

# Development of a functional eating and drinking ability classification system for individuals with cerebral palsy.

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The University of Brighton in collaboration with Chailey Heritage Clinical Services, Sussex Community NHS Trust.

## **ABSTRACT:**

**Background:** Disorders of movement and posture associated with cerebral palsy (CP) often lead to childhood difficulties with feeding, eating, drinking and swallowing which extend into adulthood. The consequences of compromised eating and drinking skills include respiratory disease, due to food and fluid entering the lungs, and malnutrition, leading to poor growth and health. There is no agreement in clinical and research contexts about the classification of eating and drinking abilities of people with CP to reflect severity of limitations to function. The study aim was to develop a valid and reliable system to classify eating and drinking performance of people with CP, using a pragmatic Mixed Methods approach.

**Method:** The first draft of the Eating and Drinking Ability Classification System (EDACS) was developed from my clinical experience, the research literature and clinical assessments. A series of groups were held, using a Nominal Group Process (NGP), inviting experts to closely examine the content and wording of EDACS. After each group, EDACS was modified and presented to the following group until no new ideas or comments were made. A Delphi Survey (DS) was conducted with a wider group of international experts to further examine and modify the content of EDACS; the DS was repeated until 80% of panellists agreed with the content. In the final stage, EDACS was used by speech and language therapists (SaLTs) and parents to classify the eating and drinking abilities of children with CP; the agreement and reliability between classifications was tested.

**Findings:** Fifty six UK experts participated in 7 nominal groups. The revised EDACS draft was examined by 95 expert panellists in an international DS; more than 80% of panellists agreed with the content of EDACS, after two rounds of the DS. Experts included people with CP, parents, health professionals and researchers. When SaLTs used EDACS to classify 100 children, absolute agreement was 78%, kappa=0.72; ICC=0.93 (95% CI 0.90 to 0.95). Any disagreement was only by one level, with one exception. When SaLTs and parents classified 48 children, absolute agreement was 58%, kappa=0.45, ICC=0.86 (95% CI 0.76 to 0.92). Parents either agreed with SaLTs, or rated their children as more able by one level.

The new Eating and Drinking Ability Classification System provides a valid and reliable system for classifying eating and drinking performance of people with CP. EDACS describes the whole range of ability from age 3 years, providing a context for parents to consider their own child's eating and drinking.



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Finally I would like to thank my family for giving me the space and time to write, especially Duncan, because if you were not here, none of this would have happened.



**Author's Declaration:**

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed:

*Dani Seller*

Dated:

*30.1.2014*



**Abbreviations:**

- CFCS – Communication Function Classification System (Hidecker et al. 2011)
- CP – Cerebral Palsy
- DDS – Dysphagia Disorders Survey (Sheppard 2003)
- DS – Delphi Survey (Delbecq et al. 1975)
- EDACS – Eating and Drinking Ability Classification System (Sellers et al. 2013b)
- EDAT – Exeter Dysphagia Assessment Technique (Selley et al. 1990)
- FEES - Fibreoptic Endoscopic Evaluation of Swallowing
- FEEST – Fibreoptic Endoscopic Evaluation of Swallowing with Sensory Testing
- GMFCS – Gross Motor Function Classification System (Palisano et al. 1997)
- GMFM – Gross Motor Function Measure (Russell et al.1989).
- GORD – Gastro-oesophageal Reflux Disease
- IRAS – Integrated Research Application System ([www.myresearchproject.org.uk](http://www.myresearchproject.org.uk))
- MACS – Manual Ability Classification System (Eliasson et al. 2006)
- MM – Mixed Methods Research
- NGP – Nominal Group Process (Delbecq et al. 1975)
- NHS – National Health Service
- NIHR – National Institute for Health Research
- OT – Occupational Therapist
- PEDI – Pediatric Evaluation of Disability Inventory (Haley et al. 1998)
- RCP – Royal College of Physicians
- RDA – Recommended Daily Allowance

RfPB – Research for Patient Benefit (research grant funding stream within the NIHR)

QUAL – Qualitative Research

QUAN – Quantitative Research

SaLT – Speech and Language Therapist or Speech and Language Pathologist

SCPE – Survey of Cerebral Palsy in Europe collaborative group (SCPE 2000)

SOMA – Schedule of Oral Motor Assessment (Reilly et al. 2000)

VFSS – Videofluoroscopic Swallowing Studies

WHO ICF – World Health Organisation International Classification of Functioning Disability and Health

# 1 Chapter 1 - Introduction

*“Can you credit all the fuss that was made of a cripple, mused Joseph Meehan as he settled his back against the seat for the flight home to Dublin... Heretofore he had always declined any offer of refreshment, fearful always of creating a scene if fluid swallowed awkwardly went against his breath... It came as a surprise to Nora when Joseph indicated in his silent code that he was bold enough now to attempt the arduous feat for him of swallowing down something in public. As his mother sensed his new found bravery, she determined to pour small slurps of coffee into his nervous mouth. Determinedly he smuggled the beverage past his decidedly stubborn tongue and let it seep down into his stomach.”*

From the novel: “Under the Eye of the Clock” by Christopher Nolan (1987 p.1).

## 1.1 Introduction

The act of eating and drinking is essential for survival, a means of providing the body with sufficient food and drink to satisfy two of the most basic needs of any living organism. A great deal of thought is often given to what we eat or drink such as its taste and texture and whether it will satisfy our appetite and sensory urges. Food and drink will often form the backdrop for social gatherings whether that is at family mealtimes, celebrations or special occasions. In contrast, very little thought is given to the mechanics behind eating and drinking, that is, how food and drink are transferred from the entry point into the body, the mouth, on to the stomach for digestion.

Individuals with cerebral palsy (CP) cannot use the full range of physical movement available to most of us, with difficulties arising in the development of walking, speech and hand function. The movements involved in biting, chewing and swallowing are also frequently affected. Individuals with CP, unable to move their mouth muscles to eat and drink efficiently, are likely to have problems eating enough food to grow and to stay healthy. Some will have problems with frequent chest infections connected to the entry of particles of food or drink into the lungs when they swallow. These difficulties continue throughout their lives.

## 1.2 Background to project

The research question at the heart of the project arose from my work as a speech and language therapist at Chailey Heritage Clinical Services, a specialist NHS centre providing care for children and young people with complex physical disability. Many of the individuals in our care have CP, the most common motor disability affecting children, arising in early childhood.

As a member of the Nutrition Team, I worked with a paediatrician, dietitian and nutrition nurse specialist to provide appropriate nutritional management for children and young people with complex physical disability. My role was to assess each child's ability to bite, chew and swallow food and drink. I would describe each child's eating and drinking skills to my colleagues as part of the formulation of a multi-professional management plan. The question "Was there a simple rating scale of a child's eating and drinking abilities?" to supplement or replace the clinical descriptions I provided, arose frequently. Searches at the time for such a scale revealed that the answer to this question was "no".

We examined some of the ordinal scales or classification systems in use to describe other aspects of functioning for individuals with cerebral palsy, particularly the Gross Motor Function Classification System (GMFCS, Palisano et al. 1997) and the Manual Ability Classification System (MACS, Eliasson et al. 2006). It became apparent that the development of such scales, of use in clinical and research contexts, was contributing significantly to knowledge about the impact of CP on function.

The GMFCS is a 5 point ordinal scale which classifies how individuals with CP are able to move, that is their ability to walk, walk with aids, or their reliance upon a wheelchair for mobility. By arranging five narrative descriptions or "word pictures" in order of functional limitation, the GMFCS established a simple rating scale, akin to the grading scales used elsewhere in medicine such as those describing tumours (Rosenbaum et al. 2008). The influence of the GMFCS can be seen in the numerous citations within leading international journals (Morris 2008). It has replaced previously used variously defined terms such as "mild", "moderate" and "severe" applied to motor problems with precisely defined terms that have shared meaning for a wide range of people, parents as well as professionals. The GMFCS is used internationally, in research, clinical and social care contexts.

### **1.3 Professional motivation**

In my clinical work, there have been many occasions when significant others such as parents, carers, doctors or nurses have shown limited awareness of the vital features of someone's eating and drinking skills. Difficulties in eating and drinking are not apparent in a typical consultation with a paediatrician, unlike other areas of functioning such as mobility and communication. I have noticed children struggling to make the movements to bite, chew and swallow food, experiencing frequent episodes of choking and coughing. Because the mealtime "struggles" were ever present, some parents or carers were unconcerned by what I considered to be alarming clinical signs. My concerns have been heightened when observing children who were unable to use speech, facial expressions, body language or movement to communicate unequivocally their discomfort, protests or struggles, being completely dependent upon the other to understand or interpret their meaning. I have attended a number of studies of swallowing ability where a dynamic X-Ray recording, known as a videofluoroscopy, revealed the unsuspected and potentially life threatening leakage of food and drink in to an individual's lungs every time something was swallowed. Such investigations were followed by the unfolding emotional and physical journey of that individual and their parents coming to terms with that knowledge and making the decision whether or not to limit oral eating and drinking. The decision to replace the normal experience of eating and drinking with an artificial milk feed delivered to the stomach via a tube is a very challenging one to make.

The absence of a functional classification system describing limitations to the eating and drinking performance has an impact on clinical care and advancement of knowledge through research. It is important as a speech and language therapist to develop my skills to attend to subtle signs of eating and drinking difficulty and to consider how that information is communicated to others. The research literature investigating the impact of eating and drinking difficulties on health, growth and development of individuals with CP makes use of a plethora of measures (Sullivan et al. 2000 and 2002, Fung et al. 2002, Reilly et al. 1996, Gisel and Patrick 1988, Day et al. 2007, Parkes et al. 2010). There is no agreement about how to classify the severity of an individual's eating and drinking difficulty, that is the ability to move muscles to bite, chew and swallow. The words "severe", "moderate", and "mild" are all used without an agreed definition. For some researchers, a "severe" difficulty is when an

individual cannot feed themselves. Others mistakenly assume that only individuals with more severe general movement difficulties have problems with eating and drinking.

Having identified a “gap” in knowledge, the source of some confusion and unhelpful assumptions, I embarked upon a research project with the potential to fill that gap.

## **1.4 Project aim**

The project aim was to develop a valid and reliable system to classify the eating and drinking abilities of individuals with CP, in the context of other functional classification systems such as the GMFCS and MACS. The focus of the classification system was on the range of movement of the component parts of the mouth and throat and the impact on eating and drinking performance. The name of the system, that has evolved through the different stages of the project, is the “Eating and Drinking Ability Classification System” or EDACS.

EDACS was drafted from clinical assessments, current literature and clinical experience, based on an original idea currently in use at Chailey Heritage Clinical Services. The content of EDACS has been examined by experts from diverse backgrounds in two additional development phases: Nominal Group Process and Delphi Survey. Parents and people with CP were considered to be experts because of their direct knowledge of eating and drinking; they were consulted alongside a diverse selection of professionals with expert knowledge of eating and drinking, nutrition, communication, care and management of individuals with CP. The development process gave the opportunity for a range of potential users of EDACS to comment and influence the content of the system.

The reliability of EDACS when used by parents and speech and language therapists was examined using inter-observer reliability studies, where statistical measures of reliability (Cohen’s kappa and ICC) were calculated.

The potential benefits to individuals with CP and families include:

- Increased awareness of the mouth movements necessary for efficient and safe eating and drinking, distinguishing them from other types of movement.
- Clear and efficient communication about an individual’s eating and drinking skills between professionals, parents and individuals with CP.

- Means of directing limited resources to those with the most severe difficulties, highest risk of malnutrition and therefore the greatest need.
- Reduction of risks to health when eating or drinking.
- Contribution to the identification of treatment needs such as alternative feeding methods, or intensive movement therapy to improve skills.
- Improved planning concerning levels of training and experience of care staff.
- Facilitation of research including large scale surveillance of individuals with CP.

## **1.5 Funding**

The National Institute for Health Research (NIHR) commissioned this independent research project through the Research for Patient Benefit competition, for a period of three years (1<sup>st</sup> April 2010 to 31<sup>st</sup> March 2013). The views expressed are not necessarily the views of the NHS, NIHR or the Department of Health.

A significant requirement in applying for funding from the NIHR is the inclusion of views of users of the service at all levels of the project. People with CP and their parents were involved in all stages of the project. The NIHR funded the involvement of an expert Project Team, including a parent of a young person with CP, and a research administrator.

Funding for my doctoral studies at the University of Brighton has been provided by the Research Department at Chailey Heritage Clinical Services.

## **1.6 NHS Ethics and Research Governance**

The project received all the necessary approvals from the NHS Ethics Committee – see Appendix 1. The research project has been conducted within the Research Governance Framework for Health and Social Care. The sponsor for the project, that is the organisation responsible for securing the arrangements to initiate, manage and finance the study, is the Sussex NHS Research Consortium, based at Worthing Hospital.

## **1.7 Intellectual property**

The intellectual work described here in the thesis is the property of the University of Brighton. The Eating and Drinking Ability Classification System is the property of Sussex Community NHS Trust and Chailey Heritage Clinical Services, and is subject to copyright.

The classification system will be free to download from the EDACS webpages ([www.EDACS.org](http://www.EDACS.org)), part of Sussex Community NHS Trust website, following the same pattern of distribution created by the authors of the GMFCS and MACS.

A log book was kept in order to record details of the intellectual process of EDACS design. The Project Team and I assert our moral right to be identified as the creators of EDACS.

## **1.8 Project Team**

The Project Team, which included three of my academic supervisors, proved to be an invaluable source of guidance and inspiration. Contributions from the team were made at the regular Project Team meetings and through electronic communication via e-mail. All significant decisions about the project involved consultation with the whole team. The members of the Project Team and their relevant experience are listed below:

Mr Mike Carter is the parent of young person with CP. Mike Carter knows what it is like to care for someone who is dependent upon him to meet all their basic needs. He has direct experience of the eating and drinking difficulties of someone with CP and the impact of these difficulties upon growth and health. Mike also has experience of multiple interactions with a wide range of health, social care and educational professionals, concerning his child's care. Mike works as a Pharmacist.

\*Dr Matthew Hankins is a senior lecturer in Public Health at the University of Southampton. Matthew Hankins teaches quantitative research methods, statistics, psychometrics and epidemiology at undergraduate and postgraduate level. His research is generally in the area of behavioural medicine across the health professions, but more specifically in the area of patient reported outcome measures.

\*Dr Anne Mandy from the University of Brighton in Sussex is currently a Director of Postgraduate Studies. Anne Mandy joined the Project Team in her capacity as Reader and Research Student Division Leader for the Clinical Research Centre in the School of Health Professions and academic supervisor for the author. Her current research interest and activity includes assistive technology, children and adults with complex disability and health psychology.



Dr Chris Morris is a Senior Research Fellow, leading the Peninsula Cerebra Research Unit at the University of Exeter. The Peninsula Cerebra Research Unit carries out a broad programme of applied health services research aimed at evaluating ways to improve the health and wellbeing of disabled children and their families. Chris Morris' principal research interests include addressing measurement issues in childhood disability, the appraisal and use of patient reported outcome measures, and involving families in all aspects of research. Chris has considerable experience in the development and testing of the GMFCS and other classification systems for individuals with CP.

Dr Lindsay Pennington is a senior lecturer and speech and language therapist at Newcastle University. Lindsay Pennington's research focusses on the causes and prevalence of oro-motor and communication disorders in childhood neuro-disability, the impact of these disorders on young people's health and well-being and the effectiveness and acceptability of speech and language therapy interventions.

\*Dr Terry Pountney was the Head of Research, at Chailey Heritage Clinical Services, Sussex at the start of the project. Terry Pountney's research has focussed on improving the quality of life for children with complex disability and their families, with particular reference to postural management. Unfortunately, Dr Pountney had to withdraw from the Project Team and discontinue academic supervision in September 2012.

Ms Sarah Ford was the Research Administrator for the project, based at Chailey Heritage Clinical Services.

\*Indicates members of the Project Team who were also academic supervisors for the project.

Dr Graham Stew kindly agreed to replace Dr Pountney as the third academic supervisor.

## **1.9 Overview of Chapters**

I adopted a Mixed Methods research strategy to develop EDACS within a pragmatic paradigm. There were distinct strands at each stage of the project, collecting both qualitative and quantitative data. Traditionally, research strategies to collect and analyse quantitative data, within a post-positivist paradigm, are reported using a particular style of writing using third person, passive tense as if the researcher was not part of the research process. In contrast, research strategies to collect qualitative data, using a constructivist paradigm are

typically reported using language based in the first person, reflecting the direct experiences of the researcher that are part of the research strategy. As a researcher using Mixed Methods I am faced with the dilemma of which writing style to adopt. At times, it has felt appropriate to write in the third person and at others to be explicitly present in the research process and write from “my” perspective. I have made a deliberate choice to make use of both writing styles depending upon what is being written and where “I” am in relation to what is being discussed.

The chapters giving details of the literature review, methods, results and discussion were written in the third person. The chapters giving details of methodology and philosophical background, ethical considerations and my reflective account of the project were written in the first person.

Chapter 2 provides a review of the research literature underpinning the project. Challenges to eating and drinking arising from CP and associated risks to health are considered. An overview of the different ways of measuring and examining the eating and drinking abilities of individuals with CP is given, followed by an exploration of functional classification systems for CP and different models of disability. A brief overview of the systematic review conducted as part of the programme of research is also included. Chapter 3 details the research strategy utilised within the project including a description of the philosophical standpoint adopted. Chapter 4 details the ethical considerations in developing EDACS, including the National Health Service ethics processes and Research Governance requirements.

