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TITLE PAGE: A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy.

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Abstract: 182 words.

**Aim:** To examine systematically the scope, validity and reliability of ordinal scales used to classify the eating and drinking ability of people with cerebral palsy.

**Method:** Six electronic databases were searched to identify measures used to classify eating and drinking ability; in addition, two databases were used to track citations of key texts. The constructs assessed by each measure were examined in relation to the WHO International Classification of Functioning Disability and Health. Evidence of validity and reliability of the identified scales was appraised from peer-reviewed studies using standard criteria. This systematic review and protocol was registered on the Prospero database ([http://www.crd.york.ac.uk/NIHR\\_PROSPEROreference:CRD42013003701](http://www.crd.york.ac.uk/NIHR_PROSPEROreference:CRD42013003701)).

**Results:** Fifteen scales were identified in 23 papers. Clinician or researcher assessment was required for 13 scales; nine scales made use of information from parents and carers through interviews or questionnaires. The terms mild, moderate and severe were used by eight scales to describe different aspects of eating and drinking ability. There was an assessment of either content validity and/or reliability for five scales; however, none met recommended psychometric quality standards.

**Interpretation:** There is currently no valid and reliable scale to classify functional eating and drinking abilities of people with cerebral palsy.

- What this paper adds:
- Currently, there is no valid and reliable scale to classify the functional eating and drinking abilities of people with cerebral palsy, suitable for use in use in both clinical and research contexts by healthcare professionals, people with cerebral palsy or their parents.

Individuals with cerebral palsy (CP) experience activity limitations including sitting, standing, walking, handling objects, and speaking. Impairments can also interfere with oral functions required for eating, drinking and swallowing,<sup>(1,2)</sup> and the ability to bring food and drink to the mouth<sup>(3)</sup>. Limitations in the ability to bite, chew and swallow, and self-feed are often associated with prolonged mealtimes, and food and fluid loss from the mouth; this can lead to insufficient food and fluid intake to ensure growth and good health,<sup>(3-7)</sup> with adverse respiratory consequences such as episodes of choking and aspiration.<sup>(1,8-10)</sup>

The prevalence of eating and drinking difficulties in CP is unclear.<sup>(11)</sup> Estimates range from 27%<sup>(12)</sup> to 90%,<sup>(13)</sup> depending upon definitions and measurement tools used. It has been proposed that prevalence is related to severity of motor impairment,<sup>(14)</sup> although eating and drinking difficulties also occur in individuals with mildly affected gross motor function.<sup>(5,15)</sup>

Although valid and reliable systems are available to classify movement,<sup>(16,17)</sup> manual<sup>(18)</sup> and communication ability<sup>(19)</sup> in CP, there is inconsistent use of measures of eating, drinking and feeding difficulties.<sup>(3,20,21)</sup> A survey of international CP surveillance registers revealed that in 2009, 13 of 21 active CP registries collected eating and drinking data using 11 different measures.<sup>(22)</sup> The use of a consistent indicator of eating and drinking ability would enable more rigorous investigation of prevalence, and associations between severity of eating and drinking limitations and other health issues such as growth, respiratory health and gastrostomy use.<sup>(23)</sup>

A recent systematic review examined the psychometric performance and clinical utility of quantitative measures of oropharyngeal dysphagia with children with neurodevelopmental disabilities.<sup>(21)</sup> The aim of this review was to examine evidence of the validity and reliability of descriptive ordinal scales used to classify the eating and drinking ability of individuals with CP which could be adopted in clinical and population based research.

## **METHOD**

### **Search strategy**

This systematic review and protocol was registered on the Prospero database ([http://www.crd.york.ac.uk/NIHR\\_PROSPEROreference:CRD42013003701](http://www.crd.york.ac.uk/NIHR_PROSPEROreference:CRD42013003701)). A systematic

search was conducted using bibliographic databases, MEDLINE, EMBASE, CINAHL, PsycINFO, BNI and AMED. An example of the search strategy used in MEDLINE and modified for other databases is given in Table SI in Appendix. The searches were conducted up to 14<sup>th</sup> June 2013. Additionally, forward chasing of citations of key texts (listed in Table SII in Appendix) were tracked through Web of Knowledge and Scirus; backward chasing (two generations) of references cited in these key texts were also checked.<sup>(24)</sup>

### **Inclusion and Exclusion Criteria**

Studies were included in the review if they described an ordinal scale used to classify the eating and drinking ability of people with CP. The definition of 'ordinal scale' included technical and clinical assessments, questionnaire items, surveys, and generic classification systems. Papers were excluded if they were not related to individuals with CP. We excluded scales if an English language version of the instrument was not reported.

### **Study selection**

Titles and abstracts were screened by one author (DS); full texts of papers appearing to meet the inclusion criteria were retrieved and reviewed by one reviewer (DS), and 15% were checked independently by a second reviewer (LP). Agreement between reviewers was checked for quality assurance; absolute agreement and chance corrected agreement (kappa)<sup>(25)</sup> were calculated. Authors were contacted for further information about the instruments if details were not explicit in the source papers.

