate analysis.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Childhood Fetal and Neonatal Edition, 93, F121-F126, 2008	
Himmelmann,K., Uvebrant,P., Function and neuroimaging in cerebral palsy: a population-based study, <i>Developmental Medicine and Child Neurology</i> , 53, 516-521, 2011	No prognosis included.
Hutton, J. L., Colver, A. F., Mackie, P. C., Effect of severity of disability on survival in north east England cerebral palsy cohort, <i>Archives of Disease in Childhood</i> , 83, 468-74, 2000	Results from multivariate model is incomplete: life expectancy for prognostic indicator not provided.
Hutton,J.L., Cooke,T., Pharoah,P.O., Life expectancy in children with cerebral palsy, <i>BMJ</i> , 309, 431-435, 1994	Life expectancy published prior to 2000 excluded.
Hutton,J.L., Pharoah,P.O., Effects of cognitive, motor, and sensory disabilities on survival in cerebral palsy, <i>Archives of Disease in Childhood</i> , 86, 84-89, 2002	Incomplete reporting: results from multivariate analysis not provided.
Ibrahim,A.I., Hawamdeh,Z.M., Evaluation of physical growth in cerebral palsied children and its possible relationship with gross motor development, <i>International Journal of Rehabilitation Research</i> , 30, 47-54, 2007	Case-control study design.
Katz, R. T., Life expectancy for children with cerebral palsy and mental retardation: implications for life care planning, <i>NeuroRehabilitation</i> , 18, 261-70, 2003	Narrative review.
Kennes,J., Rosenbaum,P., Hanna,S.E., Walter,S., Russell,D., Raina,P., Bartlett,D., Galuppi,B., Health status of school-aged children with cerebral palsy: information from a population-based sample, <i>Developmental Medicine and Child Neurology</i> , 44, 240-247, 2002	No multivariate analysis.
Khan, N. Z., Ferdous, S., Munir, S., Huq, S., McConachie, H., Mortality of urban and rural young children with cerebral palsy in Bangladesh, <i>Developmental Medicine &amp; Child Neurology</i> , 40, 749-53, 1998	No life expectancy.
Krakovsky,G., Huth,M.M., Lin,L., Levin,R.S., Functional changes in children, adolescents, and young adults with cerebral palsy, <i>Research in Developmental Disabilities</i> , 28, 331-340, 2007	Prognostic indicators not included.
LeBlanc,M.H., Graves,G.R., Rawson,T.W., Moffitt,J., Long-term outcome of infants at the margin of viability, <i>Journal of the Mississippi State Medical Association</i> , 40, 111-114, 1999	Prognosis for CP not provided.
Leigh, S., Granby, P., Turner, M., Wieteska, S., Haycox, A., Collins, B., The incidence and implications of cerebral palsy following potentially avoidable obstetric complications: a preliminary burden of disease study, <i>BJOG: An International Journal of Obstetrics &amp; Gynaecology</i> , 121, 1720-8, 2014	Economic model for survival and quality of life.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Maanum,G., Jahnsen,R., Froslic,K.F., Larsen,K.L., Keller,A., Walking ability and predictors of performance on the 6-minute walk test in adults with spastic cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 52, e126-e132, 2010	Cross-sectional study design.
Mitchell, L. E., Ziviani, J., Boyd, R. N., Characteristics associated with physical activity among independently ambulant children and adolescents with unilateral cerebral palsy, <i>Developmental Medicine &amp; Child Neurology</i> , 57, 167-74, 2015	Cross-sectional study design.
Molnar,G.E., Gordon,S.U., Cerebral palsy: predictive value of selected clinical signs for early prognostication of motor function, <i>Archives of Physical Medicine and Rehabilitation</i> , 57, 153-158, 1976	Effect size not provided.
Motion,S., Northstone,K., Emond,A., Stucke,S., Golding,J., Early feeding problems in children with cerebral palsy: weight and neurodevelopmental outcomes, <i>Developmental Medicine and Child Neurology</i> , 44, 40-43, 2002	No multivariate analysis.
Nordberg,A., Miniscalco,C., Lohmander,A., Himmelmann,K., Speech problems affect more than one in two children with cerebral palsy: Swedish population-based study, <i>Acta Paediatrica</i> , 102, 161-166, 2013	Descriptive study, no prognosis.
Novak,I., Hines,M., Goldsmith,S., Barclay,R., Clinical prognostic messages from a systematic review on cerebral palsy, <i>Pediatrics</i> , 130, e1285-e1312, 2012	Review includes both cross-sectional and cohort study designs. This review was checked for relevant cohort studies.
Odding, E., Roebroeck, M. E., Stam, H. J., The epidemiology of cerebral palsy: Incidence, impairments and risk factors, <i>Disability and Rehabilitation</i> , 28, 183-191, 2006	Cross-sectional study, no prognosis. Reserved for Comorbidities.
Opheim,A., Jahnsen,R., Olsson,E., Stanghelle,J.K., Walking function, pain, and fatigue in adults with cerebral palsy: a 7-year follow-up study, <i>Developmental Medicine and Child Neurology</i> , 51, 381-388, 2009	Narrative review
Parish,A.P., Bunyapen,C., Cohen,M.J., Garrison,T., Bhatia,J., Seizures as a predictor of long-term neurodevelopmental outcome in survivors of neonatal extracorporeal membrane oxygenation (ECMO), <i>Journal of Child Neurology</i> , 19, 930-934, 2004	Prognosis of walking, talking or life expectancy for CP not included.
Reddihough, D. S., Baikie, G., Walstab, J. E., Cerebral palsy in Victoria, Australia: mortality and causes of death, <i>Journal of Paediatrics &amp; Child Health</i> , 37, 183-6, 2001	No statistical analysis.
Ross,S.A., Engsborg,J.R., Relationships between spasticity, strength, gait, and the GMFM-66 in persons with spastic diplegia cerebral palsy, <i>Archives of Physical Medicine and Rehabilitation</i> , 88, 1114-1120, 2007	Cross-sectional design. All participants had surgery (not included in protocol).



<b>Excluded studies - In infants, children and young people with cerebral palsy, what are the clinical and developmental prognostic indicators in relation to: the ability to walk the ability to talk life expectancy?</b>	
Sigurdardottir,S., Vik,T., Speech, expressive language, and verbal cognition of preschool children with cerebral palsy in Iceland, <i>Developmental Medicine and Child Neurology</i> , 53, 74-80, 2011	Univariate analysis.
Smith, S. W., Camfield, C., Camfield, P., Living with cerebral palsy and tube feeding: A population-based follow- up study, <i>Journal of Pediatrics</i> , 135, 307-310, 1999	No multivariate analysis, pre 2000.
Strauss, D., Ojdana, K., Shavelle, R., Rosenbloom, L., Decline in function and life expectancy of older persons with cerebral palsy, <i>NeuroRehabilitation</i> , 19, 69-78, 2004	Incomplete reporting: adjusted survival not provided for prognostic indicators.
Strauss,D.J., Shavelle,R.M., Anderson,T.W., Life expectancy of children with cerebral palsy, <i>Pediatric Neurology</i> , 18, 143-149, 1998	Life expectancy published prior 2000.
Thompson,N., Stebbins,J., Seniorou,M., Newham,D., Muscle strength and walking ability in diplegic cerebral palsy: implications for assessment and management, <i>Gait and Posture</i> , 33, 321-325, 2011	Case-control study design. No prognosis.
Watt,J.M., Robertson,C.M., Grace,M.G., Early prognosis for ambulation of neonatal intensive care survivors with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 31, 766-773, 1989	Incomplete data reporting: confidence intervals from multivariate analysis not provided.
Zafeiriou,D.I., Kontopoulos,E.E., Tsikoulas,I., Characteristics and prognosis of epilepsy in children with cerebral palsy, <i>Journal of Child Neurology</i> , 14, 289-294, 1999	Incomplete data reporting (no effect size)

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## K.83 Information and support

<b>Excluded studies - What information and information types (written or verbal) are perceived as helpful and supportive by children and young people with cerebral palsy and their family members and carers?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Bell,E., Wallace,T., Chouinard,I., Shevell,M., Racine,E., Responding to requests of families for unproven interventions in neurodevelopmental disorders: hyperbaric oxygen "treatment" and stem cell "therapy" in cerebral palsy, <i>Developmental Disabilities Research Reviews</i> , 17, 19-26, 2011	Study does not include any theme related with information and support
Cooley, W. C., American Academy of Pediatrics Committee on Children With Disabilities, Providing a primary care medical home for children and youth with cerebral palsy, <i>Pediatrics</i> , 114, 1106-13, 2004	This is a review and not a qualitative study
Craig,G.M., Scambler,G., Spitz,L., Why parents of children with neurodevelopmental disabilities	Does not include any theme related with information and support

<b>Excluded studies - What information and information types (written or verbal) are perceived as helpful and supportive by children and young people with cerebral palsy and their family members and carers?</b>	
requiring gastrostomy feeding need more support, Developmental Medicine and Child Neurology, 45, 183-188, 2003	
Cussen,A., Howie,L., Imms,C., Looking to the future: adolescents with cerebral palsy talk about their aspirations--a narrative study, Disability and Rehabilitation, 34, 2103-2110, 2012	Does not include any theme related with information and support needed by children with CP or their parents and carers
Darrah, J., Wiart, L., Magill-Evans, J., Ray, L., Andersen, J., Are family-centred principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy?, Child: Care, Health & Development, 38, 41-7, 2012	Does not include any theme related with information and support
Gulmans, J., Vollenbroek-Hutten, M. M., Van Gemert-Pijnen, J. E., Van Harten, W. H., Evaluating quality of patient care communication in integrated care settings: a mixed method approach, International Journal for Quality in Health Care, 19, 281-8, 2007	This study does not include any theme regarding information and support
Knott, G. P., Attitudes and needs of parents of cerebral palsied children, Rehabilitation Literature, 40, 190-5, 1979	This is a review and not a qualitative study
Milner, J., Bungay, C., Jellinek, D., Hall, D. M., Needs of disabled children and their families, Archives of Disease in Childhood, 75, 399-404, 1996	Semi-structured interviews with quantitative data
Msall, M. E., Family needs and profiles for children with cerebral palsy: understanding supports in times of scarcity, Child: Care, Health & Development, 38, 807-8, 2012	Not a qualitative study
Neely-Barnes, S. L., Graff, J. C., Roberts, R. J., Hall, H. R., Hankins, J. S., "It's our job": qualitative study of family responses to ableism, Intellectual & Developmental Disabilities, 48, 245-58, 2010	Qualitative evidence relating to the child's disability and the different experiences that parents have had (not specific to information and support)
Piggot, J., Hocking, C., Paterson, J., Parental adjustment to having a child with cerebral palsy and participation in home therapy programs, Physical & Occupational Therapy in Pediatrics, 23, 5-29, 2003	Does not include any theme related with information and support

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### **K.9.3 Assessment of eating, drinking and swallowing difficulties**

<b>Excluded studies- In infants, children and young people with cerebral palsy, what is the value of videofluoroscopy or fibroscopic endoscopy in addition to clinical assessment in assessing difficulties with eating, drinking and swallowing?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Anonymous , Identification and management of dysphagia in children with neurological	Narrative guideline for identification and management of dysphagia.

<b>Excluded studies- In infants, children and young people with cerebral palsy, what is the value of videofluoroscopy or fibroscopic endoscopy in addition to clinical assessment in assessing difficulties with eating, drinking and swallowing?</b>	
impairments, Australian Nursing Journal, 18, 31-4, 2011	
Araujo, B. C., Motta, M. E., de Castro, A. G., de Araujo, C. M., Clinical and videofluoroscopic diagnosis of dysphagia in chronic encephalopathy of childhood, Radiologia Brasileira, 47, 84-8, 2014	Videofluoroscopy carried out on the bases of encephalopathy and does not state if the children were referred for or had eating, drinking or swallowing (EDS) difficulties (such as dysphagia). Therefore, the study does not fit the outcome of the review: identifying the mechanisms underlying EDS difficulties.
Ashwal, S., Russman, B. S., Blasco, P. A., Miller, G., Sandler, A., Shevell, M., Stevenson, R., Quality Standards Subcommittee of the American Academy of Neurology, Practice Committee of the Child Neurology Society, Practice parameter: diagnostic assessment of the child with cerebral palsy: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society, Neurology, 62, 851-63, 2004	Quality standard, assessment of eating, drinking and swallowing not included.
Baikie, G., South, M. J., Reddihough, D. S., Cook, D. J., Cameron, D. J., Olinsky, A., Ferguson, E., Agreement of aspiration tests using barium videofluoroscopy, salivagram, and milk scan in children with cerebral palsy, Developmental Medicine and Child Neurology, 47, 86-93, 2005	Reference tests (salivagram and milk scan) not included in the protocol.
Centre for Reviews and Dissemination, Identification and nursing management of dysphagia in individuals with neurological impairment (Structured abstract), Database of Abstracts of Reviews of Effects, 2015	Results not reported.
Centre for Reviews and Dissemination, The pros and cons of videofluoroscopic assessment of swallowing in children (Structured abstract), Database of Abstracts of Reviews of Effects, 2015	Abstract, no evidence reported.
Dos Santos, R. R., Sales, A. V., Cola, P. C., Jorge, A., Peres, F., Carvalho, S. M., Furkim, A. M., Berti, L., Da Silva, R., Accuracy of the clinical severity scale in the oropharyngeal dysphagia in cerebral palsy, Dysphagia, 27 (4), 594, 2012	Abstract (originally in Portuguese), full paper and clinical trial record not found.
Mezoff, E. A., Focus on diagnosis: Dysphagia, Pediatrics in Review, 33, 518-520, 2012	Narrative review.
Mirrett, P. L., Riski, J. E., Glascott, J., Johnson, V., Videofluoroscopic assessment of dysphagia in children with severe spastic cerebral palsy, Dysphagia, 9, 174-179, 1994	No comparison/reference test outcome.
Ortega Ade, O., Ciamponi, A. L., Mendes, F. M., Santos, M. T., Assessment scale of the oral motor performance of children and adolescents with neurological damages, Journal of Oral Rehabilitation, 36, 653-9, 2009	Does not include videofluoroscopy or FEES.

<b>Excluded studies- In infants, children and young people with cerebral palsy, what is the value of videofluoroscopy or fibroscopic endoscopy in addition to clinical assessment in assessing difficulties with eating, drinking and swallowing?</b>	
Pinillos, S., Garcia, R., Meavilla, S., Gutierrez, A., Mila, A., Marquez, A., Trias, M., Alcaraz, R., Ortiz, C., Varea, V., Oropharyngeal dysphagia in children. Evaluation and treatment in a specific unit of a department of pediatric gastroenterology and nutrition, <i>Dysphagia</i> , 28 (2), 328, 2013	Abstract only, no reference test conducted.
Schweikert, K., Wilmes, S., Dunkel, N., Weber, M., Schlaegel, W., Videoendoscopic evaluation of swallowing (VEES) in patients with motor neuron disease/amyotrophic lateral sclerosis, <i>Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration</i> , 14, 82, 2013	Abstract only, includes motor neurone disease, above 25 years.
Suiter, D.M., Leder, S.B., Karas, D.E., The 3-ounce (90-cc) water swallow challenge: a screening test for children with suspected oropharyngeal dysphagia, <i>Otolaryngology - Head and Neck Surgery</i> , 140, 187-190, 2009	Cerebral palsy not reported.
Van Den Engel-Hoek, L., Erasmus, C., Van Hulst, K., Arvedson, J., De Groot, I., De Swart, B., Patterns of dysphagia on videofluoroscopic swallow study in children with different neurologic etiologies, <i>Dysphagia</i> , 26 (4), 468, 2011	Abstract only, results not reported.
Weir, K., McMahon, S., Barry, L., Masters, I.B., Chang, A.B., Clinical signs and symptoms of oropharyngeal aspiration and dysphagia in children, <i>European Respiratory Journal</i> , 33, 604-611, 2009	Cerebral palsy not reported.
Wright, R.E., Wright, F.R., Carson, C.A., Videofluoroscopic assessment in children with severe cerebral palsy presenting with dysphagia, <i>Pediatric Radiology</i> , 26, 720-722, 1996	No comparison/reference test outcome.

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## K.10<sub>2</sub> Management of eating, drinking and swallowing difficulties

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in managing difficulties with eating, drinking and swallowing?</b>	
Study	Reason for Exclusion
Andrew, M. J., Parr, J. R., Montague-Johnson, C., Braddick, O., Laler, K., Williams, N., Baker, B., Sullivan, P. B., Optimising nutrition to improve growth and reduce neurodisabilities in neonates at risk of neurological impairment, and children with suspected or confirmed cerebral palsy, <i>BMC Pediatrics</i> , 15, 2015	This is a protocol (2015)
Arvedson, J., Clark, H., Lazarus, C., Schooling, T., Frymark, T., The Effects of Oral-Motor Exercises on Swallowing in Children: An Evidence-Based Systematic Review, <i>Developmental Medicine &amp; Child Neurology</i> , 52(11): 1000-1013, 2010	The individual studies in this systematic review were checked against our review protocol, which have already been included or excluded in our review

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in managing difficulties with eating, drinking and swallowing?</b>	
Arvedson, J.C., Feeding children with cerebral palsy and swallowing difficulties, <i>European Journal of Clinical Nutrition</i> , 67, S9-S12, 2013	Individual studies in the systematic review were checked for inclusion of our review
Bailey, R. L., Angell, M. E., Improving Feeding Skills and Mealtime Behaviors in Children and Youth with Disabilities, <i>Education and Training in Developmental Disabilities</i> , 40(1): 80-96, 2005	This was a within-subject study, only two of the 9 patients had CP
Baker, Tricia, Haines, Sara, Yost, Jennifer, DiClaudio, Stacy, Braun, Carli, Holt, Sheryl, The role of family-centered therapy when used with physical or occupational therapy in children with congenital or acquired disorders, <i>Physical Therapy Reviews</i> , 17, 29-37, 2012	The interventions and outcomes did not match the criteria of our review protocol
Bell, K.L., Boyd, R.N., Tweedy, S.M., Weir, K.A., Stevenson, R.D., Davies, P.S., A prospective, longitudinal study of growth, nutrition and sedentary behaviour in young children with cerebral palsy, <i>BMC Public Health</i> , 10, 179-, 2010	This was a review protocol
Blockley, J., Miller, G., Feeding techniques with cerebral-palsied children, <i>Physiotherapy</i> , 57, 300-8, 1971	Narrative review
Brown, L., Burns, Y., Watter, P., Gray, P., Physiotherapy intervention to improve motor co-ordination in ELBW preschool children: A randomised controlled trial, <i>Developmental Medicine and Child Neurology</i> , 54, 67, 2012	Study did not meet PICO of review protocol
Brun, A.C., Stordal, K., Johannesdottir, G.B., Bentsen, B.S., Medhus, A.W., The effect of protein composition in liquid meals on gastric emptying rate in children with cerebral palsy, <i>Clinical Nutrition</i> , 31, 108-112, 2012	Outcomes of this study did not match inclusion criteria of our review protocol
Chu, M. L., Sala, D. A., The use of tiagabine in pediatric spasticity management, <i>Developmental Medicine and Child Neurology</i> , 48, 456-459, 2006	Before and after study investigated the use of tiagabine to reduce spasticity and changes in feeding
Gangil, A., Patwari, A.K., Aneja, S., Ahuja, B., Anand, V.K., Feeding problems in children with cerebral palsy, <i>Indian Pediatrics</i> , 38, 839-846, 2001	Reporting of the time point of outcomes was not clear
Garcia-Contreras, A.A., Vasquez-Garibay, E.M., Romero-Velarde, E., Ibarra-Gutierrez, A.I., Troyo-Sanroman, R., Sandoval-Montes, I.E., Intensive nutritional support improves the nutritional status and body composition in severely malnourished children with cerebral palsy, <i>Nutricion Hospitalaria</i> , 29, 838-843, 2014	The intervention was formula plus corn syrup, which was not part of the inclusion criteria in the protocol
Gerek, M., Ciyiltepe, M., Dysphagia management of pediatric patients with cerebral palsy, <i>British Journal of Developmental Disabilities</i> , 51, 57-72, 2005	Wrong study design, no data on outcomes reported
Gisel, E. G., Applegate-Ferrante, T., Benson, J., Bosma, J. F., Oral-motor skills following sensorimotor therapy in two groups of moderately dysphagic children with cerebral	Did not meet PICO for review protocol

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in managing difficulties with eating, drinking and swallowing?</b>	
palsy: aspiration vs nonaspiration, Dysphagia, 11, 59-71, 1996	
Gisel, E. G., Tessier, M., Lapierre, G., Seidman, E., Drouin, E., Filion, G., Feeding management of children with severe cerebral palsy and eating impairment: an exploratory study, Physical & Occupational Therapy in Pediatrics, 23, 19-45, 2003	Study only consisted of 3 patients, individual cases
Gisel, E.G., Oral-motor skills following sensorimotor intervention in the moderately eating-impaired child with cerebral palsy, Dysphagia, 9, 180-192, 1994	Did not meet PICO for review
Gisel, E.G., Alphonse, E., Ramsay, M., Assessment of ingestive and oral praxis skills: children with cerebral palsy vs. controls, Dysphagia, 15, 236-244, 2000	Case control study
Gisel, E.G., Schwartz, S., Petryk, A., Clarke, D., Haberfellner, H., "Whole body" mobility after one year of intraoral appliance therapy in children with cerebral palsy and moderate eating impairment, Dysphagia, 15, 226-235, 2000	Did not meet PICO for review
Haberfellner, H., Schwartz, S., Gisel, E.G., Feeding skills and growth after one year of intraoral appliance therapy in moderately dysphagic children with cerebral palsy, Dysphagia, 16, 83-96, 2001	Did not meet PICO for review
Helfrich-Miller, K.R., Rector, K.L., Straka, J.A., Dysphagia: its treatment in the profoundly retarded patient with cerebral palsy, Archives of Physical Medicine and Rehabilitation, 67, 520-525, 1986	Unclear reporting of outcomes, wrong study design
Hirata, G. C., Santos, R. S., Rehabilitation of oropharyngeal dysphagia in children with cerebral palsy: A systematic review of the speech therapy approach, International Archives of Otorhinolaryngology, 16, 396-9, 2012	This systematic review reported incidence of various rehabilitation techniques, not effectiveness of various techniques
Kong, C., Wong, H. S., Weight-for-height values and limb anthropometric composition of tube-fed children with quadriplegic cerebral palsy, Pediatrics, 116, e839-NaN, 2005	Individual studies in the systematic review were checked for inclusion in our review and did not fit our protocol criteria
Limbrock, G.J., Hoyer, H., Scheying, H., Drooling, chewing and swallowing dysfunctions in children with cerebral palsy: treatment according to Castillo-Morales, Journal of Dentistry for Children, 57, 445-451, 1990	Narrative review
McCarey, D.W., Buchanan, E., Gregory, M., Clark, B.J., Weaver, L.T., Home enteral feeding of children in the west of Scotland, Scottish Medical Journal, 41, 147-149, 1996	The intervention did not match the criteria of our review protocol
Miyazawa, R., Tomomasa, T., Kaneko, H., Arakawa, H., Shimizu, N., Morikawa, A., Effects of pectin liquid on gastroesophageal reflux disease in children with cerebral palsy, BMC Gastroenterology, 8, 11-, 2008	Study looked at viscosity of enteral formula and oesophageal pH

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in managing difficulties with eating, drinking and swallowing?</b>	
Pinnington, L., Hegarty, J., Effects of consistent food presentation on efficiency of eating and nutritive value of food consumed by children with severe neurological impairment, <i>Dysphagia</i> , 14, 17-26, 1999	Within study design, patients were their own control
Redstone, F., West, J. F., The importance of postural control for feeding, <i>Pediatric Nursing</i> , 30, 97-100, 2004	Narrative review
Reilly, S., Skuse, D., Mathisen, B., Wolke, D., The objective rating of oral-motor functions during feeding, <i>Dysphagia</i> , 10, 177-91, 1995	The study did not report separate subgroups
Rempel, G., Moussavi, Z., The effect of viscosity on the breath-swallow pattern of young people with cerebral palsy, <i>Dysphagia</i> , 20, 108-112, 2005	Wrong study design
Samson-Fang, L., Butler, C., O'Donnell, M., Effects of gastrostomy feeding in children with cerebral palsy: an AACPDM evidence report, <i>Developmental Medicine &amp; Child Neurology</i> , 45(6): 415-426, 2003	This was a report of effects of gastrostomy feeding in children with CP, which was not an intervention for our review
Sanders, K.D., Cox, K., Cannon, R., Blanchard, D., Pitcher, J., Papathakis, P., Varella, L., Maughan, R., Growth response to enteral feeding by children with cerebral palsy, <i>Journal of Parenteral and Enteral Nutrition</i> , 14, 23-26, 1990	This study looked at growth of children after enteral feeding
Serel, S., Demir, N., Karaduman, A., Olmez, S., Management of drooling in children with cerebral Palsy, <i>Dysphagia</i> , 26 (4), 433-434, 2011	Drooling, not part of review protocol
Sleigh, G., Sullivan, P. B., Thomas, A. G., Gastrostomy feeding versus oral feeding alone for children with cerebral palsy, <i>Cochrane Database of Systematic Reviews</i> , CD003943, 2004	This Cochrane review investigated the effectiveness of nutritional supplementation given via gastrostomy or jejunostomy, no studies were identified
Sleigh, G., Brocklehurst, P., Gastrostomy feeding in cerebral palsy: A systematic review, <i>Archives of Disease in Childhood</i> , 89, 534-539, 2004	Study did not meet PICO of review protocol
Snider, L., Majnemer, A., Darsaklis, V., Feeding interventions for children with cerebral palsy: A review of the evidence, <i>Physical and Occupational Therapy in Pediatrics</i> , 31, 58-77, 2011	The individual studies in the systematic review were checked for inclusion of our review
Song, W. J., Park, J. H., Lee, J. H., Kim, M. Y., Effects of neuromuscular electrical stimulation on swallowing functions in children with cerebral palsy: A pilot randomised controlled trial, <i>Hong Kong Journal of Occupational Therapy</i> , 25, 1-6, 2015	Intervention not relevant or specified by the review protocol.
Sullivan, P.B., Morrice, J.S., Vernon-Roberts, A., Grant, H., Eltumi, M., Thomas, A.G., Does gastrostomy tube feeding in children with cerebral palsy increase the risk of respiratory morbidity?, <i>Archives of Disease in Childhood</i> , 91, 478-482, 2006	Study did not meet PICO of review protocol

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in managing difficulties with eating, drinking and swallowing?</b>	
Vekerdy,Z., Management of seating posture of children with cerebral palsy by using thoracic-lumbar-sacral orthosis with non-rigid SIDO frame, Disability and Rehabilitation, 29, 1434-1441, 2007	This was a before and after intervention study, which did not meet the protocol criteria for our review
Vernon-Roberts, A., Wells, J., Grant, H., Alder, N., Vadamalayan, B., Eltumi, M., Sullivan, P. B., Trial of a micronutrient rich, high fibre, low energy density enteral feeding formula for gastrostomy feeding disabled children, Journal of Pediatric Gastroenterology and Nutrition, 50, E41-E42, 2010	The intervention did not match the criteria of our review protocol
Vernon-Roberts,A., Wells,J., Grant,H., Alder,N., Vadamalayan,B., Eltumi,M., Sullivan,P.B., Gastrostomy feeding in cerebral palsy: enough and no more, Developmental Medicine and Child Neurology, 52, 1099-1105, 2010	The intervention was low energy feed, which was not in the inclusion criteria of the protocol
Weir, A., Bell, L., Caristo, Fiona, Ware, S., Davies, S., Fahey, Michael, Rawicki, Barry, Boyd, N., Reported Eating Ability of Young Children With Cerebral Palsy: Is There an Association With Gross Motor Function?, Archives of Physical Medicine & Rehabilitation, 94, 495-503, 2013	Outcomes reported did not match PICO of our review protocol

## K.11<sub>1</sub> Optimising nutritional status

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS</b>	
Reference	Reason for Exclusion
Backman,T., Sjovie,H., Mellberg,M., Borjesson,A., Anderberg,M., Kullendorff,C.M., Arnbjornsson,E., Pre- and postoperative vomiting in children undergoing video-assisted gastrostomy tube placement, Surgery Research and Practice Print, 2014, 871325-, 2014	Nutritional status not examined.
Brun,A.C., Stordal,K., Johannesdottir,G.B., Bentsen,B.S., Medhus,A.W., The effect of protein composition in liquid meals on gastric emptying rate in children with cerebral palsy, Clinical Nutrition, 31, 108-112, 2012	Nutritional status not examined.
Ferluga,E.D., Sathe,N.A., Krishnaswami,S., Mcpheeters,M.L., Surgical intervention for feeding and nutrition difficulties in cerebral palsy: a systematic review, Developmental Medicine and Child Neurology, 56, 31-43, 2014	Did not undertake evidence synthesis. Used for references only.
Forsberg,K.A., Bjorkman,T., Sandman,P.O., Sandlund,M., Influence of a lifestyle intervention among persons with a psychiatric disability: a cluster randomised controlled trail on symptoms, quality of life and sense of coherence, Journal of Clinical Nursing, 19, 1519-1528, 2010	Population not of interest (psychiatric disabilities)
Gangil,A., Patwari,A.K., Aneja,S., Ahuja,B., Anand,V.K., Feeding problems in children with cerebral palsy, Indian Pediatrics, 38, 839-846, 2001	Comparison not population of interest (children without CP).



