National Institute for Health and Care Excellence

Final

Cerebral palsy in adults

[B3] Assessing and monitoring complications and comorbidities: feeding and nutritional problems

NICE guideline NG119 Evidence reviews January 2019

Final

These evidence reviews were developed by the National Guideline Alliance hosted by the Royal College of Obstetricians and Gynaecologists



FINAL

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ISBN: 978-1-4731-3223-8

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Monitoring feeding and nutritional problems

Review question

B3 What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Introduction

Adults with cerebral palsy may experience problems with eating or feeding due to a number of co-morbidities. Difficulties with weakness, hand-eye co-ordination, muscle tone, gastro-oesophageal reflux, medications, positioning, carer training and behaviour can all lead to nutritional concerns and there may even be a need for enteral feeding tubes. This review question looks at the evidence available on effective ways of assessment and monitoring of feeding and nutrition.

PICO/PIRO table

Please see Table 1 for a summary of the Population, Intervention / Index test, Comparison / Reference standard and Outcome (PICO/PIRO) characteristics of this review.

Adults aged 25 and over with cerebral palsy and with suspected feeding and nutritional problems (at least 50% of study participants). For diagnostic questions include intake/sample/setting of people to be tested.
Monitoring protocol for feeding and nutritional problems involving any of the following: • Dietary assessment, including gastrointestinal issues such as: • dysphagia • fore gut dysmotility • hind gut dysmotility • Clinical assessment • Anthropometric assessment • BMI • Fat measure • skinfold measurement • Screening tools • MUST
Any other monitoring protocol
Critical • Function • HR-QoL • Chest infection Important • Patient satisfaction • Mortality • Weight • Skin integrity

Table 1: Summary of the protocol (PICO/PIRO table)

 Feeding time TOMS – swallowing outcome
In the absence of test and treat studies ¹ :
Diagnostic accuracy:
∘ Sensitivity
◦ Specificity
 Positive/Negative likelihood ratios

BMI: Body Mass Index; HR-QoI: Health-Related Quality of Life; MUST: Malnutrition Universal Screening Tool; TOMS: Therapy Outcome Measures-Swallowing.

1 The review question was framed as an intervention review but in the absence of test and treat studies diagnostic accuracy studies would be included, with the assumption that accurate identification of feeding problems is likely to improve outcomes.

For full details see review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in <u>Developing NICE guidelines: the manual 2014</u>. Methods specific to this review question are described in the review protocol in appendix A and for a full description of the methods see supplementary document C.

As GRADE is designed only for RCTs and observational studies, a modified version of this tool was used in order to appraise the confidence in the included diagnostic test accuracy evidence. The QUADAS-2 checklist risk of bias and applicability items were used for evaluating the risk of bias and indirectness, respectively, of the studies. The quality assessment of inconsistency and imprecision were adapted to take into account the methodological features of diagnostic studies.

Declaration of interests were recorded according to NICE's 2014 conflicts of interest policy from May 2016 until April 2018. From April 2018 onwards they were recorded according to NICE's 2018 <u>conflicts of interest policy</u>. Those interests declared until April 2018 were reclassified according to NICE's 2018 conflicts of interest policy (see Interests Register).

Clinical evidence

Included studies

One prospective observational study was included (Benigni 2011; number of participants in study, N=365) which evaluated a malnutrition screening tool in adults with CP (MST-CP). This tool was based on a score obtained from measuring four variables: body weight < 40 kg; uncomfortable or impossible sitting position; partial or total help needed for eating; and suspicion of gastro-oesophageal reflux. The highest score possible was 21 points. A score higher than 10 points indicated high risk (severe malnutrition). A score higher than 0 and less than 10 points indicated mild risk (moderate malnutrition). A score equal to 0 indicated low risk (no malnutrition). The overall accuracy of this screening tool was evaluated by comparing its diagnostic accuracy with a composite reference standard based on three variables: weight loss from usual body weight; BMI; and albuminuria.

The clinical studies included in this evidence review are summarised in Table 2 and evidence from these are summarised in the clinical evidence profile below (Table 3).

See also the search strategy in appendix B, study selection flow chart in appendix C, clinical evidence tables in appendix D and forest plots in appendix E.

No studies were included that evaluated dietary, clinical or anthropometric assessments as tools to screen for risk of malnutrition in adults with cerebral palsy.

Excluded studies

Studies excluded from this systematic review, with reasons for their exclusion, are provided in appendix K.

Summary of clinical studies included in the evidence review

Table 2 provides a brief summary of the included studies.

Table 2: Summary of included studies

Study	Design	Participants	Index test	Reference standard	Outcomes
Benigni 2011	Prospective observational study	N=365, mean age 36 years. France	 Malnutrition screening tool for adults with CP (MST-CP) 	Composite based on: • weight loss from usual body weight • BMI • albuminuria	Weight (malnutrition)

BMI: Body Mass Index; CP: Cerebral Palsy; MST-CP: Malnutrition Screening Tool for Cerebral Palsy; N: number of participants in study

See appendix D for the full evidence tables.

Quality assessment of clinical outcomes included in the evidence review

The clinical evidence profile for this comparison is presented in Table 3.

Table 3: Summary of clinical evidence of MST-CP (at thresholds of 0 and 10) to differentiate between high risk and low risk of malnutrition in adults with cerebral palsy.