Chapter 5 contains details of the research methods used in the development of EDACS, including the Nominal Group Process, Delphi Survey and inter-observer reliability studies. Because of the sequential nature of the research design, results from the Nominal Group Process and some results from the Delphi Survey are detailed in Chapter 5. Chapter 6 provides full details of the newly developed classification system, further results from the Delphi Survey and results from the inter-observer reliability studies. The whole project, including the results, is discussed in Chapter 7. My personal reflections on the journey of the research project are given in Chapter 8.

## **2 Chapter 2 - Literature Review**

### **2.1 Introduction**

The focus of this research concerns the classification of the eating and drinking abilities of individuals with cerebral palsy (CP). The following chapter provides an overview of CP and current models for thinking about disability in a social context. The functional skills that are required to eat and drink safely and efficiently are considered, so too are the different ways that eating and drinking have been investigated. Other functional classification systems that have been developed for use with individuals with CP will be described and the methods that were used to create them will be appraised.

### **2.2 Eating and drinking**

The ability to eat and drink is essential for health and survival. Whilst in utero, the unborn foetus develops functional swallowing skills practising on amniotic fluid. Ross et al. (1998) document that spontaneous in utero swallowing and ingestive behaviour by the developing foetus contributes importantly to the regulation of amniotic fluid volume and composition. This practised skill is one of the first things that a new-born infant actively does, making use of reflex patterns of movement to draw milk into its body. An infant's early dependency on sucking to consume an exclusively liquid diet is replaced as the infant matures physically. Increasing head control, postural stability and physical maturation lead to significant changes in how the infant moves the parts of its body necessary for eating solid food. The infant gradually learns to isolate the movements of the jaw, lips and tongue from each other.

The age at which solid food is introduced to developing infants is culturally dependent. The current UK Department of Health / UNICEF weaning guidelines (2008) recommend that babies are ready to eat a mixed diet at approximately 6 months when they are able to sit up, when they want to chew, when they are putting toys and other objects in their mouth, and when they are reaching and grabbing efficiently. As can be seen from these guidelines, there is a close relationship between the overall physical development of the infant and the development of oral skills needed for eating and drinking. Whilst there is a lack of extensive research into the ages at which eating and drinking milestones are typically reached, there is a general consensus that by the age of three years most children have the necessary skills to bite, chew and swallow a wide range of food and fluid textures (Arvedson and Brodsky 2002;

Evans Morris and Dunn Klein 2001). The development that takes place after this age involves a gradual refinement of these skills leading to increased strength and efficiency, with a reduction in the food loss and messiness that generally accompanies a young child's mealtimes.

The American Academy of Pediatrics' (2010) policy statement and guidelines to prevent choking in children were based on extensive epidemiological surveillance. The statement highlighted that the greatest risk occurred for children younger than 3 years of age and that choking on food causes the death of approximately 1 child every 5 days in the United States. Hot dogs accounted for 17% of food-related asphyxiations among children younger than 10 years of age because of the physical properties of the food. Food which is cylindrical, airway sized and compressible can become wedged into the back of a child's throat, blocking off the airway. The statement identified other high-risk foods such as hard "candy", peanuts/nuts, seeds, whole grapes, raw carrots, apples, popcorn, and chunks of peanut butter, marshmallows, chewing gum, and sausages. They identified the greatest risk of food related choking to occur in children younger than 4 years and in children with chewing and swallowing disorders. This risk is linked to less efficient eating, and also that younger infants are more easily distracted during eating.

Typically, people pay scant attention to the physical movements needed to bite, chew and swallow food safely and efficiently. For many of us there is heightened awareness of the sensory pleasures of food: **what** is eaten rather than **how** it is eaten. The movements of eating and drinking involve many different parts of the body, most obviously the muscles and structures associated with the lips, jaw, cheeks, throat, and tongue. We may be more aware of a disruption to these co-ordinated movements on the occasions when we bite our tongue or cheek or inhale a small crumb or tiny volume of fluid or something gets stuck in our throats. Most of us will have experienced the powerful uncontrollable coughing that continues until the blockage or irritant is removed.

The chewing and swallowing disorders referred to in the American Academy of Pediatrics' (2010) policy statement frequently occur in individuals with cerebral palsy.

## 2.3 Cerebral Palsy

Cerebral Palsy (CP) is a neurodevelopmental condition beginning in early childhood and persisting throughout life; CP is the clinical description or umbrella term given to a group of disorders of the development of movement and posture in childhood attributable to disturbances to the developing foetal or infant brain (Bax et al. 2005). According to Cans (2007) the prevalence of CP is somewhere between 1.5 to 3 children for every 1000 live births, although estimates are hampered by inconsistencies in the definition of CP. As a result of these disturbances to the brain, there will be limitations to how an individual with CP moves, for example in activities of walking, sitting and use of hands but also with the movements required for speech, eating, drinking and swallowing. These motor disorders are often accompanied by additional features frequently associated with neurological disturbances (Rosenbaum et al. 2007). These include seizure disorders and disturbances to sensation including vision and hearing and proprioception, cognition, communication, perception and behaviour, and secondary musculoskeletal problems.

Whilst the underlying disturbance to the developing brain is non-progressive, there is frequently a progression of musculoskeletal difficulties, occurring with advancing age. The non-progressive nature of the underlying disturbance to the brain associated with CP sets it apart from other childhood progressive neurological conditions linked to neurodegenerative or metabolic disorders.

Morris (2007) reflects on the 150 year long historical struggle to define CP and to reliably classify the different types of movement patterns typically associated with CP. The most recent definition proposed by Rosenbaum et al. (2007) is a modification of the definition made by Bax et al. (2005), arrived at after three days of debate at a specially convened workshop which received mixed reviews. The lack of precision in the 2005 definition was thought by some to interfere with epidemiological studies of CP. Morris writes that whilst the precision with which clinicians apply the term “*may have negligible consequences for treatment, the implications for measuring rates of CP over time are more profound*” (Morris 2007 p6).

There is a plethora of terms used in the literature to classify the different movement patterns of CP that have changed over time as understanding has become increasingly refined. The fluid uncontrolled movements of athetoid CP are distinct from the movement patterns

associated with raised muscle tone or spasticity of muscles on one or both sides of the body (bilateral or unilateral spasticity). Other distinct patterns include those associated with the shaking low muscle tone and lack of balance of ataxic CP and the predominantly slow movements with muscle rigidity and persistent abnormal frequently painful postures of dystonic CP. For the purposes of the study, the definitions of the different subtypes of CP as set out by the Surveillance of CP in Europe collaborative group (SCPE 2000) have been adopted, details of which are contained within Appendix 2.

Morris (2007) acknowledges that progress has been made in developing precise measurement tools of use in conducting population studies for individuals with CP at the level of function, with the creation of systems to classify children's movement and manual ability. The consensus within the research community about the meaning and utility of such systems is marked by their widespread use. Morris notes that the Gross Motor Function Classification System (GMFCS Palisano et al. 1997 - see Appendix 2) has become the principal way to describe the severity of limitations to gross motor function for children with CP, that is, the ability to sit, stand and walk. The GMFCS is a 5 level ordinal scale describing distinct levels of functional gross motor ability in a series of word pictures. The summary headings for each of these levels for children aged 6 to 12 years are:

- **Level I** – walks without limitations
- **Level II** – walks with limitations
- **Level III** – walks using a hand held mobility device
- **Level IV** – self-mobility limitations; may use powered mobility
- **Level V** – transported in a manual wheelchair

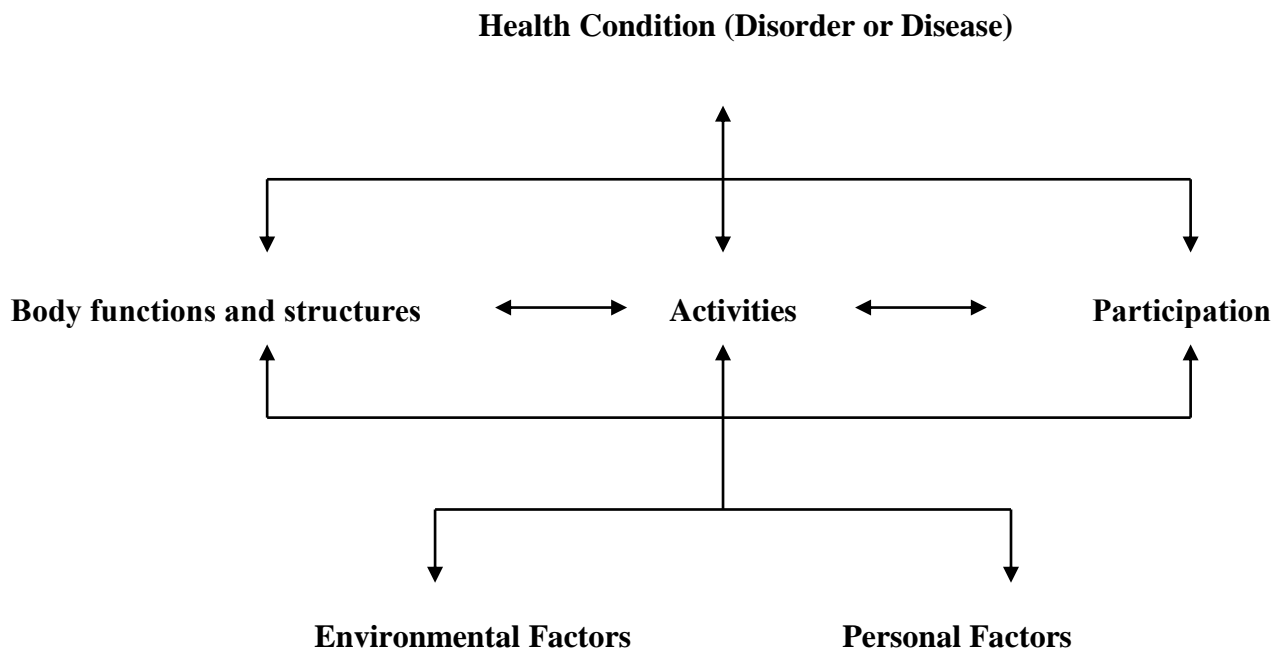
The GMFCS will be considered in more detail later in this chapter.

## **2.4 World Health Organisation – International Classification of Functioning, Disability and Health**

Stewart et al. (2003) reflect on the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation in the context of childhood disability. The ICF aims “*to provide a unified and standard language and framework for the description of health and health related states*” (WHO ICF 2001 p3). The ICF manual includes a new model of human functioning and disability shown schematically in Figure 2-1.

Stewart et al. note that the model reflects the change in the use of the term disability to an umbrella term representing the dynamic interaction between an individual and the environment. It challenges the view that a disability resides just within the person and reflects the idea that disability is a social construction involving an interaction of the person and the social world around them.

**Figure 2-1: WHO International Classification of Functioning, Disability and Health showing interaction between the component parts (WHO ICF 2001 p18)**



Another key change noted by Stewart et al. is the shift in language from what might be considered negative terms used in ICF, published in 1980, such as “impairment” or “disability” and “handicap” to the more positive terms of “body functions and structures”, “activities” and “participation”.

The ICF provides a helpful framework to consider different viewpoints of health from biological, individual and social perspectives. Stewart et al. (2003) suggest it provides the building blocks for clinical and research applications.

## **2.5 Challenges to eating and drinking arising from cerebral palsy**

The co-ordination and range of movements necessary to eat and drink efficiently and safely can be compromised in people with CP. Biting, chewing, sucking and swallowing are all physical skills requiring coordinated muscle activity. This muscle activity is dependent upon the integration of sensory and motor pathways in the brain and body. The movements of eating and drinking involve synchronised interactions with other parts of the body including respiration and digestion, as well as postural stability and head control. If the challenges to eating and drinking arising from CP are considered using the ICF framework, the complex interactional nature of this area of human functioning becomes apparent.

Limitations associated with CP will have an impact on the body functions and structures associated with eating and drinking, the activities that someone engages with and the extent to which an individual participates in life situations involving food and drink. Environmental factors and personal factors will interact with body functions and structures, activities and participation. For example, environmental factors such as noise levels, provision of staff trained to help, suitable seating or equipment, or appropriate fluid consistencies and food textures will influence eating and drinking; personal factors may include an individual's unwillingness to trust the assistance of unfamiliar carers.

The following sections detail important aspects of eating and drinking for individuals with CP. The complex interactions between different features as represented by the ICF model need to be held in mind.

### **2.5.1 Posture and movement**

All physical activity with the peripheral parts of the body, that is the hands, mouth, face, head or feet, takes place against the physical backdrop of the whole body. If postural stability is compromised by low muscle tone in the trunk, fine movements of the peripheral parts of the body will be challenged. CP has an impact on movement and posture to a greater or lesser degree; therefore it is imperative that attention is given to the postural management of the whole body to those individuals that need it. Gericke (2006) defines postural management as a planned approach including all activities and interventions that impact on an individual's posture and function. It may include special seating suitable for mealtimes if an individual requires it. Individually tailored postural management programmes are helpful for children



with bilateral CP to facilitate functional skills including communication and eating and drinking.

Evans Morris and Dunn Klein (2001) write about the importance of positioning and its impact on oral skills. Their book is considered by many speech and language therapists (SaLTs or Speech and Language Pathologists) to be an essential resource for those clinicians working to improve eating and drinking skills of individuals with CP. Their book provides detailed clinical descriptions based on the authors' extensive clinical knowledge and experience; it does not however, have a strong peer reviewed research base. They detail how the position of the head, neck and trunk influence the ability to coordinate and make the necessary movements with the mouth and throat for safe and efficient eating and drinking. Movement problems linked to CP usually occur as a result of having muscle tone that is too high, too low or fluctuating. Mothers provide considerable postural support for their babies when feeding, in order to compensate for postural instability and lack of head control evident in the young infant. In the same way a child with weak head control or trunk control will need to be supported in a specialized chair for optimal feeding success.

Larnert and Ekberg (1995) detail the impact of postural control and seating on eating and drinking for children with CP. If a child has low tone in the trunk, when in an upright sitting position the head and neck will often be tilted forward with a kyphotic thoracic spine and lordotic cervical spine. In order to retain food and fluid in the mouth the head will sometimes be tipped backwards even further. Eating and drinking with the head and body in this position is compromised because of the impact of gravity, which will tend to draw fluid and food to the back of throat. Careful oral control will be required in order to avoid the entry of food or fluid into lungs, which is usually termed aspiration.

Larnert and Ekberg (1995) examined the effects of positioning on swallowing function in five children with CP, using dynamic X-ray filming, known technically as videofluoroscopy studies (VFSS). This technique shows the passage of food or fluid through the mouth and throat. The children studied by Larnert and Ekberg all had severe CP and all showed signs of aspiration when feeding, accompanied by regular episodes of pneumonia. The swallowing studies were carried out for each child in two distinct positions: upright sitting and tilted sitting with child's head and neck supported in flexion. When head and neck were flexed aspiration decreased in all children in the study both for fluid and purees. With tilting there

was also a reduction in the amount of food and fluid lost from the front of the mouth for some of the children. The authors noted that when a child's head was tilted backwards with an extended neck, that the protective mechanism of the closure of the laryngeal vestibule was impaired. It is not clear from the study what the long term consequences to respiratory health were for the children, how the "decrease" in aspiration was quantified and whether it was fully eliminated. Any replication of the study would need to give close attention to ethical concerns about children's safety from exposure to aspiration and radiation associated with VFSS. The position of the head and its effects on swallowing has also been detailed for people with other health conditions (Logemann et al. 1994, Ertekin et al. 2001).

Evans Morris et al. (2001) detail the straight planes of movement that infants develop before they develop lateral or rotary skills which involves alternate pulls from extensor and flexor muscle systems. Once stability is gained either from an external support or internal stability it is then possible to get lateral flexing or righting with the head whilst rolling for example. It is the same for oral motor patterns – as head control and stability in sitting improve a more secure foundation emerges for more skilled mouth movement, enabling lateral and rotary skills with the tongue and jaw. Stability can be provided externally and gradually assumed by the child as postural responses against gravity are developed. Evans Morris et al. (2001 p209) assert that "*Trunk and head control provide the stable foundation upon which the muscle systems supporting feeding and breathing can act efficiently*". They suggest that without head control it is impossible for a child to develop the fine motor control required for efficient oral motor skills. However, good head control does not necessarily mean that safe and efficient oral skills will develop.

### **2.5.2 Oral skills necessary for eating and drinking**

The WHO ICF classifies the oral actions of eating and drinking as body functions. Different terms are used in the literature to refer to the process of eating and drinking. Professor Jerilyn Logemann is highly respected by members of the SaLT profession, because of her considerable research and publications concerning the evaluation and treatment of swallowing disorders. Logemann (1998) notes that the term "deglutition" is sometimes used to refer to the whole process of biting, chewing and swallowing whereas some authors use the term to refer to the stage in the swallowing process when the oesophagus (gullet) becomes involved. The term "swallowing" is used by Logemann to refer to the whole process by which food is

prepared and manipulated in the mouth and swallowed; the term “feeding” is used to refer to the placement of food or drink in the “oral cavity”, the manipulation of food or drink prior to the initiation of swallowing and the oral stage of the swallow. The term “feeding” is also used in the context of feeding a baby reflecting the high level of dependency required when infants are fed by their carers. In medical circles the term “dysphagia” is defined as “difficulty swallowing or difficulty moving food from mouth to stomach” (Logemann 2013 p1). The “oral cavity” is the area of the mouth that is defined by the body structures of the palate, cheek, gums, teeth and lips; the “pharynx” is the structure and physical space at the back of the throat behind the back of the tongue; the “larynx” is the cartilaginous structure at the top of the trachea leading into the lungs with a protective function as well as the location of muscle folds that vibrate in the air coming out of the lungs to produce voice. The oesophagus is the tube that transports food or fluid in to the stomach. The term “bolus” refers to a mass of food or fluid that has been swallowed.