<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS</b>	
Garcia-Contreras,A.A., Vasquez-Garibay,E.M., Romero-Velarde,E., Ibarra-Gutierrez,A.I., Troyo-Sanroman,R., Sandoval-Montes,I.E., Intensive nutritional support improves the nutritional status and body composition in severely malnourished children with cerebral palsy, <i>Nutricion Hospitalaria</i> , 29, 838-843, 2014	Sample size below requirement and no comparison.
Gatti,C., di Abriola,G.F., Villa,M., De,Angelis P., Laviani,R., La,Sala E., Dall'Oglio,L., Esophagogastric dissociation versus fundoplication: Which is best for severely neurologically impaired children?, <i>Journal of Pediatric Surgery</i> , 36, 677-680, 2001	Not population of interest (children without CP).
Gillette,M.L., Stough,C.O., Beck,A.R., Maliszewski,G., Best,C.M., Gerling,J.K., Summar,S., Outcomes of a weight management clinic for children with special needs, <i>Journal of Developmental and Behavioral Pediatrics</i> , 35, 266-273, 2014	Very small CP sample size (n = 2)
Gisel,E.G., Oral-motor skills following sensorimotor intervention in the moderately eating-impaired child with cerebral palsy, <i>Dysphagia</i> , 9, 180-192, 1994	Applicable for eating and swallowing review question.
Gisel,E.G., pplegate-Ferrante,T., Benson,J.E., Bosma,J.F., Effect of oral sensorimotor treatment on measures of growth, eating efficiency and aspiration in the dysphagic child with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 37, 528-543, 1995	Not relevant and low sample (n = 27). Reserved for eating, drinking and swallowing question.
Hoffer,E.K., Cosgrove,J.M., Levin,D.Q., Herskowitz,M.M., Sclafani,S.J., Radiologic gastrojejunostomy and percutaneous endoscopic gastrostomy: a prospective, randomized comparison, <i>Journal of Vascular and Interventional Radiology</i> , 10, 413-420, 1999	Not population interest (children without CP).
Holenweg-Gross,C., Newman,C.J., Faouzi,M., Poirot-Hodgkinson,I., Berard,C., Roulet-Perez,E., Undernutrition in children with profound intellectual and multiple disabilities (PIMD): its prevalence and influence on quality of life, <i>Child: Care, Health and Development</i> , 40, 525-532, 2014	Cross-sectional design with no comparison.
Horner-Johnson,W., Drum,C.E., Abdullah,N., A randomised trial of a health promotion intervention for adults with disabilities, <i>Disability and Health Journal</i> , 4, 254-261, 2011	Population and outcome do not match protocol.
Huerta,G., Puri,V.K., Nasoenteric feeding tubes in critically ill patients (fluoroscopy versus blind), <i>Nutrition</i> , 16, 264-267, 2000	Not population of interest (terminally ill).
Idzinga,J.C., de Jong,A.L., van den Bemt,P.M.L., The effect of an intervention aimed at reducing errors when administering medication through enteral feeding tubes in an institution for individuals with intellectual disability, <i>Journal of Intellectual Disability Research</i> , 53, 932-938, 2009	Intervention does not match protocol.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS</b>	
Kurtze,N., Gundersen,K.T., Svebak,S., Quality of life, functional disability and lifestyle among subgroups of fibromyalgia patients: The significance of anxiety and depression, <i>Br J Med Psychol</i> , 72, 471-484, 1999	Not population of interest (children without CP).
Lai,M., Inglis,G.D.T., Hose,K., Jardine,L.A., Davies,M.W., Methods for securing endotracheal tubes in newborn infants, <i>Cochrane Database of Systematic Reviews</i> , 2009. Article Number, -, 2009	Not population of interest (children without CP).
Ljungdahl,M., Sundbom,M., Complication rate lower after percutaneous endoscopic gastrostomy than after surgical gastrostomy: a prospective, randomised trial, <i>Surgical Endoscopy</i> , 20, 1248-1251, 2006	Not population of interest (children without CP).
Lucas,A., Morley,R., Cole,T.J., Randomised trial of early diet in preterm babies and later intelligence quotient, <i>BMJ</i> , 317, 1481-1487, 1998	RCT of neurologically impaired children. Nutritional status not examined for CP subgroup.
Maiano,C., Normand,C.L., Aime,A., Begarie,J., Lifestyle interventions targeting changes in body weight and composition among youth with an intellectual disability: A systematic review, <i>Research in Developmental Disabilities</i> , 35, 1914-1926, 2014	Not population of interest (children without CP).
McGrath,S.J., Splaingard,M.L., Alba,H.M., Kaufman,B.H., Glicklick,M., Survival and functional outcome of children with severe cerebral palsy following gastrostomy, <i>Archives of Physical Medicine and Rehabilitation</i> , 73, 133-137, 1992	No comparison group.
Messent,P.R., Cooke,C.B., Long,J., Physical activity, exercise and health of adults with mild and moderate learning disabilities, <i>British Journal of Learning Disabilities</i> , 26, 17-22, 1998	Low sample size (n = 27) and number of CP patients not reported.
Miyazawa,R., Tomomasa,T., Kaneko,H., Arakawa,H., Shimizu,N., Morikawa,A., Effects of pectin liquid on gastroesophageal reflux disease in children with cerebral palsy, <i>BMC Gastroenterology</i> , 8, 11-, 2008	RCT - Nutrition not examined.
Morgan,Jessie, Young,Lauren, McGuire,William, Slow advancement of enteral feed volumes to prevent necrotising enterocolitis in very low birth weight infants, <i>Cochrane Database of Systematic Reviews</i> , -, 2013	Not population of interest (children without CP).
Motion,S., Northstone,K., Emond,A., Persistent early feeding difficulties and subsequent growth and developmental outcomes, <i>Ambulatory Child Health</i> , 7, 231-237, 2001	No comparison group.
Pacilli,M., Eaton,S., McHoney,M., Kiely,E.M., Drake,D.P., Curry,J.I., Lindley,K.J., Pierro,A., Four year follow-up of a randomised controlled trial comparing open and laparoscopic Nissen fundoplication in children, <i>Archives of Disease in Childhood</i> , 99, 516-521, 2014	Does not include Cerebral Palsy patients with gastrostomy as subgroup, only provides nutrition evidence for all all children in study.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS</b>	
Pattamanuch,N., Novak,I., Loizides,A., Montalvo,A., Thompson,J., Rivas,Y., Pan,D., Single-center experience with 1-step low-profile percutaneous endoscopic gastrostomy in children, <i>Journal of Pediatric Gastroenterology and Nutrition</i> , 58, 616-620, 2014	Does not include CP as subgroup, only states 'neurological impairment'.
Plasschaert,F., Jones,K., Forward,M., The effect of simulating weight gain on the energy cost of walking in unimpaired children and children with cerebral palsy, <i>Archives of Physical Medicine and Rehabilitation</i> , 89, 2302-2308, 2008	Comparison does not match protocol.
Reading,R., Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study, <i>Child: Care, Health and Development</i> , 31, 491-492, 2005	No comparison group.
Rimmer,J.H., Wang,E., Pellegrini,C.A., Lullo,C., Gerber,B.S., Telehealth weight management intervention for adults with physical disabilities: a randomised controlled trial, <i>American Journal of Physical Medicine and Rehabilitation</i> , 92, 1084-1094, 2013	Very small CP sample size (n = 7)
Roebroek,M.E., Van,DenBergemonsH, Nieuwenhuijsen,C., Hilberink,S.R., Van,DerSlotW, Van,MeeterenJ, Stam,H.J., Innovating transition and lifespan care for people with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 52, 74-, 2010	Cross-sectional design, no intervention.
Savage,K., Kritas,S., Schwarzer,A., Davidson,G., Omari,T., Whey-based enteral formula and gastrointestinal function in children with cerebral palsy: A randomised double-blind controlled trial, <i>Journal of Pediatric Gastroenterology and Nutrition</i> , 52, E219-, 2011	No outcomes of interest reported (anthropometric measures).
Skrinar,G.S., Huxley,N.A., Hutchinson,D.S., Menninger,E., Glew,P., The role of a fitness intervention on people with serious psychiatric disabilities, <i>Psychiatric rehabilitation journal</i> , 29, 122-127, 2005	Not population of interest (children without CP).
Sobus,K.M.L., Karkos,J.B., Rehabilitation care and management for the individual with cerebral palsy, ages 13 through early adulthood, <i>Critical Reviews in Physical and Rehabilitation Medicine</i> , 21, 117-165, 2009	Review.
Srivastava,R., Downey,J., Feola,P., O'Gorman,M., Samore,M., Coburn,L., Holubkov,R., Mundorff,M., James,B.C., Rosenbaum,P., Young,P.C., Dean,J.M., Fundoplication versus gastrojejunal feeding tubes to prevent aspiration pneumonia in children with neurological impairment, <i>Developmental Medicine and Child Neurology</i> , 48, 10-10, 2006	Nutritional status not examined.
Strine,T.W., Hootman,J.M., Chapman,D.P., Okoro,C.A., Balluz,L., Health-related quality of life, health risk behaviors, and disability among adults with pain-related activity difficulty,	Study design and population do not match protocol.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS</b>	
American Journal of Public Health, 95, 2042-2048, 2005	
Sullivan,P.B., Morrice,J.S., Vernon-Roberts,A., Grant,H., Eltumi,M., Thomas,A.G., Does gastrostomy tube feeding in children with cerebral palsy increase the risk of respiratory morbidity?, Archives of Disease in Childhood, 91, 478-482, 2006	Nutritional status not examined.
swarte-Wallace,J., Firouzbakhsh,S., Finklestein,J.Z., Using research to change practice: enteral feedings for pediatric oncology patients, Journal of Pediatric Oncology Nursing, 18, 217-223, 2001	Population not of interest (cancer patients).
Tofail,F., Hamadani,J.D., Ahmed,A.Z., Mehrin,F., Hakim,M., Huda,S.N., The mental development and behavior of low-birth-weight Bangladeshi infants from an urban low-income community, European journal of clinical nutrition, 66, 237-243, 2012	Cerebral palsy patients not included as a subgroup.
Torsvik,I., Ueland,P.M., Markestad,T., Bjarke-Monsen,A.L., Cobalamin supplementation improves motor development and regurgitations in infants: Results from a randomised intervention study, American Journal of Clinical Nutrition, 98, 1233-1240, 2013	Intervention does not match protocol.
Valentin-Gudiol,M., Bagur-Calafat,C., Girabent-Farres,M., Hadders-Algra,M., Mattern-Baxter,K., ngulo-Barroso,R., Treadmill interventions with partial body weight support in children under six years of age at risk of neuromotor delay: a report of a Cochrane systematic review and meta-analysis, European journal of physical and rehabilitation medicine., 49, 67-91, 2013	Outcomes not of interest.
van den Bemt,P.M., Robertz,R., de Jong,A.L., van Roon,E.N., Leufkens,H.G., Drug administration errors in an institution for individuals with intellectual disability: an observational study, Journal of Intellectual Disability Research, 51, 528-536, 2007	Not population of interest (children without CP).
van der Slot,W.M., Roebroek,M.E., Nieuwenhuijsen,C., Bergen,M.P., Stam,H.J., Burdorf,A., van den Berg-Emons RJ, Cardiovascular disease risk in adults with spastic bilateral cerebral palsy, Journal of Rehabilitation Medicine 2013 Oct;45(9):866-72., 45, 866-872	Population above 25 years of age.
Vohr,B.R., Stephens,B.E., McDonald,S.A., Ehrenkranz,R.A., Lupton,A.R., Pappas,A., Hintz,S.R., Shankaran,S., Higgins,R.D., Das,A., Extended Hypothermia Follow-up Subcommittee of the NICHD Neonatal Research Network., Cerebral palsy and growth failure at 6 to 7 years, Pediatrics, 132, e905-e914, 2013	Comparison are non-CP patients.
Wales,P.W., Diamond,I.R., Dutta,S., Muraca,S., Chait,P., Connolly,B., Langer,J.C., Fundoplication and gastrostomy versus image-guided gastrojejun tube for enteral feeding in	Cohort - does not assess nutrition in Cerebral Palsy patients.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS</b>	
neurologically impaired children with gastroesophageal reflux, <i>Journal of Pediatric Surgery</i> , 37, 407-412, 2002	
Wolf,A.M., Siadaty,M.S., Crowther,J.Q., Nadler,J.L., Wagner,D.L., Cavalieri,S.L., Elward,K.S., Bovbjerg,V.E., Impact of lifestyle intervention on lost productivity and disability: improving control with activity and nutrition, <i>Journal of Occupational and Environmental Medicine</i> , 51, 139-145, 2009	Not population of interest (children without CP).
Young,Lauren, Morgan,Jessie, McCormick,Felicia M., McGuire,William, Nutrient-enriched formula versus standard term formula for preterm infants following hospital discharge, <i>Cochrane Database of Systematic Reviews</i> , -, 2012	Not population of interest (children without CP).
Yuen,H.K., Hanson,C., Body image and exercise in people with and without acquired mobility disability, <i>Disability and Rehabilitation</i> , 24, 289-296, 2002	Comparison and outcome does not match protocol.
Arrowsmith,F.E., Allen,J.R., Gaskin,K.J., Somerville,H., Birdsall,J., Barzi,F., O'Loughlin,E.V., Nutritional rehabilitation increases the resting energy expenditure of malnourished children with severe cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 54, 170-175, 2012	Low sample size of CP patients with anthropometric measures (n = 14).
Elmahgoub,S.S., Calders,P., Lambers,S., Stegen,S.M., Van,Laethem C., Cambier,D.C., The effect of combined exercise training in adolescents who are overweight or obese with intellectual disability: the role of training frequency, <i>Journal of Strength and Conditioning Research</i> , 25, 2274-2282, 2011	No cerebral palsy included.
Peters,R.T., Balduyck,B., Nour,S., Gastrostomy complications in infants and children: a comparative study, <i>Pediatric Surgery International</i> , 26, 707-709, 2010	Nutritional status not examined.
Rempel,G.R., Colwell,S.O., Nelson,R.P., Growth in children with cerebral palsy fed via gastrostomy, <i>Pediatrics</i> , 82, 857-862, 1988	No comparison group.
Sharma,R., Williams,A.N., Zaw,W., Timing of gastrostomy insertion in children with a neurodisability: a cross-sectional study of early versus late intervention, <i>BMJ Open</i> , 2, -, 2012	Low sample of CP patients (n=8)
Soylu,O.B., Unalp,A., Uran,N., Dizdarer,G., Ozgonul,F.O., Conku,A., Ataman,H., Ozturk,A.A., Effect of nutritional support in children with spastic quadriplegia, <i>Pediatric Neurology</i> , 39, 330-334, 2008	No comparison group.
Strauss,D.J., Shavelle,R.M., Anderson,T.W., Life expectancy of children with cerebral palsy, <i>Pediatric Neurology</i> , 18, 143-149, 1998	No outcomes of interest. Reserved for prognostic indicators question.
Sullivan,P.B., Juszczak,E., Bachlet,A.M., Lambert,B., Vernon-Roberts,A., Grant,H.W., Eltumi,M., McLean,L., Alder,N., Thomas,A.G.,	No control group.

**Excluded studies - In children and young people with cerebral palsy, what interventions are effective in optimising nutritional status? - RCTS**

Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study, <i>Developmental Medicine and Child Neurology</i> , 47, 77-85, 2005	
Viswanath,N., Wong,D., Channappa,D., Kukkady,A., Brown,S., Samarakkody,U., Is prophylactic fundoplication necessary in neurologically impaired children?, <i>European Journal of Pediatric Surgery</i> , 20, 226-229, 2010	Intervention and outcomes not in protocol.

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### K.12<sup>3</sup> Improving speech and communication: Speech 4 intelligibility

**Excluded studies - In children and young people with cerebral palsy, what interventions are effective in improving speech intelligibility?**

Study	Reason for Exclusion
Relationship of sialorrhea and motor speech function in children with cerebral palsy of different motor severities, <i>Journal of Rehabilitation Medicine (Stiftelsen Rehabiliteringsinformation)</i> , 22-23, 2012	Full text unavailable.
Alacam,A., Kolcuoglu,N., Effects of two types of appliances on orofacial dysfunctions of disabled children, <i>British Journal of Developmental Disabilities</i> , 53 part 2, 111-123, 2007	No relevant outcomes studied; mixed population.
Allison, K. M., Hustad, K. C., Impact of sentence length and phonetic complexity on intelligibility of 5-year-old children with cerebral palsy, <i>International Journal of Speechlanguage Pathology</i> , 16, 396-407, 2014	No intervention, but rather assessment of speech.
Boliek, C. A., Fox, C. M., Individual and environmental contributions to treatment outcomes following a neuroplasticity-principled speech treatment (LSVT LOUD) in children with dysarthria secondary to cerebral palsy: a case study review, <i>International Journal of Speechlanguage Pathology</i> , 16, 372-85, 2014	From a dataset of 25 children with CP the authors only reported conclusions from 2 cases (examples of weak and strong responder).
Centre for Reviews and Dissemination, Interaction training for conversational partners of children with cerebral palsy: a systematic review (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Not relevant intervention used.
Centre for Reviews and Dissemination, Evidence for effectiveness of treatment of loudness, rate, or prosody in dysarthria: a systematic review (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Mixed population studied.
Centre for Reviews and Dissemination, The feasibility of universal screening for primary speech and language delay: findings from a systematic review of the literature (Structured	Screening studies considered mixed population studied.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in improving speech intelligibility?</b>	
abstract), Database of Abstracts of Reviews of Effects, 2015	
Centre for Reviews and Dissemination, Direct speech and language therapy for children with cerebral palsy: findings from a systematic review (Structured abstract), Database of Abstracts of Reviews of Effects, 2015	Single case studies only considered.
Christie,B., A clinical evaluation of an approach to language assessment and remediation with six language-impaired children, South African Journal of Communication Disorders - die Suid-Afrikaanse Tydskrif vir Kommunikasieafwykings, 26, 46-61, 1979	Small sample size of 6 patients, of whom 4 only with CP.
Cockerill, H., Elbourne, D., Allen, E., Scrutton, D., Will, E., McNee, A., Fairhurst, C., Baird, G., Speech, communication and use of augmentative communication in young people with cerebral palsy: the SH&PE population study, Child: Care, Health & Development, 40, 149-57, 2014	Speech evaluation (not an intervention study) data on AAC use.
Fox, Cm, Ramig, Lo, Ciucci, Mr, Sapir, S, McFarland, Dh, Farley, Bg, The Science and Practice of LSVT/LOUD: Neural Plasticity - Principled Approach to Treating Individuals with Parkinson Disease and Other Neurological Disorders, Seminars in Speech and Language, 27, 283-99., 2006	Descriptive paper.
Hanson, E. K., Yorkston, K. M., Beukelman, D. R., Speech supplementation techniques for dysarthria: a systematic review, Journal of Medical Speech Language Pathology, 12(2): 9-24, 2004	Review paper on supplementation techniques for dysarthria - no restriction on population considered included studies that 'reported data on at least one person with dysarthria'.
Hunter, L, Pring, T, Martin, S, The use of strategies to increase speech intelligibility in cerebral palsy: an experimental evaluation, Br J Disord Commun, 26, 163-74., 1991	Small sample size (8 patients) no intervention used.
Hurkmans, J., de Bruijn, M., Boonstra, A. M., Jonkers, R., Bastiaanse, R., Arendzen, H., Reinders-Messelink, H. A., Music in the treatment of neurological language and speech disorders: A systematic review, Aphasiology, 26, 1-19, 2012	Only 1 patient with CP in population considered intervention not relevant to review protocol.
Hustad, K. C., Effects of speech supplementation strategies on intelligibility and listener attitudes for a speaker with mild dysarthria, AAC: Augmentative & Alternative Communication, 21, 256-263, 2005	Case study.
Hustad, K. C., Auker, J., Natale, N., Carlson, R., Improving intelligibility of speakers with profound dysarthria and cerebral palsy, AAC: Augmentative & Alternative Communication, 19, 187-198, 2003	Small sample size (3 patients).
Hustad, K. C., Sassano, K., Effects of rate reduction on severe spastic dysarthria in cerebral palsy, Journal of Medical Speech-Language Pathology, 10, 287-292, 2002	Study on 2 individuals with dysarthria.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in improving speech intelligibility?</b>	
Hustad, Kc, Effects of speech supplementation strategies on intelligibility and listener attitudes for a speaker with mild dysarthria, Augmentative and Alternative Communication, 21, 256-63., 2005	Case study.
Hustad, Kc, Mertz, Garcia J, Aided and Unaided Speech Supplementation Strategies: Effect of Alphabet Cues and Iconic Hand Gestures on Dysarthric Speech, J Speech Lang Hearing Res, 48, 996-1012., 2005	Small sample size = 3 patients.
Lass, N. J., Pannbacker, M., The application of evidence-based practice to nonspeech oral motor treatments, Language, Speech, and Hearing Services in Schools, 39(3): 408-421, 2008	Descriptive paper review of studies on nonspeech oral motor treatments with no restriction on population of interest.
Lee, J., Hustad, K. C., Weismer, G., Predicting speech intelligibility with a multiple speech subsystems approach in children with cerebral palsy, Journal of Speech Language & Hearing Research, 57, 1666-78, 2014	Full text unavailable.
Levy, E. S., Implementing two treatment approaches to childhood dysarthria, International Journal of Speechlanguage Pathology, 16, 344-54, 2014	Descriptive paper.
Levy, Erika S., Ramig, Lorraine O., Camarata, Stephen M., The Effects of Two Speech Interventions on Speech Function in Pediatric Dysarthria, Journal of Medical Speech-Language Pathology, 20, 82-87, 2012	Population n=3 children with CP
McCauley, R. J., Strand, E., Lof, G. L., Schooling, T., Frymark, T., Evidence-based systematic review: Effects of nonspeech oral motor exercises on speech, American Journal of Speech Language Pathology, 18(4): 343-360, 2009	Wide variation in population studied.
Pachalska, M., Franczuk, B., Macqueen, B. D., Jastrzebowska, G., Perzanowski, Z., Neldon, K., The impact of art therapy on the intelligibility of speech in children with cerebral palsy, Ortopedia Traumatologia Rehabilitacja, 3, 508-18, 2001	Full text unavailable.
Pennington, L., Goldbart, J., Marshall, J., Direct speech and language therapy for children with cerebral palsy: Findings from a systematic review, Developmental Medicine and Child Neurology, 47, 57-63, 2005	Single case studies considered.
Pennington, L., Goldbart, J., Marshall, J., Interaction training for conversational partners of children with cerebral palsy: a systematic review, International Journal of Language & Communication Disorders, 39, 151-70, 2004	Intervention not relevant to review protocol.
Pennington, Lindsay, Miller, Nick, Robson, Sheila, Speech therapy for children with dysarthria acquired before three years of age, Cochrane Database of Systematic Reviews, -, 2009	No controlled studies were found in this review. Alos, not specific to cerebral palsy patients only.



<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in improving speech intelligibility?</b>	
Sigan,S., Uzunhan,T., Aydinli,N., Eraslan,E., Ekici,B., Caliskan,M., Effects of oral motor therapy in children with cerebral palsy, Annals of Indian Academy of Neurology, 16, 342-346, 2013	Outcomes not relevant to review protocol.
Speech and language therapy with cerebral palsied children, Journal of Rehabilitation in Asia, 17, 24-26, 1976	No comparison; no details provided on intervention used; sample size = 24 patients.
Ukhanova, T. A., Gorbunov, F. E., Ivanova, V. V., [Reflexotherapy combined with cortexin in the complex treatment of speech disorders in patients with cerebral palsy], Zhurnal nevrologii i psikiatrii imeni S.S. Korsakova / Ministerstvo zdravookhraneniia i meditsinskoi promyshlennosti Rossiiskoi Federatsii, Vserossiiskoe obshchestvo nevrologov [i] Vserossiiskoe obshchestvo psikiatrov. 111, 19-22, 2011	Not relevant intervention; Russian only.
Yorkston, K. M., Hakel, M., Beukelman, D. R., Fager, S., Evidence for effectiveness of treatment of loudness, rate, or prosody in dysarthria: a systematic review, Journal of Medical Speech Language Pathology, 15(2): 11-36, 2007	Review paper on supplementation techniques for dysarthria - no restriction on population considered included studies that 'reported data on at least one person with dysarthria'.
Zou, X. Y., Yu, Z. H., He, Y. M., Yang, H., Dong, X. L., [Effect of acupuncture combined language training on cerebral palsy children with language retardation], Zhongguo Zhong Xi Yi Jie He Za Zhi Zhongguo Zhongxiyi Jiehe Zazhi/Chinese Journal of Integrated Traditional & Western Medicine/Zhongguo Zhong Xi Yi Jie He Xue Hui, Zhongguo Zhong Yi Yan Jiu Yuan Zhu Ban, 33, 924-6, 2013	This paper is in Chinese.