Study	N	Risk of bias ¹	Screeni ng score²	Inconsis tency	Indirect ness ³	Imprec ision ⁴	Sensiti vity (95% Cl)	Specifi city (95% Cl)	Positi ve likeli hood ratio ⁵	Negati ve likelih ood ratio ⁵	Qual ity
1 observati onal study	365	Seriou s ⁶	score=0	Not applicabl e	Not serious	Seriou s ⁷	0.78 (0.72 - 0.84)	0.51 (0.43– 0.60)	1.60	0.42	Low
1 observati onal study	365	Seriou s ⁶	score>1 0 ²	Not applicabl e	Not serious	Seriou s	0.55 (0.44- 0.66)	0.87 (0.82- 0.90)	4.24	0.51	Mod erate

CI: confidence interval; CP: cerebral Palsy; MST-CP: malnutrition screening tool for cerebral palsy; N: number of participants in study

1 Risk of bias evaluated using risk of bias items of QUADAS-2 checklist.

2 Index screening test – model based on the following variables: 1) body weight < 40 kg (10 points); 2) uncomfortable or impossible sitting position (4 points); 3) partial or total help needed for eating (4 points) and 4) suspicion of gastro-oesophageal reflux (3 points). The highest score possible was 21 points: A score higher than 10 points indicated high risk (severe malnutrition). A score higher than 0 and less than 10 points indicated mild risk (moderate malnutrition). A score equal to 0 indicated low risk (no malnutrition). 3 Indirectness was evaluated using the applicability items of QUADAS-2.

4 Judgement of imprecision was based on consideration of the 95% CIs of test sensitivity as this was considered to be the primary measure of interest as a false negative - missing malnourished patients, whilst a false positive - indicating risks of malnutrition when there is none. Studies were considered to be of high sensitivity (and not imprecise) if the 95% CI was above 0.9 or of low sensitivity if it was below 0.75. Studies were assessed as subject to serious imprecision if the 95% CI crossed either 0.75 or 0.9, or subject to very serious imprecision if it crossed both 0.75 and 0.9.

5 Positive and negative likelihood ratios calculated from sensitivity and specificity estimates.

6 Unclear risk of review bias (lack of blinding in the interpretation both of the index test and reference standard – no details are given in the text) and patient selection; with flow and timing of patient unclear 7 95% CI for sensitivity crosses 0.75.

See appendix F for the full GRADE table.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no studies were identified which were applicable to this review question.

Excluded studies

No studies were identified which were applicable to this review question.

Summary of studies included in the economic evidence review

No economic evaluations were included in this review.

Economic model

This topic was not prioritised for health economic modelling because the committee assumed that better recognition would lead to earlier identification of possible nutritional deficits and more timely treatment. This would therefore be cost-neutral or cost saving.

Resource impact

No unit costs were presented to the committee as these were not prioritised for decision making purposes.

Evidence statements

Screening tools - Malnutrition Screening Tool for adults with cerebral palsy (MST-CP)

Critical outcomes

Function

No evidence was found for this outcome.

Health related quality of life

No evidence was found for this outcome.

Chest infection

No evidence was found for this outcome.

Important outcomes

Patient satisfaction

No evidence was found for this outcome.

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Mortality

No evidence was found for this outcome.

Weight

No evidence was found for this outcome.

Skin integrity

No evidence was found for this outcome.

Feeding time

No evidence was found for this outcome.

Diagnostic accuracy for malnutrition

- Low quality evidence from 1 observational study (N=356) found that the Malnutrition Screening Tool for adults with cerebral palsy (MST-CP) with a score of 0 points had moderate sensitivity (78%) and low specificity (51%) for detecting risk of malnutrition in adults with cerebral palsy. The positive and negative likelihood ratios of 1.60 and 0.42 respectively suggest this test is not useful for ruling malnutrition in or out.
- Moderate quality evidence from 1 observational study (N=356) found that MST-CP with a score higher than 10 points had a low sensitivity (55%) and a moderate specificity (87%) for detecting risk of malnutrition in adults with cerebral palsy. The positive and negative likelihood ratios of 4.24 and 0.51 respectively suggess suggest this test is not useful for ruling malnutrition in or out.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

Function, health-related quality of life, and chest infection were considered to be the critical outcomes because problems with feeding and swallowing can have serious adverse effects on health and wellbeing. Patient satisfaction, mortality, weight, skin integrity, feeding time and TOMS (Therapy Outcome Measures-Swallowing) were considered to be the important outcomes for this question.

Nutritional status was reported in the included study, but there was no evidence for the critical outcomes: function, health-related quality of life, and chest infection or the important outcomes: patient satisfaction, mortality, weight, skin integrity, feeding time and TOMS. The included studies reported how accurate the tools were in identifying nutritional status. In the absence of any other outcomes the committee considered statistical accuracy measures (such as sensitivity and specificity, as well as positive and negative likelihood ratios) because it was assumed that a more accurate assessment would lead to better management of the nutritional problem and therefore better patient level outcome.

The quality of the evidence

The quality of the evidence was assessed using a GRADE approach modified for diagnostic test accuracy reviews (see supplementary document C for methods). The quality of the diagnostic accuracy outcomes ranged from moderate to low. The quality was downgraded due to risk of bias and imprecision in the diagnostic accuracy estimates.

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Although there was some evidence for one nutritional screening tool, due to the absence of evidence about other dietary, clinical or anthropometric assessments the committee based their recommendations mainly on their expertise and experience.

Benefits and harms

The committee noted that healthy eating and healthy weight (and body mass index) is as important for adults with cerebral palsy as it is in the general population and that checking weight is therefore important. Based on their experience the committee agreed that there are some factors related to feeding behaviour and ability to feed themselves that may indicate that the adult with cerebral palsy is likely to lose or gain weight. Recognising these early to target treatment is important to improve outcomes and therefore a discussion should be had with the adult with cerebral palsy and their family to see whether their feeding behaviour or ability has changed.

Based on their experience and expertise the committee considered that undernutrition and obesity in adults with cerebral palsy can be influenced by a variety of elements. These elements (for example medications, carers' support, and feeding abilities and problems) can be either a cause of an improvement in nutritional status and appetite, or a consequence of deterioration in appetite (for example through side effect of medications). They therefore made recommendations to be aware of these factors in prescribing medications, when addressing undernutrition and obesity in adults with cerebral palsy. A discussion should take place at every review about such factors to be able to address them early and prevent undernutrition or excessive weight gain.