The terms “eating” and “drinking” were used deliberately in the development of the Eating and Drinking Ability Classification System (EDACS) because they have meaning in different social contexts and refer to all aspects of the process, including swallowing, self-feeding, biting and chewing. Eating and drinking are not medical or technical terms, but words that are meaningful to a wide range of people including parents and individuals with CP. Technical words have been avoided if possible. Where technical words were necessary, they were defined in plain language.

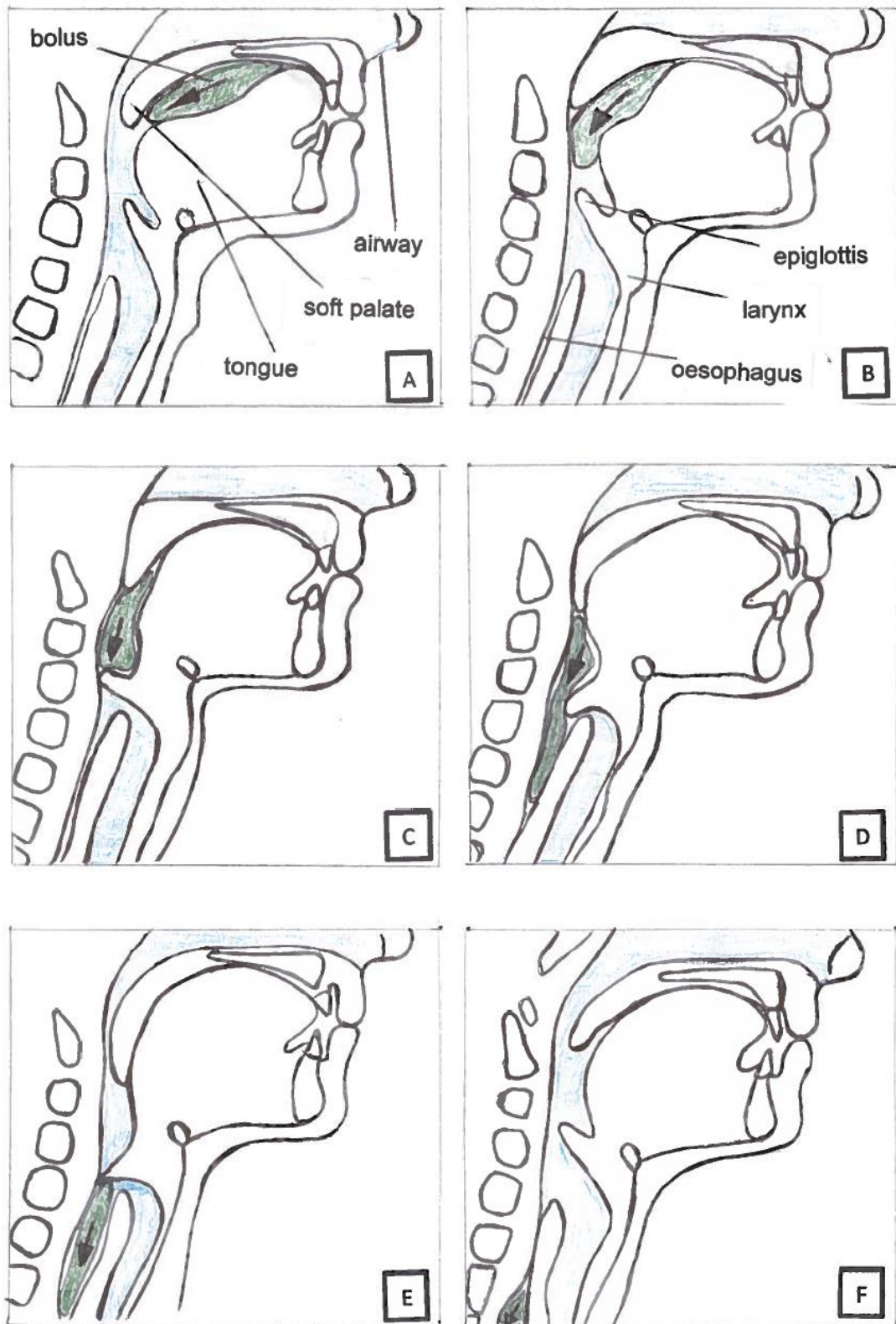
Speech and language therapists are taught four distinct stages of swallowing, originating from the work of Logemann and colleagues with adults with acquired dysphagia following stroke or other neurological conditions, as well as in a population of individuals with head and neck cancer. Using dynamic X-ray recordings of the swallowing process, known as videofluoroscopy (VFSS), it became possible to describe important physiological events that had until then had been invisible. VFSS is generally considered to be the “gold standard” means of measuring aspiration in the process of eating and drinking, that is, when food and fluid enter the lungs.

The stages of swallowing (Logemann 1998) detailed here are supplemented diagrammatically by Figure 2-2. The simplified diagram of a mid-sagittal section of the head and neck is similar to the view obtained during VFSS assessment.

## **Stages of Swallowing:**

1. **Anticipatory stage** - when an individual anticipates that they are going to eat or drink something. This might involve smelling and seeing the food as well as making a choice about what to bring to the mouth first, the selection of appropriate cutlery and the act of bringing food or drink to the mouth.
2. **Oral Stage** - when the bolus is formed through biting and chewing which breaks down food and mixes it with saliva. The lips, cheeks and jaw are used to retain the bolus in the mouth; the tongue pushes the bolus in between the molars at each side of the mouth if it requires chewing and then draws the bolus together ready for swallowing. The bolus is positioned in the middle of the tongue for transport towards the back of the throat (pharynx) or the liquid bolus is cupped and held by the tongue in readiness for transport to the back of the mouth. The oral transit stage starts when the bolus is propelled towards the back of the throat. See Panel A in Figure 2-2.
3. **Pharyngeal Stage** - when the bolus is transported to the pharynx, accompanied by the elevation of the soft palate, preventing food or fluid from entering the nasal passages. The epiglottis and vocal cords in the larynx close off the trachea, the upper entrance to the lungs, as the tongue moves backwards and the pharyngeal wall moves forward. Breathing is suspended in this phase of the swallow in order that food and fluid does not enter the lungs. See Panels B, C and D in Figure 2-2.
4. **Oesophageal Stage** - when the bolus enters the oesophagus with an opening of a muscular valve at the top of this tube. A smooth peristaltic wave of muscle contraction and relaxation moves the bolus through the oesophagus in to the stomach. The valve at the entrance to the stomach closes off to prevent the re-entry of stomach contents into the oesophagus. See Panels E and F in Figure 2-2.

**Figure 2-2: Schematic sequence of events during swallowing with mid-sagittal section of the head and neck**



Sloan (1977) was the first to document the occurrence of oral phase and pharyngeal phase abnormalities for five children with CP using cinefluoroscopic studies, the precursor to VFSS. He noted limited lip function, lack of mobility of the front and back of the tongue, retraction of the root of the tongue, incompetent soft palate movement and poor mobility of the back wall of the pharynx.

Rogers et al. (1994) used VFSS to detail the characteristics of dysphagia for a group of 90 children with CP, all referred for examination because of concerns about airway protection during eating and drinking. They noted the following characteristics:

**Oral Phase:**

- Delay in movements of the tongue
- Limited tongue control
- Piecemeal deglutition meaning that the bolus was not drawn together in the mouth ready for swallowing
- Multiple swallows

**Pharyngeal Phase:**

- Delay in swallowing
- Pooling in the pharynx prior to swallowing
- Residue in the pharynx after swallowing
- Aspiration
- Mealtime coughing and choking
- Multiple swallows

Concerns were expressed for 51 of the 90 children regarding coughing, choking and trouble breathing whilst eating and drinking. This was significantly associated with aspiration, although only 49% of this group were shown to aspirate on VFSS. For the 37 children where there were not these concerns, 22% of them were shown to aspirate on VFSS. This is termed “silent aspiration”, where there are no outward signs such as coughing to indicate that food or fluid has entered the larynx. Silent aspiration occurred for 97% of the children assessed with VFSS. The incidence of “silent aspiration” detailed in studies such as this using VFSS, has led to an increased reliance on the use of VFSS with children with CP and a suspicion about

the reliability of clinical observations. However, it is important to note that the children examined by Rogers et al. (1994) were not a random selection of children with CP but children referred for investigation because of concerns about airway protection whilst eating and drinking. There was no examination of the incidence of “silent aspiration” for children with CP who were not referred to the service.

“Silent aspiration” is a key feature of swallowing that VFSS studies will reveal with certainty whereas clinical observations can only hint at its occurrence through deduction. Weir et al. (2009) examined the relationship between the clinical markers of aspiration used in the medical notes and aspiration events shown on VFSS for a population of children attending the VFSS clinic at a children’s hospital. Eleven clinical markers were identified: cough, wheeze, stridor, throat clearing, gagging, choking, apnoea/desaturations, wet voice, wet/ gurgly breathing, laboured breathing and temperature spikes. After multivariate analysis, only the clinical markers of “wet voice” “wet breathing” and “cough” were significantly associated with oro-pharyngeal aspiration on thin fluid. There were no significant associations between recorded clinical markers and aspiration of smooth puree. The study design was limited in that it involved a retrospective examination of clinical observations recorded in medical notes for children attending the VFSS clinic at a children’s hospital, rather than an explicit assessment of eating and drinking by referring clinicians for the purposes of the research study. The terms used by health professionals to record clinical observations would have been influenced by local culture and practice.

Weir et al.’s (2009) findings support the clinically held viewpoint that what is observed externally when someone with CP is eating and drinking conveys only part of the picture. The detection of aspiration (silent or otherwise) is a task frequently undertaken by SaLTs in the UK, deducing it from clinical observations and examination with VFSS. Occupational therapists sometimes undertake this role in other countries, particularly North America. Because the significant events of swallowing are hidden within the mouth and throat, SaLTs will often explain these events to individuals with CP and their parents. It is often the SaLT who carries this aspect of clinical risk within the multi-professional team caring for that individual. It is frequently an area of contention between health professionals, parents and individuals with CP. When aspiration, silent or otherwise, is seen on VFSS, health professionals will tend to advocate low risk or no risk management decisions such as

modified or severely restricted oral intake for individuals with CP as a way to limit actual or potential damage to respiratory health.

Significantly, Cass et al. (2005) examine the assumption that aspiration and pneumonia or lower respiratory tract infections were inevitably linked for individuals with CP. They report their findings from a clinic developed especially for families whose children had been shown to aspirate on VFSS who refused to stop oral feeding in the absence of any signs of respiratory compromise. Cass and colleagues report that aspiration of small amounts of gastric or oral secretions occurs in up to 45% of the healthy population and is not thought to be harmful. They go on to ask the really important question about why aspiration observed in children with disabilities is always assumed to be significant, warranting action such as restrictions to oral feeding and replacement with tube feeding.

Although the literature shows an association between aspiration and respiratory illness, there are a number of misleading assumptions held by health professionals, including SaLTs who frequently run VFSS clinics, that need to be challenged. The first is the assumption of the linear relationship between the severity of oro-pharyngeal aspiration and the development of respiratory disease. Although VFSS is able to show aspiration, it is challenging to quantify the amount aspirated during this snap shot X-ray procedure. It is also challenging to make a calculation about how much an individual is aspirating every mealtime and the level of risk entailed in eating and drinking. Few studies have been conducted to provide evidence to support the common clinical practice of implementing low risk or no risk mealtime regimes, based on the premise that minimal or trace aspiration is less likely to lead to respiratory disease. Cass et al. (2005) provide 4 case reports from the range of children attending the clinic to illustrate that there is not an absolute correlation between oro-pharyngeal aspiration, shown on VFSS, and respiratory morbidity. One child aspirating on small amounts of puree contracted a severe pneumonia, requiring hospitalisation and following major complications, was away from school for one year. This case contrasts with another child who chose to eat and drink, mealtimes being accompanied by distressing episodes of coughing, choking and cyanosis. She had no major chest infections and her chest X-ray showed virtually clear lung fields. Cass et al. (2005) advocate a pragmatic approach to the monitoring of damage to the lungs by keeping note of the frequency of chest infections and other respiratory signs such as chronic cough or wheeze.



The pragmatic approach proposed by Cass et al. (2005) is now being discussed by SaLTs although SaLTs continue to express concern about the reduction in importance of observed aspiration on VFSS. This issue is still contentious, and was discussed in detail at the London based Paediatric Dysphagia Special Interest Group in a presentation by Cockerill and Aloysius (2010), entitled “*Videofluoroscopy – a public brawl*”. The Royal College of Physicians (RCP 2010) summarised the findings of a multi-professional working party that had explored the difficulties and dilemmas of oral feeding. Similar concerns were expressed about the over emphasis on the safety of swallowing. The RCP urge professionals working with individuals with compromised eating and drinking skills to think carefully about what it is that the team of health professionals are trying to achieve and to consider more than that individual’s swallow safety. On balance, the position emerging is that assessments of swallowing viewed through the VFSS lens should be supplemented with clinical assessment and feeding history in order to provide a full picture of the skills at the oral stage for individuals with CP. It is important to discuss issues with people with CP, their parents and carers, taking into account environmental, personal and social factors.

It is important to bear in mind the potential fatal consequences of aspiration. A recent study examined cause of death as described on the death certificates of people with CP, finding that 22% of identified deaths for people with CP resulted from solids or liquids in their lungs or windpipe (Glover and Ayub 2010). Difficulty swallowing was mentioned on the death certificate in only 3% of cases, but cause of death in 60% of these cases was solids or liquids in the lungs or windpipe. The stories behind these figures are not outlined; however, it seems likely that some of these deaths may have been preventable with greater awareness of risks associated with eating and drinking.

Chadwick and Joliffe (2009) consider the limitations to oral movement and its impact on function associated with dysphagia for a group of adults with intellectual impairment (n=99), taking a broader view of eating and drinking than primarily swallow safety. Almost half of the group of individuals studied had CP. They detailed the indicators of dysphagia at all three of the stages outlined above with reference to observable clinical signs or as seen on VFSS. Their observations of limitations to the oral stage of eating and drinking delineate important features in addition to those given above for the pharyngeal stage and oesophageal stage and include:

- Atypical muscle tone led to lack of lip seal with consequent food loss
- Atypical tongue function led to the absence of the full range, speed and strength of tongue movements
- Chewing or mastication difficulties were marked by no chewing activity or immature chewing patterns
- Oral preparatory problems were marked by difficulty forming a bolus and positioning the bolus mid tongue ready for transit to the pharynx
- Oral transit problems were marked by difficulties moving the bolus through the oral cavity to back of the tongue
- Premature loss of the bolus into the pharynx was defined as the bolus or parts of the bolus falling into the pharynx during the oral stage
- Saliva loss from the front of the mouth.

Evans Morris et al. (1987) identify the confusion that occurs as a result of poorly defined nomenclature applied to patterns of movement observed in the mouth. For example, the term “tongue thrust” can be used to describe the forceful forward protrusion of the tongue seen in many children who have CP as well as to describe typical patterns of movement in the developing infant whilst feeding. Evans Morris et al. (1987) provide comprehensive descriptions of oral patterns of movement observed in individuals with CP, making helpful distinctions between individual oral structures, the processes of eating and drinking to which they contribute and the “limiting movement patterns” frequently encountered in children with disturbances of movement and posture (CP). Table 2-1 provides a summary of these distinctions and clinical observations, which supplement the information available within the published peer reviewed research literature (Evans Morris et al. 1987 p83 -96):

**Table 2-1: Summary of distinctions made between oral structures, activity and limiting movement patterns for people with CP**

Individual Oral Structures	Movement options - activity	Limiting Movement Patterns
<p><b>Jaw</b> - provides stable base from which tongue and lips can operate</p>	<p>Vertical movements - chewing                      Rotary or diagonal movements - chewing                      Controlled sustained jaw pressure against maxilla – biting                      Relaxed open jaw - sucking</p>	<p>Phasic bite – rhythmical opening and closing of the jaw                      Tonic bite – forceful or tense biting pattern, difficult to release the bite                      Jaw thrust – sudden downward movement of lower jaw                      Jaw retraction – pulling backwards of lower jaw                      Jaw clenching</p>
<p><b>Tongue</b> - close anatomical connections between the head, neck and shoulder girdle.                      Muscle tone in surrounding body structures affects tongue’s ability to change shape.                      Tongue moves to become thick, thin, flat, bunched, cupped or humped.</p>	<p>Skilled food transfers within mouth from side to side, back to front, middle to sides and sides to middle – chewing                      Contain food and fluid in the centre of tongue prior to swallowing                      Skilled transfer of food and fluid from the front to the back of the pharynx via central tongue groove - swallowing</p>	<p>Tongue retraction                      Tongue protrusion                      Tongue thrust                      Thick bunched tongue                      Low or high tone tongue</p>

Individual Oral Structures	Movement options - activity	Limiting Movement Patterns
<p><b>Lips and cheeks</b> work together, influenced by the extension and retraction patterns in neck and shoulder girdle</p>	<p>Create an efficient barrier to food as it is moved against the teeth or gums – chewing</p> <p>Prevent food from falling in the cheek cavity – chewing and biting</p> <p>Keep food, fluid and saliva in the mouth – biting, chewing and swallowing</p>	<p>Lip retraction</p> <p>Low tone in lips and cheeks</p> <p>Lip pursing</p>
<p><b>Palate</b> - anatomical divider between oral and nasal cavities.</p>	<p>Soft palate moves to block off nose during swallowing process</p> <p>Soft palate relaxes to allow breathing during chewing and biting</p>	<p>Low or high tone contribute to inaccurate closure during swallowing</p> <p>Short soft palate</p>

**Table 2-1: Summary of distinctions made between oral structures, activity and limiting movement patterns for people with CP**

Table 2-1 does not include many other important dimensions of eating and drinking such as rhythmicity, economy and efficiency of movement, but there is sufficient detail to provide an adequate background to the research project. One dimension that requires further exploration however, is the interaction between eating, drinking and breathing.