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## **K.13<sub>2</sub> Improving speech, language and communication:**

### **3 Communication systems**

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Anttila, H., Samuelsson, K., Salminen, A. L., Brandt, S., Quality of evidence of assistive technology interventions for people with disability: An overview of systematic reviews, Technology and Disability, 24, 9-48, 2012	Narrative review.
Barker, M. R., Saunders, K. J., Brady, N. C., Reading Instruction for Children who use AAC: Considerations in the Pursuit of Generalizable Results, Augmentative and Alternative Communication, 28(3): 160-170, 2012	Narrative review.
Blain, S., Huggins, J., Toward a practical brain-computer interface for individuals with	Intervention and outcome not in protocol.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
severe motor disabilities, Archives of physical medicine and rehabilitation, 92 (10), 1690, 2011	
Branson, D., Demchak, M., The use of augmentative and alternative communication methods with infants and toddlers with disabilities: a research review, Augmentative and Alternative Communication, 25(4): 274-286, 2009	Narrative review.
Carter, M., Maxwell, K., Promoting Interaction with Children Using Augmentative Communication through a Peer-Directed Intervention, International Journal of Disability, Development and Education, 45(1): 75-96, 1998	Below sample size requirement.
Conklin, C. G., Mayer, G. R., Effects of Implementing the Picture Exchange Communication System (PECS) with Adults with Developmental Disabilities and Severe Communication Deficits, Remedial and Special Education, 32(2): 155-166, 2011	Adult participants (above 25 years old).
Davies, T. C., Mudge, S., Ameratunga, S., Stott, N. S., Enabling self-directed computer use for individuals with cerebral palsy: a systematic review of assistive devices and technologies, Developmental Medicine & Child Neurology, 52, 510-6, 2010	Narrative review, not AAC.
Drager, K.D., Anderson, J.L., Debarros, J., Hayes, E., Liebman, J., Panek, E., Speech synthesis in background noise: effects of message formulation and visual information on the intelligibility of American English DECTalk, Aac: Augmentative and Alternative Communication, 23, 177-186, 2007	Study includes 1 CP speaker who is above age limit (35 yrs old) and non-CP participants.
Eisenwort, B., Willinger, U., Schattauer, A., Willnauer, R., [Language development disorders in childhood: nonverbal intelligence and language comprehension], Klinische Padiatrie, 211, 442-4, 1999	In German.
Hunt, P., Soto, G., Maier, J., Muller, E., Goetz, L., Collaborative teaming to support students with augmentative and alternative communication needs in general education classrooms, Augmentative and Alternative Communication, 18(1): 20-35, 2002	No AAC intervention.
Hustad, K. C., Garcia, J. M., The influences of alphabet supplementation, iconic gestures, and predictive messages on intelligibility of a speaker with cerebral palsy, Journal of Medical Speech Language Pathology, 10(4): 279-285, 2002	The study includes 1 CP speaker and 24 listeners. This review aims to compare AAC intervention among CP users.
Johnston, S. S., Davenport, L., Kanarowski, B., Rhodhouse, S., McDonnell, A. P., Teaching Sound Letter Correspondence	Below sample size requirement.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
and Consonant-Vowel-Consonant Combinations to Young Children who Use Augmentative and Alternative Communication, Augmentative and Alternative Communication, 25(2): 123-135, 2009	
K. Whittingham, D. Wee, R. Boyd, Systematic review of the efficacy of parenting interventions for children with cerebral palsy, Child: Care, Health & Development, 37, 475-83, 2011	Narrative review.
Lancioni, G. E., O'Reilly, M. F., Cuvo, A. J., Singh, N. N., Sigafos, J., Didden, R., PECS and VOCAs to enable students with developmental disabilities to make requests: An overview of the literature, Research in Developmental Disabilities, 28(5): 468-488, 2007	Narrative review.
Meuris, K., Maes, B., De Meyer, A. M., Zink, I., Manual signing in adults with intellectual disability: influence of sign characteristics on functional sign vocabulary, Journal of Speech Language & Hearing Research, 57, 990-1010, 2014	Number with CP not reported.
Meuris, K., Maes, B., Zink, I., Evaluation of language and communication skills in adult key word signing users with intellectual disability: advantages of a narrative task, Research in Developmental Disabilities, 35, 2585-601, 2014	CP not reported and mean age = 38.7 years.
Millar, D. C., Light, J. C., Schlosser, R. W., The impact of augmentative and alternative communication intervention on the speech production of individuals with developmental disabilities: a research review, Journal of Speech Language & Hearing Research, 49, 248-64, 2006	Narrative review.
Pennington, L., Goldbart, J., Marshall, J., Interaction training for conversational partners of children with cerebral palsy: a systematic review, International Journal of Language & Communication Disorders, 39, 151-70, 2004	Narrative review.
Pueyo, R., Ariza, M., Narberhaus, A., Ballester-Plane, J., Laporta-Hoyos, O., Junque, C., Vendrell, P., Does verbal and gestural expression ability predict comprehension ability in cerebral palsy?, Perceptual and Motor Skills, 116, 512-527, 2013	No AAC or communication partners intervention.
Quach, W., Beukelman, D., Facilitating children's learning of dynamic-display AAC devices: the effect of two instructional methods on the performance of 6- and 7-year-olds with typical development using a dual-screen prototype, Aac: Augmentative	RCT of 'typically developing' children - no CP.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
& Alternative Communication, 26, 1-11, 2010	
Ribeiro, D. M., Elias, N. C., Goyos, C., Miguel, C. F., The Effects of Listener Training on the Emergence of Tact and Mand Signs by Individuals with Intellectual Disabilities, Analysis of Verbal Behavior, 26: 65-72, 2010	Below sample size requirement.
Rispoli, M. J., Franco, J. H., van der Meer, L., Lang, R., Camargo, S. P., The use of speech generating devices in communication interventions for individuals with developmental disabilities: a review of the literature, Developmental Neurorehabilitation, 13, 276-93, 2010	Narrative review.
Romski, M., Sevcik, R. A., Adamson, L. B., Cheslock, M., Smith, A., Barker, R. M., Bakeman, R., Randomised comparison of augmented and nonaugmented language interventions for toddlers with developmental delays and their parents, Journal of Speech Language & Hearing Research, 53, 350-64, 2010	RCT of AAC with mixed population: autism, CP, down syndrome etc. Number of CP participants not reported and results for CP participants not stratified. Therefore, evidence for CP participants cannot be extracted and analysed. Additionally, due to the possible different uses of AAC among these different populations, to include the study as an indirect population may introduce bias.
Shamir, A., Lazerovitz, T., Peer mediation intervention for scaffolding self-regulated learning among children with learning disabilities, European Journal of Special Needs Education, 22, 255-273, 2007	Intervention not in protocol (education).
van der Meer, L., Sigafoos, J., O'Reilly, M. F., Lancioni, G. E., Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: a review of the literature, Research in Developmental Disabilities, 32, 1422-31, 2011	Narrative review.
Whitmore, A. S., Romski, M. A., Sevcik, R. A., Early augmented language intervention for children with developmental delays: potential secondary motor outcomes, Aac: Augmentative & Alternative Communication, 30, 200-12, 2014	CP not reported in participants.
Wilkinson, K. M., O'Neill, T., McIlvane, W. J., Eye-tracking measures reveal how changes in the design of aided AAC displays influence the efficiency of locating symbols by school-age children without disabilities, Journal of Speech Language & Hearing Research, 57, 455-66, 2014	Below sample size requirement, CP not stated in participant characteristics.
Yoder, P. J., Warren, S. F., Intentional communication elicits language-facilitating maternal responses in dyads with children who have developmental disabilities, American Journal of Mental Retardation, 106, 327-35, 2001	CP not reported in participants.
Adamson, L. B., Romski, M., Bakeman, R., Sevcik, R. A., Augmented language	Number of participants with CP not reported.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
intervention and the emergence of symbol-infused joint engagement, <i>Journal of Speech Language &amp; Hearing Research</i> , 53, 1769-73, 2010	
Barker, R. M., Akaba, S., Brady, N. C., Thiemann-Bourque, K., Support for AAC use in preschool, and growth in language skills, for young children with developmental disabilities, <i>Aac: Augmentative &amp; Alternative Communication</i> , 29, 334-46, 2013	Results for CP participants (n = 4) not stratified from all sample (n = 71).
Beck, A. R., Stoner, J. B., Dennis, M. L., An investigation of aided language stimulation: does it increase AAC use with adults with developmental disabilities and complex communication needs?, <i>Aac: Augmentative &amp; Alternative Communication</i> , 25, 42-54, 2009	Adult participants (above 25 years old).
Bedrosian, J.L., Hoag, L.A., Johnson, D., Calculator, S.N., Communicative competence as perceived by adults with severe speech impairments associated with cerebral palsy, <i>Journal of Speech Language and Hearing Research</i> , 41, 667-675, 1998	Adult participants (mean age 39.5 yrs).
Betke, M., Gips, J., Fleming, P., The camera mouse: visual tracking of body features to provide computer access for people with severe disabilities, <i>IEEE Transactions on Neural Systems &amp; Rehabilitation Engineering</i> , 10, 1-10, 2002	Below sample size requirement.
Bowler, D. M., Kiernan, C., Free recall of lists of word and sign labels by severely handicapped children, <i>Journal of Mental Deficiency Research</i> , 34, 157-68, 1990	CP not reported in participants, only 'learning difficulties'.
Broberg, M., Ferm, U., Thunberg, G., Measuring responsive style in parents who use AAC with their children: development and evaluation of a new instrument, <i>Aac: Augmentative and Alternative Communication</i> , 28, 243-253, 2012	Results for CP participants (n = 3) not stratified from all sample (n = 28 children).
Calandrella, A. M., Wilcox, M. J., Predicting language outcomes for young prelinguistic children with developmental delay, <i>Journal of Speech Language &amp; Hearing Research</i> , 43, 1061-71, 2000	Below sample size requirement and no participants with CP diagnosis.
Carbone, V. J., Sweeney-Kerwin, E. J., Attanasio, V., Kasper, T., Increasing the vocal responses of children with autism and developmental disabilities using manual sign mand training and prompt delay, <i>Journal of Applied Behavior Analysis</i> , 43, 705-9, 2010	Below sample size requirement and no participants with CP diagnosis.
Cascella, P. W., Receptive communication abilities among adults with significant intellectual disability, <i>Journal of Intellectual</i>	CP not reported in participant characteristics.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
and Developmental Disability, 29, 70-78, 2004	
Chen, S. C., Tang, F. T., Chen, Y. L., Chen, W. L., Li, Y. C., Shih, Y. Y., Lai, J. S., Kuo, T. S., Infrared-based communication augmentation system for people with multiple disabilities, <i>Disability &amp; Rehabilitation</i> , 26, 1105-9, 2004	Communication intervention not stated in protocol.
Choi, H., O'Reilly, M., Sigafoos, J., Lancioni, G., Teaching requesting and rejecting sequences to four children with developmental disabilities using augmentative and alternative communication, <i>Research in Developmental Disabilities</i> , 31, 560-7, 2010	CP not reported in participant characteristics.
Chung, Y. C., Carter, E. W., Sisco, L. G., Social interactions of students with disabilities who use augmentative and alternative communication in inclusive classrooms, <i>American Journal on Intellectual &amp; Developmental Disabilities</i> , 117, 349-67, 2012	Cross-sectional design, no comparison.
Clarke, M. T., Newton, C., Griffiths, T., Price, K., Lysley, A., Petrides, K. V., Factors associated with the participation of children with complex communication needs, <i>Research in Developmental Disabilities</i> , 32, 774-80, 2011	Cross-sectional design, no comparison.
Clarke, M., Wilkinson, R., The collaborative construction of non-serious episodes of interaction by non-speaking children with cerebral palsy and their peers, <i>Clinical Linguistics and Phonetics</i> , 23, 583-597, 2009	Below sample size requirement.
Clarke, M., Wilkinson, R., Interaction between children with cerebral palsy and their peers 2: understanding initiated VOCA-mediated turns, <i>Aac: Augmentative and Alternative Communication</i> , 24, 3-15, 2008	Below sample size requirement.
Crews, W.D., Jr., Sanders, E.C., Hensley, L.G., Johnson, Y.M., Bonaventura, S., Rhodes, R.D., Garren, M.P., An evaluation of facilitated communication in a group of nonverbal individuals with mental retardation, <i>Journal of Autism and Developmental Disorders</i> , 25, 205-213, 1995	Below sample size requirement.
Cummings, A. R., Carr, J. E., LeBlanc, L. A., Experimental evaluation of the training structure of the picture exchange communication system (PECS), <i>Research in Autism Spectrum Disorders</i> , 6(1): 32-45, 2012	Below sample size requirement.
Dada, S., Huguet, A., Bornman, J., The iconicity of picture communication symbols	Descriptive design.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
for children with English additional language and mild intellectual disability, <i>Aac: Augmentative &amp; Alternative Communication</i> , 29, 360-73, 2013	
Dahlgren Sandberg, A., Smith, M., Larsson, M., An analysis of reading and spelling abilities of children using AAC: Understanding a continuum of competence, <i>Aac: Augmentative &amp; Alternative Communication</i> , 26, 191-202, 2010	Below sample size requirement.
Damen, S., Kef, S., Worm, M., Janssen, M. J., Schuengel, C., Effects of video-feedback interaction training for professional caregivers of children and adults with visual and intellectual disabilities, <i>Journal of Intellectual Disability Research</i> , 55, 581-95, 2011	CP not reported.
Damper, R. I., Burnett, J. W., Gray, P. W., Straus, L. P., Symes, R. A., Hand-held text-to-speech device for the non-vocal disabled, <i>Journal of Biomedical Engineering</i> , 9, 332-40, 1987	Descriptive design.
Danielsson, H., Ronnberg, J., Andersson, J., What am I doing in Timbuktu: person-environment picture recognition for persons with intellectual disability, <i>Journal of Intellectual Disability Research</i> , 50, 127-38, 2006	CP not reported in participant characteristics.
De Bortoli, T., Arthur-Kelly, M., Mathisen, B., Foreman, P., Balandin, S., Where are teachers' voices? A research agenda to enhance the communicative interactions of students with multiple and severe disabilities at school, <i>Disability &amp; Rehabilitation</i> , 32, 1059-72, 2010	Narrative review.
DeVeney, S. L., Hoffman, L., Cress, C. J., Communication-based assessment of developmental age for young children with developmental disabilities, <i>Journal of Speech Language &amp; Hearing Research</i> , 55, 695-709, 2012	Results for CP participants (n = 18) not stratified from whole sample.
Duarte, E., Rebelo, F., Teles, J., Wogalter, M. S., Safety sign comprehension by students, adult workers and disabled persons with cerebral palsy, <i>Safety Science</i> , 61, 66-77, 2014	Outcome (comprehension) not in protocol.
Egan, D. F., Brown, E. R., Developmental assessment: 18 months to 4 1/2 years. The miniature toys test, <i>Child: Care, Health &amp; Development</i> , 12, 167-81, 1986	Intervention not in protocol, number of CP not reported.
Fenn, G., Rowe, J. A., An experiment in manual communication, <i>British Journal of Disorders of Communication</i> , 10, 3-16, 1975	No CP participants reported.
Franklin, B., The effect of tactile aids on communication skills of children with dual	No CP participants reported.

<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
sensory handicaps, International Journal of Rehabilitation Research, 11, 91-93, 1988	
Hamm, B., Miranda, P., Post-school quality of life for individuals with developmental disabilities who use AAC, Aac: Augmentative & Alternative Communication, 22, 134-47, 2006	Below sample size requirement.
Hammal,D., Jarvis,S.N., Colver,A.F., Participation of children with cerebral palsy is influenced by where they live, Developmental Medicine and Child Neurology, 46, 292-298, 2004	No AAC intervention.
Harwin,W.S., Jackson,R.D., Analysis of intentional head gestures to assist computer access by physically disabled people, Journal of Biomedical Engineering, 12, 193-198, 1990	Single case design.
Hetzroni, O. E., A positive behaviour support: A preliminary evaluation of a school-wide plan for implementing AAC in a school for students with intellectual disabilities, Journal of Intellectual and Developmental Disability, 28, 283-296, 2003	Below sample size requirement.
Hillman, M. R., Interfacing the BBC microcomputer for use with profoundly handicapped children, Journal of Medical Engineering & Technology, 10, 196-8, 1986	Descriptive study.
Jackson, S. A., Stirling, J. M., Dixon, C. R., A speech-prompted communication aid for the severely handicapped, Journal of Medical Engineering & Technology, 7, 88-91, 1983	Descriptive study.
Kritzinger, A., Louw, B., Rossetti, L. M., A transdisciplinary conceptual framework for the early identification of risks for communication disorders in young children, South African Journal of Communication Disorders - die Suid-Afrikaanse Tydskrif vir Kommunikasieafwykings, 48, 33-44, 2001	Descriptive study - risk factors for communication disorders.
Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafoos, J., Oliva, D., Baccani, S., Teaching 'Yes' and 'No' responses to children with multiple disabilities through a program including microswitches linked to a vocal output device, Perceptual & Motor Skills, 102, 51-61, 2006	Below sample size requirement.
Lund,S.K., Light,J., Long-term outcomes for individuals who use augmentative and alternative communication: Part III--contributing factors, Aac: Augmentative and Alternative Communication, 23, 323-335, 2007	Below sample size requirement.
Pennington,L., McConachie,H., Mother-child interaction revisited: communication with non-speaking physically disabled	No comparison for intervention.



<b>Excluded studies - In children and young people with cerebral palsy, which communication systems (alternative or augmentative) are effective in improving communication?</b>	
children, International Journal of Language and Communication Disorders, 34, 391-416, 1999	
Reichle, J., PECS training for mands may lead to the emergence of other untrained verbal operants in adults with severe disabilities, but the comparison of PECS and manual-sign training is compromised, Evidence-Based Communication Assessment and Intervention, 2, 203-207, 2008	Below sample size requirement, adult CP participants.
Sevcik, R. A., Comprehension: an overlooked component in augmented language development, Disability & Rehabilitation, 28, 159-67, 2006	Below sample size requirement. CP not reported (reports 'developmental disabilities').
Udwin, O., Yule, W., Augmentative Communication Modes Taught to Cerebral Palsied Children: Findings from a Longitudinal Study, International Journal of Rehabilitation Research, 10(2): 202-206, 1987	Results presented in follow-up paper Udwin and Yule, 1990 (included in the review).
Udwin, O., Yule, W., Augmentative communication systems taught to cerebral-palsied children- A longitudinal study. III. Teaching practices and exposure to sign and symbol use in schools and homes, British Journal of Disorders of Communication, 26, 149-162, 1991	No intervention given to teachers and family members, study assesses family perception of AAC use.

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### K.14<sub>3</sub> Managing saliva control

<b>Excluded studies - What interventions are effective in the management of poor saliva control (drooling) in children and young people with cerebral palsy? - Non-RCTS (Medline and Embase only)</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Chakravarti,A., Gupta,R., Garg,S., Aneja,S., Bilateral submandibular duct transposition with sublingual gland excision for cerebral palsy children with drooling, Indian Journal of Pediatrics, 81, 623-624, 2014	Not relevant study design: non-randomised controlled trial.
Lee,Z.I., Cho,D.H., Choi,W.D., Park,D.H., Byun,S.D., Effect of botulinum toxin type a on morphology of salivary glands in patients with cerebral palsy, Annals of Rehabilitation Medicine, 35, 636-640, 2011	Not relevant study design: this study is not a RCT.
Nordgarden,H., Osterhus,I., Moystad,A., Asten,P., Johnsen,U.L., Storhaug,K., Loven,J.O., Drooling: are botulinum toxin injections into the major salivary glands a good treatment option?, Journal of Child Neurology, 27, 458-464, 2012	Wrong comparison: the study compared BoNT-A injections between both parotid and submandibular glands and submandibular glands only.
Parr, J. R., Weldon, E., Pennington, L., Steen, N., Williams, J., Fairhurst, C., O'Hare, A., Lodh, R., Colver, A., The drooling reduction intervention trial (DRI): a single blind trial comparing the	The paper is reporting on the study protocol. Study status: ongoing.

<b>Excluded studies - What interventions are effective in the management of poor saliva control (drooling) in children and young people with cerebral palsy? - Non-RCTS (Medline and Embase only)</b>	
efficacy of glycopyrronium and hyoscine on drooling in children with neurodisability, <i>Trials</i> [Electronic Resource], 15, 60	
Reddihough,D., Johnson,H., Staples,M., Hudson,I., Exarchos,H., Use of benzhexol hydrochloride to control drooling of children with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 32, 985-989, 1990	Not relevant study design: non-randomised clinical trial.
Wilken,B., Aslami,B., Backes,H., Successful treatment of drooling in children with neurological disorders with botulinum toxin A or B, <i>Neuropediatrics</i> , 39, 200-204, 2008	Mixed population: 12 patients had CP, 16 children had neurodegenerative, neurometabolic or neuromuscular disorders, and 2 children were undiagnosed.
Bailey,C.M., Wadsworth,P.V., Treatment of the drooling child by submandibular duct transposition, <i>Journal of Laryngology and Otology</i> , 99, 1111-1117, 1985	Non-comparative evidence.
Becmeur,F., Horta-Geraud,P., Brunot,B., Maniere,M.C., Prulhiere,Y., Sauvage,P., Diversion of salivary flow to treat drooling in patients with cerebral palsy, <i>Journal of Pediatric Surgery</i> , 31, 1629-1633, 1996	Non-comparative evidence. Sample size <20 patients.
Becmeur,F., Schneider,A., Flaum,V., Klipfel,C., Pierrel,C., Lacreuse,I., Which surgery for drooling in patients with cerebral palsy?, <i>Journal of Pediatric Surgery</i> , 48, 2171-2174, 2013	Non-comparative evidence.
Brody,G.S., Control of drooling by translocation of parotid duct and extirpation of mandibular gland, <i>Developmental Medicine and Child Neurology</i> , 19, 514-517, 1977	Descriptive review of methodology.
Brown,A.S., Silverman,J., Greenberg,S., Malamud,D.F., Album,M., Lloyd,R.W., Sarshik,M., A team approach to drool control in cerebral palsy, <i>Annals of Plastic Surgery</i> , 15, 423-430, 1985	Non-comparative evidence. Sample size <20 patients.
Brundage,S.R., Moore,W.D., Submandibular gland resection and bilateral parotid duct ligation as a management for chronic drooling in cerebral palsy, <i>Plastic and Reconstructive Surgery</i> , 83, 443-446, 1989	No comparison reported (post-intervention results only).
Burton,M.J., The surgical management of drooling. [41 refs], <i>Developmental Medicine and Child Neurology</i> , 33, 1110-1116, 1991	Descriptive review of surgical interventions.
Celet,OzdenB, Aydin,A., Kuvat,S.V., Yazar,M., Ozmen,M., Tatli,B., Quadruple salivary duct diversion for drooling in cerebral palsy, <i>Journal of Craniofacial Surgery</i> , 23, 738-741, 2012	Population: less than 20 patients included.
Chang,C.J., May-Kuen,Wong aA, Intraductal laser photocoagulation of the bilateral parotid ducts for reduction of drooling in patients with cerebral palsy, <i>Plastic and Reconstructive Surgery</i> , 107, 907-913, 2001	Non-comparative evidence.
Crysdale,W.S., Management options for the drooling patient, <i>Ear, Nose, and Throat Journal</i> , 68, 820-826, 1989	Descriptive review.
Crysdale,W.S., Raveh,E., McCann,C., Roske,L., Kotler,A., Management of drooling in individuals with neurodisability: a surgical experience, <i>Developmental Medicine and Child Neurology</i> , 43, 379-383, 2001	Population: diverse group of neurologically impaired people and no data on neurological diagnosis provided.
Crysdale,W.S., White,A., Submandibular duct relocation for drooling: a 10-year experience with 194 patients, <i>Otolaryngology - Head and Neck Surgery</i> , 101, 87-92, 1989	The study only reports rates of drooling after surgery treatment. Non-comparative evidence.

<b>Excluded studies - What interventions are effective in the management of poor saliva control (drooling) in children and young people with cerebral palsy? - Non-RCTS (Medline and Embase only)</b>	
Dundas,D.F., Peterson,R.A., Surgical treatment of drooling by bilateral parotid duct ligation and submandibular gland resection, <i>Plastic and Reconstructive Surgery</i> , 64, 47-51, 1979	Non-comparative evidence. Sample size <20 patients.
El-Hakim,H., Richards,S., Thevasagayam,M.S., Major salivary duct clipping for control problems in developmentally challenged children, <i>Archives of Otolaryngology - Head and Neck Surgery</i> , 134, 470-474, 2008	Population: less than 20 patients included with various neurological diseases.
Faggella,R.M.,Jr., Osborn,J.M., Surgical correction of drool: a comparison of three groups of patients, <i>Plastic and Reconstructive Surgery</i> , 72, 478-483, 1983	The study reported on outcomes that are not relevant to the review protocol.
Gallagher,T.Q., Hartnick,C.J., Bilateral submandibular gland excision and parotid duct ligation, <i>Advances in Oto-Rhino-Laryngology</i> , 73, 70-75, 2012	Descriptive review.
Greensmith,A.L., Johnstone,B.R., Reid,S.M., Hazard,C.J., Johnson,H.M., Reddihough,D.S., Prospective analysis of the outcome of surgical management of drooling in the pediatric population: A 10-year experience, <i>Plastic and Reconstructive Surgery</i> , 116, 1233-1242, 2005	Indirect population (38/72 had CP).
Hallett,K.B., Lucas,J.O., Johnston,T., Reddihough,D.S., Hall,R.K., Dental health of children with cerebral palsy following sialodochoplasty, <i>Special Care in Dentistry</i> , 15, 234-238, 1995	Outcomes reported are not relevant to the review protocol.
Heywood,R.L., Cochrane,L.A., Hartley,B.E.J., Parotid duct ligation for treatment of drooling in children with neurological impairment, <i>Journal of Laryngology and Otology</i> , 123, 997-1001, 2009	Non-comparative evidence.
Katona,G., Csakanyi,Z., Lorincz,A., Gerlinger,I., Bilateral submandibular duct relocation by high-frequency radiosurgery, <i>European Archives of Oto-Rhino-Laryngology</i> , 265, 1103-1108, 2008	Non-comparative evidence. Sample size <20 patients.
Khadivi,E., Ashraf,Zadeh F., Bakhshae,M., Fooladvand,T., Movahed,S.R., Nabavi,S.S., Afzal,Aghaee M., Bilateral submandibular duct rerouting: assessment of results on drooling in cerebral palsy cases, <i>Auris, Nasus, Larynx</i> , 40, 487-490, 2013	Non-comparative evidence. Sample size <20 patients.
Leong,S.C., Patel,M., Prasad,S., Sharma,R., The drooling child, <i>Otorhinolaryngologist</i> , 4, 5-13, 2011	Unavailable.
Massengill,R.,Jr., A follow-up investigation of patients who have had parotid duct transplantation surgery to control drooling, <i>Annals of Plastic Surgery</i> , 2, 205-208, 1979	Non-comparative evidence. Sample size <20 patients.
McAloney,N., Kerawala,C.J., Stassen,L.F., Management of drooling by transposition of the submandibular ducts and excision of the sublingual glands, <i>Journal of the Irish Dental Association</i> , 51, 126-131, 2005	Non-comparative evidence.
O'Dwyer,T.P., Conlon,B.J., The surgical management of drooling-a 15 year follow-up, <i>Clinical Otolaryngology and Allied Sciences</i> , 22, 284-287, 1997	Indirect population (27/53 had CP).
O'Dwyer,T.P., Timon,C., Walsh,M.A., Surgical management of drooling in the neurologically damaged child, <i>Journal of Laryngology and Otology</i> , 103, 750-752, 1989	Non-comparative evidence. Sample size <20 patients.
Osorio,A., Moreira-Pinto,J., Oliveira,L., Ferreira-de-Sousa,J.A., Cidade-Rodrigues,J.A., Bilateral submandibulectomy for the treatment of drooling in children with neurological disability, <i>European Journal of Pediatric Surgery</i> , 19, 377-379, 2009	Population defined as 'neurological disability' with no further specification provided.