### **Data Extraction**

Each identified measure was classified according to their type:<sup>(26)</sup>

- Clinical measures –clinician administered assessments and checklists;
- Technical measures – such as the dynamic fluoroscopic imaging of swallowing (videofluoroscopy), electromyography, FEES, measures of respiration;
- Patient reported measures – such as patient and/or proxy questionnaires;

Data generated by each measure was classified (as nominal, ordinal, interval or ratio) in order to identify the subset of ordinal scales.

## Appraisal

The validity and reliability of the selected measures were examined using defined quality criteria.<sup>(27–29)</sup> Evidence of the psychometric properties of scales was eligible for appraisal if results were published in peer-reviewed publications. The scope and content of the included instruments were coded with reference to a core set of identified categories defined within WHO International Classification of Functioning, Disability and Health<sup>(30)</sup> (Table I).

Content validity is considered satisfactory if the purpose of assessment, the target population and concepts being measured are clearly identified; content should be identified with input from the target population as well as experts and investigators. Construct validity is assessed through hypothesis testing with related instruments, using a priori estimations of the direction and magnitude of statistical association.<sup>(27)</sup> Measures of reliability were examined with reference to kappa<sup>(25,31)</sup> and Intraclass correlation coefficients (ICC).<sup>(28)</sup> Reliability is considered satisfactory for population-based research if the ICC (or weighted Kappa) is at least 0.7 in a sample size of at least 50 patients.<sup>(27)</sup>

## RESULTS

The search identified 6299 references after duplicates were removed. Following screening, 722 full text papers were obtained, of which 464 papers were excluded. Two hundred and fifty four papers detailed clinical, instrumental, and patient or proxy reported measures. From this group, 23 papers describing 15 ordinal scale measures used to classify the eating and drinking ability of people with CP were identified (Figure I). Agreement between reviewers was 98% (kappa = 0.95).

Thirteen of the 15 measures were developed as clinical assessments by health professionals;<sup>(3,6,8,13,20,32–39)</sup> nine of the measures made use of information from parents of children with CP / developmental disabilities gathered in interviews or questionnaires.<sup>(3,6,20,33,35,37,38,40,41)</sup> One study<sup>(42)</sup> made use of a single item taken from the Pediatric Evaluation of Disability Index.<sup>(41)</sup> One scale was developed for use in the context of

a CP surveillance programme.<sup>(40)</sup> Two measures were used in conjunction with videofluoroscopic examinations of swallowing.<sup>(8,39)</sup>

All measures were developed for use with children, ranging in age from 5 months to 18 years. All reported eating and drinking performance, that is what a person actually does in their current environment; rather than capacity, which is their highest level of functioning. The measures reported the range of ability utilising between 3 to 6 different categories. The age ranges and constructs covered by each of the measures are provided in Table II.

Seven of the measures included information about whether a child is fed via a tube.<sup>(3,6,20,32,33,38,40)</sup> Seven measures included information about food texture or fluid consistency managed by the child.<sup>(3,33,34,36,38,40,41)</sup> Seven measures included details about swallowing<sup>(3,32,33,36–38,40)</sup> and five scales included information about the oral skills required to bite and chew food.<sup>(3,32,36,38,40)</sup> Five scales reported “feeding dysfunction” or “difficulties” although this was not defined.<sup>(3,13,33,36,37)</sup> The safety of oral feeding was included in six scales<sup>(3,32,37–40)</sup> with aspiration being specifically noted by two measures.<sup>(8,39)</sup> Respiratory function or respiratory illness was included in three measures.<sup>(3,8,38)</sup> Four measures included details about level of assistance required by the child to eat or drink.<sup>(6,20,35,40)</sup> Three measures made use of time taken or duration to define the categories assigned to a child,<sup>(6,34,40)</sup> two of these measures used duration of mealtimes as an indication of severity.<sup>(6,40)</sup>

The number of constructs assessed to assign a classification category in the different measures ranged from one, such as level of assistance required<sup>(35)</sup> or number of chest infections,<sup>(8)</sup> to fifteen.<sup>(38)</sup> The content assessed by the included measures were coded with reference to the WHO ICF<sup>(30)</sup> (Table I). Table III shows the frequency of use of ICF categories across all identified measures. Six of the identified measures included more than one category within each level, creating the potential to assign a child to more than one category:<sup>(3,6,20,33,38,40)</sup> for example, children able to swallow safely and self-feed but also receiving some of their nutrition by tube would not be easily categorised. One measure identified the ability to feed oneself and the ability to bite, chew and swallow safely as distinct skills;<sup>(38)</sup> one measure combined the level of assistance required with swallowing

safety, assuming close correspondence of these constructs with increasing severity.<sup>(40)</sup> The terms “mild”, “moderate” and “severe” were used by eight different scales, each with a different definition.<sup>(3,13,32–34,36,38,39)</sup>

Available evidence of the validity and reliability of the different scales are summarised in Table II. The scale from the North American Growth Project<sup>(3)</sup> was derived from acknowledged expert sources<sup>(13,43)</sup>. The Gisel and Alphonse Classification system<sup>(34)</sup> explicitly states the source of content for the ordinal scale from laboratory based studies: eating curves were developed for the typically developing population based on time taken to swallow a specified quantity of three different food textures;<sup>(44,45)</sup> the categories of the ordinal scale were based on standard deviations. The validity and reliability of the single item used by Weir et al.(2013)<sup>(42)</sup> taken from the PEDI (Self Care Domain Item A)<sup>(41)</sup> have not been reported. The content of the Dysphagia Severity Scale<sup>(32)</sup> was derived from the Dysphagia Disorders Survey,<sup>(46)</sup> a detailed measure of oropharyngeal dysphagia; correlations between the two instruments were low to moderate ( $r = -0.18-0.46$ ). The remaining eleven measures make no report of content validity.<sup>(6,8,13,20,33,35–40)</sup> Only one scale<sup>(40)</sup> reported measures of reliability when used by different observers ( $n=30$ ; kappa values = 0.43 to 0.61).

