

Cerebral palsy in adults

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

NICE guideline <TBC>

Evidence reviews

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Draft for Consultation

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

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1 Monitoring feeding and nutritional 2 problems

3 Review question

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

7 Introduction

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

14 PICO/PIRO table

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

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

Population	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.
Intervention / index test	Monitoring protocol for feeding and nutritional problems involving any of the following: <ul style="list-style-type: none"> • Dietary assessment, including gastrointestinal issues such as: <ul style="list-style-type: none"> ○ dysphagia ○ fore gut dysmotility ○ hind gut dysmotility • Clinical assessment • Anthropometric assessment <ul style="list-style-type: none"> ○ BMI ○ Fat measure ○ skinfold measurement • Screening tools <ul style="list-style-type: none"> ○ MUST
Comparison / reference standard	Any other monitoring protocol
Outcome	<p>Critical</p> <ul style="list-style-type: none"> • Function • HR-QoL • Chest infection <p>Important</p> <ul style="list-style-type: none"> • Patient satisfaction • Mortality • Weight • Skin integrity

- Feeding time
 - TOMS – swallowing outcome
- In the absence of test and treat studies¹:*
- Diagnostic accuracy:
 - Sensitivity
 - Specificity
 - Positive/Negative likelihood ratios

1 BMI: Body Mass Index; HR-QoL: Health-Related Quality of Life; MUST: Malnutrition Universal Screening Tool;
2 TOMS: Therapy Outcome Measures-Swallowing.
3 ¹The review question was framed as an intervention review but in the absence of test and treat studies diagnostic
4 accuracy studies would be included, with the assumption that accurate identification of feeding problems is likely
5 to improve outcomes.

6 For full details see review protocol in appendix A.

7 **Methods and process**

8 This evidence review was developed using the methods and process described in
9 [Developing NICE guidelines: the manual 2014](#). Methods specific to this review question are
10 described in the review protocol in appendix A and for a full description of the methods see
11 supplementary document C.

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

18 Declaration of interests were recorded according to NICE's 2014 conflicts of interest policy
19 from May 2016 until April 2018. From April 2018 onwards they were recorded according to
20 NICE's 2018 [conflicts of interest policy](#). Those interests declared until April 2018 were
21 reclassified according to NICE's 2018 conflicts of interest policy (see Interests Register).

22 **Clinical evidence**

23 **Included studies**

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

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

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

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

1 Excluded studies

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

4 Summary of clinical studies included in the evidence review

5 Table 2 provides a brief summary of the included studies.

6 **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	<ul style="list-style-type: none"> Malnutrition screening tool for adults with CP (MST-CP) 	Composite based on: <ul style="list-style-type: none"> weight loss from usual body weight BMI albuminuria 	Weight (malnutrition)

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

9 See appendix D for full evidence tables.

10 Quality assessment of clinical outcomes included in the evidence review

11 The clinical evidence profile for this comparison is presented in Table 3 and Table 8.

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

Study	N	Risk of bias ¹	Screening score ²	Inconsistency	Indirectness ³	Imprecision ⁴	Sensitivity (95% CI)	Specificity (95% CI)	Positive likelihood ratio ⁵	Negative likelihood ratio ⁵	Quality
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
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	Moderate

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

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

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

23 ³ Indirectness was evaluated using the applicability items of QUADAS-2.

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

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

1 6 Unclear risk of review bias (lack of blinding in the interpretation both of the index test and reference standard –
2 no details are given in the text) and patient selection; with flow and timing of patient unclear
3 7 95% CI for sensitivity crosses 0.75.

4 See appendix F for the full GRADE table.

5 **Economic evidence**

6 **Included studies**

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

9 **Excluded studies**

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

11 **Summary of studies included in the economic evidence review**

12 No economic evaluations were included in this review.

13 **Economic model**

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

17 **Resource impact**

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

20 **Evidence statements**

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

22 **Critical outcomes**

23 **Function**

24 No evidence was found for this outcome.

25 **Health related quality of life**

26 No evidence was found for this outcome.

27 **Chest infection**

28 No evidence was found for this outcome.

29 **Important outcomes**

30 **Patient satisfaction**

31 No evidence was found for this outcome.

1 **Mortality**

2 No evidence was found for this outcome.

3 **Weight**

4 No evidence was found for this outcome.

5 **Skin integrity**

6 No evidence was found for this outcome.

7 **Feeding time**

8 No evidence was found for this outcome.

9 **Diagnostic accuracy for malnutrition**

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

20 **Recommendations**

21 B3.1 Offer adults with cerebral palsy a regular weight check and BMI evaluation, and identify
22 people who may be at risk of undernutrition or obesity (see also the NICE guideline on
23 [obesity: identification, assessment and management](#) for information on assessment of
24 obesity).