Based on their knowledge the committee discussed that adults with dyskinetic cerebral palsy or severe spastic cerebral palsy may have an increased metabolic rate and need to increase their calorie intake to account for this. The committee recognised that reduction in dyskinesia or spasticity by treatment such as intrathecal baclofen may result in weight gain. They agreed that this is under-recognised in practice and that greater awareness of this could help people to achieve the appropriate calorie intake according to their individual needs.

Due to the serious consequences that malnutrition can have the committee agreed that formal and informal carers should receive training on the recognition of malnutrition and feeding difficulties to prevent ill health, in line with NICE's guideline on <u>nutrition support for adults</u>.

The committee agreed that feeding difficulties and malnutrition have severe and potentially life threatening consequences and therefore decided that it would be necessary to refer adults with cerebral palsy to a specialist appropriate to their individual needs. Due to this risks associated with these difficulties and malnutrition the committee decided, based on consensus to make this a strong recommendation.

On consideration of the limited evidence the committee agreed that there are many individual factors that could relate to feeding and nutritional problems and that the assessment therefore needs to be tailored to each adult with cerebral palsy. This means that there is not one tool that should be given to adults with cerebral palsy that is better than all other ones. The committee therefore did not prioritise this for further research because assessment would have to be individualised according to each adult's needs and circumstances.

Cost effectiveness and resource use

The committee noted that no relevant published economic evaluations had been identified for this topic.

The committee considered that the recommendations made were unlikely to result in a substantial increase in resource use. Any additional costs would be small, given the minimal

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change in practice, and any increase would be offset by a reduction in the costs associated with dealing with malnutrition.

Other factors the committee took into account

The committee also noted that the NICE guideline on <u>obesity: identification, assessment and</u> <u>management</u> includes generic information on the identification and assessment of obesity in all adults which can be generalised to people with cerebral palsy. They therefore cross-referenced to this.

The committee acknowledged that the identification of malnutrition in adults without cerebral palsy was covered in detail in the NICE guideline CG32 on <u>nutrition support for adults</u>. They decided that the general principles of recognition of malnutrition including the use of tools (for example the Malnutrition Universal Screening Tool), would be generalisable to adults with cerebral palsy. The committee therefore cross-referred to this guideline.

References

Benigni 2011

Benigni,I., Devos,P., Rofidal,T., Seguy,D., The CP-MST, a malnutrition screening tool for institutionalized adult cerebral palsy patients, Clinical Nutrition, 30, 769-773, 2011

Appendices

Appendix A – Review protocols

Review protocol for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Field (based on <u>PRISMA-P</u>	Content
Review question	What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?
Type of review question	Test and treat and diagnostic accuracy review.
Objective of the review	This review question looks at the evidence available on effective ways of assessment and monitoring of feeding and nutrition.
Eligibility criteria – population/disease/condition/issue/domain	Adults aged 25 and over with cerebral palsy with suspected feeding and nutritional problems (at least 50% of study participants). For diagnostic questions include intake/sample/setting of people to be tested.
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	 Monitoring protocol for feeding and nutritional problems involving any of the following: Dietary assessment, including gastrointestinal issues such as: dysphagia fore gut dysmotility hind gut dysmotility Clinical assessment Anthropometric assessment BMI Fat measure skinfold measurement Screening tools MUST

Table 4:	Review protocol	for monitoring feedir	ig and nutritional problems
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Field (based on <u>PRISMA-P</u>	Content
Eligibility criteria – comparator(s)/control or reference (gold) standard	Any other monitoring protocol
Outcomes and prioritisation	Critical outcomes
	Function
	 for example as measured using the International Classification of Functioning, Disability and Health
	• HR-QoL
	Chest infection
	Important outcomes
	Patient satisfaction
	Mortality
	Weight
	Skin integrity
	Feeding time
	 TOMS – swallowing outcome
	In the absence of test & treat studies:
	Diagnostic accuracy:
	 Sensitivity
	• Specificity
	 Positive/Negative likelihood ratios
	Minimally important differences
	 Any statistically significant improvement in mortality will be considered clinically important
	Other dichotomous outcomes will use default MIDs [RR thresholds of 0.80 and 1.2]
	Other continuous outcomes will use default MIDs [0.5 times the SD of the control group]
	The thresholds for clinical usefulness of tests:
	Sensitivity and specificity (sensitivity will be prioritised):

Field (based on <u>PRISMA-P</u>	Content
	• High >90%
	Moderate 75-90%
	• Low <75%
	Positive likelihood ratio:
	Very useful test >10
	Moderately useful test 5-10
	Not a useful test <5
	Negative likelihood ratio:
	Very useful test <0.1
	Moderately useful test 0.1 to 0.2
	Not a useful test>0.2
Eligibility criteria – study design	This review will look for so-called "test and treat" studies – because an effective monitoring protocol will lead to treatment or management changes that should improve clinical outcomes
	Only published full text papers -
	 systematic reviews of randomised trials
	randomised trials
	 cross sectional studies (in the absence of RCTs)
	 cohort studies (in the absence of RCTs)
	In the absence of test and treat studies, cross sectional diagnostic accuracy studies may be included, with the assumption that accurate identification of problems is likely to improve outcomes.
Other inclusion exclusion criteria	Date restriction: studies published in 1990 or later (due to developments in treatments since then).
Proposed sensitivity/sub-group analysis, or meta-	Groups that will be reviewed and analysed separately:
regression	Ambulant versus non-ambulant
	Dystonic and dyskinetic
	• LD
	In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis:
	 Population subgroups (for example. age groups, presentation, severity):
	$_{\circ}$ Severity of feeding, nutrition, swallow or aspiration problems