Eleven of these measures were found only in peer reviewed publications from the research groups who developed the scales. Two<sup>(6,34)</sup> of the remaining four scales are cited once each by research teams other than the original developers.<sup>(47,48)</sup> Use of the Dysphagia Management Staging Scale<sup>(38)</sup> is restricted to clinicians who have attended certification workshops; the PEDI<sup>(41)</sup> has been used widely in research, but more specifically to examine eating and drinking ability of individuals with CP in four papers.<sup>(42,49–51)</sup>

## DISCUSSION

Fifteen ordinal scales used to classify the eating and drinking ability of people with CP were identified in this systematic review. The terms mild, moderate and severe were used without any agreed definition by eight of the scales. The terms “feeding problem” or “feeding dysfunction” also lacked precise definition, and might refer to limitations in the ability to bring food and drink to the mouth, or limitations in ability to bite, chew and

swallow. There appears to be a dearth of evidence to support validity and reliability for any of the published scales.

Attempts to provide simple objective measures of eating and drinking have been challenged because of the multidimensional nature of the activity.<sup>(52,53)</sup> Some of the measures use no more than two constructs such as time taken, food texture or the ability to self-feed to clearly define distinct categories necessary for a categorical ordinal scale. An individual's ability to bite, chew, move food and fluid in the mouth and swallow will impact on the food textures and fluid consistencies that can be managed and the time taken to eat. However, significant information related to the safety of eating and drinking is omitted from these scales. It may be possible to categorise eating and drinking ability by food textures that can be "managed" by an individual with CP although the definition of "managed" needs clarification: someone may "manage" chopped food with occasional episodes of choking requiring intervention from others, whilst another individual may eat the same food textures with minimal risk of choking; someone may be able to eat a roughly mashed diet and drink thin fluids with regular respiratory illnesses associated with primary aspiration, contrasting with someone ingesting the same diet without respiratory compromise.

When different constructs are combined within distinct categories of an ordinal scale, it is not always possible to make clear distinctions between levels. For example, when the need for assistance in bringing food and drink to the mouth is categorised together with the oral skills required to bite, chew and swallow, severely limited performance in one construct will mask the classification of relatively unaffected performance in another area. People with CP may require assistance bringing food and drink to the mouth but have no limitations to the oral skills required to bite, chew and swallow a full range of foods. The reverse can also be observed, most obviously for people with Worster Drought Syndrome who experience limitations to the oral skills required to bite, chew and swallow safely and no limitations on bringing food and fluid to the mouth.<sup>(15)</sup> The relationship between eating and drinking ability and other aspects of function such as gross motor function or hand to mouth function cannot be clarified when these functions are combined in the same ordinal scale. In the same way, whilst eating and drinking ability will have an impact upon intake of food and fluid, it may not be helpful to combine eating and drinking ability with the ability to meet

nutrition and hydration needs. The nutritional and hydrational requirements of one person with CP will be different from another's, even though they may have similar eating and drinking abilities. Another assumption present in some of the scales is that there will always be an association between the presence of a feeding tube and the greatest limitations to eating and drinking ability.<sup>(20,32,33,40)</sup>

The authors of the measures take different viewpoints on the question of who is best placed to report a child's eating and drinking ability across a range of foods and environmental settings: six measures<sup>(8,13,32,34,36,39)</sup> are based on information available to healthcare professionals or investigators; whilst the remaining nine measures make use of information from parents, only two have the potential to be used by both parents and healthcare professionals.<sup>(40,41)</sup> Disagreements between parent judgements about aspects of their children's eating and drinking ability and judgements made by healthcare professionals have been explicitly identified at the level of mealtime duration, eating and drinking difficulty and food texture safety.<sup>(13,32,54)</sup> Concerns about the potential discrepancy between parents' judgements about their children's eating and drinking ability expressed through questionnaires and judgements made by specially trained healthcare professionals have been acknowledged.<sup>(3,5)</sup> None of the identified measures allow for a direct comparison between ratings made by people themselves or parents and professionals.