The pharyngeal stage detailed above refers to the cessation of breathing (apnoea) in the middle of the swallowing process. Selley et al. (1990) developed the Exeter Dysphagia Assessment Technique (EDAT) enabling the observation of the complex respiratory rhythm that occurs in the background to eating and drinking. Using technical measures of respiration, nasal airflow and swallowing they showed well organised patterns of inspiration and expiration linked to the different stages of swallowing for subjects without neurological impairment (n=81 age range 2 to 90 years):

1. Anticipatory phase - as food and drink approached lips expiration is curtailed, with evidence of “pacing”. During lip / spoon contact subjects used the same pattern of inspiration or inspiration / expiration in combination
2. Oral phase – one teaspoonful of drink was given at a time to avoid the need for chewing and was accompanied by either expiration or apnoea.
3. Pharyngeal phase - the apnoea of swallowing was followed by continued expiration.

In contrast, Parrott et al. (1992 p218) describe the “*random arrangement of expirations and inspirations*”, multiple swallows and “*prolonged swallowing apnoea*” observed in a population of children with CP measured using the EDAT. The likelihood of aspiration is increased if inhalation occurs immediately after swallowing, especially if there are any residues of food or fluid in the pharynx. Whilst the findings provide valuable insights into the coordination of respiration and eating and drinking for people with CP, it is likely that there would have been some influence from the unusual circumstances in which the subjects were required to eat and drink.

McPherson et al. (1992) also detail the differences in respiration for normal and CP children in a number of different test situations including quiet breathing, breath holding, taking a sip of fluid from a cup then swallowing, continuous drinking, eating a piece of biscuit. One half of the children with CP fed themselves. The children were grouped according to their physical abilities: 11 children were typically developing, 11 children were described as having spastic

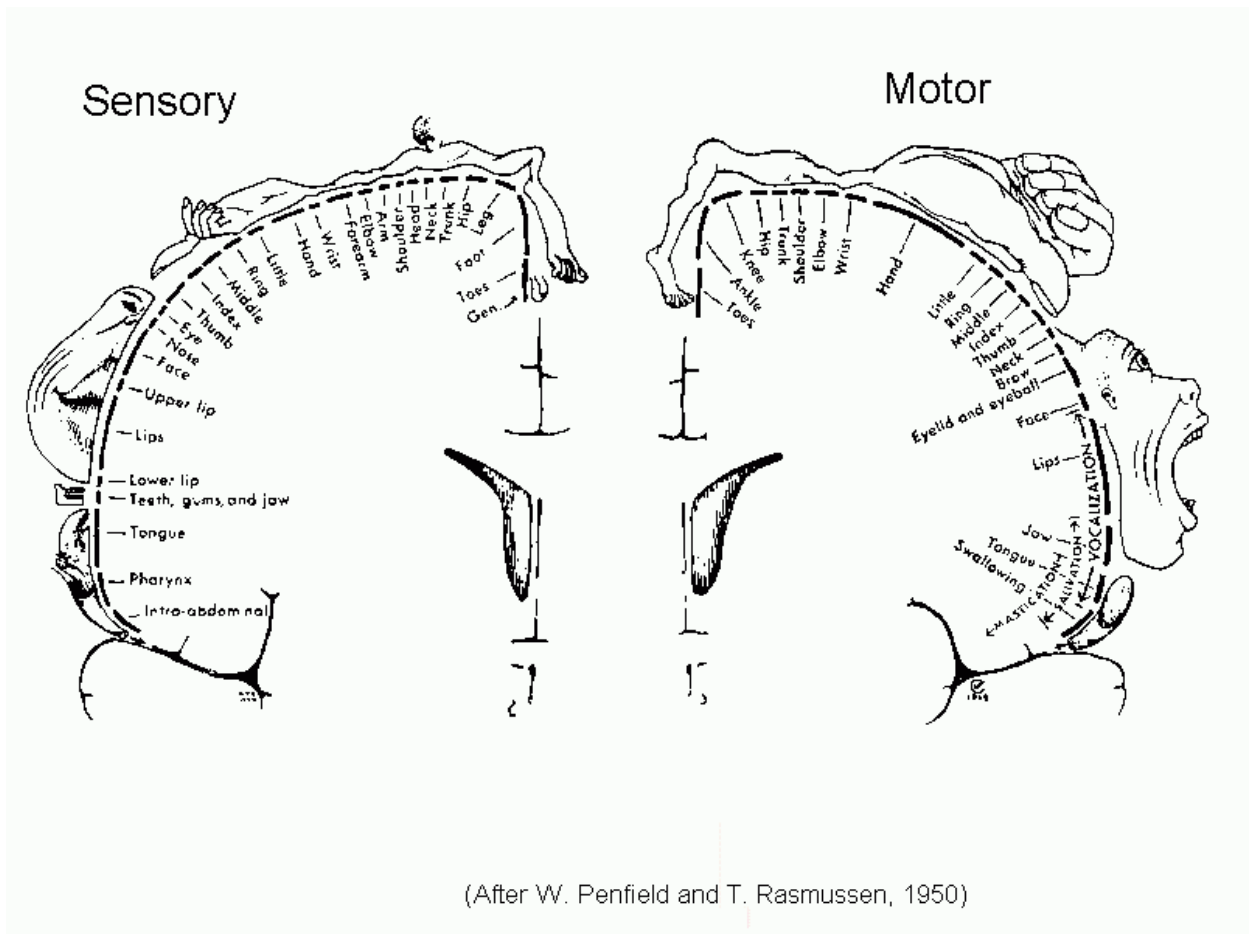
CP and 11 described as having athetoid CP. When asked to take a big breath, all typically developing children were able to complete the task whereas nearly 60% of children with athetoid CP and 12% of children in the spastic CP group could not. There were significant differences between typically developing children and children with CP in the amount of time that breath could be held for. When swallowing a teaspoon of liquid, multiple swallows were more frequently observed for children with CP (36.5% for group with spastic CP; 68% for group with athetoid CP) than for typically developing children (7.6%). Typically developing children swallowed liquid at the peak or above the peak of the ventilation cycle 72% of the time whereas children with CP around 50% of the time. McPherson et al. (1992) found that children with CP were significantly more likely to inspire at the end of the swallow for liquid tasks. No consistent relationship between swallowing and breathing was observed, concurring with the description of “random arrangement of expirations and inspirations” by Parrott et al. (1992). Very few differences were seen between the groups when chewing and swallowing the biscuit because there was more time available for the co-ordination of breathing and swallowing. McPherson et al. suggested that this linked to the ease with which it is possible to intersperse breaths between swallows without risk of aspiration reducing the amount of preparation before swallowing. The range of eating and drinking abilities of the children with CP within the subject group was not considered by McPherson et al. It was not clear whether children with CP who were unable to complete all eating and drinking tasks because of aspiration and choking risks were excluded from the study.

Selley et al. (1990) highlighted the importance of sensory feedback within the mouth and throat in order to co-ordinate respiration and swallowing. Abnormal sensation in the back of the mouth was created in two subjects through the use of a topical analgesia spray. Whilst motor ability remained the same, the effects of the absence of sensation were marked, with coughing episodes after the swallowing sounds suggestive of aspiration and changes to the normal patterns of swallowing and breathing for these subjects. The trial was discontinued in one subject because of the apprehension associated with the experience of aspiration.

The association between an absence of sensation in the mouth, throat and larynx and the increased likelihood of incoordination and aspiration is detailed elsewhere in the literature. Willging and Link (2005) describe the use of Fiberoptic Endoscopic Evaluation of Swallowing (FEES) with sensory testing which they term FEEST. The fiberoptic endoscope is passed

through the nose in order to obtain a clear view of the larynx. The sensitivity of the patients' larynxes was then tested with pulses of air. Link et al. (2000) reported that reduced laryngeal sensitivity in children with CP, measured by FEEST, correlated with previous clinical diagnoses of recurrent pneumonia, pooled secretions and aspiration. Kapur et al. (1990) detailed the effects of experimentally induced peripheral sensory impairment on chewing efficiency for subjects when eating peanuts. Either the top of the mouth was anaesthetised, or one side of the mouth top and bottom was anaesthetised for comparison with non-anaesthetised performance. The size of the peanut pieces left after equal number of chewing strokes was compared in each of the conditions. There was a marked reduction in performance for both anaesthetised conditions in contrast with non-anaesthetised performance.

Figure 2-3 shows the classical image of the sensory and motor homunculus from the work in the 1940s and 50s of Wilder Penfield, a neurosurgeon. It has been included to highlight the large surface area of the brain connected to the face, lips, jaw, tongue, swallowing, salivation and mastication in the motor cortex, and face, upper lip, lips, lower lips, teeth, gums, jaw, tongue and pharynx in the sensory cortex.



(After W. Penfield and T. Rasmussen, 1950)

**Figure 2-3: Classical picture of the homunculi, based on the work of Wilder Penfield, showing the relative amount of cerebral cortex surface area given over to processing the different sensory inputs and motor outputs of the human nervous system (Kiernan 2007).**

Bundy and Murray (2002) describe what they consider to be the vital role of sensation in motor planning or skilled movement. Sensory information from the skin and joints, including the sensory information inside the mouth will contribute to the model or internal scheme of the body represented within the brain. Proprioception through active movement assists in the development of the body scheme facilitating the planning of complex movements. Bobath and Bobath (1984) suggest that CP interferes with the child's growth and maturation on many levels. They suggest that associated sensory and perceptual losses are secondary to the limitations to movement which prevent a child exploring himself and the world around him. The child with CP does not necessarily develop a concept of his or her body, which they term the "body percept" as does a typically developing child during the first 18 months of life. The gross motor development of the baby marked by sitting independently, crawling, standing and



then walking take place alongside other significant development, of interest here being the use of the mouth. The young child typically explores the world by mouthing objects, developing a body percept of the inside of the mouth and extending the available range of oral skills.

The movements required of the lips, tongue, jaw and cheeks in the oral stage are directly related to the physical and sensory properties of the food textures and fluid consistencies consumed. A reflection on our own experience will highlight the skill with which the tongue seeks out foreign objects in the mouth such as a stray particle of food stuck between the teeth. The strenuous workout that the lips, jaw and tongue receive when eating something like a toffee contrasts greatly with the effort required to eat a soft mousse. The physical properties of the food determine the strength and range of oral movements required (Tetsu Tsukada et al. 2009). The physical properties of food are also linked with the risk of choking (see American Academy of Pediatrics 2010).

### **2.5.3 Food textures and fluid consistencies**

Fluid consistency and food texture are features of the environment that have an impact upon function (WHO ICF). Certain food textures and fluid consistencies are frequently recommended by SaLTs to individuals with limited abilities with eating and drinking in order to reduce risks of choking, aspiration and malnutrition. It can be challenging to describe in words or pictures the physical features of food and fluid so that it can be readily comprehended and replicated for presentation to someone with compromised eating and drinking skills. The “Dysphagia Diet Food Texture Descriptors” was published in 2012 to meet a request from industrial food providers and in-house caterers for detailed guidance on “texture categories” for individuals with dysphagia. The descriptors were developed in response to concerns relating to patient safety but were not developed for people with CP, their parents or carers. The descriptors consist of specific detailed standards for each texture and audit checklists so that the food can be measured against the standards for each texture. The texture categories are:

- Thin Purée Dysphagia Diet.
- Thick Purée Dysphagia Diet
- Pre-mashed Dysphagia Diet
- Fork Mashable Dysphagia Diet

- Normal (not defined here).

The category “normal” is not described; it is therefore necessary to look further afield for descriptions of food textures that are challenging. Cichero et al. (2007) outline food textures suitable for individuals with dysphagia and consider the physical properties of food identified as a choking risk. “Choking risk” refers to objects that have been retrieved from the airways of individuals attending hospitals where research surveillance programmes were in operation. Table 2-2 gives details of Cichero’s physical description of these food items together with examples of different foods with these physical properties.

**Table 2-2: Descriptors of physical properties of foods and examples, identified as posing a choking risk (Cichero et al. 2007).**

Food Descriptor	Example
Stringy	Rhubarb, beans, celery
Crunchy	Popcorn, toast, dry biscuits, chips/crisps
Crumbly	Cakes or biscuits
Hard or dry foods	Nuts, raw broccoli, raw cauliflower, apple, crackling, hard crusted rolls/breads, seeds, raw carrots
Floppy textures	Lettuce, cucumber, uncooked baby spinach leaves - adheres to mucosa when moist, conforming material
Fibrous or ‘tough’ foods	Steak, pineapple
Skins and outer shells	Corn, peas, apple with peel, grapes
Round or long shaped	Whole grapes, whole cherries, raisins, hot dogs, sausages
Chewy or sticky	Lollies (adhere to mucosa); cheese chunks, fruit roll-ups, gummy lollies, marshmallows chewing gum, sticky mashed potato, dried fruits
Husks	Corn, bread with grains, shredded wheat, bran
Mixed’ or ‘dual’ consistencies	Foods that retain solids within a liquid base e.g. minestrone soup, breakfast cereal such as cornflakes with milk, watermelon

In order to change the rheological properties of fluids, SaLTs often recommend the use of thickening agents to reduce flow rate, thereby reducing the risks of aspiration. Matta et al.

(2006) provide a description of the sensory characteristics of fluid viscosity using US standard descriptions:

- a) thin, including all un-thickened beverages and supplements
- b) nectar-like
- c) honey-like
- d) spoon-thick

There are a few studies which detail the impact of changes to food texture and fluid consistency on eating and drinking for individuals with CP. Rempel and Moussavi (2005) explored the effects of fluid viscosity on the breath swallow pattern of young people with CP. They found that subjects with CP were more likely to breathe in after swallowing than controls when drinking thin fluids but not when eating pudding or thick liquid. Subjects with CP had greater variability and duration of deglutition apnoea than controls. These two factors, associated with uncoordinated breathing and swallowing, may contribute to an increased aspiration risk, as detailed in Section 2.5.2).

Weir et al. (2013) used parents' rating of their children's ability to manage certain food textures, taken from one item of the Pediatric Evaluation of Disability Inventory (PEDI Haley et al. 1998). Whilst the content validity and reliability of the PEDI as a whole has been examined, the reliability and content validity of that single item have not been considered. The relationship between food textures selected and their children's gross motor function as classified on the GMFCS was examined. The food textures labels selected were: pureed / blended food, ground / lumpy food, cut up / chunky food or all textures. There was a close association between gross motor function and food texture: children with the greatest limitations to gross motor function were deemed by their parents to be less capable of managing foods demanding the most oral processing during eating. Weir et al (2013) do not provide details about the level of agreement between parents and health professionals about whether a child could "manage" a particular food texture. It is not clear whether the food texture experiences of some of the individuals with CP, with the greatest limitation to gross motor function, were unnecessarily limited.

Taniguchi et al. (1994) conducted a retrospective analysis of case records of all children undergoing VFSS at a children's hospital in 1 year period which included 35% with CP. They

compared suspected dysphagic children who developed pneumonia with control children who did not. The presence or absence of aspiration was recorded for thin fluids, thickened liquids and pureed food. 35% of children referred had a history of pneumonia. There was a clear effect on the rates of pneumonia associated with the consistency of aspirated food or fluid:

- Children who aspirated purees were 9 times more likely to develop pneumonia than controls
- Children who aspirated thickened fluids were 2-6 times more likely to develop pneumonia
- Children who aspirated thin liquids had no significant increase in pneumonia risk.

Taniguchi et al. (1994) concluded that the ability to manage different thicknesses of food may be indicative of the severity of dysphagia. They noted that aspiration of inert fluids was infrequently associated with pulmonary morbidity.

#### **2.5.4 Developmental milestones of eating and drinking**

Developmental milestones for the typically developing population have been outlined by Arvedson and Brodsky (2002) from observational data. Arvedson (2006) provides details of swallowing development from 10 weeks gestational age. The pharyngeal swallow is observable from 10 -14 weeks gestational age in the developing foetus; true suckling is observed at 18 to 24 weeks and tongue cupping from 28 weeks. An infant is able to sustain nutrition totally orally from 34 to 37 weeks gestational age. Different patterns of suckle swallowing are described for infants ranging from no suction, arrhythmic expression of milk through to rhythmic, well defined suction and expression of milk (Arvedson 2006).

In the same article, Arvedson (2006) details the feeding skills and milestones present in the developing infant from birth to 36 months. These details are reproduced in Table 2-3.