<b>Excluded studies - What interventions are effective in the management of poor saliva control (drooling) in children and young people with cerebral palsy? - Non-RCTS (Medline and Embase only)</b>	
Ozgenel,G.Y., Ozcan,M., Bilateral parotid-duct diversion using autologous vein grafts for the management of chronic drooling in cerebral palsy, British Journal of Plastic Surgery, 55, 490-493, 2002	Non-comparative evidence. Sample size <20 patients.
Puraviappan,P., Dass,D.B., Narayanan,P., Efficacy of relocation of submandibular duct in cerebral palsy patients with drooling, Asian Journal of Surgery, 30, 209-215, 2007	Non-comparative evidence. Sample size <20 patients.
Sellars,S.L., Surgery of sialorrhoea, Journal of Laryngology and Otology, 99, 1107-1109, 1985	Surgical technique: tympanic neurectomy.
Shott,S.R., Myer,C.M.,III, Cotton,R.T., Surgical management of sialorrhea, Otolaryngology - Head and Neck Surgery, 101, 47-50, 1989	Population reported as 'handicapped patients' but no further specification is provided.
Varma,S.K., Henderson,H.P., Cotton,B.R., Treatment of drooling by parotid duct ligation and submandibular duct diversion, British Journal of Plastic Surgery, 44, 415-417, 1991	Non-comparative evidence. Sample size <20 patients.
Walker,P., Management of sialorrhoea in a multi-disciplinary saliva control clinic, Australian Journal of Otolaryngology, 4, 27-32, 2001	Indirect population (27/97 had CP).
Wilkie,T.F., The surgical treatment of drooling. A follow-up report of five years' experience, Plastic and Reconstructive Surgery, 45, 549-554, 1970	Non-comparative evidence. Sample size <20 patients.

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### K.15<sub>3</sub> Risk factors for low bone mineral density

<b>Excluded studies - In children and young people with cerebral palsy, what are the risk factors for reduced bone mineral density and low-impact fractures?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Centre for Reviews and Dissemination, Informing evidence-based clinical practice guidelines for children with cerebral palsy at risk of osteoporosis: a systematic review (Provisional abstract), Database of Abstracts of Reviews of Effects, 2015	Abstract - full article requested.
Centre for Reviews and Dissemination, Psychotropic medications and the risk of fracture: a meta-analysis (Structured abstract), Database of Abstracts of Reviews of Effects, 2015	Abstract - full text requested.
Cohen, M., Lahat, E., Bistrizter, T., Livne, A., Heyman, E., Rachmiel, M., Evidence-based review of bone strength in children and youth with cerebral palsy, Journal of Child Neurology, 24, 959-967, 2009	Narrative review.
Finbraten, A. K., Syversen, U., Skranes, J., Andersen, G. L., Stevenson, R., Vik, T., Bone mineral density and vitamin d status in children with cerebral palsy, Archives of Disease in Childhood, 99, A524-A525, 2014	Duplicate.
Henderson,R.C., Kairalla,J.A., Barrington,J.W., Abbas,A., Stevenson,R.D., Longitudinal	Outcome reported as rate of change in BMD (no risk factors analysis).

<b>Excluded studies - In children and young people with cerebral palsy, what are the risk factors for reduced bone mineral density and low-impact fractures?</b>	
changes in bone density in children and adolescents with moderate to severe cerebral palsy, <i>Journal of Pediatrics</i> , 146, 769-775, 2005	
Henderson,R.C., Lark,R.K., Gurka,M.J., Worley,G., Fung,E.B., Conaway,M., Stallings,V.A., Stevenson,R.D., Bone density and metabolism in children and adolescents with moderate to severe cerebral palsy, <i>Pediatrics</i> , 110, e5-, 2002	No data provided for multivariate analysis.
Houlihan, C. M., Bone health in cerebral palsy: who's at risk and what to do about it?, <i>Journal of Pediatric Rehabilitation Medicine</i> , 7, 143-53, 2014	Narrative review.
Leet, A. I., Mesfin, A., Pichard, C., Launay, F., Brintzenhofeszoc, K., Levey, E. B., D. Sponseller P, Fractures in children with cerebral palsy, <i>Journal of Pediatric Orthopedics</i> , 26, 624-7, 2006	Non-normally distributed data treated as normally distributed (wrong statistics).
McGill, C. A., Bryant, E., Walker-Bone, K., To what extent are risk factors for osteoporosis and fracture measured and recorded among children with severe and complex disabilities: An audit, <i>Osteoporosis International</i> , 1), S684-S685, 2014	Unadjusted analysis only presented.
Mergler, S., Evenhuis, H. M., Boot, A. M., De Man, S. A., Bindels-De Heus, K. G., Huijbers, W. A., Penning, C., Epidemiology of low bone mineral density and fractures in children with severe cerebral palsy: a systematic review, <i>Developmental Medicine &amp; Child Neurology</i> , 51, 773-8, 2009	Unclear whether both adjusted and unadjusted studies have been included. No pooling of data presented.
Presedo,A., Dabney,K.W., Miller,F., Fractures in patients with cerebral palsy, <i>Journal of Pediatric Orthopedics</i> , 27, 147-153, 2007	No risk factors analysis presented.
Samaniego, E. A., Sheth, R. D., Bone consequences of epilepsy and antiepileptic medications, <i>Seminars in Pediatric Neurology</i> , 14, 196-200, 2007	Narrative review, not CP specific.
Takkouche, B., Montes-Martinez, A., Gill, S. S., Etminan, M., Psychotropic medications and the risk of fracture: a meta-analysis, <i>Drug Safety</i> , 30, 171-84, 2007	Not CP specific; population considered not relevant to review protocol.

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### K.163 Prevention of reduced bone mineral density

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in preventing reduced bone mineral density and low-impact fractures?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Allington, N., Vivegnis, D., Gerard, P., Cyclic administration of pamidronate to treat osteoporosis in children with cerebral palsy or a neuromuscular disorder: a clinical study, <i>Acta Orthopaedica Belgica</i> , 71, 91-7, 2005	non-randomised design, mixed population (CP Duchene dystrophy)

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in preventing reduced bone mineral density and low-impact fractures?</b>	
Bachrach, S. J., Kecskemethy, H. H., Harcke, H. T., Lark, R. K., Miller, F., Henderson, R. C., Pamidronate treatment and posttreatment bone density in children with spastic quadriplegic cerebral palsy, <i>Journal of Clinical Densitometry</i> , 9, 167-74, 2006	Non-randomised design, pre/post intervention, very small sample size.
Bachrach, S. J., Kecskemethy, H. H., Harcke, H., Hossain, J. R., Decreased fracture incidence after 1 year of pamidronate treatment in children with spastic quadriplegic cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 52, 837-842, 2010	Non-randomised, pre/post intervention study.
Caglar Okur, S., Senel, K., Pekin Dogan, Y., Sayiner Caglar, N., Seferoglu, B., Osteopenia in ambulatory cerebral palsy, <i>Journal of Clinical Densitometry</i> , 17 (3), 415, 2014	Full text unavailable.
Centre for Reviews and Dissemination, Effectiveness of static weight-bearing exercises in children with cerebral palsy (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Studies of any design were eligible, used for references.
Damcott, M., Blochlinger, S., Foulds, R., Effects of passive versus dynamic loading interventions on bone health in children who are nonambulatory, <i>Pediatric Physical Therapy</i> , 25, 248-55, 2013	Less than 10 patients, non-randomised.
Fehlings, D. L., Stevenson, R., Paediatric osteopenia in childhood disability: Evidence-informed clinical practice guidelines, <i>Developmental Medicine and Child Neurology</i> , 52, 77-78, 2010	Narrative review.
Fehlings, D., Switzer, L., Agarwal, P., Wong, C., Sochett, E., Stevenson, R., Sonnenberg, L., Smile, S., Young, E., Huber, J., Milo-Manson, G., Kuwaik, G.A., Gaebler, D., Informing evidence-based clinical practice guidelines for children with cerebral palsy at risk of osteoporosis: a systematic review, <i>Developmental Medicine and Child Neurology</i> , 54, 106-116, 2012	Criteria for study inclusion did not match the review protocol, used for references.
Franki, I., Desloovere, K., De Cat, J., Feys, H., Molenaers, G., Calders, P., Himpens, E., Vanderstraeten, G., Van Den Broeck, C., Evidence-based physical therapy in cerebral palsy: A systematic review of literature in an ICF framework. Part A: Basic physical therapy techniques, <i>Developmental Medicine and Child Neurology</i> , 53, 44-45, 2011	Not relevant to review protocol.
Grissom, L. E., Harcke, H. T., Radiographic features of bisphosphonate therapy in pediatric patients, <i>Pediatric Radiology</i> , 33, 226-9, 2003	Non-randomised design, mixed population.
Grissom, L. E., Kecskemethy, H. H., Bachrach, S. J., McKay, C., Harcke, H. T., Bone densitometry in pediatric patients treated with pamidronate, <i>Pediatric Radiology</i> , 35, 511-7, 2005	Non-randomised design, all patients received pamidronate, mixed population.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in preventing reduced bone mineral density and low-impact fractures?</b>	
Gupta, S., Lundy, C., Fairhurst, C., Oral bisphosphonates in children with non-ambulant cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 51, 30-31, 2009	Not randomised design, pre/post treatment analysis.
Gusso, S., Colle, P., Derraik, J. G. B., Biggs, J., Munns, C., Cutfield, W., Hofman, P., Whole-body vibration training improves physical function and increases bone and muscle mass in youngsters with mild cerebral palsy, <i>Hormone Research in Paediatrics</i> , 84, 160-161, 2015	No control group.
Gusso, S., Munns, C. F., Cutfield, W. S., Hofman, P. L., Short-term whole body vibration therapy improves bone density and muscle function in adolescents with cerebral palsy, <i>Endocrine Reviews</i> , 1), 2013	Full text unavailable.
Hough, J. P., Boyd, R. N., Keating, J. L., Systematic review of interventions for low bone mineral density in children with cerebral palsy, <i>Pediatrics</i> , 125, e670-8, 2010	Full text unavailable.
Houlihan, C., Kuperminc, M., Gurka, M., Stevenson, R., Longitudinal assessment of low bone mineral density and its association with severe pain in children with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 51, 30, 2009	Not interventional study.
Iwasaki, T., Nonoda, Y., Ishii, M., Long-term outcomes of children and adolescents who had cerebral palsy with secondary osteoporosis, <i>Current Medical Research &amp; Opinion</i> , 28, 737-47, 2012	Full text unavailable.
Kilebrant, S., Braathen, G., Emilsson, R., Glansen, U., Soderpalm, A. C., Zetterlund, B., Westerberg, B., Magnusson, P., Swolin-Eide, D., Whole-body vibration therapy in children with severe motor disabilities, <i>Journal of Rehabilitation Medicine</i> , 47, 223-8, 2015	Full text unavailable.
Kilpinen-Loisa, P., Nenonen, H., Pihko, H., Makitie, O., High-dose vitamin D supplementation in children with cerebral palsy or neuromuscular disorder, <i>Neuropediatrics</i> , 38, 167-172, 2007	Not measuring BMD.
Kim, M. J., Kim, S. N., Lee, I. S., Chung, S., Lee, J., Yang, Y., Lee, I., Koh, S. E., Effects of bisphosphonates to treat osteoporosis in children with cerebral palsy: a meta-analysis, <i>Journal of Pediatric Endocrinology</i> , 28, 1343-50, 2015	Unavailable.
Kitsios, A., Tsaklis, P., Koronas, K., Varsamis, P., Abatzides, G., Agelopoulou, N., The effects of a physiotherapeutic programme on bone mineral density, in individuals of postpuberty age (18-30 years), with cerebral palsy, <i>Journal of Back and Musculoskeletal Rehabilitation</i> , 15, 41-45, 2000	Average age 25-27 years.
Lee, S., Kim, J. H., Choi, E., Effects of vitamin D treatment for cerebral palsy patients,	Retrospective chart review, pre/post treatment.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in preventing reduced bone mineral density and low-impact fractures?</b>	
Developmental Medicine and Child Neurology, 56, 46, 2014	
Mogul, H., Preventing fractures among people with developmental disabilities, Western Journal of Medicine, 171, 77-8, 1999	Not interventional study.
Mughal, M. Z., Fractures in children with cerebral palsy, Current Osteoporosis Reports, 12, 313-8, 2014	Narrative review. Used for references.
Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S. A., Goldsmith, S., A systematic review of interventions for children with cerebral palsy: state of the evidence, Developmental Medicine & Child Neurology, 55, 885-910, 2013	All interventions considered, all study designs. Used for references.
Olama, K. A., Low bone density management via capacitively coupled electrical fields and low intensity pulsed ultrasound in hemiparetic cerebral palsy, Egyptian Journal of Medical Human Genetics, 12, 147-150, 2011	Intervention is not relevant to the review protocol.
Paksu, M. S., Vurucu, S., Karaoglu, A., Karacalioglu, A. O., Polat, A., Yesilyurt, O., Unay, B., Akin, R., Osteopenia in children with cerebral palsy can be treated with oral alendronate, Childs Nervous System, 28, 283-6, 2012	Not randomised study, pre/post treatment analysis only.
Paleg, G. S., Smith, B. A., Glickman, L. B., Systematic review and evidence-based clinical recommendations for dosing of pediatric supported standing programs, Pediatric Physical Therapy, 25, 232-47, 2013	Used for references.
Paleg, G.S., Glickman, L.B., Rgeigle, P., Passive standing: A systematic review focusing on clinical outcomes and decision making, Developmental Medicine and Child Neurology, 5th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine Christchurch New Zealand. Conference Start, 65-, 2010	No analysis presented.
Pin, T. W., Effectiveness of static weight-bearing exercises in children with cerebral palsy, Pediatric Physical Therapy, 19, 62-73, 2007	Study of any design were eligible, used for references.
Presedo, A., Dabney, K.W., Miller, F., Fractures in patients with cerebral palsy, Journal of Pediatric Orthopedics, 27, 147-153, 2007	Retrospective study, not relevant to the review protocol.
Razmdjou, S., Rensing-Zimmermann, C., Seufert, J., Korinthenberg, R., Bone health and vitamin D metabolism in children and adolescents with Duchenne muscular dystrophy compared with other neuromuscular diseases and cerebral palsy, Neuropediatrics, 44 (2), 2013	Mixed population (CP Duchene dystrophy)
Reyes, M. L., Hernandez, M., Holmgren, L. J., Sanhueza, E., Escobar, R. G., High-frequency, low-intensity vibrations increase bone mass and muscle strength in upper limbs, improving	Mixed population, with less than 50% having CP.



<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective in preventing reduced bone mineral density and low-impact fractures?</b>	
autonomy in disabled children, Journal of Bone & Mineral Research, 26, 1759-66, 2011	
Rothenbuhler,A., Marchand,I., Bougneres,P., Lingart,A., Risk of corrected QT interval prolongation after pamidronate infusion in children, Journal of Clinical Endocrinology and Metabolism, 95, 3768-3770, 2010	Non-randomised design, outcomes studied are not relevant to review protocol.
Sharan, D., Mohandoss, M., Ranganathan, R., Bone mineral density in children with cerebral palsy: Effect of sequenced rehabilitation protocol following a single event multilevel surgery, Prosthetics and Orthotics International, 39, 511, 2015	Abstract only, non-RCT.
Speiser, P. W., Clarson, C. L., Eugster, E. A., Kemp, S. F., Radovick, S., Rogol, A. D., Wilson, T. A., Lwipes Pharmacy, Therapeutic, Committee, Bisphosphonate treatment of pediatric bone disease, Pediatric Endocrinology Reviews, 3, 87-96, 2005	Narrative review, not CP specific.
Thompson,C.R., Figoni,S.F., Devocelle,H.A., Fifer-Moeller,T.M., Lockhart,T.L., Lockhart,T.A., Effect of dynamic weight bearing on lower extremity bone mineral density in children with neuromuscular impairment, Clinical Kinesiology, 54, 13-18, 2000	Mixed population (progressive diseases) non-randomised design
Thorpe, D., McMurray, R., Turk, M., Tosti, K., Henderson, R., Adults with cerebral palsy training to increase overall wellness: Project act now, Physiotherapy (United Kingdom), 97, eS1233-eS1234, 2011	Wrong population: adults only.
Unay, B., Sarici, U., Vurucu, S., Inanc, N., Akin, R., Gokcay, E., Evaluation of bone mineral density in children with cerebral palsy, Turkish Journal of Pediatrics, 45, 11-14, 2003	Not an interventional study.
Wilmshurst, S., Ward, K., Adams, J. E., Langton, C. M., Mughal, M. Z., Mobility status and bone density in cerebral palsy, Archives of Disease in Childhood, 75, 164-5, 1996	Not interventional study.
Wren, T. A., Lee, D. C., Hara, R., Rethlefsen, S. A., Kay, R. M., Dorey, F. J., Gilsanz, V., Effect of high-frequency, low-magnitude vibration on bone and muscle in children with cerebral palsy, Journal of Pediatric Orthopedics, 30, 732-8, 2010	All children received both intervention and control (a RCT is available for this particular intervention).

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### **K.17<sup>3</sup> Causes of pain, distress and discomfort and sleep disturbance**

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<b>Excluded studies - In children and young people with cerebral palsy, what are the common causes of pain, discomfort and distress?</b>	
Study	Reason for Exclusion

<b>Excluded studies - In children and young people with cerebral palsy, what are the common causes of pain, discomfort and distress?</b>	
Atmawidjaja, R. W., Wong, S. W., Yang, W. W., Ong, L. C., Sleep disturbances in Malaysian children with cerebral palsy, <i>Developmental Medicine &amp; Child Neurology</i> , 56, 681-5, 2014	Case-control study design.
Badia, M., Riquelme, I., Orgaz, B., Acevedo, R., Longo, E., Montoya, P., Pain, motor function and health-related quality of life in children with cerebral palsy as reported by their physiotherapists, <i>BMC Pediatrics</i> , 14, 192, 2014	Indirect measure of pain (physiotherapist reported pain). Outcome not included in evidence review (correlation between physiotherapist reported pain and quality of life).
Barney,C.C., Krach,L.E., Rivard,P.F., Belew,J.L., Symons,F.J., Motor function predicts parent-reported musculoskeletal pain in children with cerebral palsy, <i>Pain Research and Management</i> , 18, 323-327, 2013	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Berrin, S. J., Malcarne, V. L., Varni, J. W., Burwinkle, T. M., Sherman, S. A., Artavia, K., Chambers, H. G., Pain, fatigue, and school functioning in children with cerebral palsy: A path-analytic model, <i>Journal of Pediatric Psychology</i> , 32, 330-337, 2007	Prevalence of cause of pain not provided.
Bischof,F.M., Chirwa,T.F., Daily care activities and hip pain in non-ambulatory children and young adults with cerebral palsy, <i>Journal of Pediatric Rehabilitation Medicine</i> , 4, 219-223, 2011	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Boldingh, E. J., Jacobs-van der Bruggen, M. A., Bos, C. F., Lankhorst, G. J., Bouter, L. M., Determinants of hip pain in adult patients with severe cerebral palsy, <i>Journal of Pediatric Orthopaedics, Part B</i> , 14, 120-5, 2005	Mean age greater than 25 years.
Breau, L. M., Camfield, C. S., McGrath, P. J., Finley, G. A., Pain's impact on adaptive functioning, <i>Journal of Intellectual Disability Research</i> , 51, 125-134, 2007	Cerebral palsy not reported.
Breau,L.M., Camfield,C.S., McGrath,P.J., Finley,G.A., The incidence of pain in children with severe cognitive impairments, <i>Archives of Pediatrics and Adolescent Medicine</i> , 157, 1219-1226, 2003	Indirect population (cognitive impairments).
Breau,L.M., Camfield,C.S., McGrath,P.J., Finley,G.A., Risk factors for pain in children with severe cognitive impairments, <i>Developmental Medicine and Child Neurology</i> , 46, 364-371, 2004	Cause of pain not reported for cerebral palsy, but for children with 'cognitive impairment' (indirect population).
Castle,K., Imms,C., Howie,L., Being in pain: a phenomenological study of young people with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 49, 445-449, 2007	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Choi, Y., Lee, S. H., Chung, C. Y., Park, M. S., Lee, K. M., Sung, K. H., Won, S. H., Lee, I. H., Choi, I. H., Cho, T. J., Yoo, W. J., Lee, S. Y., Anterior knee pain in patients with	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.

<b>Excluded studies - In children and young people with cerebral palsy, what are the common causes of pain, discomfort and distress?</b>	
cerebral palsy, Clinics in Orthopedic Surgery, 6, 426-31, 2014	
Cigala, F., Marmo, C., Lotito, F. M., Cigala, M., Lombardi, P., Hip surgery in cerebral palsy, Chirurgia Degli Organi di Movimento, 88, 23-32, 2003	Prevalence of pain due to hip surgery not reported.
Coffelt, T.A., Bauer, B.D., Carroll, A.E., Inpatient characteristics of the child admitted with chronic pain, Pediatrics, 132, e422-e429, 2013	Cerebral palsy not reported.
Cohen, R., Halevy, A., Shuper, A., Children's sleep disturbance scale in differentiating neurological disorders, Pediatric Neurology, 49, 465-8, 2013	Indirect population, n = 4 with CP.
Del Giudice, E., Staiano, A., Capano, G., Romano, A., Florimonte, L., Miele, E., Ciarla, C., Campanozzi, A., Crisanti, A. F., Gastrointestinal manifestations in children with cerebral palsy, Brain and Development, 21, 307-311, 1999	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Dickinson, H.O., Parkinson, K.N., Ravens-Sieberer, U., Schirripa, G., Thyen, U., Arnaud, C., Beckung, E., Fauconnier, J., McManus, V., Michelsen, S.I., Parkes, J., Colver, A.F., Self-reported quality of life of 8-12-year-old children with cerebral palsy: a cross-sectional European study, Lancet, 369, 2171-2178, 2007	Prevalence of cause of pain not provided.
Didden, R., Korzilius, H., van Aperlo, B., van Overloop, C., de Vries, M., Sleep problems and daytime problem behaviours in children with intellectual disability, Journal of Intellectual Disability Research, 46, 537-47, 2002	Cerebral palsy not included.
Dudgeon, B. J., Gerrard, B. C., Jensen, M. P., Rhodes, L. A., Tyler, E. J., Physical disability and the experience of chronic pain, Archives of Physical Medicine & Rehabilitation, 83, 229-35, 2002	All participants over 25 years of age.
Engel, J. M., Petrina, T. J., Dudgeon, B. J., McKearnan, K. A., Cerebral palsy and chronic pain: a descriptive study of children and adolescents, Physical & Occupational Therapy in Pediatrics, 25, 73-84, 2005	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found. Prevalence of specific cause not reported (frequency reported).
Engel, J.M., Jensen, M.P., Hoffman, A.J., Kartin, D., Pain in persons with cerebral palsy: extension and cross validation, Archives of Physical Medicine and Rehabilitation, 84, 1125-1128, 2003	Mean age greater than 25 years.
Fitzgerald, D. A., Follett, J., Van Asperen, P. P., Assessing and managing lung disease and sleep disordered breathing in children with cerebral palsy, Paediatric Respiratory Reviews, 10, 18-24, 2009	Narrative review.

<b>Excluded studies - In children and young people with cerebral palsy, what are the common causes of pain, discomfort and distress?</b>	
Hadden,K.L., von Baeyer,C.L., Pain in children with cerebral palsy: common triggers and expressive behaviors, <i>Pain</i> , 99, 281-288, 2002	Mixed population (majority CP, 12% non-CP). Prevalence of pain due to all health care procedures not reported.
Hayashi, M., Inoue, Y., Iwakawa, Y., Sasaki, H., REM sleep abnormalities in severe atheroid cerebral palsy, <i>Brain and Development</i> , 12, 494-497, 1990	Prevalence of cause of sleep disturbance not provided.
Hodgkinson,I., Jindrich,M.L., Duhaut,P., Vadot,J.P., Metton,G., Berard,C., Hip pain in 234 non-ambulatory adolescents and young adults with cerebral palsy: a cross-sectional multicentre study, <i>Developmental Medicine and Child Neurology</i> , 43, 806-808, 2001	Mean and median age is greater than 25 years.
Houlihan,C.M., O'donnell,M., Conaway,M., Stevenson,R.D., Bodily pain and health-related quality of life in children with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 46, 305-310, 2004	Cause of pain not reported, frequency of pain reported.
Jensen,M.P., Engel,J.M., Hoffman,A.J., Schwartz,L., Natural history of chronic pain and pain treatment in adults with cerebral palsy, <i>American Journal of Physical Medicine and Rehabilitation</i> , 83, 439-445, 2004	Cause of pain not identified, mean age over 25 years.
Jensen,M.P., Moore,M.R., Bockow,T.B., Ehde,D.M., Engel,J.M., Psychosocial factors and adjustment to chronic pain in persons with physical disabilities: A systematic review, <i>Archives of Physical Medicine and Rehabilitation</i> , 92, 146-160, 2011	Literature review, does not include studies with cerebral palsy population of over 250 sample size.
Jozwiak,M., Harasymczuk,P., Koch,A., Kotwicki,T., Incidence and risk factors of hip joint pain in children with severe cerebral palsy, <i>Disability and Rehabilitation</i> , 33, 1367-1372, 2011	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Kotagal,S., Gibbons,V.P., Stith,J.A., Sleep abnormalities in patients with severe cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 36, 304-311, 1994	Interventional study, n= 9 CP. Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Lelis, A. L. P. A., Cardoso, M. V. L. M., Hall, W. A., Sleep disorders in children with cerebral palsy: An integrative review, <i>Sleep Medicine Reviews</i> , 30, 63-71, 2016	All the studies included in this review have a small sample size
Malone,L.A., Vogtle,L.K., Pain and fatigue consistency in adults with cerebral palsy, <i>Disability and Rehabilitation</i> , 32, 385-391, 2010	Prevalence of cause of pain not reported.
McKearnan, K. A., Kieckhefer, G. M., Engel, J. M., Jensen, M. P., Labyak, S., Pain in children with cerebral palsy: a review, <i>Journal of Neuroscience Nursing</i> , 36, 252-9, 2004	Narrative review.
Ming, X., Pak, J., Mulvey, M. A., O'Sullivan, T., Reddy, C., Schwab, J., Pecor, K. W., Sleep complaints in cerebral palsy and/or epilepsy: A pediatric sleep questionnaire	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.