Direct observation of eating and drinking is limited because much activity takes place within the oral cavity, pharynx and larynx out of view. Inferences about eating and drinking ability can be drawn from observation of subtle clinical signs.<sup>(55)</sup> Potentially harmful limitations to eating and drinking leading to aspiration of food and fluid into the lungs, visible through instrumental means such as videofluoroscopic examination of swallowing, have been documented.<sup>(1,9,56)</sup> "Silent aspiration" has also been documented, where aspiration takes place without the usual outward signs such as coughing.<sup>(8-10)</sup> Only six of the scales refer to aspiration or the consequences of aspiration presenting as respiratory illness,<sup>(3,8,32,38-40)</sup> two of these scales have been developed for use in the context of videofluoroscopy.<sup>(8,39)</sup>

Limitations of this systematic review include the inclusion only of those scales that had been produced or translated into English, and evidence of reliability and validity published in

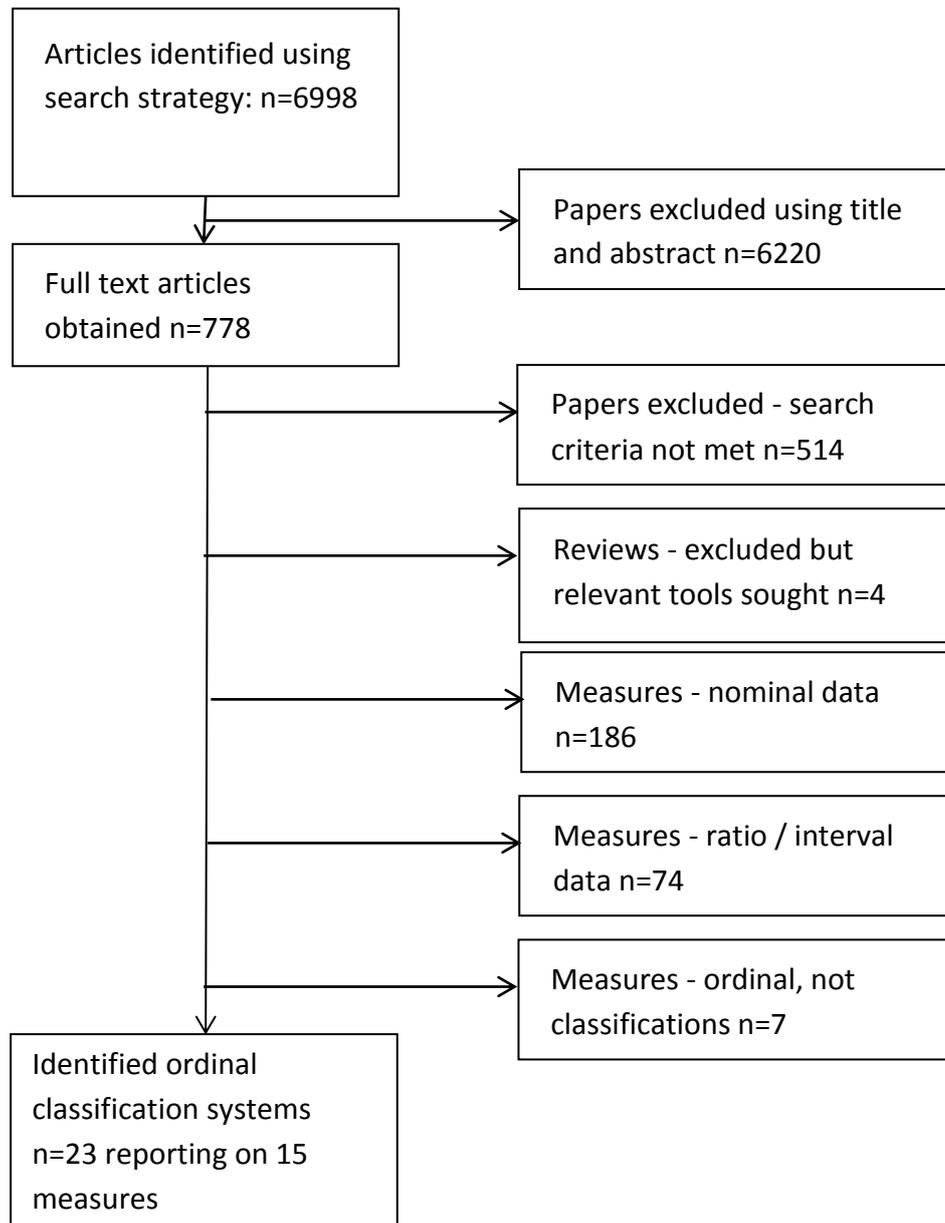
peer-reviewed studies. Scales used within CP surveillance registers<sup>(22)</sup> were only included if published. Scales assessing emotional and behavioural disturbances to eating and drinking function occurring in the paediatric population were not included. There may be unpublished data regarding validity and reliability of scales, and contact with the developers of the DDS<sup>(46)</sup> suggests this may be the case. However, we preferred to include data only from peer-reviewed publications so that an appraisal of the methodological quality of those studies could be examined. We considered using the COSMIN checklist to appraise methodological quality of studies examining validity and reliability,<sup>(57)</sup> but data emerging in the review were too limited to warrant the approach.

None of the scales identified can be considered as valid and reliable ordinal classification systems of eating and drinking ability for people with CP, of use in both clinical and research contexts by healthcare professionals, people with CP or their parents. This systematic review supports the development of a new system to classify eating and drinking through methods used to develop other classification systems,<sup>(16–19)</sup> this includes agreement about content in consultation with potential users. The adoption of such a system by clinical and research communities would be enhanced by paying attention to levels of consensus about its content and reliability of its use. A classification system of eating and drinking for use by parents and healthcare professionals would have the potential to facilitate working in partnership,<sup>(58)</sup> and facilitate more robust clinical and population-based research.