Field (based on PRISMA-P	Content
	 Assessment subgroups Type of assessment Treatment or management change following assessment Important confounders: severity of feeding, nutrition, swallow or aspiration problems, treatment given for such problems.
Selection process – duplicate screening/selection/analysis	A random sample of the references identified in the search will be sifted by a second reviewer. This sample size will be 10% of the total, or 100 studies if the search identifies fewer than 1000 studies. All disagreements in study inclusion will be discussed and resolved between the two reviewers. The senior systematic reviewer or guideline lead will be involved if discrepancies cannot be resolved between the two reviewers.
Data management (software)	STAR was used to sift through the references identified by the search, and for data extraction. Diagnostic analysis was performed using Cochrane Review Manager (RevMan5).
Information sources – databases and dates	Database(s): Embase 1974 to Present, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present. Cochrane Library and Web of Science. Last searched 22/03/2018.
Identify if an update	Not an update
Author contacts	For details please see the guideline in development web site.
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual 2014
Search strategy – for one database	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of <u>Developing NICE guidelines: the manual 2014</u> The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group <u>http://www.gradeworkinggroup.org/</u>

Field (based on <u>PRISMA-P</u>	Content
Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual 2014
Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see section 6.4 of <u>Developing NICE guidelines: the manual 2014</u>
Meta-bias assessment – publication bias, selective reporting bias	For details please see the methods in supplementary document C.
Confidence in cumulative evidence	For details please see section 6.2 of Developing NICE guidelines: the manual 2014
Rationale/context – what is known	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual 2014
Describe contributions of authors and guarantor	For details please see the introduction to the evidence review.
Sources of funding/support	A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Alliance (NGA) and chaired by Dr Paul Eunson in line with section 3 of <u>Developing</u> <u>NICE guidelines: the manual 2014</u> .
	Staff from the NGA undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods in supplementary document C
Name of sponsor	The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
Roles of sponsor	The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
PROSPERO registration number	NICE funds NGA to develop guidelines for those working in the NHS, public health and social care in England

BMI: body mass index; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HR-QoI: Health-Related Quality of Life; LD: learning disability; MID: minimally important difference; MUST: Malnutrition Universal Screening Tool; NGA: National Guideline Alliance; NICE: National Institute for Health and Care Excellence; RCT: randomised controlled trial; TOMS: Therapy Outcome Measures-Swallowing

Appendix B – Literature search strategies

Literature search strategies for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Database: Medline & Embase (Multifile)

Database(s): Embase 1974 to 2018 March 22, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present.

Table 5: Last search on 22 March 2018

#	Searches
1	exp Cerebral Palsy/ use prmz
2	exp cerebral palsy/ use oemezd
3	((cerebral or brain or central) adj2 (pal* or paralys#s or pares#s)).tw.
4	cerebral palsy.ti,ab.
5	little? disease.tw.
6	((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj5 spastic*).tw.
7	((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj3 ataxi*).tw.
8	or/1-6
9	limit 8 to english language
10	limit 9 to (adult <18 to 64 years> or aged <65+ years>) use oemezd [Limit not valid in Ovid MEDLINE(R),Ovid MEDLINE(R) In-Process; records were retained]
11	limit 9 to "all adult (19 plus years)" [Limit not valid in Embase; records were retained]
12	11 use prmz
13	or/10,12
14	exp Nutrition Policy/ or exp Nutrition Disorders/ or exp Nutrition Assessment/ or exp Nutrition Therapy/ or exp "Feeding and Eating Disorders"/ or exp Feeding Behavior/ or exp Diet/ or exp Deglutition Disorders/ or exp Gastrointestinal Motility/ or exp Esophageal Motility Disorders/ or exp Dyspepsia/ or exp Constipation/ or exp Gastroesophageal Reflux/ or exp Obesity/ or exp Anthropometry/ or exp Overweight/ or exp Body Composition/ or exp Body Weight/ or exp Nutritional Status/ or exp Body Mass Index/ or exp Skinfold Thickness/ or exp Deglutition/ or exp Respiratory Aspiration/ or exp Drinking/ or exp Eating/ or exp Mastication/ or exp Diet, Reducing/ or exp Weight Loss/ or exp Calorimetry, Indirect/ or exp Mainutrition/ or exp Dietary Supplements/ or exp Nutritional Support/ or exp Food, Fortified/ or exp Protein- Energy Malnutrition/ or exp Metabolism/ or exp Basal Metabolism/ or exp Digestion/ or exp Enteral Nutrition/ or exp "Cooking and Eating Utensils"/ or exp Equipment Design/ or exp Meals/ or exp "Task Performance and Analysis"/ or exp Biomechanical Phenomena/ or exp Human Engineering/ or exp "Activities of Daily Living"/ or exp Self Care/ or exp airway obstruction/
15	exp Disability Evaluation/ or exp Disease Progression/ or exp "Severity of Illness Index"/
16	14 or 15 use prmz
17	exp nutritional health/ or exp diet/ or exp nutrition policy/ or exp food/ or exp nutrition/ or exp obesity/ or exp nutritional disorder/ or exp nutritional assessment/ or exp diet therapy/ or exp eating disorder/ or exp feeding behavior/ or exp dysphagia/ or exp swallowing/ or exp