<b>Excluded studies - In children and young people with cerebral palsy, what are the common causes of pain, discomfort and distress?</b>	
study, Journal of Pediatric Neurology, 12, 127-135, 2014	
Molin, I., Alicrsson, M., Physical activity and health among adolescents with cerebral palsy in Sweden, International Journal of Adolescent Medicine & Health, 21, 623-33, 2009	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Noonan, K. J., Jones, J., Pierson, J., Honkamp, N. J., Leverson, G., Hip function in adults with severe cerebral palsy, Journal of Bone and Joint Surgery - Series A, 86, 2607-2613, 2004	Mean age greater than 25 years.
Opheim,A., Jahnsen,R., Olsson,E., Stanghelle,J.K., Walking function, pain, and fatigue in adults with cerebral palsy: a 7-year follow-up study, Developmental Medicine and Child Neurology, 51, 381-388, 2009	Cause of pain not reported in those under 25 years.
Ramstad, K., Loge, J. H., Jahnsen, R., Diseth, T. H., Self-reported mental health in youth with cerebral palsy and associations to recurrent musculoskeletal pain, Disability & Rehabilitation, 37, 144-50, 2015	Prevalence of cause of pain not provided.
Ramstad,K., Jahnsen,R., Skjeldal,O.H., Diseth,T.H., Mental health, health related quality of life and recurrent musculoskeletal pain in children with cerebral palsy 8-18 years old, Disability and Rehabilitation, 34, 1589-1595, 2012	Prevalence of cause of pain not provided.
Rethlefsen, S. A., Nguyen, D. T., Wren, T. A., Milewski, M. D., Kay, R. M., Knee Pain and Patellofemoral Symptoms in Patients With Cerebral Palsy, Journal of Pediatric Orthopedics, 35, 519-22, 2015	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Riquelme, I., Cifre, I., Montoya, P., Are physiotherapists reliable proxies for the recognition of pain in individuals with cerebral palsy? A cross sectional study, Disability & Health Journal, 8, 264-70, 2015	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Riquelme,I., Cifre,I., Montoya,P., Age-related changes of pain experience in cerebral palsy and healthy individuals, Pain Medicine, 12, 535-545, 2011	Prevalence of cause of pain not provided.
Robin,J., Murnaghan,L., Graham,K., Selber,P., Simpson,P., Baker,R., Thomason,P., The cerebral palsy hip classification, Developmental Medicine and Child Neurology, 3rd International Cerebral Palsy Conference Sydney, NSW Australia. Conference Start, 26-, 2009	Abstract, Prevalence of cause of pain not provided.
Romeo, D. M., Brogna, C., Musto, E., Baranello, G., Pagliano, E., Casalino, T., Ricci, D., Mallardi, M., Sivo, S., Cota, F., Battaglia, D., Bruni, O., Mercuri, E., Sleep disturbances in preschool age children with cerebral palsy: a questionnaire study, Sleep Medicine, 15, 1089-93, 2014	Prevalence of cause of sleep disturbance not reported (questionnaire scores reported).

<b>Excluded studies - In children and young people with cerebral palsy, what are the common causes of pain, discomfort and distress?</b>	
Russo,R.N., Miller,M.D., Haan,E., Cameron,I.D., Crotty,M., Pain characteristics and their association with quality of life and self-concept in children with hemiplegic cerebral palsy identified from a population register, <i>Clinical Journal of Pain</i> , 24, 335-342, 2008	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Sakai, T., Yamada, H., Nakamura, T., Nanamori, K., Kawasaki, Y., Hanaoka, N., Nakamura, E., Uchida, K., Goel, V. K., Vishnubhotla, L., Sairyu, K., Lumbar spinal disorders in patients with athetoid cerebral palsy: a clinical and biomechanical study, <i>Spine</i> , 31, E66-70, 2006	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Sandella,D.E., O'Brien,L.M., Shank,L.K., Warschausky,S.A., Sleep and quality of life in children with cerebral palsy, <i>Sleep Medicine</i> , 12, 252-256, 2011	Prevalence of cause of sleep disturbance not provided.
Swiggum, M., Hamilton, M. L., Gleeson, P., Roddey, T., Pain in children with cerebral palsy: implications for pediatric physical therapy, <i>Pediatric Physical Therapy</i> , 22, 86-92, 2010	Literature review on management of pain due to physical therapy.
Tuzun,E.H., Guven,D.K., Eker,L., Pain prevalence and its impact on the quality of life in a sample of Turkish children with cerebral palsy, <i>Disability and Rehabilitation</i> , 32, 723-728, 2010	Prevalence of cause of pain not reported.
Van Der Slot, W. M., Nieuwenhuijsen, C., Van Den Berg-Emons, R. J., Bergen, M. P., Hilberink, S. R., Stam, H. J., Roebroek, M. E., Chronic pain, fatigue, and depressive symptoms in adults with spastic bilateral cerebral palsy.[Erratum appears in <i>Dev Med Child Neurol</i> . 2012 Nov;54(11):1064], <i>Developmental Medicine &amp; Child Neurology</i> , 54, 836-42, 2012	Excluded on the basis that for the cause identified, more relevant studies (eg larger sample size) have been found.
Wayte, S., McCaughey, E., Holley, S., Annaz, D., Hill, C. M., Sleep problems in children with cerebral palsy and their relationship with maternal sleep and depression, <i>Acta Paediatrica</i> , 101, 618-23, 2012	Case-control study design, prevalence of cause in children with CP not reported.
Zuculo, G. M., Knap, C. C., Pinato, L., Correlation between sleep and quality of life in cerebral palsy, <i>Codas</i> , 26, 447-56, 2014	Case-control study design.

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## K.18<sup>1</sup> Assessment of pain, distress and discomfort and sleep 2 disturbances

Excluded studies - What is the validity and reliability of published tools to identify and aid understanding of discomfort, pain and/or distress in children and young people with cerebral palsy?	
Study	Reason for Exclusion
Boldingh, E. J., Jacobs-van der Bruggen, M. A., Lankhorst, G. J., Bouter, L. M., Assessing pain in patients with severe cerebral palsy: development, reliability, and validity of a pain assessment instrument for cerebral palsy, Archives of Physical Medicine & Rehabilitation, 85, 758-66, 2004	Validation of new pain assessment tool for CP patients (not listed in review protocol)
Breau, L. M., Camfield, C., McGrath, P. J., Rosmus, C., Finley, G. A., Measuring pain accurately in children with cognitive impairments: refinement of a caregiver scale, Journal of Pediatrics, 138, 721-7, 2001	No validation of tool.
Campbell, C., Kong, C., Pain in children with cerebral palsy, Paediatrics and Child Health, 15, 60A, 2010	Reports on causes of pain rather than on psychometric properties of scales.
Crosta, Q. R., Ward, T. M., Walker, A. J., Peters, L. M., A review of pain measures for hospitalized children with cognitive impairment, Journal for Specialists in Pediatric Nursing: JSPN, 19, 109-18, 2014	Very informative narrative review - used to quality assure included studies.
Fanurik, D., Koh, J. L., Harrison, R. D., Conrad, T. M., Tomerlin, C., Pain assessment in children with cognitive impairment. An exploration of self-report skills, Clinical Nursing Research, 7, 103-19; discussion 120-4, 1998	The study reports on self-reported skills (not relevant to review protocol).
Ghai, B., Makkar, J. K., Wig, J., Postoperative pain assessment in preverbal children and children with cognitive impairment, Paediatric Anaesthesia, 18, 462-77, 2008	Narrative review.
Glegg, Stephanie M., Tatla, Sandy K., Holsti, Liisa, The GestureTek virtual reality system in rehabilitation: A scoping review, Disability and Rehabilitation: Assistive Technology, 9, 89-111, 2014	The paper reports on 'gesture tek' (software for rehab).
Hunt, A., Wisbeach, A., Seers, K., Goldman, A., Crichton, N., Perry, L., Mastroyannopoulou, K., Development of the paediatric pain profile: role of video analysis and saliva cortisol in validating a tool to assess pain in children with severe neurological disability, Journal of Pain and Symptom Management, 33, 276-289, 2007	Small sample size (below 50) and another study has been found that validates the same tool.
Kingsnorth, S., Adler, E., Ami, N., Gresley-Jones, T., Mankad, D., Joachimides, N., Fay, L., Slonim, N., Fehlings, D., Developing a cerebral palsy chronic pain assessment toolkit: A systematic review of the evidence, Developmental medicine and child neurology, 55, 39, 2013	Abstract - No specific psychometric properties reported.
Kingsnorth, S., Orava, T., Provvienza, C., Adler, E., Ami, N., Gresley-Jones, T., Mankad, D., Slonim, N., Fay, L., Joachimides, N.,	Narrative review, used to quality assure the included studies.

<b>Excluded studies - What is the validity and reliability of published tools to identify and aid understanding of discomfort, pain and/or distress in children and young people with cerebral palsy?</b>	
Hoffman, A., Hung, R., Fehlings, D., Chronic Pain Assessment Tools for Cerebral Palsy: A Systematic Review, <i>Pediatrics</i> , 136, e947-60, 2015	
McKearnan, K. A., Kieckhefer, G. M., Engel, J. M., Jensen, M. P., Labyak, S., Pain in children with cerebral palsy: a review, <i>Journal of Neuroscience Nursing</i> , 36, 252-9, 2004	Narrative review.
Morales, N. M., Funayama, C. A., Rangel, V. O., Frontarolli, A. C., Araujo, R. R., Pinto, R. M., Rezende, C. H., Silva, C. H., Psychometric properties of the Child Health Assessment Questionnaire (CHAQ) applied to children and adolescents with cerebral palsy, <i>Health &amp; Quality of Life Outcomes</i> , 6, 109, 2008	The paper reports on quality of life rather than using measures of pain and/or distress.
Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., Clarke, C., Understanding distress in people with severe communication difficulties: Developing and assessing the Disability Distress Assessment Tool (DisDAT), <i>Journal of Intellectual Disability Research</i> , 51, 277-292, 2007	Median population age = 55 years.
Schade, Julia G., Joyce, Betsy A., Gerkenmeyer, Janis, Keck, Juanita F., Comparison of three preverbal scales for postoperative pain assessment in a diverse pediatric sample, <i>Journal of pain and symptom management</i> , 12, 348-359, 1996	Population: regardless of developmental stage or cognitive or physical disability. 2/3 scales not relevant to review protocol.
Solodiuk, J., Curley, M. A. Q., Pain assessment in nonverbal children with severe cognitive impairments: The individualised numeric rating scale (INRS), <i>Journal of Pediatric Nursing</i> , 18, 295-299, 2003	Tool not listed in the review protocol.
Townley, A., Kingsnorth, S., Orava, T., Provvidenza, C., An evidence-informed approach to the identification and assessment of chronic pain in children with cerebral palsy, <i>Journal of Pain</i> , 1), S3, 2015	Abstract - no specific psychometric properties reported.
Voepel-Lewis, T., Malviya, S., Tait, A. R., Merkel, S., Foster, R., Krane, E. J., Davis, P. J., A comparison of the clinical utility of pain assessment tools for children with cognitive impairment, <i>Anesthesia &amp; Analgesia</i> , 106, 72-8, table of contents, 2008	Comparison of scales utility. Small sample size.
Atmawidjaja, R. W., Wong, S. W., Yang, W. W., Ong, L. C., Sleep disturbances in Malaysian children with cerebral palsy, <i>Developmental Medicine &amp; Child Neurology</i> , 56, 681-5, 2014	No validity data reported.
Cook, J., Burd, L., Preliminary report on construction and validation of a pediatric sleep disturbance questionnaire, <i>Perceptual and Motor Skills</i> , 70, 259-267, 1990	Not CP specific as well as not listed in the review protocol.
Elsayed, R. M., Hasanein, B. M., Sayyah, H. E., El-Auoty, M. M., Tharwat, N., Belal, T. M., Sleep assessment of children with cerebral palsy:	The study reports on incidence of sleep disturbance types - no validity data.



**Excluded studies - What is the validity and reliability of published tools to identify and aid understanding of discomfort, pain and/or distress in children and young people with cerebral palsy?**

Using validated sleep questionnaire, Annals of Indian Academy of Neurology, 16, 62-5, 2013	
Raina, S. K., A comment on sleep assessment of children with cerebral palsy: Using validated sleep questionnaire, Annals of Indian Academy of Neurology, 16, 455, 2013	Comment.

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### K.19<sub>3</sub> Management of pain, distress and discomfort

**Excluded studies - In children and young people with cerebral palsy, which interventions are effective in managing discomfort and/or pain and distress with no apparent cause?**

Study	Reason for Exclusion
Beecham, E., Candy, B., Howard, R., McCulloch, R., Laddie, J., Rees, H., Vickerstaff, V., Bluebond-Langner, M., Jones, L., Pharmacological interventions for pain in children and adolescents with life-limiting conditions, Cochrane Database of Systematic Reviews, 3, CD010750, 2015	The review reports on Botox and Baclofen. These two interventions are not listed in the current review protocol as they have been covered in the Spasticity guideline.
Wyatt, K., Edwards, V., Franck, L., Britten, N., Creanor, S., Maddick, A., Logan, S., Cranial osteopathy for children with cerebral palsy: a randomised controlled trial, Archives of Disease in Childhood, 96, 505-12, 2011	Intervention not relevant to review protocol.

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### K.20<sub>6</sub> Management of sleep disturbances

**Excluded studies - In children and young people with cerebral palsy, which interventions are effective in managing sleep disturbance arising from no identifiable cause?**

Study	Reason for Exclusion
Austin, Kristie L., Gordon, Jocelyne E., O'Connell, Annie, Preliminary evaluation of Sleepwise program for children with sleep disturbance and developmental delay, Child & Family Behavior Therapy, 35, 195-211, 2013	Small sample size (n=6), no RCT.
Blake, S. F., Logan, S., Humphreys, G., Matthews, J., Rogers, M., Thompson-Coon, J., Wyatt, K., Morris, C., Sleep positioning systems for children with cerebral palsy, Cochrane Database of Systematic Reviews, 11, CD009257, 2015	Not relevant study design
Braam, W., Smits, M. G., Didden, R., Korzilius, H., Van Geijlswijk, I. M., Curfs, L. M., Exogenous melatonin for sleep problems in individuals with intellectual disability: a meta-analysis, Developmental Medicine & Child Neurology, 51, 340-9, 2009	Relevant studies with regards to population included have been picked up from this meta-analysis.

<b>Excluded studies - In children and young people with cerebral palsy, which interventions are effective in managing sleep disturbance arising from no identifiable cause?</b>	
De Leersnyder, H., Zisapel, N., Laudon, M., Prolonged-release melatonin for children with neurodevelopmental disorders, <i>Pediatric Neurology</i> , 45, 23-6, 2011	Follow up study (no RCT), no CP patients considered.
Giannasi, L. C., Matsui, M. Y., de Freitas Batista, S. R., Hardt, C. T., Gomes, C. P., Amorim, J. B., de Carvalho Aguiar, I., Collange, L., Dos Reis Dos Santos, I., Dias, I. S., de Oliveira, C. S., de Oliveira, L. V., Gomes, M. F., Effects of neuromuscular electrical stimulation, laser therapy and LED therapy on the masticatory system and the impact on sleep variables in cerebral palsy patients: a randomized, five arms clinical trial, <i>BMC Musculoskeletal Disorders</i> , 13, 71, 2012	Protocol.
Gringras, P., Gamble, C., Jones, A. P., Wiggs, L., Williamson, P. R., Sutcliffe, A., Montgomery, P., Whitehouse, W. P., Choonara, I., Allport, T., Edmond, A., Appleton, R., Mends Study Group, Melatonin for sleep problems in children with neurodevelopmental disorders: randomised double masked placebo controlled trial, <i>BMJ</i> , 345, e6664, 2012	Related to HTA paper.
Hill, C.M., Parker, R.C., Allen, P., Paul, A., Padoa, K.A., Sleep quality and respiratory function in children with severe cerebral palsy using night-time postural equipment: a pilot study, <i>Acta Paediatrica</i> , 98, 1809-1814, 2009	Part of the Cochrane systematic review on sleep positioning.
Jan, J. E., Hamilton, D., Seward, N., Fast, D. K., Freeman, R. D., Laudon, M., Clinical trials of controlled-release melatonin in children with sleep-wake cycle disorders, <i>Journal of Pineal Research</i> , 29, 34-9, 2000	Very small sample size and not clear how many CP patients entered the randomisation.
Montgomery, P., Stores, G., Wiggs, L., The relative efficacy of two brief treatments for sleep problems in young learning disabled (mentally retarded) children: a randomised controlled trial, <i>Archives of Disease in Childhood</i> , 89, 125-30, 2004	Comparison of two interventions not listed in the review protocol CP patients not included.
Moss, A. H., Gordon, J. E., O'Connell, A., Impact of sleepwise: an intervention for youth with developmental disabilities and sleep disturbance, <i>Journal of Autism &amp; Developmental Disorders</i> , 44, 1695-707, 2014	Before and after study, no mention of CP participants.
N. H. S. Quality Improvement Scotland, Melatonin to assist in the management of sleep disorders in children with neuro-developmental disorders (Structured abstract), 2015	Descriptive.
Nguyen, M., Tharani, S., Rahmani, M., Shapiro, M., A review of the use of clonidine as a sleep aid in the child and adolescent population, <i>Clinical Pediatrics</i> , 53, 211-216, 2014	Narrative review.
Niederhofer, H., Staffen, W., Mair, A., Pittschieler, K., Brief report: melatonin facilitates sleep in individuals with mental retardation and	Population = mentally retarded adolescents with sleep problems (self-reported). small sample size

<b>Excluded studies - In children and young people with cerebral palsy, which interventions are effective in managing sleep disturbance arising from no identifiable cause?</b>	
insomnia, Journal of Autism & Developmental Disorders, 33, 469-72, 2003	
O'Connell, A., Gordon, J., Koppelman-Guthrie, J., Moss, A., Sleepwise-an evaluation of a multicomponent sleep education and home based intervention for older children and adolescents with developmental disabilities and sleep disturbance, Sleep and Biological Rhythms, 10, 22, 2012	Descriptive.
O'Connell, A., Vannan, K., Sleepwise: addressing sleep disturbance in young children with developmental delay, Australian Occupational Therapy Journal, 55, 212-4, 2008	No RCT, description of Sleepwise approach.
Phillips, L., Appleton, R. E., Systematic review of melatonin treatment in children with neurodevelopmental disabilities and sleep impairment, Developmental Medicine & Child Neurology, 46, 771-5, 2004	No CP patients.
Spruyt, K., Curfs, L. M., Non-pharmacological management of problematic sleeping in children with developmental disabilities, Developmental Medicine & Child Neurology, 57, 120-36, 2015	Not CP specific descriptive study.
Spruyt, Karen, Curfs, Leopold M. G., Non-pharmacological management of problematic sleeping in children with developmental disabilities, Developmental Medicine & Child Neurology, 57, 120-136, 2015	No children with cerebral palsy were included
Tan, H. L., Kheirandish-Gozal, L., Gozal, D., Obstructive sleep apnea in children: Update on the recognition, treatment and management of persistent disease, Expert Review of Respiratory Medicine, 10, 431-439, 2016	Not relevant study design
Wiggs, L., Stores, G., Behavioural treatment for sleep problems in children with severe learning disabilities and challenging daytime behaviour: Effect on sleep patterns of mother and child, Journal of Sleep Research, 7, 119-126, 1998	Population criteria = sleep problems and daytime challenging behavior.
Wiggs, L., Stores, G., Behavioural treatment for sleep problems in children with severe learning disabilities and challenging daytime behaviour: effect on daytime behaviour, Journal of Child Psychology & Psychiatry & Allied Disciplines, 40, 627-35, 1999	Population = children with learning disabilities behavioral programme as intervention.

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### K.21.3 Assessment of mental health problems

<b>Excluded studies - In children and young people with cerebral palsy, what assessments are effective in identifying the presence of mental health problems?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Bertoncelli, C., Bertoncelli, D., Psychiatric disorders in children with cerebral palsy,	Only structured abstract. Structured Clinical Interview for DSM-IV (SCDI) used. No

<b>Excluded studies - In children and young people with cerebral palsy, what assessments are effective in identifying the presence of mental health problems?</b>	
European Archives of Psychiatry and Clinical Neuroscience, 261, S78, 2011	information regarding which other psychometric tests were used.
Bjorgaas,H.M., Hysing,M., Elgen,I., Psychiatric disorders among children with cerebral palsy at school starting age, Research in Developmental Disabilities, 33, 1287-1293, 2012	None of the tolls listed in the review protocol has been validated in this paper. Only the Kiddie-SADS was used as a diagnostic instrument.
Bode, H., Kohleis, K., Storck, M., Mental health problems in children and adolescents with cerebral palsy: Predictors, impact on family burden and quality of life, Developmental medicine and child neurology, 54, 8, 2012	Only structured abstract. No specific psychometric properties reported in relation with the CP population.
Majnemer,A., Shevell,M., Rosenbaum,P., Law,M., Poulin,C., Determinants of life quality in school-age children with cerebral palsy, Journal of Pediatrics, 151, 470-475, 2007	No specific psychometric properties reported.
Parkes,J., McCullough,N., Madden,A., McCahey,E., The health of children with cerebral palsy and stress in their parents, Journal of Advanced Nursing, 65, 2311-2323, 2009	No specific psychometric properties reported.
Ramstad, K., Jahnsen, R., Diseth, T. H., Self-reported mental health in children with cerebral palsy 8-18 years old and associations with recurrent musculoskeletal pain, Developmental medicine and child neurology, 55, 81-82, 2013	Only structured abstract. No specific psychometric properties reported.
Ramstad, K., Loge, J. H., Jahnsen, R., Diseth, T. H., Self-reported mental health in youth with cerebral palsy and associations to recurrent musculoskeletal pain, Disability & Rehabilitation, 37, 144-50, 2015	Only structured abstract. No specific psychometric properties reported.
Ramstad,K., Jahnsen,R., Skjeldal,O.H., Diseth,T.H., Mental health, health related quality of life and recurrent musculoskeletal pain in children with cerebral palsy 8-18 years old, Disability and Rehabilitation, 34, 1589-1595, 2012	No specific psychometric properties reported.
Ramstad,K., Jahnsen,R., Skjeldal,O.H., Diseth,T.H., Parent-reported participation in children with cerebral palsy: the contribution of recurrent musculoskeletal pain and child mental health problems, Developmental Medicine and Child Neurology, 54, 829-835, 2012	This study references other studies already included in this review for reporting on the psychometric properties of the assessments used.
Tuzun, E. H., Eker, L., Daskapan, A., An assessment of the impact of cerebral palsy on children's quality of life, Fizyoterapi Rehabilitasyon, 15, 3-8, 2004	No specific psychometric properties reported in relation with the CP population.
Vles,G.F., Hendriksen,R.G., Vles,J.S., Kessels,A.G., Hendriksen,J.G., Psychosocial adjustment in a Dutch sample of children with cerebral palsy, European Journal of Paediatric Neurology, 16, 365-372, 2012	PARS-III was used to measure psychosocial adjustment. The CBCL scale was used to assess participants (only the narrowband scales) but no psychometric properties were reported.
Wake, M., Salmon, L., Reddihough, Dinah, Health status of Australian children with mild to severe cerebral palsy: Cross-sectional survey using the Child Health Questionnaire,	Study already included in the systematic review by McCullough,2008

**Excluded studies - In children and young people with cerebral palsy, what assessments are effective in identifying the presence of mental health problems?**

Developmental Medicine & Child Neurology, 45, 194-199, 2003

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### K.22<sub>3</sub> Management of mental health problems

**Excluded studies - What is the clinical and cost-effectiveness of interventions to manage mental health problems in children and young people with moderate to severe cerebral palsy? - RCTS & SRs**

Study	Reason for Exclusion
Andersson, Gerhard, Ljotsson, Brjann, Weise, Cornelia, Internet-delivered treatment to promote health, Current Opinion in Psychiatry, 24, 168-172, 2011	No outcome measures listed and no information regarding GMFCS levels of the participants.
Anttila, H., Autti-Ramo, I., Suoranta, J., Makela, M., Malmivaara, A., Effectiveness of physical therapy interventions for children with cerebral palsy: A systematic review, BMC Pediatrics, 8, 2008	Outcome measures no relevant for the protocol and no information regarding the GMFCS levels of the participants.
Barlow, Jane, Bennett, Cathy, Midgley, Nick, Larkin, Soili K., Wei, Yinghui, Parent-infant psychotherapy for improving parental and infant mental health, Cochrane Database of Systematic Reviews, 2015	Population not relevant for the protocol (no-CP population)
Brogren Carlberg, E., Lowing, K., Does goal setting in activity-focused interventions for children with cerebral palsy influence treatment outcome?, Developmental Medicine and Child Neurology, 55, 47-54, 2013	Outcome measures not relevant for the protocol (Pediatric evaluation of disability inventory [PEDI], GMFCS, Family empowerment scales [FES])
Capelovitch, S., Amro, A., Empowering Palestinian and Israeli mothers to apply a home intervention program for their children with cerebral palsy, Developmental medicine and child neurology, 55, 2013	Only structured abstract. Outcome measures not relevant to the protocol
Centre for Reviews and Dissemination, Effectiveness of physical therapy interventions for children with cerebral palsy: a systematic review (Structured abstract), Database of Abstracts of Reviews of Effects, 2015	Structured abstract only. Outcome measures no relevant for the protocol.
Engle, H.A., The effect of diazepam (Valium) in children with cerebral palsy: a double-blind study, Developmental Medicine and Child Neurology, 8, 661-667, 1966	No GMFCS levels were included; crossover design; no evidence of outcome measures; no information regarding washout period.
Gates, P. E., Banks, D., Johnston, T. E., Campbell, S. R., Gaughan, J. P., Ross, S. A., Engsborg, J. R., Tucker, C., Randomised controlled trial assessing participation and quality of life in a supported speed treadmill training exercise program vs. a strengthening program for children with cerebral palsy, Journal of Pediatric Rehabilitation Medicine, 5, 75-88, 2012	GMFCS levels of the included population are not relevant for the protocol (levels III and IV and severely impaired cases excluded); outcome measures were not relevant for the protocol.