25 B3.2 At every review, discuss with adults with cerebral palsy (and their family and carers, if
26 agreed) whether they have difficulties with eating or there have been any changes in their
27 eating habits. Ask about issues including:

- 28 • changes in appetite
- 29 • changes in the person's ability to feed themselves
- 30 • coughing or choking when eating
- 31 • food refusal
- 32 • increased frequency of chest infections (which may be related to
33 swallowing difficulties or gastro-oesophageal reflux)
- 34 • an increase in the length of meal times.

35 B3.3 Discuss if any of the following factors might be affecting the person's appetite, eating
36 habits or weight:

- 37 • changes in carer support
- 38 • pain and depression
- 39 • reduced physical activity
- 40 • side effects of medications.

- 1 B3.4 Be aware that adults with cerebral palsy with severe spasticity and dyskinesia may
2 have an increased metabolic rate and a higher risk of malnutrition.
- 3 B3.5 Follow the recommendations on screening for malnutrition, indications for nutrition
4 support, and education and training of staff and carers related to nutrition in NICE's guideline
5 on [nutrition support for adults](#).
- 6 B3.6 Refer adults with cerebral palsy to a relevant clinical specialist if assessment suggests
7 they have difficulties with eating or malnutrition.

8 **Rationale and impact**

9 **Why the committee made the recommendations**

10 There was some evidence on tools for assessing nutritional status in adults with cerebral
11 palsy, but the committee concluded that the evidence was not good enough to recommend a
12 specific tool. In addition, many factors can affect feeding and nutrition, so they agreed that a
13 single tool is unlikely to be suitable for everyone.

14 Based on their experience, the committee agreed that assessment should be individualised
15 to reflect each adult's needs and circumstances. Current good practice includes regular
16 weight and BMI checks, and talking to the person and their families and carers about feeding
17 behaviour and other factors affecting feeding and weight. People identified as at risk of
18 undernutrition or with eating difficulties can then be referred to a specialist to assess for and
19 treat specific feeding or nutrition problems. Because the recommendations focus on
20 individualised assessment, the committee agreed that specific tools for assessing nutrition
21 are not a priority for further research.

22 The committee discussed the role of people caring for adults with cerebral palsy and agreed
23 that training should be provided in line with the NICE guideline on [nutrition support for adults](#),
24 to help pick up any problems between reviews.

25 The committee noted that adults with dyskinetic cerebral palsy or severe spasticity may have
26 an increased metabolic rate and need to increase their calorie intake to prevent malnutrition.
27 The committee recognised that reduction in dyskinesia or spasticity by treatment such as
28 intrathecal baclofen may result in weight gain. They agreed that, from their experience, this
29 can go unrecognised and that greater awareness could help people get the support they
30 need.

31 **Impact of the recommendations on practice**

32 The recommendations will reinforce current best practice.

33 **The committee's discussion of the evidence**

34 **Interpreting the evidence**

35 ***The outcomes that matter most***

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

41 Nutritional status was reported in the included study, but there was no evidence for the
42 critical outcomes: function, health-related quality of life, and chest infection or the important
43 outcomes: patient satisfaction, mortality, weight, skin integrity, feeding time and TOMS. The

1 included studies reported how accurate the tools were in identifying nutritional status. In the
2 absence of any other outcomes the committee considered statistical accuracy measures
3 (such as sensitivity and specificity, as well as positive and negative likelihood ratios) because
4 it was assumed that a more accurate assessment would lead to better management of the
5 nutritional problem and therefore better patient level outcome.

6 ***The quality of the evidence***

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

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

14 ***Benefits and harms***

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

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

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

38 Due to the serious consequences that malnutrition can have the committee agreed that
39 formal and informal carers should receive training on the recognition of malnutrition and
40 feeding difficulties to prevent ill health, in line with NICE's guideline on [nutrition support for
41 adults](#).