#	Searches
	gastrointestinal motility/ or exp esophagus function disorder/ or exp dyspepsia/ or exp constipation/ or exp gastroesophageal reflux/ or exp anthropometry/ or exp body composition/ or exp body weight/ or exp nutritional status/ or exp body mass/ or exp skinfold thickness/ or exp skinfold/ or exp acid aspiration/ or exp drinking/ or exp eating/ or exp eating habit/ or exp mastication/ or exp low calory diet/ or exp weight reduction/ or exp indirect calorimetry/ or exp waist circumference/ or exp body fat/ or exp malnutrition/ or exp dietary supplement/ or exp nutritional support/ or exp metabolism/ or exp fordified food/ or exp basal metabolic rate/ or exp digestion/ or exp enteric feeding/ or exp kitchen/ or exp equipment design/ or exp bioengineering/ or exp ergonomics/ or exp motion analysis system/ or exp task performance/ or exp daily life activity/ or exp self help/ or exp feeding apparatus/ or exp airway obstruction/
18	exp disability/ or exp disease course/ or exp "severity of illness index"/
19	17 or 18 use oemezd
20	("Eating and Drinking Ability Classification System" or EDACS or "Fatigue Impact and Severity Self-Assessment" or FISSA or "Mann Assessment of Swallowing Ability" or MASA or "Functional Dysphagia Scale" or FDS).ti,ab.
21	((problem* or difficult* or safe*) adj2 (feeding or eat* or drink* or chew* or metabol* or nutrition* or swallow* or aspiration)).ti,ab.
22	(nutriti* or feed* or eat* or drink* or biting or choke* or choking or cough* or gagging or gag* or vomit* or meal* or energy or chew* or digest* or metabolism* or swallow* or diet* or deglut* or motilit* or dyspeps* or constipat* or reflux or dysphag* or obes* or weigh* or overweigh* or underweigh* or anthropometr* or malnutri* or aspirat*).ti,ab.
23	(nutrition* adj (supplement* or optim* or deficient* or support* or require*)).ti,ab.
24	(((skin?fold* or fat or body or weight or bowel) adj (measure* or protocol* or assess* or monitor* or screen* or safe* or scale* or symptom* or dysfunction*)) or BMI or calorimetry).ti,ab.
25	(body composition or waist circumference).ti,ab.
26	16 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27	13 and 26
28	conference abstract.pt. use oemezd
29	letter.pt. or LETTER/ use oemezd
30	Letter/ use prmz
31	EDITORIAL/ use prmz
32	editorial.pt. use oemezd
33	NEWS/ use prmz
34	exp HISTORICAL ARTICLE/ use prmz
35	note.pt. use oemezd
36	ANECDOTES AS TOPIC/ use prmz
37	COMMENT/ use prmz
38	CASE REPORT/ use prmz
39	CASE REPORT/ use oemezd
40	CASE STUDY/ use oemezd
41	(letter or comment* or abstracts).ti.
42	or/28-41

#	Searches
43	RANDOMIZED CONTROLLED TRIAL/ use prmz
44	RANDOMIZED CONTROLLED TRIAL/ use oemezd
45	random*.ti,ab.
46	or/43-45
47	42 not 46
48	ANIMALS/ not HUMANS/ use prmz
49	ANIMAL/ not HUMAN/ use oemezd
50	exp ANIMALS, LABORATORY/ use prmz
51	exp ANIMAL EXPERIMENTATION/ use prmz
52	exp MODELS, ANIMAL/ use prmz
53	exp RODENTIA/ use prmz
54	NONHUMAN/ use oemezd
55	exp ANIMAL EXPERIMENT/ use oemezd
56	exp EXPERIMENTAL ANIMAL/ use oemezd
57	ANIMAL MODEL/ use oemezd
58	exp RODENT/ use oemezd
59	(rat or rats or mouse or mice).ti.
60	or/47-59
61	27 not 60
62	limit 61 to yr="1990 -Current"

Database: Cochrane Library

Table 6: Last searched on 22 March 2018

ID	Search
#1	MeSH descriptor: [Cerebral Palsy] explode all trees
#2	((cerebral or brain or central) N2 (pal* or paralys?s or pare?s))
#3	((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) N5 spastic*)
#4	((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) N3 ataxi*)
#5	#1 or #2 or #3 or #4
#6	MeSH descriptor: [Nutrition Policy] explode all trees
#7	MeSH descriptor: [Nutrition Disorders] explode all trees
#8	MeSH descriptor: [Nutrition Assessment] explode all trees
#9	MeSH descriptor: [Nutrition Therapy] explode all trees
#10	MeSH descriptor: [Feeding and Eating Disorders] explode all trees
#11	MeSH descriptor: [Feeding Behavior] explode all trees
#12	MeSH descriptor: [Diet] explode all trees
#13	MeSH descriptor: [Deglutition Disorders] explode all trees
#14	MeSH descriptor: [Gastrointestinal Motility] explode all trees
#15	MeSH descriptor: [Esophageal Motility Disorders] explode all trees
#16	MeSH descriptor: [Dyspepsia] explode all trees
#17	MeSH descriptor: [Constipation] explode all trees