<b>Excluded studies - What is the clinical and cost-effectiveness of interventions to manage mental health problems in children and young people with moderate to severe cerebral palsy? - RCTS &amp; SRs</b>	
Gross-Tsur, Varda, Shalev, Ruth S., Badihi, Navah, Manor, Orly, Efficacy of Methylphenidate in Patients With Cerebral Palsy and Attention-Deficit Hyperactivity Disorder (ADHD), <i>Journal of Child Neurology</i> , 17, 863-866, 2002	Design not considered in the protocol (prospective, crossover, double-blind paradigm); intervention not relevant for the protocol (methylphenidate)
Maher, C. A., Williams, M. T., Olds, T., Lane, A. E., An internet-based physical activity intervention for adolescents with cerebral palsy: a randomised controlled trial, <i>Developmental Medicine &amp; Child Neurology</i> , 52, 448-55, 2010	Outcome measure not relevant for the protocol (MARCA: multimedia recall for children and young people; which reports activities undertaken during the previous day).
Metin Okmen, B., Dogan Aslan, M., Cuhadaroglu Cetin, F., Nakipoglu Yuzer, G. F., Kose Donmez, B., Ozgirgin, N., The effect of virtual reality therapy on psychological adaptation in children with cerebral palsy, <i>Noropsikiyatri Arsivi</i> , 50, 70-4, 2013	Not English
Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S. A., Goldsmith, S., A systematic review of interventions for children with cerebral palsy: state of the evidence, <i>Developmental Medicine &amp; Child Neurology</i> , 55, 885-910, 2013	Excluded on the basis that all types of interventions for cerebral palsy were included. Article was used to check for references but no relevant was found
Roux, Gemma, Sofronoff, Kate, Sanders, Matthew, A randomised controlled trial of group Stepping Stones Triple P: A mixed-disability trial, <i>Family Process</i> , 52, 411-424, 2013	mixed population with < 10% CP
Slaman, J., Roebroek, M., Dallmijer, A., Twisk, J., Stam, H., Van Den Berg-Emons, R., Learn 2 Move Research, Group, Can a lifestyle intervention programme improve physical behaviour among adolescents and young adults with spastic cerebral palsy? A randomised controlled trial, <i>Developmental Medicine &amp; Child Neurology</i> , 57, 159-66, 2015	Population was not relevant (only children with GMFCS levels were included and participants with severe cognitive disorders were excluded)
Slaman, J., Roebroek, M., Van Der Slot, W. M., Van Den Berg-Emons, R., Effectiveness of a lifestyle program among adolescents and young adults with cerebral palsy: A randomised controlled trial, <i>Developmental medicine and child neurology</i> , 56, 65-6, 2014	Only participants with GMFCS levels I-IV were included; outcome measures are not relevant for the protocol.
Tsoi, W. S., Zhang, L. A., Wang, W. Y., Tsang, K. L., Lo, S. K., Improving quality of life of children with cerebral palsy: a systematic review of clinical trials, <i>Child: Care, Health &amp; Development</i> , 38, 21-31, 2012	Excluded on the basis that all types of interventions for cerebral palsy were included. Article was used to check for references but no relevant was found
Turner, W. A., Casey, L. M., Outcomes associated with virtual reality in psychological interventions: where are we now?, <i>Clinical Psychology Review</i> , 34, 634-644, 2014	Meta-analysis which includes one article related with CP, but outcome measures and intervention are not relevant for the protocol
Van Wely, L., Becher, J. G., Reinders-Messelink, H. A., Lindeman, E., Verschuren, O., Verheijden, J., Dallmeijer, A. J., LEARN 2 MOVE 7-12 years: a randomised controlled trial on the effects of a physical activity stimulation	Population not relevant for the protocol (GMFCS levels I-III)

<b>Excluded studies - What is the clinical and cost-effectiveness of interventions to manage mental health problems in children and young people with moderate to severe cerebral palsy? - RCTS &amp; SRs</b>	
program in children with cerebral palsy, BMC Pediatrics, 10, 77, 2010	
Wallen, Margaret, Majnemer, Annette, No differences were observed between six months of context- versus child-focussed intervention for young children with cerebral palsy on self-care, mobility, range-of-motion or participation, Australian Occupational Therapy Journal, 61, 126-127, 2014	Structured abstract only. Intervention and outcome measures not relevant for the protocol.
Whittingham, K., Sanders, M., McKinlay, L., Boyd, R. N., Parenting intervention improves behavioral and emotional outcomes of children with CP: An RCT, Developmental medicine and child neurology, 55, 24-5, 2013	Structured abstract only. Relevant outcome measures have already been reported in the full text on an included article by the same author in the same population.
Whittingham, K., Sanders, M., McKinlay, L., Boyd, R. N., Stepping stones triple p and acceptance and commitment therapy for parents of children with cerebral palsy: Trial protocol, Brain impairment, 14, 270-80, 2013	Trial protocol. Does not include information about intervention or results.
Whittingham, K., Sanders, M., McKinlay, L., Boyd, R. N., Stepping Stones Triple P combined with ACT improves child behaviour and parenting in families of children with CP: A randomised controlled trial, Developmental medicine and child neurology, 56, 54-55, 2014	This is the structured abstract of a full text article already included in the review.
Whittingham, K., Sanders, M., McKinlay, L., Boyd, R. N., Improving child quality of life and parent psychological functioning with a parenting intervention incorporating acceptance and commitment therapy, Developmental medicine and child neurology, 55, 80-81, 2013	Only structured abstract. Study excluded on the basis of other articles by the same author have already been included in the review using the same population, intervention and outcome measures.
Whittingham, Koa, Sanders, Matthew, McKinlay, Lynne, Boyd, Roslyn N., "Stepping stones triple p and acceptance and commitment therapy for parents of children with cerebral palsy: Trial protocol": Corrigendum, Brain impairment, 15, 234, 2014	Corrigendum of an article excluded from the review.
Whittingham, K., Wee, D., Boyd, R., Systematic review of the efficacy of parenting interventions for children with cerebral palsy, Child: Care, Health and Development, 37, 475-483, 2011	Pre-post design.

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### **K.23<sub>3</sub> Management of sensory and perceptual difficulties**

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective for managing difficulties in registering and processing of sensory and perceptual information?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Arai, H., Torise, Y., Miura, M., Shima, M., Ohashi, T., Short-term effect of handling methods of Bobath therapy on children with	The study focuses more on generic rehabilitation/physiotherapy and not on perceptual interventions as such.

<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective for managing difficulties in registering and processing of sensory and perceptual information?</b>	
bilateral spastic cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 56, 4, 2014	
Auld, M. L., Russo, R., Moseley, G. L., Johnston, L. M., Determination of interventions for upper extremity tactile impairment in children with cerebral palsy: a systematic review, <i>Developmental Medicine &amp; Child Neurology</i> , 56, 815-32, 2014	This is a review including 5 studies on children with CP, of which only one has considered sensorimotor training and it has been included as single study (Bumin et al).
Auld, M., Johnston, L., Boyd, R., Moseley, L., Seeing the gaps: A review of visual assessments for congenital hemiplegia, <i>Developmental Medicine and Child Neurology</i> , 51, 64, 2009	No interventions assessed.
Auld, M., Johnston, L., Boyd, R., Moseley, L., Tactile assessment in children with congenital hemiplegia: Which tool to use?, <i>Developmental Medicine and Child Neurology</i> , 51, 64-65, 2009	No interventions assessed.
Auld, M., Russo, R., Moseley, G. L., Johnston, L., Tactile interventions for children with cerebral palsy: A systematic review, <i>Developmental Medicine and Child Neurology</i> , 56, 22, 2014	Abstract of a full text that we have requested (star id 347723)
Barton, E. E., Reichow, B., Schnitz, A., Smith, I. C., Sherlock, D., A systematic review of sensory-based treatments for children with disabilities, <i>Research in Developmental Disabilities</i> , 37, 64-80, 2015	This is a review that includes a study that we have requested and included. Used to check references.
Brogren Carlberg, E., Lowing, K., Does goal setting in activity-focused interventions for children with cerebral palsy influence treatment outcome?, <i>Developmental Medicine and Child Neurology</i> , 55, 47-54, 2013	This review searched for study designs that are not relevant to our review (case-control studies, single subject experimental design, etc). Used to check references.
Cho, M., Kim, D., Yang, Y., Effects of visual perceptual intervention on visual-motor integration and activities of daily living performance of children with cerebral palsy, <i>Journal of Physical Therapy Science</i> , 27, 411-3, 2015	No comparison presented at all.
Darrah, J., Law, M., Focus on function: A clinical trial of two intervention approaches for children with cerebral palsy, <i>Physiotherapy</i> , 97, 2011	This paper is an abstract of a full text that we have requested and included.
Jackman, M., Novak, I., Lannin, N., Effectiveness of functional hand splinting and the cognitive orientation to occupational performance (CO-OP) approach in children with cerebral palsy and brain injury: Two randomised controlled trial protocols, <i>BMC Neurology</i> , 14, 2014	This paper is a protocol for future trial.
James, S., Ziviani, J., Boyd, R. N., Efficacy of a web-based multimodal therapy program on occupational performance, upper limb function, and visual perception for children with unilateral cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 56, 85-6, 2014	Duplicate of a full text that we have requested.



<b>Excluded studies - In children and young people with cerebral palsy, what interventions are effective for managing difficulties in registering and processing of sensory and perceptual information?</b>	
James, S., Ziviani, J., Ware, R. S., Boyd, R. N., Relationships between activities of daily living, upper limb function, and visual perception in children and adolescents with unilateral cerebral palsy, <i>Developmental medicine and child neurology</i> , 57, 852-857, 2015	The study presents regression models for associations, but no interventions are assessed.
Kerem, M., Livanelioglu, A., Topcu, M., Effects of Johnstone pressure splints combined with neurodevelopmental therapy on spasticity and cutaneous sensory inputs in spastic cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 43, 307-313, 2001	Outcomes assessed (range of movement) are not relevant to the review protocol.
Law, M., Darrah, J., Pollock, N., Rosenbaum, P., Russell, D., Walter, S. D., Petrenchik, T., Wilson, B., Wright, V., Focus on Function - a randomised controlled trial comparing two rehabilitation interventions for young children with cerebral palsy, <i>BMC Pediatrics</i> , 7, 31, 2007	This paper is a protocol for future trial.
McLean, B., Garbellini, S., Valentine, J., Carey, L., Elliott, C., Improving sensation for children with cerebral palsy, what are we doing? A systematic review, <i>Developmental Medicine and Child Neurology</i> , 56, 21, 2014	Abstract only, with scarce info.
Morgan, C., Novak, I., Badawi, N., Environmental enrichment utilizing motor learning enhances motor outcomes of infants at high risk of CP: Randomised controlled pilot study, <i>Developmental Medicine and Child Neurology</i> , 56, 2014	Population = children at risk of cerebral palsy.
Sellick, K. J., Over, R., Effects of vestibular stimulation on motor development of cerebral-palsied children, <i>Developmental Medicine and Child Neurology</i> , 22, 476-83, 1980	Very small sample size vestibular stimulation not part of the review protocol.
Shamsoddini, A.R., Hollisaz, M.T., Effect of sensory integration therapy on gross motor function in children with cerebral palsy, <i>Iranian Journal of Child Neurology</i> , 3, 43-48, 2009	The developers felt the results couldn't be trusted as when inputting raw data into Review Manager this was showing different conclusions.
Zhang, N. X., Wang, X. Y., Li, Y. B., Liu, G. Z., Zhang, H. Y., Effects of individualized therapeutic program with heat-reinforcing needling in combination with Bobath therapy on gross motor dysfunction in children with cerebral palsy: A randomised controlled trial, <i>World Journal of Acupuncture - Moxibustion</i> , 24, 21-31, 2014	Acupuncture isn't part of the interventions for this review.
Zhang, N. X., Wang, X. Y., Liu, G. Z., Li, Y. B., Zhang, H. Y., [Randomised controlled clinical trials of individualised treatment of cerebral palsy children by warm-reinforcing needling combined with Bobath rehabilitation training], <i>Zhen ci yan jiu = Acupuncture research / [Zhongguo yi xue ke xue yuan Yi xue qing bao yan jiu suo bian ji]</i> , 39, 318-23, 2014	Duplicate of a full text that we have requested.

## K.24<sub>2</sub> Other comorbidities in cerebral palsy

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Aaberg, K. M., Suren, P., Soraas, C. L., Bakken, I. J., Gunnes, N., Haberg, S. E., Lossius, M. I., Stoltenberg, C., Chin, R., Epilepsy beyond seizures. A nationwide registry study of comorbidity in childhood epilepsy, <i>Epilepsia</i> , 55, 100, 2014	Comorbidities for cerebral palsy not reported, abstract only, non-UK.
Akpınar, P., Tezel, C. G., Eliasson, A. C., İcagasioglu, A., Reliability and cross-cultural validation of the Turkish version of Manual Ability Classification System (MACS) for children with cerebral palsy, <i>Disability and Rehabilitation</i> , 32, 1910-1916, 2010	Small sample size.
Aksu, F., Nature and prognosis of seizures in patients with cerebral palsy, <i>Developmental Medicine &amp; Child Neurology</i> , 32, 661-8, 1990	Small sample size.
Al Ajlouni, S. F., Aqrabawi, M., Oweis, N., Daoud, A. S., Clinical spectrum of cerebral palsy in Jordanian children: An analysis of 200 cases, <i>Journal of Pediatric Neurology</i> , 4, 251-255, 2006	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Al-Asmari, A., Al Moutaery, K., Akhdar, F., Al Jadid, M., Cerebral palsy: incidence and clinical features in Saudi Arabia, <i>Disability &amp; Rehabilitation</i> , 28, 1373-7, 2006	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Alsem, M. W., Ketelaar, M., Verhoef, M., The course of health-related quality of life of preschool children with cerebral palsy, <i>Disability and Rehabilitation</i> , 35, 686-693, 2013	Small sample size.
Al-Sulaiman, A. A., Bademosi, O. F., Ismail, H. M., Al-Quliti, K. W., Al-Shammery, S. F., Abumadini, M. S., Al-Umran, K. U., Magbool, G. M., Cerebral palsy in Saudi children, <i>Neurosciences</i> , 8, 26-29, 2003	Small sample size non UK data.
Al-Sulaiman, A. A., Epilepsy in Saudi children with cerebral palsy, <i>Saudi Medical Journal</i> , 22, 19-21, 2001	Small sample size, non-UK.
Andersen, G., Mjoen, T., Vik, T., Communicative skills in children with cerebral palsy (CP), <i>Developmental medicine and child neurology</i> , 51, 14, 2009	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Andersen, G. L., Irgens, L. M., Haagaas, I., Skranes, J. S., Meberg, A. E., Vik, T., Cerebral palsy in Norway: prevalence, subtypes and severity, <i>European Journal of Paediatric Neurology</i> , 12, 4-13, 2008	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Andersen, J. C., Robertson, C. M., Joffe, A. R., Sauve, R. S., Alton, G. Y., Dinu, I. A., Ross, D. B., Rebeyka, I. M., Prevalence and profile of cerebral palsy 4 years after newborn complex heart surgery, <i>Developmental Medicine and Child Neurology</i> , 51, 30-31, 2009	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Aneja,S., Ahuja,B., Taluja,V., Bhatia,V.K., Epilepsy in children with cerebral palsy, Indian Journal of Pediatrics, 68, 111-115, 2001	Not registry, non-UK.
Anwar,S., Chowdhury,J., Khatun,M., Mollah,A.H., Begum,H.A., Rahman,Z., Nahar,N., Clinical profile and predisposing factors of cerebral palsy, Mymensingh Medical Journal: MMJ, 15, 142-145, 2006	Small sample size.
Arai, H., Hirai, S., Kitai, Y., Clinical features of congenital bulbar palsy, Developmental medicine and child neurology, 54, 113-114, 2012	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Arnfield, E., Jordan, R., Pareezer, L., Ware, R., Boyd, R. N., Impact of preterm versus term birth on comorbidities and functional outcomes in preschool age children with cerebral palsy, Developmental medicine and child neurology, 55, 69, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Arnoldi, K. A., Pendarvis, L., Jackson, J., Batra, N. N., Cerebral Palsy for the Pediatric Eye Care Team Part III: Diagnosis and Management of Associated Visual and Sensory Disorders, American Orthoptic Journal, 56, 97-107, 2006	Small sample size.
Arnoldi, K., Jackson, J. H., Cerebral palsy for the pediatric eye care team part 1: epidemiology, pathogenesis, and systemic findings, American Orthoptic Journal, 55, 97-105, 2005	Small sample size.
Aronu, A. E., Ibekwe, R. C., Ojinnaka, N. C., Epilepsy in Nigerian children with cerebral palsy in Enugu, Journal of Pediatric Neurology, 11, 23-27, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Bacciu, A., Pasanisi, E., Vincenti, V., Ormitti, F., Di Lella, F., Guida, M., Berghenti, M., Bacciu, S., Cochlear implantation in children with cerebral palsy. A preliminary report, International Journal of Pediatric Otorhinolaryngology, 73, 717-21, 2009	Intervention study: cochlear implantation.
Badawi,N., Felix,J.F., Kurinczuk,J.J., Dixon,G., Watson,L., Keogh,J.M., Valentine,J., Stanley,F.J., Cerebral palsy following term newborn encephalopathy: a population-based study, Developmental Medicine and Child Neurology, 47, 293-298, 2005	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Bankes, J. L., Eye defects of mentally handicapped children, British Medical Journal, 2, 533-5, 1974	No data specific to CP patients.
Bartlett, D., Chiarello, L., Chang, H., Measuring health conditions of young children with cerebral palsy, Developmental medicine and child neurology, 51, 72, 2009	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Basaran, A., Karadavut, K. I., Uneri, S. O., Balbaloglu, O., Atasoy, N., The effect of having a children with cerebral palsy on quality of life, burn-out, depression and anxiety scores: a	Small sample size study focuses on caregivers.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
comparative study, European journal of physical & rehabilitation medicine., 49, 815-22, 2013	
Beckung, E., Hagberg, G., Uldall, P., Cans, C., Surveillance of Cerebral Palsy in Europe, Probability of walking in children with cerebral palsy in Europe, Pediatrics, 121, e187-92, 2008	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found. Other studies from SCPE included.
Beckung, E., Hagberg, G., Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy, Developmental Medicine and Child Neurology, 44, 309-316, 2002	Small sample size non-UK data.
Beckung, E., Steffenburg, U., Uvebrant, P., Motor and sensory dysfunctions in children with mental retardation and epilepsy, Seizure, 6, 43-50, 1997	Small sample size not CP patients.
Beckung, E., White-Koning, M., Marcelli, M., McManus, V., Michelsen, S., Parkes, J., Parkinson, K., Thyen, U., Arnaud, C., Fauconnier, J., Colver, A., Health status of children with cerebral palsy living in Europe: a multi-centre study, Child: Care, Health and Development, 34, 806-814, 2008	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Belan, R. R., Paola, D. B., Aguas-Santas, J. S., Casares, C., Andres, J., Secondary disability in communication disorders due to childhood cerebral palsy: Assessment using a modified CETI scale, Developmental medicine and child neurology, 53, 23-24, 2011	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Belonwu, R.O., Gwarzo, G.D., Adeleke, S.I., Cerebral palsy in Kano, Nigeria--a review, Nigerian Journal of Medicine: Journal of the National Association of Resident Doctors of Nigeria, 18, 186-189, 2009	Not registry, non-UK.
Benfer, K. A., Weir, K. A., Bell, K. L., Ware, R. S., Davies, P. S., Boyd, R. N., Oropharyngeal dysphagia in preschool children with cerebral palsy: oral phase impairments, Research in Developmental Disabilities, 35, 3469-81, 2014	Small sample size not answering the review question.
Bertoncelli, C., Bertoncelli, D., Psychiatric disorders in children with cerebral palsy, European Archives of Psychiatry and Clinical Neuroscience, 261, S78, 2011	Small sample size, conference abstract, comorbidity (psychiatric disorders) not in protocol.
Bhatia, M., Joseph, B., Rehabilitation of cerebral palsy in a developing country: The need for comprehensive assessment, Pediatric Rehabilitation, 4, 83-86, 2001	Small sample size non-UK data.
Bildstein, T., Baumann, M., Gedik, A., Albrecht, U., Baumgartner, S., Janetschek, C., Rostasy, K., Haberlandt, E., Epilepsy in children with cerebral palsy, Neuropediatrics, 44 (2), 2013	Small sample size.
Birman, C.S., Elliott, E.J., Gibson, W.P., Pediatric cochlear implants: additional disabilities prevalence, risk factors, and effect on language	Small sample size, non-UK.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
outcomes, <i>Otology and Neurotology</i> , 33, 1347-1352, 2012	
Bjorgaas,H.M., Elgen,I., Boe,T., Hysing,M., Mental health in children with cerebral palsy: does screening capture the complexity?, <i>TheScientificWorldJournal</i> , 2013, 468402-, 2013	Small sample size mental health rather than behavioural problems.
Bjorgaas,H.M., Hysing,M., Elgen,I., Psychiatric disorders among children with cerebral palsy at school starting age, <i>Research in Developmental Disabilities</i> , 33, 1287-1293, 2012	Small sample size mental health issues rather than behavioural difficulties.
Bjornson,K.F., Zhou,C., Stevenson,R.D., Christakis,D., Relation of stride activity and participation in mobility-based life habits among children with cerebral palsy, <i>Archives of Physical Medicine and Rehabilitation</i> , 95, 360-368, 2014	Small sample size.
Blacher,J., McIntyre,L.L., Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact, <i>Journal of Intellectual Disability Research</i> , 50, 184-198, 2006	Population = caregivers of young adults with ID.
Black, P., Visual disorders associated with cerebral palsy, <i>British Journal of Ophthalmology</i> , 66, 46-52, 1982	Small sample size.
Blair, E., Badawi, N., Bunyard, J., Groot, J. D., Delacy, M., Edwards, K., Ewens, C., Flett, P., Gibson, C., Gibson, N., Haan, E., Ingham, C., Kippen, R., Lanigan, A., Louca, C., Love, S., McIntyre, S., Novak, I., Reddihough, D., Reid, S., Scott, H., Smithers-Sheedy, H., Van Essen, P., Venn, A., Watson, L., A profile of cerebral palsy in Australia, <i>Developmental medicine and child neurology</i> , 52, 37-38, 2010	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Blair, E., Stanley, F. J., An epidemiological study of cerebral palsy in Western Australia, 1956-1975. III: Postnatal aetiology, <i>Developmental Medicine &amp; Child Neurology</i> , 24, 575-85, 1982	Small sample size, non-UK.
Bohmer, C. J., Klinkenberg-Knol, E. C., Niezen-de Boer, M. C., Meuwissen, S. G., Gastroesophageal reflux disease in intellectually disabled individuals: how often, how serious, how manageable?, <i>American Journal of Gastroenterology</i> , 95, 1868-72, 2000	Non-systematic review.
Bohmer,C.J., Klinkenberg-Knol,E.C., Niezen-de Boer,R.C., Meuwissen,S.G., The prevalence of gastro-oesophageal reflux disease based on non-specific symptoms in institutionalized, intellectually disabled individuals, <i>European Journal of Gastroenterology and Hepatology</i> , 9, 187-190, 1997	Small sample size.
Bohmer,C.J., Taminiiau,J.A., Klinkenberg-Knol,E.C., Meuwissen,S.G., The prevalence of constipation in institutionalized people with intellectual disability, <i>Journal of Intellectual Disability Research</i> , 45, 212-218, 2001	Small sample size indirect population (patients with ID).
Bohmer,C.J., Niezen-de Boer,M.C., Klinkenberg-Knol,E.C., Deville,W.L.,	Not CP specific.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Nadorp,J.H., Meuwissen,S.G., The prevalence of gastroesophageal reflux disease in institutionalized intellectually disabled individuals, American Journal of Gastroenterology, 94, 804-810, 1999	
Bohmer,C.J., Niezen-de Boer,M.C., Klinkenberg-Knol,E.C., Nadorp,J.H., Meuwissen,S.G., Gastro-oesophageal reflux disease in institutionalised intellectually disabled individuals, Netherlands Journal of Medicine, 51, 134-139, 1997	Case-control design, CP subset of participants with GORD (prevalence not applicable).
Boo,N.Y., Ong,L.C., Lye,M.S., Chandran,V., Teoh,S.L., Zamratol,S., Nyein,M.K., Allison,L., Comparison of morbidities in very low birthweight and normal birthweight infants during the first year of life in a developing country, Journal of Paediatrics and Child Health, 32, 439-444, 1996	not CP specific; comparing comorbidities in VLBW babies.
Bottcher,L., Dammeyer,J., Disability as a risk factor? Development of psychopathology in children with disabilities, Research in Developmental Disabilities, 34, 3607-3617, 2013	Non-systematic review.
Bozkurt,M., Tutuncuoglu,S., Serdaroglu,G., Tekgul,H., Aydogdu,S., Gastroesophageal reflux in children with cerebral palsy: efficacy of cisapride, Journal of Child Neurology, 19, 973-976, 2004	Small sample size, non-UK.
Brandao, M. D., Mancini, M. C., Rodrigues, L. A., Goncalves, S. C., Crepaldi, P. V., Mambrini, J. V., Abrahao, L. C., Gross motor and hand function in children with cerebral palsy and their relation with daily living activities, Developmental medicine and child neurology, 53, 83, 2011	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Brooks, J., Strauss, D., Shavelle, R., Tran, L., Recent updates from the California database, Developmental medicine and child neurology, 55, 48, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Brossard-Racine,M., Hall,N., Majnemer,A., Shevell,M.I., Law,M., Poulin,C., Rosenbaum,P., Behavioural problems in school age children with cerebral palsy, European Journal of Paediatric Neurology, 16, 35-41, 2012	Small sample size the study focuses on parents and carers.
Bruck,I., Antoniuk,S.A., Spessatto,A., Bem,R.S., Hausberger,R., Pacheco,C.G., Epilepsy in children with cerebral palsy, Arquivos de Neuro-Psiquiatria, 59, 35-39, 2001	Small sample size.
Cans, C., Guillem, P., Arnaud, C., Baille, F., Chalmers, J., McManus, V., Cussen, G., Parkes, J., Dolk, H., Hagberg, B., Hagberg, G., Jarvis, S., Colver, A., Johnson, A., Surman, G., Krageloh-Mann, I., Michaelis, R., Platt, M. J., Pharoah, P., Topp, M., Udall, P., Torrioli, M. G., Miceli, M., Wichers, M., Prevalence and characteristics of children with cerebral palsy in Europe, Developmental Medicine and Child Neurology, 44, 633-640, 2002	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Carlsson,M., Hagberg,G., Olsson,I., Clinical and aetiological aspects of epilepsy in children with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 45, 371-376, 2003	Small sample size non-UK data.
Carlsson,M., Olsson,I., Hagberg,G., Beckung,E., Behaviour in children with cerebral palsy with and without epilepsy, <i>Developmental Medicine and Child Neurology</i> , 50, 784-789, 2008	Small sample size.
Carvalho, E. H., Valicek, J., Tavares, E. S., Araujo, A. C., Hearing assessment in children with cerebral palsy by brainstem auditory evoked potentials and wave V audiometry, <i>Journal of Neurology</i> , 258, S59, 2011	Small sample size.
Castane, M., Peris, E., Sanchez, E., Ocular dysfunction associated with mental handicap, <i>Ophthalmic and Physiological Optics</i> , 15, 489-492, 1995	Small sample size, non-UK.
Centre for Reviews and Dissemination, Screening for speech and language delay: a systematic review of the literature (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Abstract only, prevalence not reported.
Chaix, Y., Learning disabilities in children with epilepsy, <i>Troubles de l'apprentissage chez l'enfant epileptique. [French, English]</i> , <i>Annals of Physical and Rehabilitation Medicine</i> , 55, e231+e233, 2012	Abstract only, not English (French).
Chiarello,L.A., Almasri,N., Palisano,R.J., Factors related to adaptive behavior in children with cerebral palsy, <i>Journal of Developmental and Behavioral Pediatrics</i> , 30, 435-441, 2009	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Christensen, D., Van Naarden Braun, K., Doernberg, N. S., Maenner, M. J., Arneson, C. L., Durkin, M. S., Benedict, R. E., Kirby, R. S., Wingate, M. S., Fitzgerald, R., Yeargin-Allsopp, M., Prevalence of cerebral palsy, co-occurring autism spectrum disorders, and motor functioning - Autism and Developmental Disabilities Monitoring Network, USA, 2008, <i>Developmental Medicine &amp; Child Neurology</i> , 56, 59-65, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Christensen, D., Yeargin-Allsopp, M., Goodman, A., Van Naarden Braun, K., Co-occurring autism spectrum disorder, intellectual disability, and epilepsy among children with cerebral palsy, <i>Developmental medicine and child neurology</i> , 56, 73, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Clark,M., Carr,L., Reilly,S., Neville,B.G., Worster-Drought syndrome, a mild tetraplegic perisylvian cerebral palsy. Review of 47 cases, <i>Brain</i> , 123, 2160-2170, 2000	Small sample size population of Worster-drought syndrome only.
Clark,M., Harris,R., Jolleff,N., Price,K., Neville,B.G., Worster-Drought syndrome: poorly recognized despite severe and persistent difficulties with feeding and speech,	Worster-Drought syndrome only.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Developmental Medicine and Child Neurology, 52, 27-32, 2010	
Cockerill, H., Elbourne, D., Allen, E., Scrutton, D., Will, E., McNee, A., Fairhurst, C., Baird, G., Speech, communication and use of augmentative communication in young people with cerebral palsy: the SH&PE population study, Child: Care, Health & Development, 40, 149-57, 2014	Small sample size, not registry.
Coleman, A., Weir, K., Ware, R., Boyd, R. N., The relationship between communication and motor severity in children with cerebral palsy at 24 months corrected age, Developmental medicine and child neurology, 54, 65, 2012	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Coleman, A., Weir, K. A., Ware, R. S., Boyd, R. N., Relationship between communication skills and gross motor function in preschool-aged children with cerebral palsy, Archives of Physical Medicine and Rehabilitation, 94, 2210-2217, 2013	Small sample size.
Corry, P. C., Intellectual disability and cerebral palsy in a UK community, Community Genetics, 5, 201-4, 2002	Small sample size, not registry, regional data.
Cucu, T., Siric, A., Nacu, A., A comparison of children with spastic cerebral palsy, European Journal of Paediatric Neurology, 14 (6), 549, 2010	Small sample size.
Dahlgren Sandberg, A., Reading and spelling abilities in children with severe speech impairments and cerebral palsy at 6, 9, and 12 years of age in relation to cognitive development: A longitudinal study, Developmental Medicine and Child Neurology, 48, 629-634, 2006	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Dakovic, I., da Graca Andrada, M., Folha, T., Neubauer, D., Hollody, K., Honold, M., Horber, V., Duranovic, V., Bosnjak, V. M., Clinical features of cerebral palsy in children with symptomatic congenital cytomegalovirus infection, European Journal of Paediatric Neurology, 18, 618-23, 2014	Small sample size.
de Veer, A. J., Bos, J. T., Niezen-de Boer, R. C., Bohmer, C. J., Francke, A. L., Symptoms of gastroesophageal reflux disease in severely mentally retarded people: a systematic review, BMC Gastroenterology, 8, 23, 2008	Not CP specific.
Del Giudice, E., Staiano, A., Capano, G., Romano, A., Florimonte, L., Miele, E., Ciarla, C., Campanozzi, A., Crisanti, A. F., Gastrointestinal manifestations in children with cerebral palsy, Brain and Development, 21, 307-311, 1999	Small sample size.
Delacy, M., Louca, C., Johnston, L., Queensland Cerebral Palsy Register-successful consent-based ascertainment of a 10-year cohort, Developmental medicine and child neurology, 55, 78, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.