**Table 2-3: Developmental milestones of feeding skills from birth to 36 months reproduced from Arvedson (2006).**

Age (months)	Development/posture	Feeding/oral sensorimotor
<b>Birth to 4–6</b>	Neck and trunk with balanced flexor and extensor tone Visual fixation and tracking Learning to control body against gravity Sitting with support Rolling over Brings hands to mouth	Nipple feeding, breast, or bottle Hand on bottle during feeding (2–4 months) Maintains semi flexed posture during feeding Promotion of infant–parent interaction
<b>6–9</b>	Sitting independently for short time Self-oral stimulation (mouthing hands and toys) Extended reach with pincer grasp Visual interest in small objects Object permanence Stranger anxiety Crawling on belly, creeping on all fours	Feeding more upright position Spoon feeding for thin, smooth puree Suckle pattern initially Suckle → suck Both hands to hold bottle Finger feeding introduced Vertical munching of easily dissolvable solids Preference for parents to feed
<b>9–12</b>	Pulling to stand Cruising along furniture First steps by 12 months Assisting with spoon; some become independent Refining pincer grasp	Cup drinking Eats lumpy, mashed food Finger feeding for easily dissolvable solids Chewing includes rotary jaw action
<b>12–18</b>	Refining all gross and fine motor skills Walking independently Climbing stairs Running Grasping and releasing with precision	Self-feeding: grasps spoon with whole hand Holding cup with 2 hands Drinking with 4–5 consecutive swallows Holding and tipping bottle

Age (months)	Development/posture	Feeding/oral sensorimotor
18–24	Improving equilibrium with refinement of upper extremity coordination. Increasing attention and persistence in play activities Parallel or imitative play Independence from parents Using tools	Swallowing with lip closure Self-feeding predominates Chewing broad range of food Precise up–down tongue movements
24–36	Refining skills Jumping in place Pedalling tricycle Using scissors	Circulatory jaw rotations Chewing with lips closed One-handed cup holding and open cup drinking with no spilling Using fingers to fill spoon Eating wide range of solid food Total self-feeding, using fork

**Table 2-3: Developmental milestones of feeding skills from birth to 36 months reproduced from Arvedson (2006).**

Unlike the development of gross motor function, the development of eating and drinking for people with CP has not been studied in any detail. A longitudinal cohort protocol study is currently underway in Australia which is likely to contribute to the knowledge base concerning developmental trajectories for the young child with CP (Benfer et al. 2012a).

### 2.5.5 Ability to feed self

The ability to feed one-self using fingers and then progressing to use increasingly sophisticated implements to bring food and fluid to the mouth is a significant marker of independence. It is determined by familial and cultural expectations. Within the WHO ICF it is classified as an Activity:

- **d550 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”.*

- **d560 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”.* (WHO ICF 2001)

Skilled hand and arm movement are dependent upon the stability of the trunk and shoulders, as are the movements of the different parts of the mouth. Underlying disturbances to posture and movement have an impact on the development of hand control.

Beckung and Hagberg (2002) reported a close association between measures of gross motor function and bimanual fine motor function, so that children with CP with greatest limitations to gross motor function were more likely to have similarly affected hand function. Carnahan et al. (2007) point out that hand function is very closely dependent upon cognitive ability as well as voluntary motor control. They suggest that there is a significant difference between what a child *can do* and what a child *really* does with his or her hands. Even if someone can use his hands to bring food up to his mouth, it does not mean that he will do so. They suggest that performance and capacity are often more closely related in gross motor function so that if a child can sit or walk, he or she usually does so.

Carruth et al. (2004) conducted a telephone survey using a national random sample of parents of infants and toddlers (n=3,022 aged 4 to 24 months) in the USA with the aim to identify the ages at which gross motor developmental milestones and fine motor skills required for self-feeding were reported by primary caregivers. These self-feeding skills were then related to the approximate energy and nutrient intakes of each child. The majority of toddlers were able to grasp food with their hands by the age of 8 months; the skilled use of a spoon started at approximately 8 months and was being carried out by 84% of toddlers by the age of 24 months; toddlers began to drink from a sippy cup without help from the age of 8 months, with 91% of toddlers being able to do this by the age of 24 months. Carruth et al. estimated, on the basis of parent report, that those toddlers with early self-feeding skills often had higher intakes of energy and more nutrients than those who did not. Whilst the number of participants was extensive, the reliability of parent report when participating in the phone survey should be considered.

Measurements of the activities of daily living for individuals with disability frequently detail the functional ability of self-feeding. The Pediatric Evaluation of Disability Inventory (Feldman et al. 1990) was shown to discriminate between disabled and non-disabled children in 3 distinct domains (functional skill level, caregiver assistance and modifications or adaptive equipment used). It assesses the functional use of utensils and drinking containers in the Self Care Domain, with assessors deciding whether a child is capable or unable to:

- Finger feed
- Scoop with a spoon and brings to mouth
- Use a spoon well
- Use a fork well
- Use a knife to butter bread, cut soft foods
- Hold a bottle or spout cup
- Lift cup to drink but cup may tip
- Lift open cup securely with two hands
- Lift open cup securely with one hand
- Pour liquid from carton or pitcher

The dimension of self-feeding is often used as a measure in population studies that include some aspect of eating and drinking. In the extensive population studies of individuals with CP carried out by Strauss and colleagues (1998), a range of different details were collected using a questionnaire. It included the following items related to food intake:

- Feeding through a tube
- Fed by others, no feeding tube
- Some self-feeding skills

Multivariate statistical methods were used to identify predictors of mortality, and corresponding life expectancies were calculated. They found that individuals able to feed themselves using their fingers had a greater life expectancy than those fed by others; individuals unable to lift their heads and who were fed by a tube had the lowest life expectancy within the group. The scale of the population studies prevented exploration of fine details of association. It is not clear whether the ability to self-feed is a marker of overall function or whether it makes some contribution to the amount of nutrition an individual receives or both. Strauss et al. (2007) report the same calculations of mortality and life expectancy after a twenty-year gap although data was not collected about self-



feeding ability. Whilst there was a slight improvement in life expectancy for individuals who were tube fed, marking the increasing use of gastrostomy tube feeding, life expectancy for the most severely affected individuals was considerably reduced. Strauss et al. (2007) give an example: children aged 10 years who are tube fed and do not lift their heads in prone are subject to roughly 500 times the mortality rates of the general population.

Dahlseng et al. (2012a) detail feeding problems, growth and nutritional status in children with CP as part of a surveillance project in Norway. They define “feeding problems” as the inability to self-feed, using a scale developed for that purpose. Children unable to self-feed were more likely to show poor limited growth. Dahlseng et al. (2012b) acknowledge the absence of consistent descriptions of feeding difficulties, suitable for population studies investigating the associations between growth, gastrostomy use and “feeding difficulties”. Moreover, they reference the development of the Eating and Drinking Ability Classification System (EDACS Sellers et al. 2012d) as a potentially suitable scale for future use.

### **2.5.6 Association between eating and drinking and gross motor ability**

A number of studies have detailed the association between eating and drinking difficulties and overall gross motor function for individuals with CP although prevalence rates vary depending upon the definitions used (Weir et al. 2013). Whilst there is now international consensus about the use of GMFCS as a severity rating scale, there is currently no agreement about definitions concerning limitations to eating and drinking ability. Some of the different definitions used are considered in Section 2.9.1 which presents findings of a systematic review of ordinal scales, used to measure eating and drinking ability of people with CP (Sellers et al. 2013a, see Appendix 9).

A frequently cited, but relatively old paper from the research literature, by Reilly et al. (1996) demonstrates a link between overall gross motor function and eating and drinking ability. Reilly et al. (1996) found that individuals with CP with the most severe neurological involvement and four-limb and / or head involvement were more likely to have moderate and severe oral motor difficulties. People with CP affecting the lower parts of their body were more likely to have mild oral-motor difficulties with texture specific problems. The ordinal scale used by Reilly et al. (1996) to classify severity of eating and drinking ability (“no apparent feeding problems”, “mild”, “moderate”, “severe”) was not clearly defined and is not possible to replicate from the original paper (see Section 2.9.1).

More recently, Benfer et al. (2012b) examined oral motor dysfunction in feeding and its relationship with gross motor skills in young children with CP. The GMFCS was used to describe gross motor function and oral motor skills were assessed using formal clinical assessments (Dysphagia Disorders Survey (DDS), Sheppard 2003; Schedule of Oral Motor Assessment (SOMA), Reilly et al. 2000). Oral motor dysfunction was prevalent in 80.6% of sample (67 children with CP 18 – 30 months, 44 males) and significantly associated with increasing GMFCS level. In this young population, where oral skills are still developing, oral motor dysfunction was prevalent across all GMFCS levels including in children with relatively unaffected gross motor impairment. Whilst the DDS and SOMA provide standardised ways of assessing eating and drinking, neither provide a means to classify different levels of ability.

In the Oxford Feeding Study (n=271 children with CP), Sullivan et al. (2002) report that almost a third of the group identified as having eating and drinking difficulties, had hemiplegia, that is, mildly affected gross motor function (GMFCS I and II). This finding challenges the assumption that only children with more extensive motor involvement are likely to have difficulties with swallowing and feeding. Fung et al. (2002) only investigated the eating and drinking abilities of children with CP, with greater limitations to gross motor function (GMFCS levels III to V) within the extensive North American Growth Project. Children's eating and drinking ability was classified by both Sullivan et al. (2000 and 2002) and Fung et al. (2002) using their own definitions from information provided by parents in different questionnaires unique to each study.

### **2.5.7 Other associated factors**

Other aspects of human functioning are limited by the presence of CP, which also have an impact upon eating and drinking. The definition of CP used in Section 2.3 notes accompanying additional features frequently associated with neurological disturbances, including seizure disorders, disturbances to sensation including vision and hearing and proprioception as well as disturbances to cognition, communication, perception and behaviour. The disorder of posture and movement associated with CP will affect multiple levels of communication including body language, eye contact, facial expression, voice and verbal communication. Each of these will be affected to a different degree, depending upon type and severity of CP.

Pennington et al. (2003) detail the communication difficulties frequently associated with CP. These communication difficulties are often multifactorial, associated with motor,

intellectual and sensory impairments. Alternative or augmented communication strategies may be introduced to maximise an individual's independence and communication skills through the use of signing, symbol charts, or communication aids with synthetic speech with varying degrees of success.

Pennington and McConachie (2002) investigated patterns of interaction between children with CP and their mothers in order to explore the frequently used description of children with cerebral palsy (CP) as "passive communicators". They observed that familiar conversation partners tended to direct and control interactions which were linked to children's motor impairments, their intelligibility difficulties, and their levels of cognitive development. Poor speech intelligibility was the main predictor of observed restrictive communication patterns, defined as few child-initiated conversation exchanges and simpler child communicative acts such as yes/no answers.

Similar patterns of interaction at mealtimes between mothers and their young children with cerebral palsy were observed by Veness et al. (2008). The findings of Pennington and McConachie (2002) were endorsed by observations that interactions were typically maternally dominated, with mothers using directive language. The severity of feeding impairment and level of language development delay were related to the patterns of interaction shown by the children. In more challenging circumstances, Adams et al. (2012) made detailed observations of mealtime interactions between mothers and children with CP in the slums of Bangladesh. She observed physical and verbal violence at mealtimes directed by mothers to their children, associated with poor communication and stress at mealtimes. Four training sessions improved feeding practices with significant changes to maternal stress levels, the child's overall mood and co-operation at mealtimes.

In addition, the interaction between limits to verbal communication and reduced independence appears to have an impact upon the nutritional content of the diet, as noted by Fung et al. (2002). This is further supported by the findings of Carruth et al. (2004) who found that infants with greater levels of autonomy and independence generally ate a diet with higher energy composition and micronutrients than those that did not. Mealtimes for individuals more severely affected by CP will involve extended dependency upon others to bring food and drink to the mouth. The complexity of this social relationship will be influenced by the degree to which an individual is able to express and insist upon personal preferences as well as the sensitivity of the carer. Contrary to expectation, Reilly et al. (1992) observed mealtimes that were shorter in duration than a typically developing

control group; the amount of food offered to and eaten by young children with CP was also limited when being fed by their mothers.

When someone with CP is able to communicate more readily, there will be greater potential to make explicit personal preferences around eating and drinking. It may be that it is easier to assist someone when they are able to make clear what works best for them. However, the communication of personal preferences may sometimes be at odds with the decisions made for an individual with CP to reduce risks of aspiration and choking. Chadwick et al. (2006) suggest that verbal communication and higher levels of cognitive ability do not necessarily contribute to the reduction of risk. When an individual can express personal preference and a wish to disregard safe eating and drinking guidelines, they may engage in riskier behaviour than those individuals who might be considered more compliant because of their more limited verbal communication skills and cognitive ability.

Samuels and Chadwick (2006) detail the physiological and environmental factors contributing to asphyxiation risk in a population of adults with learning disabilities including individuals with CP, frequently reported to cough and choke when eating and drinking. Speed of eating and cramming of food were identified as significant predictors of asphyxiation risk in this population. Individuals with higher cognitive abilities may be able to participate more actively in bringing about changes to such maladaptive eating strategies thereby reducing the risk of asphyxiation and choking.

Large population studies as part of CP Surveillance programmes (Hidecker et al. 2009) have highlighted important associations between CP and oro-motor dysfunction including speech and swallowing and chewing, as well as communication and cognitive impairment. Parkes et al. (2010) define oro-motor dysfunction as the presence of motor speech problems (articulation), swallowing/ chewing difficulties or excessive drooling. Communication impairments were defined as expressive speech and language difficulties, excluding articulation problems. Half of the population studied had one or more of these impairments. There was a significant association between intellectual impairment and oro-motor dysfunction such that the greater the intellectual impairment the more likely it was that the individual had difficulties with oro-motor dysfunction and communication impairments. There was an increasing risk of swallowing and chewing problems associated with increasing intellectual impairment. Children with CP on the register known to have died were significantly more likely to have had swallowing and chewing difficulties and communication impairments.

Importantly, Parkes et al. (2010) document the frequently observed clinical finding that for the non-ambulant population of individuals with CP there will be a decline, overtime, in motor speech skills and the ability to manage saliva control. As the definitions of oro-motor dysfunction were represented by binary choices including the presence or absence of swallowing/chewing difficulties, it was not possible to document, with any degree of sensitivity, the changes to eating and drinking ability over time. A classification system of eating and drinking ability, based on the principles underlying the GMFCS would provide considerably more detail for large-scale or population-based research.

Furthermore, disturbances to hearing and vision, including the cortical perception of external sensation will impact upon eating and drinking, most obviously in the anticipatory stage. Selley et al. (1990) detailed the impact on respiration and the preparation of the body for eating or drinking when vision was temporarily restricted as part of the experimental condition. Selley et al. (1990) also report the impact of impaired sensation on swallow safety. For more detail, see Section 2.5.2.

Parkes et al. (2010) also draw attention to the presence of epilepsy in the population studied. Individuals with epilepsy were more likely to have communication impairments than those children with CP without seizures, after adjustments for intellectual impairment. The changes in consciousness brought about by seizure activity impact directly upon all motor activity including swallowing. The incidence of aspiration pneumonia during seizure activity was investigated by De Toledo et al. (2004); they found a much higher incidence in individuals with developmental delay than in otherwise healthy adults. The increased incidence of aspiration in developmentally delayed individuals seems to derive from a combination of factors including increased oral secretions, impaired swallowing, and positioning difficulties.

Finally, it is important to note the impact of the disorder of movement and posture from CP on the whole of the digestive system, which will affect appetite, emotional associations with eating and drinking and behaviour. Sullivan (2008) describes the gastrointestinal problems associated with CP including oesophageal dysmotility, gastro-oesophageal reflux disease (GORD), and delayed gastric emptying, which may be treated medically and / or surgically. Sullivan points out that constipation is often a problem that may be overlooked in this population. Morton et al. (1999) examined the associations between lower respiratory tract infections, aspiration and the presence of GORD where stomach contents return in to the oesophagus or pharynx for children with CP. He divided children into three groups on the basis of the prevalence of respiratory illness in the previous year. The

children who had experienced the most recurrent lower respiratory tract infections were all shown to either aspirate directly during the VFSS or have both GORD and aspiration, apart from one child who had GORD alone. GORD alone was found in the group of children with no respiratory illness.

## **2.6 Health and nutrition**

Gisel and Patrick (1988) are frequently cited as researchers first documenting the association between limitations to eating and drinking abilities and malnutrition for a small group of children with severe CP. Restrictions to eating efficiency and limited food intake resulted in growth failure in comparison with a typically developing control group.

Thommessen et al. (1991a) reported that feeding problems are common among children with neuro-motor disabilities and that there are associations with these difficulties: children with CP are shorter in height and weigh less for their age than typically developing children. Thommessen reflects that in the past this has been accepted as part of CP. Further investigation revealed that limited growth apparent in children with CP reflected poor nutrition and was not an inherent part of the condition. Thommessen et al. (1991b) found that the mean relative height and weight were significantly lower in children with mechanical feeding problems (defined as impaired self-feeding skills and oral motor difficulties) than those without. Feeding problems contribute to the short stature and low weight of severely disabled children.

Dahl et al. (1993) extended the investigation of the impact of feeding difficulties to include an assessment of the clinical condition and nutritional status of a group of children with CP. Feeding problems, as rated by staff using definitions unique to the study, were especially prevalent in the group. Dietary analysis of the children's food and fluid intake revealed that the majority of children ate less than the recommended daily allowance (RDA) of food and nutrients, ranging from 40% to 95% of RDA.