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

47 On consideration of the limited evidence the committee agreed that there are many individual
48 factors that could relate to feeding and nutritional problems and that the assessment
49 therefore needs to be tailored to each adult with cerebral palsy. This means that there is not

1 one tool that should be given to adults with cerebral palsy that is better than all other ones.
2 The committee therefore did not prioritise this for further research because assessment
3 would have to be individualised according to each adult's needs and circumstances.

4 **Cost effectiveness and resource use**

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

7 The committee considered that the recommendations made were unlikely to result in a
8 substantial increase in resource use. Any additional costs would be small, given the minimal
9 change in practice, and any increase would be offset by a reduction in the costs associated
10 with dealing with malnutrition.

11 **Other factors the committee took into account**

12 The committee also noted that the NICE guideline on [obesity: identification, assessment and](#)
13 [management](#) includes generic information on the identification and assessment of obesity in
14 all adults which can be generalised to people with cerebral palsy. They therefore cross-
15 referenced to this.

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

21 **References**

22 **Benigni 2011**

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

1 Appendices

2 Appendix A – Review protocols

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

5 **Table 4: Review protocol for monitoring feeding and nutritional problems**

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: <ul style="list-style-type: none">• Dietary assessment, including gastrointestinal issues such as:<ul style="list-style-type: none">○ dysphagia○ fore gut dysmotility○ hind gut dysmotility• Clinical assessment• Anthropometric assessment<ul style="list-style-type: none">○ BMI○ Fat measure○ skinfold measurement• Screening tools<ul style="list-style-type: none">○ MUST

Field (based on PRISMA-P)	Content
Eligibility criteria – comparator(s)/control or reference (gold) standard	Any other monitoring protocol
Outcomes and prioritisation	<p>Critical outcomes</p> <ul style="list-style-type: none"> • Function <ul style="list-style-type: none"> ◦ for example as measured using the International Classification of Functioning, Disability and Health • HR-QoL • Chest infection <p>Important outcomes</p> <ul style="list-style-type: none"> • Patient satisfaction • Mortality • Weight • Skin integrity • Feeding time • TOMS – swallowing outcome <p><i>In the absence of test & treat studies:</i></p> <ul style="list-style-type: none"> • Diagnostic accuracy: <ul style="list-style-type: none"> ◦ Sensitivity ◦ Specificity ◦ Positive/Negative likelihood ratios <p>Minimally important differences</p> <ul style="list-style-type: none"> • 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] <p>The thresholds for clinical usefulness of tests: Sensitivity and specificity (sensitivity will be prioritised):</p>

Field (based on <u>PRISMA-P</u>)	Content
	<ul style="list-style-type: none"> • High >90% • Moderate 75-90% • Low <75% Positive likelihood ratio: <ul style="list-style-type: none"> • Very useful test >10 • Moderately useful test 5-10 • Not a useful test <5 Negative likelihood ratio: <ul style="list-style-type: none"> • 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 - <ul style="list-style-type: none"> • 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-regression	Groups that will be reviewed and analysed separately: <ul style="list-style-type: none"> • Ambulant versus non-ambulant • Dystonic and dyskinetic • LD In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis: <ul style="list-style-type: none"> • Population subgroups (for example. age groups, presentation, severity): <ul style="list-style-type: none"> ◦ Severity of feeding, nutrition, swallow or aspiration problems

Field (based on <u>PRISMA-P</u>)	Content
	<ul style="list-style-type: none"> • Assessment subgroups <ul style="list-style-type: none"> ○ Type of assessment ○ Treatment or management change following assessment <p>Important confounders: severity of feeding, nutrition, swallow or aspiration problems, treatment given for such problems.</p>
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	<p>Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual 2014</p> <p>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 http://www.gradeworkinggroup.org/</p>

Field (based on PRISMA-P)	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 Developing NICE guidelines: the manual 2014
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 Developing NICE guidelines: the manual 2014 . 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

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

4

5

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 oomezd
3	((cerebral or brain or central) adj2 (pal* or paraly#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 oomezd [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 Waist Circumference/ or exp Energy Intake/ or exp Nutritional Requirements/ or exp Malnutrition/ 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 Gastric Emptying/ or exp Gastrostomy/ or exp Jejunostomy/ or exp Feeding Methods/ 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 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 calorie diet/ or exp weight reduction/ or exp indirect