<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Delacy, M., Louca, C., Johnston, L. M., Relationship between gross motor function and associated impairments in children with cerebral palsy in Queensland (birth years 1996-2005), <i>Developmental medicine and child neurology</i> , 56, 61-62, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Duckman,R., The incidence of visual anomalies in a population of cerebral palsied children, <i>Journal of the American Optometric Association</i> , 50, 1013-1016, 1979	Non-systematic review.
Dufresne, D., Dagenais, L., Shevell, M., Prevalence and characteristics of severe sensory impairment in a population-based cohort of children with cerebral palsy, <i>Annals of Neurology</i> , 72, S186, 2012	Small sample size.
Dufresne, D., Dagenais, L., Shevell, M. I., Epidemiology of severe hearing impairment in a population-based cerebral palsy cohort, <i>Pediatric Neurology</i> , 51, 641-644, 2014	Small sample size, non-UK.
Dufresne, D., Dagenais, L., Shevell, M. I., Spectrum of visual disorders in a population-based cerebral palsy cohort, <i>Pediatric Neurology</i> , 50, 324-328, 2014	Small sample size, non-UK.
Dufresne, D., Dagenais, L., Shevell, M. I., Repacq Consortium, Spectrum of visual disorders in a population-based cerebral palsy cohort, <i>Pediatric Neurology</i> , 50, 324-8, 2014	Small sample size, non-UK.
Dufresne, D., Dagenais, L., Shevell, M. I., Repacq Consortium, Epidemiology of severe hearing impairment in a population-based cerebral palsy cohort, <i>Pediatric Neurology</i> , 51, 641-4, 2014	Small sample size, non-UK.
Edebol-Tysk, K., Epidemiology of spastic tetraplegic cerebral palsy in Sweden. I. Impairments and disabilities, <i>Neuropediatrics</i> , 20, 41-5, 1989	Small sample size.
El-Tallawy, H. N., Farghaly, W. M., Shehata, G. A., Badry, R., Rageh, T. A., Epileptic and cognitive changes in children with cerebral palsy: an Egyptian study, <i>Neuropsychiatric Disease &amp; Treatment</i> , 10, 971-5, 2014	The paper reports on risk factors in relation to the development of epilepsy Small sample size.
El-Tallawy, H. N., Farghaly, W. M., Shehata, G. A., Rageh, T. A., Metwally, N. A., Badry, R., Sayed, M. A., Abd El Hamed, M., Abd-Elwarth, A., Kandil, M. R., Cerebral palsy in Al-Quseir City, Egypt: prevalence, subtypes, and risk factors, <i>Neuropsychiatric Disease &amp; Treatment</i> , 10, 1267-72, 2014	Small sample size.
Erkin,G., Culha,C., Ozel,S., Kirbiyik,E.G., Feeding and gastrointestinal problems in children with cerebral palsy, <i>International Journal of Rehabilitation Research</i> , 33, 218-224, 2010	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Falkmer, T., Gregersen, N. P., The prevalence of learner drivers with cerebral palsy who are in	Non-systematic review (narrative review).

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
need of highly specialized driver education, Journal of Traffic Medicine, 28, 23-31, 2000	
Frampton,I., Yude,C., Goodman,R., The prevalence and correlates of specific learning difficulties in a representative sample of children with hemiplegia, British Journal of Educational Psychology, 68, 39-51, 1998	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Gabis, L. V., Shilon-Hadass, A., Misgav-Tzuberi, N., Sofrin, R., Shefer, S., Evaluation of ability and comorbidity in children with cerebral palsy, Annals of Neurology, 68, S100, 2010	Small sample size.
Gabis, L. V., Tsubary, N. M., Leon, O., Ashkenasi, A., Shefer, S., Assessment of abilities and comorbidities in children with cerebral palsy, Journal of Child Neurology, 30, 1640-1645, 2015	Small sample size
Gangil,A., Patwari,A.K., Bajaj,P., Kashyap,R., Anand,V.K., Gastroesophageal reflux disease in children with cerebral palsy, Indian Pediatrics, 38, 766-770, 2001	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Ghasia,F., Brunstrom,J., Gordon,M., Tychsén,L., Frequency and severity of visual sensory and motor deficits in children with cerebral palsy: gross motor function classification scale, Investigative Ophthalmology and Visual Science, 49, 572-580, 2008	Small sample size.
Gibson, C., Smithers-Sheedy, H., Cerebral palsy in Australia, birth years 1993-2006: Findings from the Australian Cerebral Palsy Register, Developmental medicine and child neurology, 56, 43, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Goodman, R, Graham, P, Psychiatric problems in children with hemiplegia: cross sectional epidemiological survey, BMJ, 312, 1065-1069, 1996	Uses 'hemiplegia' instead of cerebral palsy. More recent data on behavioural difficulties have been considered.
Gururaj, A. K., Sztriha, L., Bener, A., Dawodu, A., Eapen, V., Epilepsy in children with cerebral palsy, Seizure, 12, 110-114, 2003	Case-control design Small sample size.
Guzzetta, A., Fazzi, B., Mercuri, E., Bertuccelli, B., Canapicchi, R., Van Hof-van Duin, J., Cioni, G., Visual function in children with hemiplegia in the first years of life, Developmental Medicine and Child Neurology, 43, 321-329, 2001	Small sample size.
Guzzetta, A., Mercuri, E., Cioni, G., Visual disorders in children with brain lesions: 2. Visual impairment associated with cerebral palsy, European Journal of Paediatric Neurology, 5, 115-9, 2001	Non-systematic review.
Hadjipanayis,A., Hadjichristodoulou,C., Youroukos,S., Epilepsy in patients with cerebral palsy, Developmental Medicine and Child Neurology, 39, 659-663, 1997	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Hadzagic-Catibusic, F., Zubcevic, S., Uzicanin, S., Epilepsy in children with hemiparetic cerebral	Small sample size.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
palsy, European Journal of Paediatric Neurology, 15, S40, 2011	
Hattier,M.A., Matson,J.L., Sipes,M., Turygin,N., Communication deficits in infants and toddlers with developmental disabilities, Research in Developmental Disabilities, 32, 2108-2113, 2011	Small sample size.
Hidecker, M. C., Poole, M. L., Taylor, K., Paneth, N., Rosenbaum, P. L., Kent, R., Functional performance profiles of children with cerebral palsy, Developmental medicine and child neurology, 52, 59-60, 2010	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Hidecker, M. J., Hanna, C. B., Rosenbaum, P., Kent, R. D., Paneth, N., Cerebral palsy surveillance of communication and eating, Developmental medicine and child neurology, 51, 79-80, 2009	No analysis of CP comorbidities presented.
Himmelman, K., Lindh, K., Hidecker, M. J., Communication ability in cerebral palsy: a study from the CP register of western Sweden, European Journal of Paediatric Neurology, 17, 568-74, 2013	Small sample size.
Himmelman,K., Beckung,E., Hagberg,G., Uvebrant,P., Gross and fine motor function and accompanying impairments in cerebral palsy, Developmental Medicine and Child Neurology, 48, 417-423, 2006	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Himmelman,K., Hagberg,G., Wiklund,L.M., Eek,M.N., Uvebrant,P., Dyskinetic cerebral palsy: a population-based study of children born between 1991 and 1998, Developmental Medicine and Child Neurology, 49, 246-251, 2007	Small sample size non-UK data.
Honold, M., Baldissera, I., Gedik, A., Albrecht, U., Tschiderer, B., Arnold, C., Rostasy, K., Visual disorders in children with cerebral palsy, Neuropediatrics, 44 (2), 2013	Small sample size, abstract only, country not specified.
Humphreys,P., Whiting,S., Pham,B., Hemiparetic cerebral palsy: clinical pattern and imaging in prediction of outcome, Canadian Journal of Neurological Sciences, 27, 210-219, 2000	Small sample size, non-UK.
Hurley, D., Gaebler-Spira, D., Thornton, L., Msall, M. E., Impact of social factors on medical, communicative, and behavioral comorbidities among children in the chicago cerebral palsy research registry, Annals of Neurology, 68, S99, 2010	Impact of family and social capital. Not answering the review question.
Jacobson,L., Rydberg,A., Eliasson,A.C., Kits,A., Flodmark,O., Visual field function in school-aged children with spastic unilateral cerebral palsy related to different patterns of brain damage, Developmental Medicine and Child Neurology, 52, e184-e187, 2010	Small sample size.
Jekovec, M., Radsel, A., Neubauer, D., Children with epilepsy in Slovenian register for cerebral	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only,

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
palsy, <i>Developmental medicine and child neurology</i> , 56, 41-42, 2014	more recent, larger sample size, subgroups analysis) have been found.
Jekovec-Vrhovsek, M., Neubauer, N., Osredkar, D., The diversity of Slovenian data in Slovenian Register for Cerebral Palsy, <i>Developmental medicine and child neurology</i> , 55, 57, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Jenks, K. M., de Moor, J., van Lieshout, E. C., Arithmetic difficulties in children with cerebral palsy are related to executive function and working memory, <i>Journal of Child Psychology &amp; Psychiatry &amp; Allied Disciplines</i> , 50, 824-33, 2009	Small sample size.
Karumuna, J.M., Mgone, C.S., Cerebral palsy in Dar Es Salaam, <i>Central African Journal of Medicine</i> , 36, 8-10, 1990	Small sample size non UK based.
Katoch, S., Devi, A., Kulkarni, P., Ocular defects in cerebral palsy, <i>Indian Journal of Ophthalmology</i> , 55, 154-156, 2007	Small sample, non-UK.
Kennes, J., Rosenbaum, P., Hanna, S.E., Walter, S., Russell, D., Raina, P., Bartlett, D., Galuppi, B., Health status of school-aged children with cerebral palsy: information from a population-based sample, <i>Developmental Medicine and Child Neurology</i> , 44, 240-247, 2002	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Khan, M. S., Moyeenuzzaman, M., Islam, M. Q., A study on patients with cerebral palsy, <i>Bangladesh Medical Research Council Bulletin</i> , 32, 38-42, 2006	Small sample size non UK based.
Khaw, C. W., Tidemann, A. J., Stern, L. M., Study of hemiplegic cerebral palsy with a review of the literature, <i>Journal of Paediatrics &amp; Child Health</i> , 30, 224-9, 1994	Small sample size.
Kilincaslan, A., Mukaddes, N.M., Pervasive developmental disorders in individuals with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 51, 289-294, 2009	The study reports on mental health problems.
Kirby, R. S., Wingate, M. S., Mulvihill, B. A., Doernberg, N., Van Naarden Braun, K., Yeargin-Allsopp, M., Arneson, C., Durkin, M., Benedict, R., Maenner, M., Prevalence and characteristics of cerebral palsy in four areas of the United States in 2006: An update from the autism and developmental disabilities monitoring network, <i>Developmental medicine and child neurology</i> , 52, 60, 2010	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Kirby, R. S., Wingate, M. S., Van Naarden Braun, K., Doernberg, N. S., Arneson, C. L., Benedict, R. E., Mulvihill, B., Durkin, M. S., Fitzgerald, R. T., Maenner, M. J., Patz, J. A., Yeargin-Allsopp, M., Prevalence and functioning of children with cerebral palsy in four areas of the United States in 2006: a report from the Autism and Developmental Disabilities Monitoring Network, <i>Research in Developmental Disabilities</i> , 32, 462-9, 2011	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Kitchener, N., El-Khayat, H., Aziz, S., Nagy, N., Epilepsy in children with cerebral palsy, <i>Journal of Neurology</i> , 258, S234, 2011	Small sample size, abstract only.
Korkalainen, J., Smithers-Sheedy, H., Karlsson, P., Communication profile of children participating in a cerebral palsy surveillance programme, <i>Developmental medicine and child neurology</i> , 56, 45, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Krageloh-Mann, I., Hagberg, G., Meisner, C., Schelp, B., Haas, G., Eeg-Olofsson, K.E., Selbmann, H.K., Hagberg, B., Michaelis, R., Bilateral spastic cerebral palsy--a comparative study between south-west Germany and western Sweden. I: Clinical patterns and disabilities, <i>Developmental Medicine and Child Neurology</i> , 35, 1037-1047, 1993	Non-UK data, not registry.
Krzan, M. J., Jekovec-Vrhovsek, M., Gosar, D., Neubauer, D., Epilepsy in children with cerebral palsy in Slovenia, <i>European Journal of Paediatric Neurology</i> , 15, S40, 2011	Small sample size.
Lauruschkus, K., Westbom, L., Hallstrom, I., Wagner, P., Nordmark, E., Physical activity in a total population of children and adolescents with cerebral palsy, <i>Research in Developmental Disabilities</i> , 34, 157-167, 2013	Non-UK data, not registry.
Legault, G., Shevell, M. I., Dagenais, L., Quebec Cerebral Palsy Registry, Consortium, Predicting comorbidities with neuroimaging in children with cerebral palsy, <i>Pediatric Neurology</i> , 45, 229-32, 2011	Small sample size, non-UK.
Legault, G., Shevell, M., Dagenais, L., Neuroimaging findings in children with cerebral palsy and the prediction of comorbidities, <i>Annals of Neurology</i> , 68, S93, 2010	The paper reported on neuroimaging findings, not specifically on CP comorbidities.
Lundqvist, L.O., Prevalence and risk markers of behavior problems among adults with intellectual disabilities: a total population study in Orebro County, Sweden, <i>Research in Developmental Disabilities</i> , 34, 1346-1356, 2013	Small sample size.
Luu, T. M., Vohr, B., Twinning on the brain: the effect on neurodevelopmental outcomes, <i>American Journal of Medical Genetics. Part C, Seminars in Medical Genetics</i> , 151C, 142-7, 2009	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Martin, A., Ford, T., Goodman, R., Meltzer, H., Logan, S., Physical illness in looked-after children: a cross-sectional study, <i>Archives of Disease in Childhood</i> , 99, 103-107, 2014	CP specific comorbidities not reported.
McAteer, J., Larison, C., Lariviere, C., Garrison, M.M., Goldin, A.B., Antireflux procedures for gastroesophageal reflux disease in children: influence of patient age on surgical management, <i>JAMA Surgery</i> , 149, 56-62, 2014	Intervention study, non-UK.
McDermott, S., Moran, R., Platt, T., Wood, H., Isaac, T., Dasari, S., Prevalence of epilepsy in	Small sample size. Average age of CP participants below 25 years.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
adults with mental retardation and related disabilities in primary care, American Journal of Mental Retardation, 110, 48-56, 2005	
McIntyre, S., Blair, E., Badawi, N., The characteristics of CP in term infants not admitted to NICU, Developmental medicine and child neurology, 51, 32-33, 2009	Abstract paper, comorbidity prevalences not reported.
McIntyre, S., Blair, E., Smithers Sheedy, H. A., Reid, S., Gibson, C., Van essen, P., De lacy, M., Kippen, R., Novak phd, I., Bunyard, J., Findings from the inaugural Australian Cerebral Palsy Register (ACPR) report, Developmental medicine and child neurology, 52, 3, 2010	Abstract only. Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
McManus, V., Guillem, P., Surman, G., Cans, C., SCPE work, standardization and definition - An overview of the activities of SCPE: A collaboration of European CP Registers, Chinese Journal of Contemporary Pediatrics, 8, 261-265, 2006	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found. Other studies included from SCPE.
Minciu, I., Clinical correlations in cerebral palsy, Medica, 7, 319-24, 2012	Non-UK, not registry.
Molteno, G., Molteno, C.D., Finchilescu, G., Dawes, A.R., Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa, Journal of Intellectual Disability Research, 45, 515-520, 2001	Indirect population non UK data.
Msall, M.E., Avery, R.C., Tremont, M.R., Lima, J.C., Rogers, M.L., Hogan, D.P., Functional disability and school activity limitations in 41,300 school-age children: relationship to medical impairments, Pediatrics, 111, 548-553, 2003	CP specific comorbidities not reported.
Nordmark, E., Hagglund, G., Lagergren, J., Cerebral palsy in southern Sweden II. Gross motor function and disabilities, Acta Paediatrica, 90, 1277-1282, 2001	Small sample size.
Nordmark, E., Hagglund, G., Lagergren, J., Cerebral palsy in southern Sweden I. Prevalence and clinical features, Acta Paediatrica, 90, 1271-1276, 2001	Small sample size.
Novak, I., Hines, M., Goldsmith, S., Barclay, R., Clinical prognostic messages from a systematic review on cerebral palsy, Pediatrics, 130, e1285-e1312, 2012	Narrative review, checked for references.
Oeseburg, B., Dijkstra, G.J., Groothoff, J.W., Reijneveld, S.A., Jansen, D.E., Prevalence of chronic health conditions in children with intellectual disability: a systematic literature review, Intellectual and Developmental Disabilities, 49, 59-85, 2011	Narrative review.
Okumura, A., Hayakawa, F., Kato, T., Kuno, K., Watanabe, K., Epilepsy in patients with spastic cerebral palsy: correlation with MRI findings at 5 years of age, Brain and Development, 21, 540-543, 1999	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Oskoui, M., Majnemer, A., Dagenais, L., Shevell, M. I., The relationship between gross motor function and manual ability in cerebral palsy, <i>Journal of Child Neurology</i> , 28, 1646-52, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK/european data) have been found.
Parkes, J., Caravale, B., Marcelli, M., Franco, F., Colver, A., Parenting stress and children with cerebral palsy: a European cross-sectional survey, <i>Developmental Medicine and Child Neurology</i> , 53, 815-821, 2011	Aim of the study to describe stress in the parents of children with CP.
Parkes, J., Dolk, H., Hill, N., Pattenden, S., Cerebral palsy in Northern Ireland: 1981--93, <i>Paediatric and Perinatal Epidemiology</i> , 15, 278-286, 2001	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK national registry, more recent, larger sample size, subgroups analysis) have been found.
Parkes, J., Hill, N., Platt, M. J., Donnelly, C., Oromotor dysfunction and communication impairments in children with cerebral palsy: a register study, <i>Developmental Medicine and Child Neurology</i> , 52, 1113-1119, 2010	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Pharoah, P. O., Cooke, T., Johnson, M. A., King, R., Mutch, L., Epidemiology of cerebral palsy in England and Scotland, 1984-9, <i>Archives of Disease in Childhood Fetal and Neonatal Edition</i> , 79, F21-F25, 1998	Regional registries. Excluded on the basis that national registry which includes the regional registries reported, have been included.
Pharoah, P. O., Cooke, T., Rosenbloom, L., Cooke, R. W., Effects of birth weight, gestational age, and maternal obstetric history on birth prevalence of cerebral palsy, <i>Archives of Disease in Childhood</i> , 62, 1035-1040, 1987	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Platt, M. J., Sellier, E., Andersen, G. L., Time trends in prevalence of cerebral palsy in Europe, 1980 to 1998, <i>Developmental medicine and child neurology</i> , 53, 57-58, 2011	Abstract only, with no data for prevalence of comorbidities.
Pruitt, D. W., Tsai, T., Common Medical Comorbidities Associated with Cerebral Palsy, <i>Physical Medicine and Rehabilitation Clinics of North America</i> , #20, 453-467, 2009	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Reddihough, D., Reid, S., Lanigan, A., Lioni, T., The victorian cerebral palsy register: Learning more about cerebral palsy, <i>Journal of Paediatrics and Child Health</i> , #2010 in Conjunction with Physicians Week Melbourne, VIC Australia. Conference Start, 12-, 2010	Abstract only, Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Reid, S. M., Meehan, E., McIntyre, S., Goldsmith, S., Badawi, N., Reddihough, D. S., Australian Cerebral Palsy Register, Group, Temporal trends in cerebral palsy by impairment severity and birth gestation, <i>Developmental Medicine &amp; Child Neurology</i> , 58 Suppl 2, 25-35, 2016	Not assessing comorbidities
Reid, S. M., Reddihough, D. S., Carlin, J. B., Impairments associated with cerebral palsy in Victoria, <i>Developmental medicine and child neurology</i> , 52, 40, 2010	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Reid, S., Modak, M., Berkowitz, R., Reddihough, D., A population-based study of hearing loss in	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only,

<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
children with cerebral palsy, Journal of paediatrics and child health, 47, 11-12, 2011	more recent, larger sample size, subgroups analysis) have been found.
Reid,S.M., Modak,M.B., Berkowitz,R.G., Reddihough,D.S., A population-based study and systematic review of hearing loss in children with cerebral palsy, Developmental Medicine and Child Neurology, 53, 1038-1045, 2011	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Shang, Q., Ma, C. Y., Lv, N., Lv, Z. L., Yan, Y. B., Wu, Z. R., Li, J. J., Duan, J. L., Zhu, C. L., Clinical study of cerebral palsy in 408 children with periventricular leukomalacia, Experimental and Therapeutic Medicine, 9, 1336-1344, 2015	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Singhi, P., Jagirdar, S., Khandelwal, N., Malhi, P., Epilepsy in children with cerebral palsy, Journal of Child Neurology, 18, 174-9, 2003	Non-UK, not registry.
Singhi, P., Saini, A. G., Changes in the clinical spectrum of cerebral palsy over two decades in North India-an analysis of 1212 cases, Journal of Tropical Pediatrics, 59, 434-440, 2013	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Srivastava, V. K., Laisram, N., Srivastava, R. K., Cerebral palsy, Indian Pediatrics, 29, 993-6, 1992	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Sullivan,P.B., Lambert,B., Rose,M., Ford-Adams,M., Johnson,A., Griffiths,P., Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study, Developmental Medicine and Child Neurology, 42, 674-680, 2000	Data presented in Odging 2005.
Venkateswaran,S., Shevell,M.I., Comorbidities and clinical determinants of outcome in children with spastic quadriplegic cerebral palsy, Developmental Medicine and Child Neurology, 50, 216-222, 2008	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Veugelers,R., Benninga,M.A., Calis,E.A., Willemsen,S.P., Evenhuis,H., Tibboel,D., Penning,C., Prevalence and clinical presentation of constipation in children with severe generalized cerebral palsy, Developmental Medicine and Child Neurology, 52, e216-e221, 2010	Small sample size, non-UK data, duplicate participants in Odging 2005.
Virella, D., Andrada, M. G., Folha, T., Cadete, A. C., Gouveia, R., Calado, E., Spastic cerebral palsy at age 5 has better functional outcome in extreme preterm birth than in term children, Developmental medicine and child neurology, 54, 59, 2012	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Virella, D., Gouveia, R., Andrada, M. G., Folha, T., Cadete, A., Alvarelhao, J. J., Calado, E., Children with dyskinetic cerebral palsy born in 2001-2004, from the Portuguese national surveillance, Developmental medicine and child neurology, 56, 48, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
von Wendt, L., Rantakallio, P., Saukkonen, A. L., Makinen, H., Epilepsy and associated handicaps in a 1 year birth cohort in northern	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only,



<b>Excluded studies - In infants, children and young people with cerebral palsy, what is the prevalence of important comorbidities with a view to informing early identification?</b>	
Finland, European Journal of Pediatrics, 144, 149-51, 1985	more recent, larger sample size, subgroups analysis) have been found.
von Wendt, L., Rantakallio, P., Saukkonen, A. L., Tuisku, M., Makinen, H., Cerebral palsy and additional handicaps in a 1-year birth cohort from northern Finland--a prospective follow-up study to the age of 14 years, Annals of Clinical Research, 17, 156-61, 1985	Small sample size.
Voorman, J.M., Dallmeijer, A.J., Schuengel, C., Knol, D.L., Lankhorst, G.J., Becher, J.G., Activities and participation of 9- to 13-year-old children with cerebral palsy, Clinical Rehabilitation, 20, 937-948, 2006	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Vos, R. C., Dallmeijer, A. J., Verhoef, M., Van Schie, P. E., Voorman, J. M., Wiegerink, D. J., Geytenbeek, J. J., Roebroek, M. E., Becher, J. G., Perrin Study Group, Developmental trajectories of receptive and expressive communication in children and young adults with cerebral palsy, Developmental Medicine & Child Neurology, 56, 951-9, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Wichers, M. J., Odding, E., Stam, H. J., van Nieuwenhuizen, O., Clinical presentation, associated disorders and aetiological moments in Cerebral Palsy: a Dutch population-based study, Disability & Rehabilitation, 27, 583-9, 2005	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Yilmaz Yalcinkaya, E., Huner, B., Dincer, U., Diracoglu, D., Aydin, R., Icagasioglu, A., Demirhan, E., Yalcin, L., Ones, K., Caglar, N., Yuksel, A., Karamehmetoglu, S. S., Turkdogan, D., Zorer, G., Yapici, Z., Erhan, B., Akyurek, B., Kuran, B., Akbas, H., Paker, N., Ucar, D., Ozturk, K., Ozaras, N., Demographic and clinical findings of cerebral palsy patients in Istanbul: A multicenter study, Turkiye Fiziksel Tip ve Rehabilitasyon Dergisi, 60, 134-138, 2014	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Zafeiriou, D.I., Kontopoulos, E.E., Tsikoulas, I., Characteristics and prognosis of epilepsy in children with cerebral palsy, Journal of Child Neurology, 14, 289-294, 1999	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.
Zhang, J. Y., Oskoui, M., Shevell, M., A population-based study of communication impairment in cerebral palsy, Journal of Child Neurology, 30, 277-84, 2015	Excluded on the basis that for the comorbidities analysed, more relevant studies (UK data only, more recent, larger sample size, subgroups analysis) have been found.