Fung et al. (2002) extended investigations into the consequences of eating and drinking difficulties as part of the North American Growth Project. It was reported that the severity of feeding dysfunction in CP was strongly associated with indicators of poor health and nutritional status. They classified 230 children's feeding dysfunction using their own ordinal scale, drawing from parents' responses in a specially developed questionnaire (North American Growth Questionnaire). They found that if children with CP had received nutritional support early on in their lives through the use of feeds via a tube such as gastrostomy, they were taller and had greater body fat stores than orally fed subjects with

similar motor impairments. It is important to note that Fung et al. (2002) also found that even children identified as having only a mild feeding dysfunction maybe at risk for poor nutritional status as measured anthropometrically. Only non-ambulant children (GMFCS III to V) were included in the study on the assumption that eating and drinking difficulties only occur in children with more severely affected gross motor function. If eating and drinking dysfunction in children with mild to severe neurological impairment had also been considered, not just the moderately to severely impaired children, eating and drinking difficulties in mildly affected children would have been found (Sullivan et al. 2000 and 2002).

The results from this study indicate that 42% of children had no feeding problems and 23% had severe problems. Children with limitations to movement at GMFCS V were most likely to have severe feeding dysfunction – 94% of the children in the severe feeding dysfunction category were at GMFCS level V. Fung et al. (2002) reported a stepwise reduction in health score as feeding dysfunction severity increased. Children with severe feeding dysfunction were more likely to spend more days in bed due to illness and more likely to miss their regular daytime activities due to illness. The children with severe feeding dysfunction also experienced more respiratory illness than those with no feeding problems. Feeding dysfunction was also associated with poor nutritional status as measured through weight, height, mid arm muscle area and skinfold thickness scores although there was not a stepwise association because of the presence of tube feeding in the most severely affected group. Children with moderate difficulties (no tube) often had lower anthropometric measures associated with poor nutrition than those in severe feeding dysfunction group because of food supplementation via the gastrostomy. A stepwise association between severity of feeding dysfunction and nutritional status was evident when only the children with CP who were not tube fed were considered.

Fung et al. (2002) noted that children who were primarily tube fed were a unique group with significant morbidity, reflected in their global health score and physical summary score. Whilst tube feeding was associated with less respiratory illness than for orally fed children in GMFCS V, the global health scores for tube fed children were significantly lower. This study suggested that oral motor dysfunction was responsible in part for limited food intake and subsequent growth failure in children with CP. Fung et al. (2002) suggested that the observed association between severity of feeding dysfunction and poor growth and depleted fat stores may reflect feeding inefficiency. It may also reflect limited food access in that the children concerned could not easily communicate their needs to

others or physically acquire the food they wanted. As detailed in Section 2.5.7, severity of feeding dysfunction was associated with communication limitations and gross motor limitations.

The impact of sub-optimal nutrition on bone density was examined by Henderson et al. (2005) as part of North American Growth Project. The results of the population study made it possible to predict the likelihood of low bone density in children and young adults with CP. For example, the results from the study support the prediction that a 10 year old non ambulatory child with quadriplegic CP, with a low weight, difficulty feeding and on anti-convulsants will be more likely to have low bone density score, and would therefore be more likely to experience bone fractures.

Another substantial contribution to what is known about nutrition and growth patterns for individuals with CP comes from the North American Growth Project, as detailed by Day et al. (2007). Growth patterns using measures of weight and height were plotted for an extensive population of children and adolescents with CP (n=24,920). From this data, growth charts were developed for children and adolescents with CP according to age, gender and level of disability. Different charts were created according to measures of gross motor function ability, ability to feed oneself and presence of a tube by which artificial nutrition could be given. Restricted patterns of growth in comparison to that of the typically developing population were increasingly evident with increased limitations to gross motor function, even when individuals received nutrition via a tube. The growth curves of individuals with the mildest forms of CP most closely resembled those of the typically developing population. However, some children with CP who were ambulant did not all follow the growth trajectory for typically developing children, particularly for males. Whilst the 90<sup>th</sup> centiles for weight had similar values for ambulant individuals with CP and the general population, the 50<sup>th</sup> and 10<sup>th</sup> centiles were lower for children with CP, warranting further investigation.

The groupings of individuals with CP for the growth charts made no reference to the eating and drinking abilities of the individuals with CP, even though this will impact upon an individual's nutritional intake and growth. By assuming that eating and drinking difficulties occur only for non-ambulant individuals with CP (reported in Fung et al. 2002), the researchers were blind to the possibility that restrictions to growth for the ambulant population of individuals with CP might be linked to limitations to eating and drinking abilities. The assumption that only children with the most severe limitations to gross motor function have oral motor feeding dysfunction was shown to be incorrect by Sullivan et al.



(2000 and 2002). The lack of consensus about a definition and means of classifying eating and drinking ability contributes to the lack of clarity about function.

## **2.7 Consideration of parents' views**

Several papers discuss the conflict that can arise between health professionals and parents around the management of children's eating and drinking difficulties. When the views of parents are considered, a suspicion is sometimes expressed that some parents are not fully aware of the important features of eating and drinking and the significance of limitations to these skills.

Speech and language therapists do not always agree with parents about the textures of food or consistencies of fluid that should be given to their children to ensure their safety. Weir et al. (2011) invited parents of children with CP (3 years of age, or younger) to describe or rate the food textures and fluid consistencies offered to their children using a questionnaire. They then compared parents' responses with the textures assessed by the SaLTs as "manageable" for the child, using a clinical assessment of oral motor ability (SOMA Reilly et al. 2000). Weir et al. (2011 p14) concluded that parents tended to include food and/ or fluid textures in their child's diet "*despite the child's inability to manage the texture orally*". However, they do not make explicit any exploration of the incidence of choking or aspiration events for this group of children and their parents, that is their experiences of what might be considered "unmanageable". Whilst the SaLTs and parents did not always agree on the textures offered to the children, this does not necessarily reflect "risky" behaviour on the part of the parents or the child's ability to protect him or herself when eating and drinking. It also does not contain any information about what preferences around food texture the children themselves are signalling.

The difference between observations made by experienced SaLT researchers and parents was also documented in an earlier study by Reilly et al. (1996). Video recordings of mealtimes of children with CP and their parents were made. Reilly et al. noted that there was a significant difference between parental reports of mealtime duration and the actual length of mealtimes observed by researchers and described by parents as typical. Reilly and colleagues noted that the children with the most severe eating and drinking difficulties tended to have shorter mealtimes. The parents' perceptions of mealtime duration may have reflected the emotional experience of feeding their children. Reilly (2001) criticised Sullivan et al.'s (2000) use of parent reported mealtime duration as a means of measuring

the severity of their children's eating and drinking difficulties because of the unreliability of that report.

Sullivan et al. (2000) and Fung et al. (2002) both assessed children's feeding difficulties by collecting parental judgements and observations through two separate questionnaires, designed specifically for each study. Each research team considered parental views to accurately reflect the eating and drinking abilities of their children with CP. In contrast, Calis et al. (2008) asserted that the parents' views expressed in their study showed poor judgement of their child's eating and drinking difficulties. However, the parental questionnaire used within the study to describe their child's difficulties bore little relation in content to the detailed assessment of eating and drinking with which it was correlated. It consisted of three questions which are given here:

1. Do you consider eating and drinking in your child as a problem? (Never, sometimes, often, always)
2. Do you think your child enjoys eating and drinking, regardless of present feeding problems? (Always, sometimes, never)
3. How long does an average meal take? (less than 15 mins, 15-30 mins, 30-45 mins, more than 45 mins)

Questions 1 and 2 are open to numerous interpretations. The length of an average meal may not be accurately reported and speed of eating or being fed does not always reflect the level of skill an individual has for eating or drinking.

In contrast, Benfer et al. (2012c) found that parents of young children with CP were able to notice clinical signs of aspiration and pharyngeal phase difficulties, most frequently reporting coughing, gagging, multiple swallows, choking and texture refusal. Whilst parents might not understand the clinical relevance of their observations, they were not oblivious to these indicators of limitations to eating and drinking in their offspring.

There is suspicion expressed here about the extent to which parents can be expected to make the same observations of their children as expert health professionals or researchers. It is unusual to ask parents what their concerns are for their children's eating and drinking difficulties. Fung et al. (2002) used a questionnaire to identify parents' perceptions of their child's overall health including components of physical function, societal role, participation, general health and bodily pain. The questionnaire also included questions examining the impact on parent time and parent emotion of caring for their children. The researchers were keen to gauge parents' perceptions of the impact of their children's health

on their own emotional health and societal participation. Fung et al. (2002) reported that the presence of feeding dysfunction in a child was associated with the inability of the family to participate in everyday activities, impacting too on parents' time and that gastrostomy tube feeding had a substantial emotional impact upon families.

More recent work by Morrow et al. (2008) found that the time taken to feed their children was a major issue for parents. In this study, the researchers sought to explore the different priorities of parents of children with CP and health professionals' perceptions of quality of life in quadriplegic CP in relation to feeding difficulties. In this unusual qualitative study, the views of health professionals and parents were collected. Parents attending the focus groups reported feelings of tension in their families and differences of opinion about the eating and drinking management choices they had made. The majority of parents reported negative experiences when communicating with health professionals, with some parents believing they were made to feel guilty or ashamed with regard to the nutritional status of their children. The clinical approach taken by health professionals excluded the "lived experience" of families.

Some of the comments reported by Morrow et al. (2008) show the concerns of parents and sensitivities to their children's difficulties in a wider context which included the narrower context of physical health upheld by health professionals. Parents commented on their anxiety that children might choke, the emotional landscape of making a decision about whether to go ahead with a gastrostomy, and the social consequences of having a child with eating and drinking difficulties. Some parents were able to look back after surgery to insert a gastrostomy with consequent improvements to their children's nutritional status, to see the viewpoints proffered by professionals prior to surgery. Professional opinion about the benefits from supplementary nutrition and hydration from a gastrostomy was not always well received prior to surgery:

*"It shocked me no end that she has chosen that she doesn't want to eat anymore. And what I thought was enjoyment was necessity I'm sure now"*

*"I knew she was underweight but she seemed fine, but when I look back at photos I think oh my God, she was just like a stick insect"* (Morrow et al. 2008 p122).

The absence of a clear set of descriptions or context to help parents understand their children's difficulties may contribute to the conflict with health professionals.

Morrow et al. (2008) found that parents and health professionals attached different values to different aspects of quality of life. They found that health professionals tended to focus more on the objective components of quality of life, which were at odds with those features of quality of life considered by parents concerning their children's emotional wellbeing and socialisation. For example, health professionals valued weight gain whilst parents valued their child feeling loved. Morrow et al. (2008) found that health professionals did not consider the full range of issues that were important to families and that differences in priorities for treatment outcomes negatively affected the parent-health professional relationship.

The conflict encountered between health professionals and parents of children with CP was also the backdrop to Craig and Scambler's work (2006). Parents were given the opportunity to express their views about their "disabled" children's eating and drinking difficulties within in-depth interviews; all parents in this study were being asked to consider a proposed gastrostomy placement for their children. Craig and Scambler acknowledge and explore the conflicting viewpoints of parents and health professionals, describing women's accounts of feeding their children as ambivalent and contradictory. Women used militaristic metaphors to describe the feeding experiences as "war", "battle" or "torture"; this contrasted with the constructions of feeding as a special time for "bonding" and "closeness" and the child's only source of pleasure and enjoyment. There was a tension between the wish to normalise their children's experiences and the decision to accept the "unnatural" path of having a gastrostomy tube surgically inserted in to their child, with all the risks entailed in that.

The decision about whether to go ahead with a gastrostomy generally rests with parents who are faced with making a decision in their child's best interests in the middle of these conflicting viewpoints. Decision-making is not helped by the lack of consensus among health professionals about the safety of oral feeding. It may also be that their child is unable cognitively to understand the dilemma and consequently is unable communicate their views. If health professionals understand the fundamentally conflicted nature of parenting a child with a disability, they may be in a better position to work with parents.

The development of EDACS to provide a clear description of the range of eating and drinking abilities by individuals with CP has the potential to clarify information shared with parents. By including parents in the development of EDACS, it should capture and clarify their experiences of helping their children at mealtimes, providing a context within which parents can place their own experiences.

## 2.8 Views of people with cerebral palsy

Parents' views have been sought in the research literature whereas the views of individuals with CP have been neglected and more rarely given a voice.

One such exceptional study comes from Balandin et al. (2008a) who considered the mealtime experiences of older adults with CP. Themes identified from in-depth interviews revealed their frustrations, concerns for the future, and fear of choking. The adults expressed their frustrations at the lack of involvement in decisions about their care, their decreasing enjoyment at mealtimes and limited opportunities to make personal choices and socialise with others.

In a second study, Balandin et al. (2008b) noted that there was a discrepancy between the self-reported eating and drinking capabilities in the interviews and the mealtime presentation during clinical assessment by an expert SaLT. It is interesting to note, however, that individuals were able to recognise features of eating and drinking that were challenging in a questionnaire developed to explore their qualitative mealtime experiences. This may be due to differences between recall and recognition memory of the individual participants or down to differences between what an individual wants to do and what has been deemed safe for that person to do. The details provided by the study are insufficient to clarify the issue.

The impact of individual choice and the potential for conflict between prescribed guidance and personal preference was highlighted by Chadwick et al. (2006), who reported on the issues affecting caregivers' compliance in following SaLT mealtime guidance. One identified area was the conflicts that arose between the textures of food and drink that had been identified by SaLTs as safe to eat and drink and the diet that the person concerned actually wanted to eat. This conflict was most marked for individuals who were verbally and cognitively more able, and therefore aware of differences and able to indicate preferences. The more physically able individuals were, the more independent they were in eating and drinking.

Chadwick et al. (2006) acknowledge that individual choice was not central to the dysphagia guidelines written by SaLTs, the primary purpose being to promote the health of people with dysphagia. As outlined by Morrow et al. (2008), conflict arises between different aspects of quality of life. Recommendations to ensure good nutrition and respiratory health may come into conflict with an individual's wish to determine their own path, including greater levels of risk and compromised health. Chadwick et al. (2006)

suggest that a greater emphasis needs to be placed on problem solving involving SaLTs, carers and clients to bring areas of conflict into greater alignment.

The Royal College of Physicians' (RCP 2010) booklet, referred to in Section 2.5.2, explored the difficulties and dilemmas of oral feeding, urging health professionals to widen their considerations to include more than swallow safety. The RCP (2010) suggest a "test of best interests" when the decision maker assesses the burdens and benefits of treatment, taking into account both the individual's values and beliefs. They recommend that oral intake should be the main aim of treatment, with appropriate modification and nutritional fortification.

"Beneficence" is the ethical principle referring to the doctor's responsibility:

*"to preserve life, restore health and relieve suffering .... to cure sometimes, to alleviate often, to comfort always"* (RCP 2010 p38).

What is inferred from this statement is the responsibility to avoid harm, also known as "nonmaleficence". The RCP working party suggests that both principles need to be applied in the decision-making around the dilemmas and difficulties of oral feeding decisions.

## **2.9 Measurements of eating and drinking ability**

What is apparent in the studies cited thus far is the plethora of ways in which eating and drinking has been assessed, and the absence of agreement about how eating and drinking skills for individuals with CP should be measured and described. As part of the exploration of the utility of developing a functional classification system of eating and drinking ability (EDACS) a systematic review was conducted as part of this study.

### **2.9.1 Systematic review of ordinal scales of eating and drinking ability**

A systematic review was conducted in order to examine all the ordinal scales that have been used in the research literature to classify the eating and drinking ability of people with CP. Further details of the review are given in the article by Sellers et al. (2013a), included in Appendix 9.

Fifteen separate ordinal scales were identified by the review (Calis et al. 2008, Da Graca Andrada 2008, Dahlseng et al. 2012a, Erkin et al. 2010, Fung et al. 2002, Gisel and Alphonse 1995, Haley et al. 1998, Hung et al. 2003, Morton et al. 1999, Reilly JJ et al. 1994, Reilly S et al. 1996, Selley et al. 2001, Sheppard 2003 and 2010, Sullivan et al. 2002, Zerilli et al. 1990). The terms "mild", "moderate" and "severe" were used variously,

without any agreed definition. 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. None of the published scales were accompanied by evidence, published in peer reviewed publications, to support their validity and reliability.

The multidimensional nature of the activity of eating and drinking presented challenges to the authors of the scales. Some of the measures defined distinct categories using 1 or 2 constructs such as time taken, food texture or the ability to self-feed. One example is the chewing curves developed by Gisel (1988, 1991) for 100 typically developing children: the curves were derived from precise measures of the time taken to eat defined quantities of different food textures in laboratory conditions. Gisel and Alphonse (1995) used the chewing “norms” to define the categories of “mild”, “moderate” or “severe” for children with CP, based on the value of the standard deviation of each child’s chewing performance in controlled conditions, from the typically developing population. Weir et al. (2013) used parental assessment of a single item of the PEDI, concerning increasingly complex food textures managed by their children. Whilst 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, significant information related to the safety of eating and drinking is omitted from such scales.

The combination of potentially conflicting constructs within the distinct categories of an ordinal scale presents challenges for interpretation. The scale developed by Da Graca Andrada (2008) provides an example where classification would be challenging: 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, such that severely limited performance in one construct masks 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 (Clark et al. 2010).

As discussed in Sections 2.5.5 and 2.5.6, 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.

The authors of the different measures identified within the systematic review express different views about who is best placed to report a child's eating and drinking ability: six ordinal scales are based on information available only to researchers or health professionals. The remaining nine measures utilise information collected from parents, although only the single item taken from the PEDI (Weir et al. 2013) and the Da Graca Andrada scale (2008) have the potential to be used by both parents and health professionals.