#	Searches
	calorimetry/ or exp waist circumference/ or exp body fat/ or exp caloric intake/ or exp nutritional requirement/ or exp protein calorie malnutrition/ or exp malnutrition/ or exp dietary supplement/ or exp nutritional support/ or exp metabolism/ or exp fortified food/ or exp basal metabolic rate/ or exp digestion/ or exp enteric feeding/ or exp kitchen/ or exp equipment design/ or exp meal/ or exp stomach emptying/ or exp gastrostomy/ or exp jejunostomy/ or exp food intake/ 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 oomezd
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 overweight* 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 oomezd
29	letter.pt. or LETTER/ use oomezd
30	Letter/ use prmz
31	EDITORIAL/ use prmz
32	editorial.pt. use oomezd
33	NEWS/ use prmz
34	exp HISTORICAL ARTICLE/ use prmz
35	note.pt. use oomezd
36	ANECDOTES AS TOPIC/ use prmz
37	COMMENT/ use prmz
38	CASE REPORT/ use prmz
39	CASE REPORT/ use oomezd
40	CASE STUDY/ use oomezd
41	(letter or comment* or abstracts).ti.
42	or/28-41
43	RANDOMIZED CONTROLLED TRIAL/ use prmz
44	RANDOMIZED CONTROLLED TRIAL/ use oomezd
45	random*.ti,ab.
46	or/43-45
47	42 not 46
48	ANIMALS/ not HUMANS/ use prmz
49	ANIMAL/ not HUMAN/ use oomezd

#	Searches
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 oomezd
55	exp ANIMAL EXPERIMENT/ use oomezd
56	exp EXPERIMENTAL ANIMAL/ use oomezd
57	ANIMAL MODEL/ use oomezd
58	exp RODENT/ use oomezd
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
#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

ID	Search
#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*
#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

ID	Search
#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

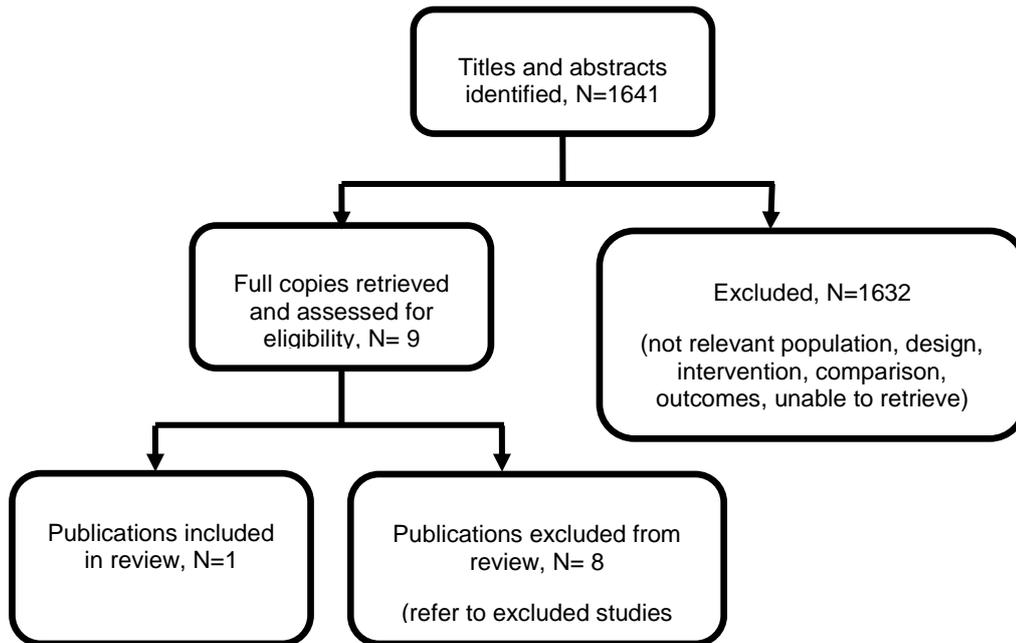
Table 7: Last searched on 22 March 2018

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?