**Table I: WHO ICF Domains and Categories relating to eating and drinking**

<b>ICF Domain</b>	<b>Categories</b>
Body Structure(s)	<b>s320</b> Structure of mouth including teeth
Body Function (b)	<p><b>b510</b> Ingestion functions. Functions related to taking in and manipulating solids or liquids through the mouth into the body including <b>b5100</b> sucking, <b>b5101</b> biting, <b>b5102</b> chewing, <b>b5103</b> manipulation of food in the mouth, <b>b5104</b> salivation and <b>b5106</b> regurgitation or vomiting.</p> <p><b>b5105</b> Swallowing. Functions of clearing the food and drink through the oral cavity, pharynx and oesophagus into the stomach at an appropriate rate and speed.</p> <p><b>b535</b> Sensations associated with digestive system.</p> <p><b>b539</b> Functions related to the digestive system, including feeding tube.</p> <p><b>b440</b> Respiration functions. Functions of inhaling air into the lungs, the exchange of gases between air and blood, and exhaling air, including aspiration.</p> <p><b>b450</b> Additional respiratory functions. Additional functions related to breathing, such as coughing, sneezing and yawning.</p> <p><b>b126</b> Temperament and personality functions including attention, awareness. General mental functions of constitutional disposition of the individual to react in a particular way to situations, including the set of mental characteristics that makes the individual distinct from others.</p> <p><b>b130</b> Energy and drive functions including appetite. General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner.</p> <p><b>b152</b> Emotional functions. Specific mental functions related to the feeling and affective components of the processes of the mind.</p>
Activity (d)	<p><b>d550</b> Eating. Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and consuming it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining.</p> <p><b>d560</b> Drinking. Taking hold of a drink, bringing it to the mouth, and consuming the drink in culturally acceptable ways, mixing, stirring and pouring liquids for drinking, opening bottles and cans, drinking through a straw or drinking running water such as from a tap or a spring; feeding from the breast.</p> <p><b>d660</b> Assisting others with their learning, communicating, self-care, movement, within the house or outside; including self-care, movement, nutrition and health.</p>
Participation (d)	<b>d9205</b> Socializing. Engaging in informal or casual gatherings with others, such as visiting friends or relatives or meeting informally in public places.
Environmental Factors (e)	<p><b>e110</b> Products or substances for personal consumption. Any natural or human-made object or substance gathered, processed or manufactured for ingestion.</p> <p><b>e1151</b> Assistive products and technology for personal use in daily living.</p> <p><b>e340</b> Personal care providers and personal assistants.</p> <p><b>e410</b> Individual attitudes of immediate family members.</p> <p><b>e5800</b> Health services and programmes at a local, community, regional, state or national level, aimed at delivering interventions to individuals for their physical, psychological and social well-being.</p>

**Figure 1: Process of identification of ordinal scales used to classify eating and drinking abilities of people with CP**



**Table II: Ordinal Measures used to classify eating and drinking performance for people with CP: content, structure, validity and reliability**

Scale / Author	Scale	User	Sampling Frame	ICF Category	Content Validity	Reliability
Andrada <sup>(40)</sup> Portuguese Survey of CP in Europe scale.	5 level ordinal scale (I to V) with increasing limitations to performance for each construct within each level. Ability to bring food and drink to the mouth, ability to chew and swallow and time taken for meals are assumed to all be related; tube feeding occurs in Level V.	Speech and language therapists, healthcare professionals and parents.	Children with CP; n=30; spastic bilateral, spastic unilateral, dyskinetic, ataxic, unspecified severity; age 4y-7y; on Portuguese CP surveillance register.	Total=6 b440 safety; b510 oral skills; b5105 swallowing; b539 tube feeding; d550/d560 assistance required; e110 food textures; unspecified "duration".	None reported.	n=30 children with CP; kappa = 0.43 healthcare professionals vs parents, kappa = 0.56 speech and language therapists vs parents, 0.61 speech and language therapists vs healthcare professionals.
Calis et al. <sup>(32)</sup> Dysphagia Severity Score (DSS).	4 levels linked to Dysphagia Disorders Survey (DDS) <sup>(46)</sup> Part 2 scores: 1)No dysphagia. 2)Mild dysphagia. 3)Moderate to severe dysphagia. 4)Profound dysphagia (nil by mouth).	Clinician / researcher qualified to use DDS.	Individuals with CP; n=166; GMFCS IV or V; age 2y 1mo-19y 1mo, mean age 9y 4mo; attending specialised day care, residential and educational centres in Western region of the Netherlands.	Total=8 b126 awareness; b440 aspiration; b510 loss of food; b510 oral skills; b510 safety of oral feeding; b5105 swallowing; b539 gastro-oesophageal signs; b539 tube feeding.	None reported.	None reported.