Section 2.5.2 outlines the challenges in directly observing eating and drinking because much activity takes place out of view within the oral cavity, pharynx and larynx. The significance of "silent aspiration" and "choking" has also been discussed. Only six of the scales made reference to aspiration or the consequences of aspiration presenting as respiratory illness, two of which had been developed specifically for use in the context of videofluoroscopy assessment (Morton et al. 1999, Zerilli et al. 1990).

The conclusion of the systematic review was that there was no ordinal scale describing distinct categories of eating and drinking ability of people with CP, for use by both parents and health professionals in clinical and research contexts.

### **2.9.2 Other measures of eating and drinking ability**

Fung et al. (2002) acknowledge that the prevalence of feeding dysfunction in their sample of children with CP is difficult to compare with other findings reported in the literature because of the variability in the definitions used to describe feeding dysfunction and the methodology used to collect the data. Some studies use parental report, others clinical assessment and others observation of mealtimes. They write:

*"One of the major limitations in oral motor care and research is the lack of widely accepted, validated screening instruments to assess the presence and severity of feeding dysfunction. Reliable tools are available for in-depth clinical assessment of oral motor function but these methods are labour intensive and not easily utilised in large multicentre research protocols or in busy clinic settings"* (Fung et al. 2002 p367).

Benfer et al. (2012d) conducted a systematic review of the "clinimetrics" of formal dysphagia assessments constructed to measure what they term oro-pharyngeal dysphagia, marking the challenges that occur for individuals with CP at the oral and pharyngeal phases. Benfer et al. acknowledge the reliance in clinical assessment on the knowledge and



experience of the person conducting the assessment and that in spite of this subjectivity it provides valuable information about an individual's oral sensorimotor and swallowing skills, behaviour and interaction in a mealtime context. They suggest that formal clinical measures with strong psychometric properties could improve the accuracy of clinical evaluations. They acknowledge however, that few measures are regularly used for children with CP. Nine measures were identified in their review and all varied in the type of information gathered and their practical application. Benfer et al. (2012d) considered the validity of all nine measures to be limited, in part because of the poorly defined construct of oro-pharyngeal dysphagia for individuals with CP. They considered the Schedule of Oral Motor Assessment (SOMA Reilly et al. 2000) and the Dysphagia Disorders Survey (DDS Sheppard 2003) to be the most comprehensive measures with good clinical utility and sound psychometric properties. Access to the DDS is only available after certification training. The SOMA is rarely used as a measure of eating and drinking in a clinical context, and is now unavailable as a publication. Whilst the SOMA provides a detailed scoring schedule to accompany standardised observations of eating and drinking, the outcome of the assessment is to distinguish infants with normal oral motor function from infants with oral motor dysfunction.

The SOMA was used by Clark et al. (2010) to examine eating and drinking difficulties of a group of children with Worster-Drought syndrome, a subtype of CP where the co-ordination and movement of the face, throat and mouth are more affected than other parts of the body. Children with Worster-Drought syndrome are typically ambulant but struggle with swallowing, feeding, speaking and saliva control. Clark et al. (2010) found that the 28 children assessed using the SOMA frequently refused to participate in the structured feeding assessment. The information revealed by the SOMA did not reflect the difficulties the children had with eating and drinking. For example, only 5 of the 28 children had abnormal scores in spite of the fact that 21 out of 28 children needed dietary modification at the time. Informal observation revealed functional difficulties and behavioural adaptations that it was not possible to score on the SOMA. For example, children compensated for the limitations to movement in the oral region by tilting their chins upwards to reduce anterior spillage of saliva and food and by using their hands to achieve lip seal; tongue impairment was overcome by using their fingers to place food between the teeth or by not chewing food but rather mashing it against the hard palate. Many overfilled their mouths compensating for food falling out or because of reduced oral awareness. Swallowing was often initiated by tipping the head back to use gravity or by placing a supporting hand at their chin.

However, the observational and textual descriptions used in the construction of the SOMA are extremely rich in detail and were used to inform the development of EDACS. The SOMA is considered in more detail in Chapter 6 (Section 6.2.8) which outlines the development of the eating and drinking ability classification system.

There is no consensus within the research literature about how to refer to the presence or severity of eating and drinking limitations associated with CP. Methods of measuring and classifying eating and drinking difficulties rely heavily on clinical judgement and technical measures which are of value in diagnosing and managing eating and drinking difficulties. Terms such as “mild”, “moderate” and “severe” are used without agreement about the meaning of the terms. Palisano et al. (1997) describe a similar situation in the measurement of gross motor function for individuals with CP, it being one of the motivations for establishing a valid and reliable classification system – the Gross Motor Function Classification System (GMFCS). It is helpful then to consider an alternative approach to classification based on the concepts employed by the creators of the GMFCS (Palisano et al. 1997) and other functional classification systems that have followed for manual ability (Eliasson et al. 2006) and communication (Hidecker et al. 2011).

## **2.10 Functional classification systems for people with cerebral palsy**

Palisano et al. (1997) based the GMFCS on concepts of disability and functional limitation captured at that time in an earlier version of the WHO ICF (WHO International Classification of Impairments, Disabilities and Handicaps 1980). They cite Nagi’s (1965) definition of functional limitation as a “*limitation in performance at the level of the whole person*”. At the time that the GMFCS was created, experience dependent terms such as “mild”, “moderate” and “severe” were used as a means of classifying gross motor function with no shared understanding about their meaning. The authors of the GMFCS understood the importance of a classification system that would enhance communication among professionals and families. They believed that a classification system of children’s gross motor abilities and limitations would help determine a child’s needs and aid management decisions. They considered that it would assist with the creation of databases describing the development of children with CP as well as facilitating the comparison and generalizability of research.

Reliable predictions can be made about children’s future prospects for independent mobility based only on the GMFCS (Rosenbaum et al. 2002). Family report of children’s gross motor function using the GMFCS has been shown to be reliable compared to

classifications made by physiotherapists and occupational therapists (Morris et al. 2004a and 2006). Morris (2008) summarises the contribution of the GMFCS to research for individuals with CP since 1997, showing how accurately the original developers of the GMFCS predicted its utility. It is now used routinely in CP population registries and most papers present research findings using the GMFCS to describe participants.

Eliasson et al. provide a useful definition of classification which underlies the Manual Ability Classification System (MACS):

*“Classification is the process of grouping data, persons or objects into classes according to common characteristics, thereby reducing the number of data elements”* (Eliasson et al. 2006 p549).

Eliasson et al. suggest that the usefulness of a classification depends on how clear and comprehensible the descriptions are. The MACS also seeks to replace the commonly used terms “mild”, “moderate” and “severe” with a more precise definition of manual ability with a 5 level ordinal scale. Following on from the GMFCS, the MACS also focusses on manual ability as defined by the WHO ICF (2001) at the level of activity performance.

The most recent classification system for individuals with CP is the Communication Function Classification System (CFCS Hidecker et al. 2011). Hidecker and colleagues also use the WHO ICF (2001) framework to classify everyday communication performance of individuals with CP into one of five levels, based on the descriptions of activity and participation. The importance of both being able to understand (receive) what is said, as well as the ability to express and send a message, is emphasised. The CFCS classifies communication function with reference to the individual’s dependence on alternative communication systems, such as signing, symbols or voice output communication aids.

The overall framework of the WHO ICF (2001) has been outlined in Section 2.4.

Consideration is now given to the detailed descriptions of eating and drinking provided within the framework as a way of informing the decisions about the features of eating and drinking for individuals with CP that need to be included within a classification system. Given the success of the GMFCS, the ICF was used to explore parallels between different aspects of gross motor function and mobility, and eating and drinking. These are given in Table 2-4. There are inconsistencies in the way that the ICF categorises the different features of eating and drinking and those features linked to mobility. It might be argued that “biting”, “chewing” and “swallowing” for example may be better categorised as activities alongside “walking”, “running”, “crawling” rather than as part of body function.

The ICF overlooks the fact that the tongue, lips, face, jaw and throat consist of muscles and joints which are affected by joint stability and muscle power for example in the same way as the legs and pelvis are, but that these features of body function are not outlined for the lips, teeth, tongue, jaw and throat. The listed activities of eating and drinking are limited to the task of self-feeding.

Whilst the overall framework is a useful one, there is inconsistent classification of detailed aspects of human activity and function.

**Table 2-4: Categorisation of the component parts of eating and drinking in contrast to some aspects of movement as described within the ICF (2001).**

<b>Component</b>	<b>Eating and Drinking</b>	<b>Movement</b>
<b>Body function</b>	Sucking Biting Chewing Oral swallowing Pharyngeal swallowing Oesophageal swallowing Moving food in the mouth Spitting Salivation Vomiting Regurgitation Appetite	Mobility of joint functions Stability of joint functions Mobility of bone functions Muscle power functions Muscle tone functions Muscle endurance functions Motor reflex functions Control of voluntary movement functions Involuntary movement functions Gait pattern functions Sensations related to muscles and movement functions
<b>Body Structures</b>	Structure of mouth Teeth Gums Palate Tongue Lips Pharynx Larynx	Structure of the pelvis Thigh Bones of thigh Hip joint Bones of lower leg Knee joint etc.
<b>Activities</b>	Bringing food to mouth and consuming in culturally acceptable ways Cutting food or breaking it into pieces Using eating implements Opening bottles or cans Taking hold of a drink and bringing it to the mouth in culturally acceptable ways. Drinking through a straw Feeding from the breast	Lying down Kneeling Sitting Standing Bending Changing body position Walking short distances Walking long distances Walking on different surfaces Walking around obstacles Running Crawling
<b>Participation</b>	Eating meals together with family Joining in with celebrations and social occasions. Feasting Dining	Engaging in any form of recreation or leisure activity such as sport, play Going to cinemas, art galleries, etc. Employment

## 2.11 Development of the Gross Motor Function Classification System (GMFCS)

Given the success of the GMFCS, it is helpful to consider the stages of development undertaken in order to establish a reliable and valid classification system. Palisano et al. (1997) outline the three distinct stages and processes involved in the development of the GMFCS:

- **Stage 1:** Construct a gross motor function classification system for children with CP, with some resemblance to the staging and grading systems used to describe tumours. Existing classification systems and research on the development of children with CP were reviewed as part of the initial process of drafting a classification system.

The researchers were struck by the patterns of gross motor development found in populations of children with CP as measured using the Gross Motor Function Measure, an instrument designed to standardize the observation of gross motor function over time in children with cerebral palsy (Russell et al. 1989). They then set out to describe each classification level as a series of “word pictures” that were congruent across time for the different age groups. Rosenbaum et al. later describe this as a conceptual exercise:

*“One might imagine trying to capture a panoramic view of a scenic vista with a camera by taking a series of photographs, the edges of each abutting the previous photograph’s boundary. In the absence of a panoramic lens to take a single wide photograph, the series of photos is meant to provide an approximation of what the eye can observe effortlessly over time and space”* (Rosenbaum et al. 2008 p250).

Distinctions between the levels focussed on functional limitations and the need for assistive technology including mobility devices and wheeled mobility. The intention was that the GMFCS be quick and easy to use, based on reported or observed gross motor function rather than on standardised testing. The descriptions were broad and were intended to determine which of the five levels most closely resembles a child’s gross motor function.

- **Stage 2:** To examine the validity of the content of the system using consensus methods (Nominal Group Process and Delphi Survey).

The Nominal Group Process (NGP) and the Delphi Survey (DS) are described by their developers as techniques “*useful for situations where individual judgements must be*

*tapped and combined to arrive at decisions which cannot be calculated by one person”* (Delbecq et al. 1975 p4). Palisano et al. (1997) describe the use of the NGP and DS as the means by which the content validity of the GMFCS was examined by a selected group of experts. Consensus in the Nominal Group Process (NGP) and Delphi Survey were each defined in advance and assigned a numerical value. Palisano et al. used the NGP to facilitate open and focussed discussion amongst participants about the proposed classification system. The group was invited to vote on 17 pre-set statements following group discussion. The NGP was used to obtain views of experts on the draft classification system. The consensus target was that at least 12 of the 15 NGP participants would approve each of the statements.

The Delphi consensus method or Delphi Survey was used to obtain expert opinion in a systematic manner through questionnaires with the ultimate aim of generating a group response after two or more rounds. The questionnaire for Delphi Round 1 included 38 statements, many followed by open-ended questions to encourage the experts to elaborate upon their responses. Each statement was associated with a seven point response scale: with ratings ranging from 1 indicating “strong disagreement”, to 7 indicating “strong agreement”. The content of each statement met the required level of agreement or “consensus” if 16 or more of the 20 participants gave it a score of 5 or higher. The questionnaire for Round 2 posed new statements for those areas where consensus had not been achieved in the first round, alongside other questions and the revised GMFCS.

Further detail of the NGP and the DS are given in the Sections 5.3 and 5.4 respectively.

- **Stage 3:** Determine how reliably the system could be used by different expert professionals in rating the same child (inter-observer reliability studies).

After two rounds of the Delphi Survey and final revisions to the GMFCS, the inter-observer reliability of the GMFCS was examined when used by physiotherapists and occupational therapists to classify children well known to them: 77 children were rated in total by 51 therapists; Kappa was calculated, a measure of chance-corrected agreement.

The GMFCS has been subsequently expanded and revised. It was originally designed for use by professionals who know a child well and within the study, different professionals showed excellent agreement beyond chance on the GMFCS level for the same child (Kappa = 0.75). The shared meaning captured within the simple GMFCS tool has proved very successful and contributes to its widespread usage within a range of professional disciplines. It has a level of predictive power so that a child is likely to track the same

classification level as they develop. It has been the model for the development of other functional classification systems for children with CP such as the Manual Ability Classification System (Eliasson et al. 2006) and the Communication Function Classification System (Hidecker et al. 2011).

## **2.12 Summary**

The review of the literature given here underlines the importance of examining the eating and drinking abilities of individuals with CP because of associations with compromised health, nutrition and growth, as well as social participation and expression of autonomy. There is potential confusion and lack of agreement among research communities and clinicians about definitions of limitations to eating and drinking abilities for individuals with CP. The ability to feed one's self is not the same as the ability to eat (i.e. bite, chew and swallow food) and drink (i.e. suck and swallow fluid) safely and efficiently. Considerable progress has been made in research and clinical practice with the precise shared definition of gross motor function, manual ability and communication functioning. There is a clearly identified need for a classification system of functional eating and drinking ability for individuals with CP.



## 3 Chapter 3 - Research Methodology

### 3.1 Introduction

I have detailed the challenges to eating and drinking ability arising for people with cerebral palsy (CP) in Chapter 2. I considered the classification systems currently in use, within research communities and clinical practice, to investigate limitations to function associated with CP. I outlined the various ways that have been utilised to measure eating and drinking ability, including a systematic review of the literature (Section 2.9.1). The systematic review confirmed that whilst much had been written about the importance of eating and drinking ability, and how ‘ability’ is related to safety of eating and drinking and adequacy of nutritional intake for individuals with CP, there is no agreement between research communities as to how eating and drinking ability should be described or classified.

There is also no functional measurement tool for eating and drinking ability which can be readily understood and utilised by clinicians, researchers, individuals with CP, their parents, caregivers and other relevant professionals. It is evident from the uptake and wide use of the Gross Motor Function Classification System (GMFCS Palisano et al. 1997) in clinical and research contexts, within a short time frame, what the potential benefits of such classification systems can provide (Morris et al. 2004b). Having examined the GMFCS in detail, I chose to use the same methods and design strategies employed by Palisano et al. (1997) to develop and evaluate a new Eating and Drinking Ability Classification System (EDACS) for individuals with CP. The original GMFCS development paper gave the briefest of outlines of the research methods employed with scant detail about the philosophical underpinnings of its development. The mistaken impression I was left with from reading the development paper in the early stages of the project was that the GMFCS had been developed using a quantitative approach. The numerical values representing the reliability and content validity of the GMFCS were emphasised. The centrality of the narrative element, the “*word pictures*” created for each of the different levels of gross motor ability, was brought to the fore in a later publication (Rosenbaum et al. 2008). As I read more about the development strategies used, it became apparent that the creators of the GMFCS had used a mixture of methods to generate both narrative and numerical data in order to create a system which “*achieved*” the required numerical measures of consensus and reliability, within a social context.

In this chapter, I consider the details of Mixed Methods research design and strategy to be used in the development of EDACS. The strategy needs to address the following central research questions:

- Is it possible to develop and agree the content of a classification system of eating and drinking abilities of individuals with CP in collaboration with a group of experts?
- What is an appropriate textual content of a proposed functional eating and drinking ability classification system (EDACS) for individuals with CP, which is acceptable to individuals with CP, parents and professionals?
- What level of agreement can be achieved among a mixed group of experts about the content of the EDACS draft?
- How reliable is the classification when used by different observers?
- What is the experience of individuals with CP and their parents, expert professionals and researchers when they use EDACS to classify levels of eating and drinking ability?

These questions require research strategies which generate both narrative data and numerical data.

The use of, or at least the explicit acknowledgement of, the use of research methods to collect both numerical and narrative data is a relatively new phenomenon (Teddlie and Tashakkori 2009). The philosophical issues associated with what is commonly termed Mixed Methods (MM) research need careful attention.

This chapter addresses questions arising in relation to the research design and strategy employed in the development of EDACS:

- What theoretical framework or research paradigm did I adopt (Paradigm)?
- What is my view on the nature of reality (Ontology)?
- What is my relationship with the topic under investigation (Epistemology)?
- What is the nature of the knowledge outlined and its justification (Epistemology)?
- What research design or strategies did I use (Methodology)?
- How did I use logic?
- How did my values influence the research? (Axiology)
- What are the possibilities for generalising from the research on completion?
- Who is the research for?