Table 8: Studies included in the evidence review for assessment and monitoring of feeding and nutritional problems

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments																																																				
<p>Full citation 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</p> <p>Ref Id 220060</p> <p>Country/ies where the study was carried out France</p> <p>Study type Observational study</p> <p>Aim of the study This study aimed to</p>	<p>Sample size N=365</p> <p>Characteristics Males/Females=197/168</p> <p>Mean age= 35.8±9.0 years</p> <p>Mean Body weight= 48.8±13.0 kg</p> <p>Mean BMI= 20.6±5.1 kg/m²</p> <p>Inclusion criteria see exclusion criteria</p> <p>Exclusion criteria The study excluded patients with: diagnoses suggesting CP of postnatal origin (traumatic brain injury, near-drowning, motor vehicle accidents, brain tumours or other acquired</p>	<p>Interventions Malnutrition screening tool for CP adult patients (CP-MST)</p>	<p>Details Reference screening tool – was based on 3 variables : weight loss from usual body weight BMI albuminuria. Accordingly 3 classes of malnutrition were defined as follows:</p> <table border="1"> <thead> <tr> <th>Malnutrition type</th> <th>Loss of weight (%)</th> <th>BMI</th> <th>Albuminemia (g/l)</th> </tr> </thead> <tbody> <tr> <td>Absent</td> <td><5 and</td> <td>≥18.5 and</td> <td>≥35</td> </tr> <tr> <td>Moderate</td> <td>≥5 to <10 or</td> <td><18.5 to ≥16 or</td> <td><35 to ≥30</td> </tr> <tr> <td>Severe</td> <td>≥10 or</td> <td><16 or</td> <td><30</td> </tr> </tbody> </table> <p>Index screening test – model based on the following variables: body weight < 40 kg (10 points) uncomfortable or impossible</p>	Malnutrition type	Loss of weight (%)	BMI	Albuminemia (g/l)	Absent	<5 and	≥18.5 and	≥35	Moderate	≥5 to <10 or	<18.5 to ≥16 or	<35 to ≥30	Severe	≥10 or	<16 or	<30	<p>Results Reference screening test results</p> <table border="1"> <thead> <tr> <th></th> <th>All patients N = 365</th> <th>Absent malnutrition* N = 155</th> <th>Moderate malnutrition* N = 120</th> <th>Severe malnutrition* N = 90</th> </tr> </thead> <tbody> <tr> <td>Low risk no.(%)</td> <td>124 (100)</td> <td>79 (63)</td> <td>33 (27)</td> <td>12 (10)</td> </tr> <tr> <td>Mild risk no.(%)</td> <td>155 (100)</td> <td>67 (43)</td> <td>60 (39)</td> <td>28 (18)</td> </tr> <tr> <td>High risk no.(%)</td> <td>86 (100)</td> <td>9 (10)</td> <td>27 (32)</td> <td>50 (58)</td> </tr> </tbody> </table> <p>* According to the reference screening tool</p> <p>Index screening results</p> <table border="1"> <thead> <tr> <th></th> <th>Malnutrition (severe + moderate)</th> <th>No malnutrition</th> <th>Tot.</th> </tr> </thead> <tbody> <tr> <td>Test +</td> <td>165</td> <td>76</td> <td>241</td> </tr> <tr> <td>Test -</td> <td>45</td> <td>79</td> <td>124</td> </tr> <tr> <td>Tot.</td> <td>210</td> <td>155</td> <td>365</td> </tr> </tbody> </table> <p>Sensitivity[^]= 78.57% (95% CI 72.40% to 83.92%) Specificity[^]= 50.97 % (95% CI 42.82% to 59.07%) Positive Likelihood Ratio[^]= 1.60 (95%</p>		All patients N = 365	Absent malnutrition* N = 155	Moderate malnutrition* N = 120	Severe malnutrition* N = 90	Low risk no.(%)	124 (100)	79 (63)	33 (27)	12 (10)	Mild risk no.(%)	155 (100)	67 (43)	60 (39)	28 (18)	High risk no.(%)	86 (100)	9 (10)	27 (32)	50 (58)		Malnutrition (severe + moderate)	No malnutrition	Tot.	Test +	165	76	241	Test -	45	79	124	Tot.	210	155	365	<p>Limitations The QUADAS-2 (Quality Assessment tool for Diagnostic Accuracy Studies – version 2) checklist for assessing the risk of bias of this observational study. Patient selection Risk of bias: Was a consecutive or random sample of patients enrolled? Yes Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? yes Could the selection of participants have introduced bias? low risk Applicability: Is there concern that the included participants do not match the review</p>
Malnutrition type	Loss of weight (%)	BMI	Albuminemia (g/l)																																																						
Absent	<5 and	≥18.5 and	≥35																																																						
Moderate	≥5 to <10 or	<18.5 to ≥16 or	<35 to ≥30																																																						
Severe	≥10 or	<16 or	<30																																																						
	All patients N = 365	Absent malnutrition* N = 155	Moderate malnutrition* N = 120	Severe malnutrition* N = 90																																																					
Low risk no.(%)	124 (100)	79 (63)	33 (27)	12 (10)																																																					
Mild risk no.(%)	155 (100)	67 (43)	60 (39)	28 (18)																																																					
High risk no.(%)	86 (100)	9 (10)	27 (32)	50 (58)																																																					
	Malnutrition (severe + moderate)	No malnutrition	Tot.																																																						
Test +	165	76	241																																																						
Test -	45	79	124																																																						
Tot.	210	155	365																																																						