Dahlseng et al. <sup>(20)</sup> Norwegian Survey of CP in Europe scale.	5 point ordinal scale (1-5): 1)Independent. 2)In need of some assistance. 3)Totally dependent upon assistance not tube feeding. 4)Partly tube fed. 5)Mainly tube fed. Levels 1 and 2 are children with no “feeding problems”; levels 3 to 5 are children with “feeding problems”.	Paediatric neurologist with parents using registration form.	Children with CP; n=661; GMFCS I-V; age3.7y-10.4y; on Norwegian CP surveillance register.	Total=2 b539 tube feeding; d550/d560 assistance required.	None reported.	None reported.
Erkin et al. <sup>(33)</sup>	4 levels defined by food textures managed: Normal, Mild dysfunction, Moderate dysfunction or Severe dysfunction (tube fed).	Clinician / researcher from maternal interview.	Children with CP; n=120; GMFCS I to V; age 2y-18y; attending Ankara Physical Medicine and Rehab Education and Research Hospital.	Total= 5 s320 structure of the mouth; b510 ingestion “feeding difficulty”; b5105 swallowing; b539 tube feeding; e110 food textures and fluid consistencies.	None reported.	None reported.
Fung et al. <sup>(3)</sup> North American Growth Project Questionnaire	4 levels defined by food textures managed: Normal, Mild, Moderate or Severe feeding dysfunction.	Clinician / researcher from parent questionnaire.	Children with CP; n=230; GMFCS III to V; age 5y-14y; recruited from 6 centres in USA and Canada.	Total=6 b440 respiratory illness; b450 coughing, safety; b510 ingestion oral skills, “feeding dysfunction”; b5105 swallowing; b539 tube feeding; e110 food textures and	None reported.	None reported.

fluid consistencies.

Gisel and Alphonse <sup>(34)</sup> Classification System.	3 levels defined by standard deviation from chewing norms based on length of time between specified food textures entering mouth and first swallow: Mild, Moderate or Severe.	Clinician / researcher.	Individuals with CP; n=100; range of severity of CP; age 2y-16y; from Montreal area.	Total=3 b510 duration of ingestion; b5105 swallowing; e110 food textures.	Chewing cycle curves developed for typical population in laboratory (n=103 2-8yrs).	None reported.
Haley et al. <sup>(41)</sup> Pediatric Evaluation of Disability Inventory (PEDI).	4 levels defined by food textures managed: 1)Pureed / blended. 2)Ground / lumpy. 3)Cut up / chunky. 4)All food textures.	Clinician / researcher from parent report.	Children with CP; n=170; GMFCS I-V; age 1y 6mo-3y; recruited across Queensland and Victoria in Australia.	Total=2 b510 ingestion; e110 food textures.	Item A in Self Care Domain of PEDI; concurrent validity reported for whole instrument not individual item.	Reliability reported for Norwegian version of whole instrument, not individual item.
Jen-Wen Hung et al. <sup>(35)</sup>	3 levels defined by level of assistance: 1)Totally dependent upon caretaker. 2)Partially dependent (some help required). 3)Totally independent in feeding.	Clinician / researcher from parent report.	Children with CP; n=75; age5mo- 10y; quadriplegia v hemi v diplegia, wheelchair bound v community walker; attending rehabilitation centre Chang Gung Memorial Hospital Kaoshiung Taiwan.	Total=1 d550/d560 level of assistance.	None reported.	None reported.

Morton et al. <sup>(8)</sup>	3 levels defined by respiratory illness: 1)No respiratory infection. 2)Minor respiratory infections requiring one course of antibiotics. 3)Recurrent respiratory tract infections with 2 or more courses of antibiotics.	Clinician / researcher.	Children with CP; n=26; spastic quadriplegia, unspecified severity; age 7mo-16y; attending Derbyshire Children's hospital.	Total=1 b440 respiratory illness.	None reported.	None reported.
Reilly JJ et al. <sup>(36)</sup>	4 levels defined: 1)No apparent feeding problem. 2)Mild swallowing / feeding difficulty. 3)Moderate swallowing or feeding difficulty. 4)Severe swallowing and feeding problems.	Clinician / researcher.	Children with CP; n=30; spastic or athetoid, unspecified severity; age 4.3y-17.9y; attending one special school for children with motor disability.	Total=3 b510 unspecified "feeding difficulty"; b5105 swallowing; e110 food textures and fluid consistency.	None reported.	None reported.
Reilly S et al. <sup>(13)</sup>	4 categories of oral motor dysfunction: None, Mild, Moderate and Severe.	Clinician / researcher.	Children with CP; n=49; range of severity and type of CP; age 1y-6y; from two inner London district health authorities.	Total=1 b510 ingestion; unspecified "feeding dysfunction".	None reported.	None reported.

Selley et al. <sup>(37)</sup> Feeding Difficulty Symptom Score.	5 groups defined: 1)General mealtime difficulties. 2)Saliva control problem only. 3)Swallowing difficulty. 4)Fear of choking or coughing, with or without a saliva control problem. 5)Both swallowing difficulty and fear of choking or coughing.	Clinician / researcher from parent report.	Children with CP; n=117; range of severity and type of CP; 1y-18y, mean 8.6y; attending Feeding and Swallowing Advisory Centre at Vbranch House Special School Age.	Total=5 b153 fear of choking; b440 choking; b450 coughing; b510 saliva control; b5105 swallowing; unspecified "general mealtime difficulties".	None reported.	None reported.
Sheppard <sup>(38)</sup> Dysphagia Management Staging Scale (DMSS).	Five levels: No symptoms, Mild, Moderate, Severe and Profound swallowing or feeding disorder. Ability to bring food and drink to the mouth is considered separately; number of management strategies used (linked to DDS assessment) determines severity rating.	Clinician / researcher qualified to use DDS; <sup>(46)</sup> information taken from parent questionnaire.	None reported.	Total=15 b126, b130 and b152 mealtime behaviours; b535 gastro-oesophageal signs; b539 tube feeding; b440 respiratory function; b450 safety; b510 ingestion oral skills; b510 saliva control; b5105 swallowing; d660 nutrition / hydration adequacy; e1151 postural management strategies; e110 food textures and fluid consistencies;	None reported.	None reported.