ID	Search
#18	MeSH descriptor: [Gastroesophageal Reflux] explode all trees
#19	MeSH descriptor: [Obesity] explode all trees
#20	MeSH descriptor: [Anthropometry] explode all trees
#21	MeSH descriptor: [Overweight] explode all trees
#22	MeSH descriptor: [Body Composition] explode all trees
#23	MeSH descriptor: [Body Weight] explode all trees
#24	MeSH descriptor: [Nutritional Status] explode all trees
#25	MeSH descriptor: [Body Mass Index] explode all trees
#26	MeSH descriptor: [Skinfold Thickness] explode all trees
#27	MeSH descriptor: [Deglutition] explode all trees
#28	MeSH descriptor: [Respiratory Aspiration] explode all trees
#29	MeSH descriptor: [Drinking] explode all trees
#30	MeSH descriptor: [Eating] explode all trees
#31	MeSH descriptor: [Mastication] explode all trees
#32	MeSH descriptor: [Diet, Reducing] explode all trees
#33	MeSH descriptor: [Diet Therapy] explode all trees
#34	MeSH descriptor: [Fat Body] explode all trees
#35	MeSH descriptor: [Weight Loss] explode all trees
#36	MeSH descriptor: [Weight Gain] explode all trees
#37	MeSH descriptor: [Calorimetry, Indirect] explode all trees
#38	MeSH descriptor: [Waist Circumference] explode all trees
#39	MeSH descriptor: [Energy Intake] explode all trees
#40	MeSH descriptor: [Nutritional Requirements] explode all trees
#41	MeSH descriptor: [Malnutrition] explode all trees
#42	MeSH descriptor: [Dietary Supplements] explode all trees
#43	MeSH descriptor: [Nutritional Support] explode all trees
#44	MeSH descriptor: [Food, Fortified] explode all trees
#45	MeSH descriptor: [Protein-Energy Malnutrition] explode all trees
#46	MeSH descriptor: [Metabolism] explode all trees
#47	MeSH descriptor: [Basal Metabolism] explode all trees
#48	MeSH descriptor: [Digestion] explode all trees
#49	MeSH descriptor: [Disability Evaluation] explode all trees
#50	MeSH descriptor: [Disease Progression] explode all trees
#51	MeSH descriptor: [Severity of Illness Index] explode all trees
#52	"Eating and Drinking Ability Classification System" or EDACS or "Fatigue Impact and Severity Self-Assessment" or FISSA or "Mann Assessment of Swallowing Ability" or MASA or "Functional Dysphagia Scale" or FDS
#53	nutrition* or feed* or eat* or drink* or biting or energy or chew* or digest* or metabolism* or swallow* or diet* or deglut* or motilit* or dyspeps* or constipat* or reflux or dysphag* or obes* or weigh* or overweigh* or underweigh* or anthropometr* or malnutri* or aspirat* or body composition or waist circumference or skin?fold* or fat or body or weight or bowel or BMI or calorimetry or supplement or anthropometry or choke* or choking or cough* or gagging or gag* or vomit*

ID	Search
#54	oral appliance* or oral sensorimotor skill* or utensil* or equipment or meal* or gastrostomy* or Jejunostom* or enteral nutrition*
#55	MeSH descriptor: [Cooking and Eating Utensils] explode all trees
#56	MeSH descriptor: [Equipment Design] explode all trees
#57	MeSH descriptor: [Meals] explode all trees
#58	MeSH descriptor: [Gastric Emptying] explode all trees
#59	MeSH descriptor: [Enteral Nutrition] explode all trees
#60	MeSH descriptor: [Gastrostomy] explode all trees
#61	MeSH descriptor: [Jejunostomy] explode all trees
#62	MeSH descriptor: [Feeding Methods] explode all trees
#63	MeSH descriptor: [Task Performance and Analysis] explode all trees
#64	MeSH descriptor: [Biomechanical Phenomena] explode all trees
#65	MeSH descriptor: [Human Engineering] explode all trees
#66	MeSH descriptor: [Activities of Daily Living] explode all trees
#67	MeSH descriptor: [Self Care] explode all trees
#68	MeSH descriptor: [Airway Obstruction] explode all trees
#69	{or #6-#68}
#70	#5 and #69

Database: Web of Science

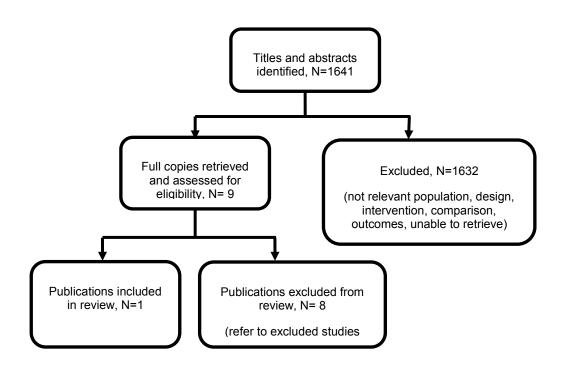
Table 7: Last searched on 22 March 2018

Set	Search
#3	#2 AND #1 1990-2017 AND LANGUAGE: (English)
#2	(ts=nutrition or ts=feed* or ts=swallow* or ts=aspiration or ts=food or ts=eat* or ts=drink* or ts=bit* or ts=chew* or ts=digest* or ts=choke* or ts=choking or ts=cough* or ts=gagging or ts=gag* or ts=vomit* or ts=airway obstruct*)
#1	ts=Cerebral Palsy

Appendix C – Clinical evidence study selection

Clinical evidence study selection for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Figure 1: Flow diagram of clinical article selection for review on assessment and monitoring of feeding and maintaining nutrition.