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments																
<p>determine the prevalence of malnutrition in adult patients with CP, and to propose a specific malnutrition screening tool in these patients (MST - CP)</p> <p>Study dates Publication date: 2011 Patients enrolment date: 2004- 2005</p> <p>Source of funding Not reported (No conflict of interest declared)</p>	<p>injuries) significant concomitant diagnoses (vascular cerebral ischemia, neuromuscular diseases, degenerative disorders, autism, psychiatric or behavioural disorders)</p> <p>enteral nutrition and those without a legal guardian's agreement for blood sampling</p>		<p>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 0 and less than 10 points indicated mild risk (moderate malnutrition). A score equal to 0 indicated high risk (no malnutrition)</p>	<p>CI 1.34 to 1.91) Negative Likelihood Ratio[^]= 0.42 (95% CI 0.31 to 0.57) [^] calculated by the NGA technical team from data</p> <table border="1"> <thead> <tr> <th></th> <th>Severe malnutrition</th> <th>No severe malnutrition (moderate + no malnutrition)</th> <th>Tot.</th> </tr> </thead> <tbody> <tr> <td>Test +</td> <td>50</td> <td>36</td> <td>86</td> </tr> <tr> <td>Test -</td> <td>40</td> <td>239</td> <td>279</td> </tr> <tr> <td>Tot.</td> <td>90</td> <td>275</td> <td>365</td> </tr> </tbody> </table> <p>Sensitivity[^]= 55.56% (95% CI 44.70% to 66.04%) Specificity[^]= 86.91 % (95% CI 82.34% to 90.66%) Positive Likelihood Ratio[^]= 4.24 (95% CI 2.97 to 6.06) Negative Likelihood Ratio[^]= 0.51 (95% CI 0.40 to 0.65) [^] calculated by the NGA technical team</p>		Severe malnutrition	No severe malnutrition (moderate + no malnutrition)	Tot.	Test +	50	36	86	Test -	40	239	279	Tot.	90	275	365	<p>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 results of the index</p>
	Severe malnutrition	No severe malnutrition (moderate + no malnutrition)	Tot.																		
Test +	50	36	86																		
Test -	40	239	279																		
Tot.	90	275	365																		

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					<p>test? Unclear (no information given about blinding)</p> <p>Could the reference standard, its conduct or interpretation have introduced bias? Unclear risk</p> <p>Applicability:</p> <p>Is there concern that the target condition as defined by the reference standard does not match the review question? Low risk</p> <p>Flow and timing</p> <p>Risk of bias:</p> <p>Was there an appropriate interval between index tests and reference standard? Yes</p> <p>Did all participants receive a reference standard? Yes</p> <p>Did participants receive the same reference standard? Not</p> <p>Were all patients included in the analysis? Yes</p> <p>Could the participant flow have introduced bias? unclear risk</p> <p>Overall risk of bias:</p>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					unclear risk of bias Other information

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



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



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% CI)	Positive likelihood ratio ⁵	Negative likelihood ratio ⁵	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?

No economic evidence was identified for this review.

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?

No economic evidence was identified for this review.

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?

No economic evidence was identified for this review.

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 sarcopenia, 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 intellectual disabilities, Journal of Clinical Nursing, 20, 3295-3303, 2011	Reference standard results were not reported for the subgroup of participants with cerebral palsy, cannot calculate sensitivity and

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
	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

Economic studies

No economic evidence was identified for this review.

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.