				e340 special techniques; e5800 management strategies.		
Sullivan et al. <sup>(6)</sup> Oxford Feeding Study.	Six levels defined: 1)Always needs help. 2)Some difficulty needs help. 3)Can feed but slow and messy - help given. 4)Tube fed or not fed by mouth 5)Some difficulty, no help 6)Self feeds.	Clinician / researcher from parent questionnaire.	Children with neurological impairment; n=100; mild, moderate, severe CP; age 4y-13y, mean 9y SD 2y5mo; from four counties of UK region.	Total=2 b539 tube feeding; d550/d560 assistance required, duration and messiness associated with self-feeding.	None reported.	None reported.
Zerilli et al. <sup>(39)</sup>	3 groups defined: 1)Minimal or no risk of aspiration. 2)Moderate risk of aspiration. 3)No oral feeding due to excessive risk of aspiration.	Clinician / researcher.	Children with CP; n=11; unspecified severity or type of CP; age 11mo-13y; attending CS Mott Children's Hospital, Michigan US.	Total=3 b440 aspiration; b5105 safety; e5800 special techniques.	None reported.	None reported.

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**Table III: Frequency of ICF categories associated with constructs of identified ordinal scales**

<b>ICF Categories</b>	<b>TOTAL</b>
<b>Body Structure:</b>	
<b>s320</b> Structure of mouth.	1 <sup>(33)</sup>
<b>Body Function:</b>	
<b>b510</b> Ingestion functions.	10 <sup>(3,13,32-34,36-38,40,41)</sup>
<b>b5105</b> Swallowing.	9 <sup>(3,32-34,36-40)</sup>
<b>b535</b> Sensations associated with digestive system.	1 <sup>(38)</sup>
<b>b539</b> Functions related to the digestive system, including feeding tube.	7 <sup>(3,6,20,32,33,38,40)</sup>
<b>b440</b> Respiration functions, including aspiration.	6 <sup>(3,8,32,38-40)</sup>
<b>b450</b> Additional respiratory functions including coughing.	3 <sup>(3,37,38)</sup>
<b>b126</b> Temperament and personality functions including attention, awareness.	2 <sup>(32,38)</sup>
<b>b130</b> Energy and drive functions including appetite.	1 <sup>(38)</sup>
<b>b152</b> Emotional functions.	2 <sup>(37,38)</sup>
<b>Activity:</b>	
<b>d550</b> Eating and <b>d560</b> drinking.	4 <sup>(6,20,35,40)</sup>
<b>d660</b> Assisting others including nutrition and health.	1 <sup>(38)</sup>
<b>Participation:</b>	
<b>d9205</b> Socializing.	0
<b>Environment:</b>	
<b>e110</b> Products or substances for personal consumption including food textures and fluid consistency.	7 <sup>(3,33,34,36,38,40,41)</sup>
<b>e1151</b> Assistive products and technology for personal use in daily living.	1 <sup>(38)</sup>
<b>e340</b> Personal care providers and personal assistants.	1 <sup>(38)</sup>
<b>e410</b> Individual attitudes of immediate family members.	0
<b>e5800</b> Health services including delivering interventions.	2 <sup>(38,39)</sup>

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**APPENDIX I:**

**Table SI: Example of Search Strategy used with MEDLINE**

	<b>Group 1 key words and higher order subject headings for "measuring" and "classifying"</b>	<b>Number of Papers</b>	
1	measur*.ti,ab	2033691	
2	assess*.ti,ab	1440951	
3	classif*.ti,ab	318669	
4	diagnos*.ti,ab	1421411	
5	tool*.ti,ab	309830	
6	scale*.ti,ab	358331	
7	categor*.ti,ab	170530	
8	quantif*.ti,ab	220069	
9	(grade* OR grading*).ti,ab	235997	
10	(rate* OR rating*).ti,ab	1692584	
11	system*.ti,ab	2034800	
12	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11	7007406	Group 1 "measuring" terms combined
	<b>Group 2 key words and higher order subject headings for "cerebral palsy"</b>		
13	"cerebral pals*".ti,ab	13124	
14	"brain injur*".ti,ab	29577	
15	"spastic quadripleg*"	412	
16	Dipleg*	1688	
17	Atheto*	798	
18	"Worster Drought"	26	
19	exp BRAIN DAMAGE, CHRONIC/	29035	
20	exp BRAIN INJURIES/	42932	
21	13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20	85335	Group 2 "cerebral palsy" terms combined
	<b>Group 3 key words and higher order subject headings for "eating and drinking ability"</b>		
22	eat*.ti,ab	50419	
23	drink*.ti,ab	81690	
24	dysphag*.ti,ab	15218	
25	swallow*.ti,ab	17100	
26	suck*.ti,ab	16027	
27	feed*.ti,ab	234297	
28	chew*.ti,ab	9725	
29	(biting OR bite*).ti,ab	24978	
30	(nutrition* OR nutrit*).ti,ab	158042	
31	deglutition.ti,ab	1754	
32	"activities of daily living".ti,ab	12340	
33	exp DEGLUTITION/	6414	
34	exp DEGLUTITION DISORDERS/	37115	
35	exp FEEDING BEHAVIOR/	105890	
36	exp FEEDING METHODS/	34775	
37	exp EATING/	53382	
38	ACTIVITIES OF DAILY LIVING/	44158	
39	22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38	666856	Group 3 "eating and drinking ability" terms combined
<b>40</b>	<b>12 AND 21 AND 39</b>	<b>1877</b>	<b>Group 1, 2 AND 3 COMBINED</b>
41	40 [Limit to: Humans]	<b>1781</b>	<b>Group 1, 2 AND 3</b>