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### K.25<sub>3</sub> Social care needs

<b>Excluded studies - What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?</b>	
Study	Reason for Exclusion

<b>Excluded studies - What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?</b>	
Physical and occupational therapy services received by young children with cerebral palsy, <i>Pediatric Physical Therapy</i> , 24, 97-97 1p, 2012	Abstract, no qualitative evidence.
Service use and family-centred care in young people with severe cerebral palsy: a population-based, cross-sectional clinical survey, <i>Disability &amp; Rehabilitation</i> , 37, 2324-2329 6p, 2015	Quantitative evidence (survey).
Almasri, N. A., Palisano, R. J., Dunst, C. J., Chiarello, L. A., O'Neil, M. E., Polansky, M., Determinants of needs of families of children and youth with cerebral palsy, <i>Children's Health Care</i> , 40, 130-154, 2011	No qualitative evidence. Reserved for health economics.
Andersson, C., Mattsson, E., Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion, <i>Developmental Medicine &amp; Child Neurology</i> , 43, 76-82, 2001	No qualitative data.
Baltor, M. R. R., Dupas, G., Experiences from families of children with cerebral paralysis in context of social vulnerability, <i>Revista Latino-Americana de Enfermagem</i> , 21, 956-963, 2013	Indirect population (reports "cerebral paralysis). Non-UK study.
Bjorquist, E., Nordmark, E., Hallstrom, I., Living in transition - Experiences of health and well-being and the needs of adolescents with cerebral palsy, <i>Child: care, health and development</i> , 41, 258-265, 2015	Non-UK study. Themes available from UK based studies. Reserved for transition evidence review.
Blum, R. W., Resnick, M. D., Nelson, R., St Germaine, A., Family and peer issues among adolescents with spina bifida and cerebral palsy, <i>Pediatrics</i> , 88, 280-285, 1991	No qualitative evidence.
Bottos, M, Feliciangeli, A, Sciuto, L, Gericke, C, Vianello, A, Functional status of adults with cerebral palsy and implications for treatment of children, <i>Developmental medicine and child neurology</i> , 43, 516-28., 2001	No qualitative evidence.
Boucher, N., Dumas, F., Maltais, D. B., Richards, C. L., The influence of selected personal and environmental factors on leisure activities in adults with cerebral palsy, <i>Disability and Rehabilitation</i> , 32, 1328-1338, 2010	Mean age > 25 years.
Bourke, L. F., Jago, J. D., Problems of persons with cerebral palsy in obtaining dental care, <i>Australian Dental Journal</i> , 28, 221-6, 1983	No qualitative evidence.
Burkhard, Agnes M., The Lived Experience of Mothers Caring for an Adolescent or Young Adult with Severe Cerebral Palsy, Ph.D., 257 p-257 p 1p, 2011	Non-UK evidence. Themes available from UK studies.
Buzio, A., Morgan, J., Blount, D., The experiences of adults with cerebral palsy during periods of hospitalisation, <i>Australian Journal of Advanced Nursing</i> , 19, 8-14, 2002	Non-UK study. Themes available from UK based studies. Adult CP population (report ages between 20 - 59).
Cada, E. A., O'Shea, R. K., Identifying barriers to occupational and physical therapy services for children with cerebral palsy, <i>Journal of Pediatric Rehabilitation Medicine</i> , 1, 127-35, 2008	No qualitative evidence.

<b>Excluded studies - What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?</b>	
Carroll, E. M., Health Care Transition Experiences of Young Adults With Cerebral Palsy, <i>Journal of Pediatric Nursing</i> , 30, e157-64, 2015	Qualitative evidence relating to transition evidence review.
Coffman, S. P., Parents' perceptions of needs for themselves and their children in a cerebral palsy clinic, <i>Issues in Comprehensive Pediatric Nursing</i> , 6, 67-77, 1983	No qualitative evidence.
Cooper, L., Balandin, S., Trembath, D., The loneliness experiences of young adults with cerebral palsy who use alternative and augmentative communication, <i>Aac: Augmentative and Alternative Communication</i> , 25, 154-164, 2009	Mean age > 25 years.
Dahl, N, Tervo, R, Symons, Fj, Treatment Acceptability of Healthcare Services for Children with Cerebral Palsy, <i>Journal of Applied Research in Intellectual Disabilities</i> , 20, 475-82., 2007	No qualitative evidence reported.
Dantas, M. S. A., Collet, N., de Moura, F. M., Torquato, I. M. B., Impact of a cerebral palsy diagnosis on the family, <i>Texto &amp; Contexto Enfermagem</i> , 19, 229-237 9p, 2010	Not English.
Darrah, J., Magil-Evans, J., Adkins, R., How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery, <i>Disability and Rehabilitation</i> , 24, 542-549, 2002	Non-UK study. Themes available from UK studies.
Demitto, Marcela de Oliveira, Furlan, Mara Cristina Ribeiro, Mai, Lilian Denise, Marcon, Sonia Silva, Perception of the home caretaker of individuals with cerebral palsy about architectural barriers and accessibility, <i>Ciencia, Cuidado e Saude</i> , 9, 651-659 9p, 2010	Not English.
Dickinson, H. O., Colver, A., Availability of items needed by children with cerebral palsy in the physical, social, and attitudinal domains of the environment, <i>Developmental Medicine &amp; Child Neurology</i> , 48, 28-29 2p, 2006	Abstract only, no qualitative evidence.
DiFazio, R. L., Harris, M., Vessey, J. A., Glader, L., Shanske, S., Opportunities lost and found: experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare, <i>Journal of Pediatric Rehabilitation Medicine</i> , 7, 17-31, 2014	Qualitative evidence relating to transition evidence review.
Glasscock, R., A phenomenological study of the experience of being a mother of a child with cerebral palsy, <i>Pediatric Nursing</i> , 26, 407-10, 2000	Non-UK study. Themes available from UK studies.
Gração, D. C., Santos, M. G. M., Mothers' perception over cerebral palsy on the family's orientation scene, <i>Fisioterapia em Movimento</i> , 21, 107-113 7p, 2008	Not English.
Gwin, L. A., Jr., Fragmentation of health care in the lives of transitional cerebral palsy patients: a	Age > 25 years.

<b>Excluded studies - What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?</b>	
preliminary case analysis of the relationship between functional social support and self-care agency, <i>Self-Care, Dependent-Care &amp; Nursing</i> , 16, 8-13 6p, 2008	
Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., Davidson, B., Parents and children with cerebral palsy discuss communication needs in hospital, <i>Developmental neurorehabilitation</i> , 16, 363-74, 2013	Qualitative evidence relating to communication needs (not social needs).
Kibele, A., Occupational therapy's role in improving the quality of life for persons with cerebral palsy, <i>American Journal of Occupational Therapy</i> , 43, 371-7, 1989	Participant ages greater than 25 years.
Knis-Matthews, L., Falzarano, M., Baum, D., Manganiello, J., Patel, S., Winters, L., Parents' experiences with services and treatment for their children diagnosed with cerebral palsy, <i>Physical &amp; Occupational Therapy in Pediatrics</i> , 31, 263-74, 2011	Qualitative evidence relating to intervention (occupational therapy).
Knott, G. P., Attitudes and needs of parents of cerebral palsied children, <i>Rehabilitation Literature</i> , 40, 190-5, 1979	Narrative study.
Kroll, T., Neri, M. T., Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury, <i>Disability &amp; Rehabilitation</i> , 25, 1106-14, 2003	Mean age > 25 years
Kruijssen-Terpstra, A. J., Ketelaar, M., Boeije, H., Jongmans, M. J., Gorter, J. W., Verheijden, J., Lindeman, E., Verschuren, O., Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review, <i>Child: Care, Health &amp; Development</i> , 40, 787-96, 2014	Literature review on qualitative studies on physical therapy and occupational therapy.
Lariviere-Bastien, D., Bell, E., Majnemer, A., Shevell, M., Racine, E., Perspectives of young adults with cerebral palsy on transitioning from pediatric to adult healthcare systems, <i>Seminars in Pediatric Neurology</i> , 20, 154-9, 2013	Qualitative evidence relating to transition evidence review.
Livingston, M.H., Stewart, D., Rosenbaum, P.L., Russell, D.J., Exploring issues of participation among adolescents with cerebral palsy: what's important to them?, <i>Physical and Occupational Therapy in Pediatrics</i> , 31, 275-287, 2011	No qualitative evidence reported.
Logan, S., In the UK the transition from youth to adulthood of people with cerebral palsy is poorly planned and co-ordinated, <i>Child: Care, Health &amp; Development</i> , 23, 480-2, 1997	Abstract only, no qualitative evidence.
Magill-Evans, J., Wiart, L., Darrah, J., Kratochvil, M., Beginning the transition to adulthood: The experiences of six families with youths with cerebral palsy, <i>Physical and Occupational Therapy in Pediatrics</i> , 25, 19-36, 2005	Qualitative evidence relating to transition evidence review.
Mei, C., Reilly, S., Reddihough, D., Mensah, F., Green, J., Pennington, L., Morgan, A. T., Activities and participation of children with	Non-UK study, themes available from UK studies.

<b>Excluded studies - What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?</b>	
cerebral palsy: parent perspectives, <i>Disability &amp; Rehabilitation</i> , 37, 2164-73, 2015	
Miller, J., Colligan, J., Colver, A., A qualitative study, using focused interviews, of the information needs of families whose children's names are on a cerebral palsy register, <i>Child: Care, Health &amp; Development</i> , 29, 465-71, 2003	Qualitative evidence relating to information in register (not social needs). Reserved for information provision review.
Msall, M. E., Family needs and profiles for children with cerebral palsy: understanding supports in times of scarcity, <i>Child: Care, Health &amp; Development</i> , 38, 807-8, 2012	Quantitative data only (survey).
Ng, S. Y., Dinesh, S. K., Tay, S. K. H., Lee, E. H., Decreased access to health care and social isolation among young adults with cerebral palsy after leaving school, <i>Journal of Orthopaedic Surgery</i> , 11, 80-89, 2003	No qualitative evidence.
Nieuwenhuijsen, C., van der Laar, Y., Donkervoort, M., Nieuwstraten, W., Roebroek, M. E., Stam, H. J., Unmet needs and health care utilization in young adults with cerebral palsy, <i>Disability &amp; Rehabilitation</i> , 30, 1254-62, 2008	No qualitative evidence reported.
Nijhuis, B. J. G., Reinders-Messelink, H. A., de Blecourt, A. C. E., Ties, J. G., Boonstra, A. M., Groothoff, J. W., Nakken, H., Postema, K., Needs, problems and rehabilitation goals of young children with cerebral palsy as formulated in the rehabilitation activities profile for children, <i>Journal of Rehabilitation Medicine</i> , 40, 347-354, 2008	No qualitative evidence.
Novak, I., Parent experience of implementing effective home programs, <i>Physical and Occupational Therapy in Pediatrics</i> , 31, 198-213, 2011	Qualitative evidence relating to intervention (home therapy program).
Piggot, J., Hocking, C., Paterson, J., Parental adjustment to having a child with cerebral palsy and participation in home therapy programs, <i>Physical &amp; Occupational Therapy in Pediatrics</i> , 23, 5-29, 2003	Qualitative evidence relating to intervention (home therapy program).
Polovina-Prolosic, T., Vidovic, V., Polovina, A., Family as a factor in cerebral palsy prevention, <i>Collegium Antropologicum</i> , 32, 137-142, 2008	Population stated as 'cognitive motor impairment'. No qualitative evidence.
Read, S. A., Morton, T. A., Ryan, M. K., Negotiating identity: a qualitative analysis of stigma and support seeking for individuals with cerebral palsy, <i>Disability &amp; Rehabilitation</i> , 37, 1162-9, 2015	Mean age > 25 years.
Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., Bartlett, D., "If I knew then what I know now": parents' reflections on raising a child with cerebral palsy, <i>Physical &amp; Occupational Therapy in Pediatrics</i> , 31, 169-83, 2011	Non-UK study. Themes available from UK based studies.
Shikako-Thomas, K., Lach, L., Majnemer, A., Nimigon, J., Cameron, K., Shevell, M., Quality of life from the perspective of adolescents with cerebral palsy: "I just think I'm a normal kid, I	Non-UK study, same themes available from UK studies.

<b>Excluded studies - What are the specific social care needs of children and young people with cerebral palsy and their family members and carers?</b>	
just happen to have a disability", Quality of Life Research, 18, 825-32, 2009	
Skok, A., Harvey, D., Reddihough, D., Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy, Journal of Intellectual & Developmental Disability, 31, 53-7, 2006	No qualitative evidence.
Stevenson, C. J., Pharoah, P. O., Stevenson, R., Cerebral palsy--the transition from youth to adulthood, Developmental Medicine & Child Neurology, 39, 336-42, 1997	Relates to transition evidence review. Not qualitative.
Stewart, D. A., Lawless, J. J., Shimmell, L. J., Palisano, R. J., Freeman, M., Rosenbaum, P. L., Russell, D. J., Social participation of adolescents with cerebral palsy: trade-offs and choices, Physical & Occupational Therapy in Pediatrics, 32, 167-79, 2012	Non-UK evidence. Themes available from UK studies.
Svedberg, L. E., Englund, E., Malaker, H., Stener-Victorin, E., Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support, European Journal of Paediatric Neurology, 14, 239-46, 2010	No qualitative evidence.
Verhoef, J. A., Bramsen, I., Miedema, H. S., Stam, H. J., Roebroek, M. E., Transition , Lifespan Research Group South West, Netherlands, Development of work participation in young adults with cerebral palsy: a longitudinal study, Journal of Rehabilitation Medicine, 46, 648-55, 2014	Not qualitative.
Verschuren, O., Wiaart, L., Hermans, D., Ketelaar, M., Identification of facilitators and barriers to physical activity in children and adolescents with cerebral palsy, Journal of Pediatrics, 161, 488-494, 2012	Non-UK study. Themes available from UK based studies.

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## K.264 Transition to adult services

<b>Excluded studies - What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Alper, S., Parents' perceptions of transition programs for youth with severe handicaps, Canadian Journal of Rehabilitation, 3, 205-212 8p, 1990	Not a qualitative study
Appleton, P. L., Boll, V., Everett, J. M., Kelly, A. M., Meredith, K. H., Payne, T. G., Beyond child development centres: care coordination for	Not qualitative evidence was presented

<b>Excluded studies - What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?</b>	
children with disabilities, Child: Care, Health & Development, 23, 29-40, 1997	
Bailey, S., O'Connell, B., Pearce, J., The transition from paediatric to adult health care services for young adults with a disability: an ethical perspective, Australian Health Review, 26, 64-9, 2003	Review study
Barron, Diana Andrea, Hassiotis, Angela, Good practice in transition services for young people with learning disabilities: A review, Advances in Mental Health and Intellectual Disabilities, 2, 18-24, 2008	Review study
Bates, K., Bartoszesky, L., Friedland, A., As the child with chronic disease grows up: transitioning adolescents with special health care needs to adult-centered health care, Delaware Medical Journal, 75, 217-20, 2003	Not a qualitative study
Beresford, B., On the road to nowhere? Young disabled people and transition, Child: Care, Health and Development, 30, 581-587, 2004	Not a qualitative study
Bhaumik, Sabyasachi, Watson, Joanna, Barrett, Mary, Raju, Bala, Burton, Tracey, Forte, Jane, Transition for teenagers with intellectual disability: Carers' perspectives, Journal of Policy and Practice in Intellectual Disabilities, 8, 53-61, 2011	This study is part of a large audit and does not present qualitative evidence
Binks, J. A., Barden, W. S., Burke, T. A., Young, N. L., What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida, Archives of Physical Medicine & Rehabilitation, 88, 1064-73, 2007	In this systematic review only 1 qualitative study was included (Young, 2007), which is already part of this review.
Bjorquist, E., Nordmark, E., Hallstrom, I., Living in transition - Experiences of health and well-being and the needs of adolescents with cerebral palsy, Child: care, health and development, 41, 258-265, 2015	Reports on Parents' feelings but not very specific to social care or health care services.
Burdo-Hartman, W. A., Patel, D. R., Medical home and transition planning for children and youth with special health care needs, Pediatric Clinics of North America, 55, 1287-97, vii-viii, 2008	Review study
Campbell, Fiona, O'Neill, Philip M., While, Alison, McDonagh, Janet, Interventions to improve transition of care for adolescents from paediatric services to adult services, Cochrane Database of Systematic Reviews, -, 2012	This is a protocol and no qualitative studies were considered
Fiorentino, L., Phillips, D., Walker, A., Hall, D., Leaving paediatrics: the experience of service transition for young disabled people and their family carers, Health & Social Care in the Community, 6, 260-270 11p, 1998	Not CP specific

<b>Excluded studies - What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?</b>	
Freeman, M., Stewart, D., Gorter, J. W., Ongoing conversations in transitional care: Clinical lessons learned from the development and evaluation of the Youth KIT, <i>Developmental Medicine and Child Neurology</i> , 55, 36, 2013	This structured abstract evaluates the use of a specific program aimed to assist children and young people with the process of transition
Hopper, Amy, Dokken, Deborah, Ahmann, Elizabeth, <i>Family Matters. Transitioning from Pediatric to Adult Health Care: The Experience of Patients And Families</i> , <i>Pediatric Nursing</i> , 40, 249-252 4p, 2014	Not a qualitative study
Householder, D, Jansen, D, Partnerships, families, employers, transition, disabled: creating the best transition outcomes for moderate and multiply disabled individuals, <i>Journal of Vocational Rehabilitation</i> , 13, 51-4., 1999	Narrative paper, no qualitative research methods applied
Kingsnorth, S., Proulx, M., Tsybina, I., Hamdani, Y., Lindsay, S., Lacombeduncan, A., Maxwell, J. M., Colantonio, A., Macarthur, C., Bayley, M., Integrating a new model of transition care into real-life systems: Issues in implementing the LIFEspan Model, <i>Developmental Medicine and Child Neurology</i> , 54, 20, 2012	Structured abstract only. Participants were health professionals and managers rather than young people and carers
Kraus de Camargo, O., Systems of care: transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health, <i>Child: Care, Health &amp; Development</i> , 37, 792-9, 2011	Descriptive study
Krebs, P. L., Block, M. E., Transition of students with disabilities into community recreation: The role of the adapted physical educator, <i>Adapted Physical Activity Quarterly</i> , 9, 305-315, 1992	Not a health care setting
Kripke, C. C., Primary Care for Adolescents with Developmental Disabilities, <i>Primary Care - Clinics in Office Practice</i> , 41, 507-518, 2014	Not a qualitative study
Laragy, C, Self-determination within Australian school transition programmes for students with a disability, <i>Disability and Society</i> , 19, 519-30., 2004	Not a qualitative study
Lin, S. C., Lee, M. L., Adirim, T. A., Transition outcomes for young adults with disabilities, <i>Journal of Pediatric Rehabilitation Medicine</i> , 8, 23-30, 2015	Population is not specific to CP and quantitative methods were used
Magill-Evans, J., Wiart, L., Darrah, J., Kratochvil, M., Beginning the transition to adulthood: The experiences of six families with youths with cerebral palsy, <i>Physical and Occupational Therapy in Pediatrics</i> , 25, 19-36, 2005	The paper reports specifically on the transition to adulthood as a phase of life, rather than on transition to adult-centered services.
Marn, L. M., Koch, L. C., The major tasks of adolescence: Implications for transition planning with youths with cerebral palsy, <i>Work</i> , 13, 51-58, 1999	Literature review and no qualitative evidence was presented
Neece, C. L., Kraemer, B. R., Blacher, J., Transition satisfaction and family well being among parents of young adults with severe	Not a qualitative study



<b>Excluded studies - What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?</b>	
intellectual disability, <i>Intellectual &amp; Developmental Disabilities</i> , 47, 31-43, 2009	
O'Connor, L., Steinbeck, K., Tracking the transition process when young people with chronic illness or disability leave pediatric care, <i>Journal of Adolescent Health</i> , 1), S35, 2009	Structured abstract only. Study design not considered in the protocol (prospective, descriptive study)
Oskoui, M., Growing up with cerebral palsy: contemporary challenges of healthcare transition, <i>Canadian Journal of Neurological Sciences</i> , 39, 23-5, 2012	Not a qualitative study
Rimmer, J. H., Health promotion for individuals with disabilities: The need for a transitional model in service delivery, <i>Disease Management and Health Outcomes</i> , 10, 337-343, 2002	Not a qualitative study
Roebroek, M. E., Van Den Bergemons, H. J. G., Nieuwenhuijsen, C., Hilberink, S. R., Van Der Slot, W. M. A., Van Meeteren, J., Stam, H. J., Innovating transition and lifespan care for people with cerebral palsy, <i>Developmental medicine and child neurology</i> , 52, 74, 2010	Structured abstract only. Not a qualitative study
Rosenbaum, P., Stewart, D., Perspectives on Transitions: Rethinking Services for Children and Youth With Developmental Disabilities, <i>Archives of Physical Medicine and Rehabilitation</i> , 88, 1080-1082, 2007	Not a qualitative study
Rous, Beth S., Hallam, Rena A., Transition services for young children with disabilities: Research and future directions, <i>Topics in Early Childhood Special Education</i> , 31, 232-240, 2012	Not a qualitative study
Rous, Beth, Hallam, Rena, Harbin, Gloria, McCormick, Katherine, Jung, Lee Ann, The transition process for young children with disabilities: A conceptual framework, <i>Infants &amp; Young Children</i> , 20, 135-148, 2007	Review study
Stevenson, C. J., Pharoah, P. O., Stevenson, R., Cerebral palsy--the transition from youth to adulthood, <i>Developmental Medicine &amp; Child Neurology</i> , 39, 336-42, 1997	Not a qualitative study
Stewart, D, Evidence to Support a Positive Transition into Adulthood for Youth with Disabilities, <i>Physical and Occupational Therapy in Pediatrics</i> , 26, 1-4., 2006	Not a qualitative study
Stewart, D., Transition to adult services for young people with disabilities: current evidence to guide future research, <i>Developmental Medicine &amp; Child Neurology</i> , 51 Suppl 4, 169-73, 2009	Not a qualitative study
Stewart, D. A., Law, M. C., Rosenbaum, P., Willms, D. G., A qualitative study of the transition to adulthood for youth with physical disabilities, <i>Physical &amp; Occupational Therapy in Pediatrics</i> , 21, 3-21, 2001	Not a qualitative study
Stewart, D., Stavness, C., King, G., Antle, B., Law, M., A critical appraisal of literature reviews	Not a qualitative study

<b>Excluded studies - What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?</b>	
about the transition to adulthood for youth with disabilities, Physical & Occupational Therapy in Pediatrics, 26, 5-24, 2006	
Stineman, Rm, Morningstar, Me, Bishop, B, Turnbull, Hr, Role of families in transition planning for young adults with disabilities: towards a method of person-centred planning, Journal of Vocational Rehabilitation, 3, 52-61., 1993	Narrative paper, no qualitative research methods were applied
Tarleton, B, Ward, L, Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition, British Journal of Learning Disabilities, 33, 70-6., 2005	No CP population included
Unwin, Gemma, LeMesurier, Nick, Bathia, Niyati, Deb, Shoumitro, Transition for adolescents and young adults with learning disabilities and mental health problems/challenging behaviours: The parent carers' views, Advances in Mental Health and Intellectual Disabilities, 2, 22-28, 2008	Population are children and young people with learning disabilities and mental health problems (not considered in the protocol)
Van Lierde, A., Menni, F., Bedeschi, M. F., Natacci, F., Guez, S., Vizziello, P., Costantino, M. A., Lalatta, F., Esposito, S., Healthcare transition in patients with rare genetic disorders with and without developmental disability: neurofibromatosis 1 and Williams-Beuren syndrome, American Journal of Medical Genetics. Part A, 161A, 1666-74, 2013	Review study
Westwood, A., Langerak, N., Fieggen, G., Transition from child- to adult-orientated care for children with long-term health conditions: a process, not an event, South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde, 104, 310-3, 2014	Review study
Young, N. L., The transition to adulthood for children with cerebral palsy: what do we know about their health care needs?, Journal of Pediatric Orthopedics, 27, 476-9, 2007	Review study
Young, N., McCormick, A., Mills, W., Barden, W., Boydell, K., Law, M., Wedge, J., Fehlings, D., Mukherjee, S., Rumney, P., Williams, J. I., The transition study: a look at youth and adults with cerebral palsy, spina bifida and acquired brain injury, Physical & Occupational Therapy in Pediatrics, 26, 25-45, 2006	Article presents information related to the study sample and subsamples, broken down by diagnostic age groups; not qualitative evidence is presented
Ytterhus, Borgunn, Wendelborg, Christian, Lundeby, Hege, Managing turning points and transitions in childhood and parenthood - insights from families with disabled children in Norway, Disability & Society, 23, 625-636, 2008	Only included children up to 12 years old (the age range considered in the protocol is from 12 to 25 y/o)

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## K.27<sup>1</sup> Health Economic global search

Excluded studies from health economics (population search)	
Study	Reason for Exclusion
Colver, A. F., Merrick, H., Deverill, M., Le Couteur, A., Parr, J., Pearce, M. S., Rapley, T., Vale, L., Watson, R., McConachie, H., Transition Collaborative, Group, Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services, BMC Public Health, 13, 675, 2013	No results reported

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