Appendix D – Clinical evidence tables

Clinical evidence tables for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Study details	Participants	Interventions	Methods					nes and		Comments				
Full citation	Sample size	Interventions	Details					R	esults	5				Limitations
Benigni,I.,					Reference screening tool –			R	eferer	nce scre	The QUADAS-2			
Devos,P., Rofidal,T., Seguy,D., The CP-MST, a malnutrition	Characteristics Males/Females=19 7/168 Mean age=	screening tool for CP adult patients (CP- MST)	was based on 3 variables : weight loss from usual body weight BMI					All patients N = 365		Absent malnutriti on* N = 155	Moderat e malnutriti on* N = 120	Severe malnutrition* N = 90	(Quality Assessment tool for Diagnostic Accuracy Studies – version 2) checklist for assessing the risk	
screening tool for institutionalized adult cerebral Mean Body weight= 48.8±13.0 kg			albuminuria. Accordingly 3 classes of malnutrition were defined as follows:					Low risk 124 no.(%) (100) 79 (63) 33 (27) 12 (10)			of bias of this observational study.			
								Mild risk no.(%) 155 (100) 67 (43) 60 (39) 28 (18)		Patient selection				
palsy patients, Clinical	Mean BMI= 20.6±5.1 kg/		Malnutriti	Loss of			Albumi		igh risk o.(%)	86 (100)	9 (10)	27 (32)	50 (58)	Risk of bias: Was a consecutive
Nutrition, 30, 769-773, 2011	m2 Inclusion criteria		on type					* According to the reference screening tool					or random sample of patients enrolled?	
Ref Id	see exclusion		Absent	<5 ai	an ≥18 d .5	≥18 an .5 d	¹ ≥35	In	Index screening r			6		Yes Was a case-control
220060 Country/ies where the	criteria Exclusion criteria The study		Moderat e	≥5 to <1 or	<1 .5 to	8 or	<35 to ≥30			Malnu n (seve mode	ere + ma	Inutrition	Tot.	design avoided? Yes Did the study avoid inappropriate
study was carried out	excluded patients with:			0	≥1	6		Те	est +	165	76		241	exclusions? yes
France	diagnoses suggesti		Severe	≥1 0 or	<1	6 or	<30	Te	est -	45	79		124	Could the selection of participants have
Study type	ng CP of postnatal origin (traumatic		Index sc	reenii	na te	est –	- model	То	ot.	210	15	5	365	introduced bias? low
Observational study Aim of the study This study aimed to	brain injury, near- drowning, motor vehicle accidents, brain tumours or		Index screening test – model based on the following variables: body weight < 40 kg (10 points)			83 Si	Sensitivity^= 78.57% 83.92%) Specificity^= 50.97 % to 59.07%)			% (95% CI 72.40% to % (95% CI 42.82%		risk Applicability: Is there concern that the included participants do not		

Table 8: Studies included in the evidence review for assessment and monitoring of feeding and nutritional problems
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Study details	Participants	Interventions	Methods	Outco	mes and R	lesults		Comments
determine the prevalence of malnutrition in adult patients with CP, and to propose a specific malnutr ition screening tool in these patients (MST - CP) Study dates Publication date: 2011 Patients enrolment date: 2004- 2005 Source of funding Not reported (No conflict of interest declared)	other acquired injuries) significant concomitant diagn oses (vascular cerebral ischemia, neuromuscular diseases, degener ative disorders, autism, psychiatric or behavioural disorders) enteral nutrition and those without a legal guardian's agreement for blood sampling		uncomfortable or impossible sitting position (4 points) partial or total help needed for eating (4 points) suspicion of gastro- oesophageal reflux (3 points) The highest score possible was 21 points: A score higher than 10 points indicated high risk (severe malnutrition). A score higher than higher than 0 and less than 10 points indicated mild risk (moderate malnutrition). A score equal to 0 indicated high risk (no malnutrition)	Positiv CI 1.34 Negati CI 0.3 ^ calcu from d Test + Test - Tot. Sensit 66.049 Specifi to 90.6 Positiv CI 2.9 Negati CI 0.4	ve Likelihoo 4 to 1.91) ive Likelihoo 1 to 0.57) ulated by the lata Severe malnutrition 50 40 90 ivity^= 55.5 %) ficity^= 86.9 66%) ve Likelihoo 7 to 6.06) ive Likelihoo 0 to 0.65)	d Ratio^= 1. od Ratio^= 0 e NGA techr No severe malnutrition (moderate + no malnutrition) 36 239 275 6% (95% CI 1 % (95% CI 1 % (95% C d Ratio^= 4. od Ratio^= 0 e NGA techr	0.42 (95% nical team Tot. 86 279 365 44.70% to I 82.34% 24 (95% 0.51 (95%	match the review question? Low risk Index tests Risk of bias: Were the index tests interpreted without knowledge of the reference standard? Unclear (no details given in the report) If a threshold was used, was it pre- specified? N/A Could the conduct or interpretation of the index test have introduced bias? Unclear risk Applicability: Is there concern that the index test, its conduct or interpretation differ from the review question? Low risk Reference standard Risk of bias: Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the

or interpreta have introdu bias? Uncle	nts
Applicability Is there con the target or as defined b reference st does not ma review ques Low risk Flow and tin Risk of bias Was there a appropriate between incl and referen standard? Y Did all participa receive a re standard? Y Did participa receive the reference st Not Were all pad included in 1 analysis? Y	f the index clear (no ion given inding) e reference l, its conduct retation roduced inclear risk ility: concern that et condition ed by the e standard t match the uestion? d timing bias: re an ate interval index tests rence l? Yes articipants a reference l? Yes cipants the same e standard? patients in the

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					Overall risk of bias: unclear risk of bias Other information Not applicable

BMI: body mass index; CI: confidence interval; CP: cerebral palsy; MST-CP: malnutrition screening tool for cerebral palsy; SD: standard deviation

Appendix E – Forest plots

Forest plots for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Screening tools

Figure 2: Forest plot of MST-CP (threshold score = 0 points - low risk) in screening for risk of malnutrition in adults with CP

 Study
 TP
 FP
 FN
 TN
 Sensitivity (95% Cl)
 Specificity (95% Cl)
 Sensitivity (95% Cl)
 Specificity (95% Cl)

CI: confidence interval; FN: false negative; FP: false positive; MST-CP: malnutrition screening tool for cerebral palsy; TN: true negative; TP: true positive

Figure 3: Forest plot of MST-CP (threshold score < 10 points - high risk) in screening for risk of malnutrition in adults with CP

 Study
 TP
 FP
 FN
 TN
 Sensitivity (95% CI)
 Specificity (95% CI)
 Sensitivity (95% CI)
 Specificity (95% CI)

CI: confidence interval; FN: false negative; FP: false positive; MST-CP: malnutrition screening tool for cerebral palsy; TN: true negative; TP: true positive

Appendix F – GRADE tables

GRADE tables for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Table 9: Clinical evidence profile: MST-CP (at thresholds of 0 and 10) to differentiate between high risk and low risk of malnutrition in adults with cerebral palsy.