			<b>COMBINED relating to humans</b>
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**Table SII: Identified key texts and number of papers from forward chasing and backward chasing of citations using Web of Knowledge and Scirus**

Paper	Web of Knowledge, forward chasing	Scirus, forward chasing citations	Backward chasing 1 <sup>st</sup> generation	Backward chasing 2 <sup>nd</sup> generation
Reilly S, Skuse D, Mathisen B, & Wolke D. The objective rating of oral-motor functions during feeding. <i>Dysphagia</i> . 1995;10 (3) 177-191.	30 imported 27.4.12	8 imported 27.4.12	61	289
Reilly S, Skuse D & Poblette X. Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. <i>J of Pediatrics</i> . 1996;129 (6) 877-882.	123 imported 27.4.12	141 imported 27.4.12	32	324
Fung EB, Samson-Fang L, Stallings VA, Conaway M, Liptak G, Henderson RC, Worley G et al. Feeding Dysfunction is Associated with Poor Growth and Health Status in Children with Cerebral Palsy. <i>J of Am Diet Assoc</i> .2002;102 (3) 361-373.	71 imported 27.4.12	22 imported 27.4.12	41	542
Gisel EG & Patrick J. Identification of children with cerebral palsy unable to maintain a normal nutritional state. <i>Lancet</i> . 1988; 1 (8580) 283-6.	82 imported 27.4.12	58 imported 27.4.12	27	106
Gisel EG & Alphonse E. Classification of eating impairments based on eating efficiency in children with cerebral palsy. <i>Dysphagia</i> .1995;10 (4) 268–74.	28 imported 27.4.12	44 imported 27.4.12	37	314
Morton R, Minford J et al. Aspiration with dysphagia: the interaction between oropharyngeal and respiratory impairments. <i>Dysphagia</i> .2002;17 192-196.	12 imported 27.4.12	11 imported 27.4.12	23	230

Morton R, Wheatley R & Minford J. Respiratory tract infections due to direct and reflux aspiration in children with severe neurodisability. <i>Dev Med&amp; Child Neuro.</i> 1999;45 (9) 603-612.	35 imported 27.4.12	27 imported 27.4.12	37	434
Selley WG, et al. The Exeter Dysphagia Assessment Technique. <i>Dysphagia.</i> 1990;4 (4) 227-235.	42 imported 27.4.12	49 imported 27.4.12		
Parrott LC et al. Dysphagia in cerebral palsy: a comparative study of the Exeter Dysphagia Assessment Technique and a multidisciplinary assessment. <i>Dysphagia.</i> 1992;7 (4) 209-219.	15 imported 27.4.12	7 imported 27.4.12		
Schoening HA and Iversen, IA. Numerical scoring of self-care status: a study of the Kenny self-care evaluation. <i>Archphys med&amp; rehab.</i> 1968;49 (4) 221-9.	44 imported 27.4.12	20 imported 27.4.12		
Schoening HA et al. Numerical scoring of self-care status of patients. <i>Arch phys med&amp; rehab.</i> 1965;46 (10) 689-97.	80 imported 27.4.12	6 imported 27.4.12		
Msall M et al. The Functional Independence Measure for Children (WEEFIM) – Conceptual Basis and Pilot Use in Children with Developmental-Disabilities. <i>Clinical Pediatrics.</i> 1994;33(7) 421-430.	152 imported 27.4.12	19 imported 24.8.12	51	141
Kenny D J et al. Development of a multidisciplinary feeding profile for children who are dependent feeders. <i>Dysphagia.</i> 1989;4(1) 16-28.	26 imported 27.4.12	1 imported 24.8.12		
Calis EA et al. Dysphagia in children with severe generalized cerebral palsy and intellectual disability. <i>Dev Med &amp; Child Neuro.</i> 2008;50 (8) 625-630.	13 imported 27.4.12	2 imported 24.8.12	23	337

Benfer KA et al. Clinimetrics of measures of oropharyngeal dysphagia for preschool children with cerebral palsy and neurodevelopmental disabilities: a systematic review. <i>Dev Med&amp; Child Neuro.</i> 2012 54784–95.	none	none	52	576
IMPORTED 1115 from Web of Knowledge deduplicated= 623				