Study	N	Risk of bias ¹	Screening score ²	Inconsistency	Indirectness ³	Imprecision ⁴	Sensitivity (95% CI)	Specificity (95% Cl)	Positive likelihood ratio⁵	Negative likelihood ratio⁵	Quality	Importance
1 observational study	365	Serious ⁶	score=0 ²	Not applicable	Not serious	Serious ⁷	0.78 (0.72 - 0.84)	0.51 (0.43–0.60)	1.60	0.42	LOW	IMPORTANT
1 observational study	365	Serious ⁶	score>10 ²	Not applicable	Not serious	Serious	0.55 (0.44-0.66)	0.87 (0.82-0.90)	4.24	0.51	CRITICAL	IMPORTANT

CI: confidence interval; CP: cerebral Palsy; MST-CP: malnutrition screening tool for cerebral palsy; N: number of participants in study

1 Risk of bias evaluated using risk of bias items of QUADAS-2 checklist.

2 Index screening test – model based on the following variables: 1) body weight < 40 kg (10 points); 2) uncomfortable or impossible sitting position (4 points); 3) partial or total help needed for eating (4 points) and 4) suspicion of gastro-oesophageal reflux (3 points). The highest score possible was 21 points: A score higher than 10 points indicated high risk (severe malnutrition). A score higher than 0 and less than 10 points indicated mild risk (moderate malnutrition). A score equal to 0 indicated low risk (no malnutrition). 3 Indirectness was evaluated using the applicability items of QUADAS-2.

4 Judgement of imprecision was based on consideration of the 95% CIs of test sensitivity as this was considered to be the primary measure of interest as a false negative missing malnourished patients, whilst a false positive - indicating risks of malnutrition when there is none. Studies were considered to be of high sensitivity (and not imprecise) if the 95% CI was above 0.9 or of low sensitivity if it was below 0.75. Studies were assessed as subject to serious imprecision if the 95% CI crossed either 0.75 or 0.9, or subject to very serious imprecision if it crossed both 0.75 and 0.9.

5 Positive and negative likelihood ratios calculated from sensitivity and specificity estimates.

6 Unclear risk of review bias (lack of blinding in the interpretation both of the index test and reference standard – no details are given in the text) and patient selection; with flow and timing of patient unclear

7 95% CI for sensitivity crosses 0.75.

Appendix G – Economic evidence study selection

Economic evidence study selection for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Appendix H – Economic evidence tables

Economic evidence tables for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Appendix I – Health economic evidence profiles

Health economic evidence profiles for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Appendix J – Health economic analysis

Health economic analysis for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

No economic analysis was included in this review.

Appendix K – Excluded studies

Clinical and economic lists of excluded studies for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

Clinical studies

Table 10: Clinical studies for monitoring feeding and nutritional problems

Excluded studies – B.3 What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?	
Study	Reason for Exclusion
Ferrang T.M., Johnson R.K., Ferrara M.S., Dietary and anthropometric assessment of adults with cerebral palsy. J Am Diet Assoc. 92,1083-1086,1992	Ineligible study design –there is not the description of a monitoring protocol and data are not comparative. This paper aimed to determine the anthropometric profile and nutrient intakes of 86 adults with cerebral palsy, but it reports only prevalence/incidence data
Mackey, A.H., Hewart, P., Walt, S.E., Stott, N.S., The sensitivity and specificity of an activity monitor in detecting functional activities in young people with cerebral palsy, Archives of Physical Medicine and Rehabilitation, 90, 1396-1401, 2009	Wrong population, mostly children with cerebral palsy
Mackey,A.H., Stott,N.S., Walt,S.E., Reliability and validity of an activity monitor (IDEEA) in the determination of temporal-spatial gait parameters in individuals with cerebral palsy, Gait and Posture, 28, 634-639, 2008	No intervention - this paper evaluates the reliability and validity of temporal-spatial gait parameters derived from the intelligent device for energy expenditure and activity monitor in adults with cerebral palsy
Peterson,M.D., Gordon,P.M., Hurvitz,E.A., Chronic disease risk among adults with cerebral palsy: the role of premature sarcopoenia, obesity and sedentary behaviour, Obesity Reviews, 14, 171-182, 2013	Narrative review about the chronic disease risk among adults with cerebral palsy
Rempel,G., Moussavi,Z., The effect of viscosity on the breath- swallow pattern of young people with cerebral palsy, Dysphagia, 20, 108-112, 2005	Not relevant for this review question - observational pilot aimed to investigate the effect of swallowing pudding and liquids of different viscosity on the breath-swallow pattern of young adults with cerebral palsy
Rogers, B., Msall, M., Shucard, D., Hypoxemia during oral feedings in adults with dysphagia and severe neurological disabilities, Dysphagia, 8, 43-48, 1993	Non-comparative study
Tsai,A.C., Hsu,H.Y., Chang,T.L., The Mini Nutritional Assessment (MNA) is useful for assessing the risk of malnutrition in adults with	Reference standard results were not reported for the

Study	Reason for Exclusion
intellectual disabilities, Journal of Clinical Nursing, 20, 3295-3303, 2011	subgroup of participants with cerebral palsy, cannot calculate sensitivity and specificity for this subgroup
Westberry,D.E., Davids,J.R., Jacobs,J.M., Pugh,L.I., Tanner,S.L., Effectiveness of serial stretch casting for resistant or recurrent knee flexion contractures following hamstring lengthening in children with cerebral palsy, Journal of Pediatric Orthopedics, 26, 109-114, 2006	Non-comparative study

Excluded studies – B.3 What is the best way to assess and monitor the safety (of swallowing

Economic studies

Appendix L – Research recommendations

Research recommendations for review question B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?

No research recommendation was made for this review.