I will adopt the convention used by Teddlie and Tashakkori (2009) of using the abbreviation QUAL to refer to qualitative research, QUAN to refer to quantitative research and MM to refer to research conducted using Mixed Methods.

### **3.2 Pragmatic paradigm**

The central issue of Mixed Methods research concerns the paradigm or theoretical framework within which the research is conducted. The two theoretical frameworks typically used for conducting research in the early 20<sup>th</sup> Century are positivism and constructivism. These two theoretical frameworks have essentially been developed in opposition to each other. Each of these paradigms has its own set of enquiry logics, particular world view, definitions around the role of theory, focus on particular types of data and styles of data analysis, sampling strategies and ways of asserting the truthfulness of research findings. Users of each of these paradigms have developed vocabulary and language styles that have come to be associated with research conducted within each framework.

I have used Mixed Methods as a research strategy for the development of EDACS, making use of methods developed within these opposing paradigms. It is important to consider whether it is possible to mix methods, conducting research outside of the theoretical frameworks within which they were originally developed. Teddlie and Tashakkori describe the “incompatibility thesis” or what is also termed the “paradigm debate”. They outline the links between specific paradigms and research methods:

*“... according to this thesis, research paradigms are associated with research methods in a kind of one to one correspondence. If the underlying premises of research paradigms conflict with one another the methods associated with those paradigms cannot be combined” (Teddlie and Tashakkori 2009 p15).*

Methods to collect and analyse qualitative data are typically associated with a constructivist paradigm, whilst methods to collect and analyse quantitative data are associated with a positivist paradigm. If one assumes that there is a one to one correspondence between different research paradigms and the methods they utilise, then a research programme which combines different methods brings into conflict two incompatible paradigms which underpin these methods. Some would argue that by combining methods, researchers are acting outside of any agreed theoretical framework or paradigm, with the potential to throw into doubt any research findings obtained in this way.

Teddle and Tashakkori (2009) write that the paradigms debate diminished considerably in the mid and late 1990s largely because most researchers were more concerned with getting on with the task of research rather than engage with repetitive philosophical discussions. However, Teddle and Tashakkori acknowledge that the MM research paradigm remains controversial in some research communities, and that the QUAL vs. QUAN debate still continues to divide. They suggest that these different research communities can co-exist if there is the understanding that some research questions can only be answered with QUAL methods, others only answered using QUAN methods and some others require MM.

Teddle and Tashakkori (2009) suggest that there is no fundamental clash between different QUAL and QUAN methods when the function of those methods is considered. The debate becomes more heated when consideration is given to questions around which form of data carries the greatest weight in relation to decision making about what is “true”. Rocco et al. (2003) suggest that as QUAL research has now gained acceptance there is no reason for the paradigm wars to continue, rather there is the need to match the research method and paradigm to the purposes, questions and issues raised.

Teddle and Tashakkori (2009) write that it is possible to adopt a stance that is a-paradigmatic as some scholars do working in applied fields, viewing the paradigm debate as distracting or unnecessary and choosing as a consequence to ignore it. On initial reading, I was drawn to the a-paradigmatic stance, as a means of side stepping what I saw to be the pledge of allegiance to a particular philosophy, paradigm or set of beliefs. The task of developing a classification system to fill an identified gap in knowledge was the focus of my enquiry – a task which I initially considered to involve concrete questions and the application of concrete methods without reference to my beliefs about what I consider to be “true”. What has become evident to me over the course of the research project is the fundamental need to examine the contents of my belief system. If I am not aware of the viewpoint from which I am acting, it is difficult to consider my beliefs in relation to the systems of beliefs of other potential users of the system, whether they be fellow clinicians, researchers, parents or individuals with CP. I have had the sense throughout the project of taking a position in the middle, seeking the place where a wide variety of participants agree about the key features of eating and drinking for individuals with CP. The alternative paradigm of pragmatism, posited to counter the arguments of paradigm incompatibility, captures that middle ground where this particular set of research questions is located.

The origins of pragmatism can be traced to the work of Charles Peirce (1878) and William James (1904), although there are philosophical connections extending back to Aristotle.

Teddle and Tashakkori (2009) describe Aristotle's Four Causes as an example of his thinking as a proto-mixed methodologist.

James (1904) outlines what he terms the pragmatic method, which he considers to be a means by which interminable metaphysical disputes may be settled. The essence of the pragmatic method is to interpret each belief or notion by tracing its respective practical consequences. A key question within the pragmatic method is to ask:

*“What difference would it practically make to anyone if this notion rather than that notion were true? If no practical difference whatever can be traced, then the alternatives mean practically the same thing and all dispute is idle”* (James 1904 p2).

It must be possible to show therefore within a serious dispute that some practical difference must follow from one side or the other being right. Drawing out the assertion by Peirce (1878) that our beliefs are really rules for action, the focus of study must be on the actions determined by the beliefs. I agree with the assertion made by James that it is important to investigate what definite differences it will make to individuals at specific moments in their lives if this world formula or that world formula be true, that the truth of an idea means its power to work.

In developing EDACS, I am seeking to create a new social convention with an agreed shared meaning in a range of settings with the power to improve the lives of individuals with CP. The focus is the convention, the instrumental truth of the system, associated with its power to work. I am not seeking for an absolute understanding of the eating and drinking abilities of individuals with CP with an imagined end point but rather a practical solution to a clinical problem. The description of the pragmatic paradigm given by James captures the essence of my experience of the careful crafting of EDACS narrative to describe eating and drinking ability:

*“You must bring out of each word its practical cash value, set it at work within the stream of your experience. It appears less as a solution, then, than as a program for more work, and more particularly as an indication of the ways in which existing realities may be changed”* (James 1904 p4).

Peirce (1878), acknowledged to be one of the earliest advocates of pragmatism, considers the question of how we make our ideas clear. He points out the need to consider that because an idea seems to be clear to us that does not mean that it really is so, suggesting

the need to question the contents of our own mind. He considers that the human mind constructs knowledge from what is observed and experienced: *“Thought is a thread of melody running through the succession of our sensations”* (Peirce 1878 p290). He identifies that our own thoughts can be unclear and that frequently we can be engaged in self-deception mistaking *“the sensation produced by our own unclearness of thought for a character of the object we were thinking”* (Peirce 1878 p292).

Pragmatism involves the rejection of binary choices suggested in traditional dualisms such as that between constructivism (QUAL) and positivism / post-positivism (QUAN) paradigms with regards to logic, methods and epistemology.

*“The project of pragmatism has been to find a middle ground between philosophical dogmatism and scepticism and to find a workable solution ... to many longstanding philosophical dualisms about which agreement has not been historically forthcoming”* (Johnson and Onwuegbuzie 2004 p18).

Teddle and Tashakkori summarise the features of pragmatism, providing a framework for enquiry. These key features are given in Table 3-1.

**Table 3-1: General characteristics of pragmatism (following Teddlie and Tashakkori 2009 p74)**

Pragmatism seeks the middle ground between philosophical dogmatisms and workable solutions to long standing philosophical problems
Pragmatism rejects the binary choices of traditional dualisms such as rationalism vs. empiricism, appearance vs. reality, free will vs. determinism, facts vs. values, subjectivism vs. objectivism
Pragmatism replaces the distinction made between subject and external object with the “ <i>naturalistic and process-orientated organism-environment transaction</i> ”.
Pragmatism views knowledge as being both constructed and based on reality of the world that is experienced and lived
Theories are viewed “ <i>instrumentally</i> ” – they may be true to different degrees depending on how well they work. The success of a theory is based on the extent to which it predicts what will happen or the degree of applicability
“ <i>Pragmatism endorses pluralism</i> ” integrating different and sometimes conflicting theories or perspectives: observation, experience and experiments can all be used to gain a better understanding of people and the world
The enquiry of research is similar to that which occurs in everyday life. Researchers test their beliefs and theories through experience and experimentation, looking to see what works, what solves problems, and what answers questions
Pragmatism understands that provisional, partial and instrumental truths are realistic aims within research
Pragmatism prefers action to philosophising and endorses “ <i>practical theory</i> ”
Pragmatism is a value-orientated approach to research derived from cultural values, specifically endorsing shared values such as democracy, freedom, equality and progress.
Reasoning is constructed as it were from numerous interconnecting fibres

Teddlie and Tashakkori (2009 p73) propose a further refinement to the paradigm of pragmatism when it is applied to MM research which they call “*dialectical pragmatism*”. This emphasises that MM always takes the different dimensions of QUAL and QUANT research seriously and that for each study these two methodologies are synthesised. Rocco and colleagues write that “*the dialectical position calls for explicitly seeking a synergistic*

*benefit from integrating both the post-positivist and constructivist paradigms” (Rocco et al. 2003 p21).*

According to Rocco et al. (2003) dialectical researchers think it is more ethical to mix methods in order to hear from a variety of perspectives, interests and voices. The underlying assumption is that research is stronger when it mixes research paradigms because a much fuller understanding of complex human phenomena is gained. The tensions that arise as a result of the juxtaposition of different paradigms can lead to enhanced, reframed or new understandings. A dialectical position is adopted when the researcher knowingly draws on the two paradigms different understandings of reality, knowledge and the place of values in research. Dialectical researchers are committed to using Mixed Methods (MM) not just because of compatibility but also because of complementarity (Rocco et al. 2003 p 22).

Greene further defines the dialectic stance as one which has potential to bring better understanding of the phenomena being studied than can a single method, as all methods only offer one perspective or partial view. She writes:

*“Understanding that is woven from strands of particularity and generality, contextual complexity and patterned regularity, inside and outside perspectives, the whole and its constituent parts, change and stability, equity and excellence, and so forth. That is [it] seeks not so much convergence as insight ... the generation of important understanding and discernments through the juxtaposition of different lenses, perspectives, and stances; in a good mixed methods study, difference is constitutive and fundamentally generative” (Greene 2007 p79).*

The theoretical framework of pragmatism is eminently suitable to examine the questions at the centre of this study. There is a clinical problem requiring action that neither post-positivist nor constructivist paradigms would satisfactorily answer alone. The utility of the GMFCS comes from the way it has meaning across different contexts: it is meaningful to individuals with CP and their parents as well as having a function in medical, social and research contexts. The proposed EDACS does not aim to be an overall theory or definitive description of all features of eating and drinking for individuals with CP. It is not an exploration of how individuals with CP feel about eating and drinking, nor is it a precise measurement of specific component parts of the overall activity of eating and drinking. It is a tool that is potentially of use across a number of different contexts, facilitating



connections between different people whose shared interest is the eating and drinking abilities of individuals with CP, whatever their personal or professional backgrounds.

Like the GMFCS, it is likely that EDACS will be used in different clinical, social and research contexts after its development. Its construction therefore needs to take place in the context of the different social worlds it aims to bridge. Following the ideas expressed by Peirce (1878), EDACS aims to make specific ideas clear within a classification system. This is achieved by navigating, naming and integrating the thoughts and experiences of all research participants within this specific context. In order to have meaning to the different communities that could potentially use EDACS, it is important to be able to describe the “truth” of it using language and methods understood by those different groups.

The content of EDACS was dictated and shaped by participants through the chosen methods. In the process of EDACS development, I was aware of a wide range of responses to the content of the system, reflecting the different philosophical or paradigmatic positions taken consciously or unconsciously by research participants. The success of EDACS will be measured by the extent to which it encapsulates and makes clear those different beliefs and experiences. Some researchers, clinicians and parents were keen to use the system because they could see its utility and did not require any further information about how others understood the system; other experienced researchers expressed their interest in using the system in future research programmes but understood the need to test the new system empirically. The development of EDACS requires a paradigm that has the potential to bridge different social worlds.

### **3.3 Ontology**

In considering the question “What is the researcher’s view on the nature of reality?” it is necessary to reflect on my world view formed as a result of personal, professional and academic experiences.

My initial academic research training was couched in the scientific study of linguistics and psychology in the early 1980s. The values of the researcher and the subject under investigation were excluded as part of the process of study. We learnt methods to study, measure and objectify speech and language and its use in human communication. I now understand these to reside within a strong positivist model of inquiry, where the knower and known are treated as independent of one another and where reality is considered to be a single and tangible entity that can be examined in small fragments. I remember struggling to join these objective “scientific facts” with my subjective, emotionally charged

experience of working as a trainee therapist. The view of reality underpinning my academic speech and language therapy training was incomplete. It did not help me to understand the subjective experience of those individuals on the receiving end of speech and language therapy. For example, I was trained to “objectively” measure someone’s speech and language skills following a life changing brain injury; I was however, not equipped to meet that person’s emotional reaction to the traumatic event, with strong expressions of emotions such as grief, anger and fear.

The absence of an adequate exploration of the emotional dimension to human communication led me to the explicit study of emotional development and expression through the completion of a Masters in Psychoanalytic Observational Studies of the infant and young child, at the Tavistock Clinic in London. The three year course, with its roots in an interpretivist tradition, facilitated my development as an observer both of the emotional lives of others as well as my own. It became obvious to me in the process of observing that I was not a neutral observer of what was happening around me but that my own values interacted with those of the individuals I was observing, always filtering and colouring in some way what I thought I saw and experienced. This process was clarified and developed within the discussions that took place in the regular weekly seminars, teaching sessions and course assignments. The richness of detail that emerged from the exploration of the emotional landscape of self and other was rewarding, fascinating and clinically relevant.

The experience of considering the nature of reality through these two opposing world views has been the source of considerable confusion, discomfort and tension for me. I was aware that the view of reality explored and shared within seminars at the Tavistock Clinic was completely at odds with that spoken about and shared with fellow health and educational professionals who were working with me at that time within a special school for children with physical disabilities.

What I have learnt from examining the world through these different world views is the centrality of actively attending to or “*noticing*” the stream of information contained within my perceptions in relation to the task I am engaged in. Mason in the Discipline of Noticing puts this succinctly:

*“It is almost too obvious even to say that what you do not notice, you cannot act upon; you cannot choose to act if you do not notice an opportunity” (Mason 2002 p7).*

As an expert clinician and novice researcher, I bring my subjective perception to the activity of research. It has been my experience throughout the project that my perceptions and understanding of all things related to the classification system have changed as the project has progressed. Comments and alternative viewpoints expressed by members of the Project Team and participants in the research process have not always made sense and I have not always been able to hear or notice what has been said.

McCrary Sullivan (2000) outlines this phenomenon of changing perception in the context of research. She describes her childhood experience of learning to give attention to the complexities of surface detail and also to attend to what lies beneath those surfaces from spending time with her Mother, a marine biologist. She identifies features of the aesthetic vision of artists and links it with the aesthetic vision of a researcher. She suggests that “*aesthetic vision does not assume that what one sees in the moment is what one will always see*” and that “*aesthetic vision adjusts the flow of time*”. She gives a poetic description of the aesthetic vision of the researcher:

*“They look at details within their contexts; perceive relations among the parts and between the parts and the whole. They look for pattern within disorder, for unity beneath superficial disruption, and for disruption beneath superficial unity. They construct forms and suggest meanings”* (McCrary Sullivan 2000 p221).

The world view adopted throughout this enquiry is a post-positivist one. I hold the view that each of us can only ever perceive reality through our senses, giving rise to a subjective view of reality that is imperfect, incomplete and subject to change. My view of reality can be expanded and changed by considering the views of others. The extent to which different inter-subjective views of reality intersect or overlap can be examined empirically. Chapter 8 contains an account of my subjective experiences in the process of creating and testing EDACS.

### **3.4 Epistemology**

Closely related to the world view is the epistemological position adopted by the researcher. The questions to be considered here are: what is the relationship between the researcher and the topic under investigation and what is the nature and justification of the knowledge outlined?

Within the context of social science, I do not consider it possible to become detached from what is being studied as is required within a positivist stance; it is essential to be conscious

of the process of observation. On its most basic level, my perception of the world around me is subject to all the usual human errors associated with glitches in consciousness. I was aware of this at many stages in the research process, with a need for checking and verification of work carried out. An example of this comes from my experience of drifting consciousness away from the task of the systematic literature review whilst engaged in the repetitive act of looking at yet another research paper. What I know as a researcher will also be affected by the limited vision imposed due to the frames of reference that I have adopted, as well as the financial motivations or political influences behind the research. My intention was to include my experiences and reflections within the area of study, rather than assume a stance separate from the object of study with the assumption that what is experienced is fundamental to that object.

The initial draft of EDACS was derived from my experiences, developed through my work as a member of a multi-professional nutrition team. The intention behind the proposed classification system is to develop a new “reality” or social convention to standardise the way in which the eating and drinking abilities of individuals with CP are referred to. It is therefore essential to engage a group of individuals who might use such a tool in its creation. The decision was taken to identify the key features of an eating and drinking classification system in advance in order to prompt comments from expert participants.

I could have chosen to start from nothing, a blank canvas. However, following the methods proposed by the developers of the GMFCS (Palisano et al. 1997) and Communication Function Classification System (CFCS Hidecker et al. 2011), the decision was taken to begin the construction of the system prior to the examination of it by study participants. In this way the Project Team and I determined the boundaries and direction of the system, arising in response to the clinical questions that prompted its development. I then set about inviting others to both examine and modify the contents of that draft. The processes adopted allowed for the perceptions of others to appraise and influence the content of each redraft of EDACS. At each development stage, the strength of the inter-subjective agreement about the system was tested in some way.

EDACS was developed in a social context. As an insider researcher, I carried considerable influence and power in the creation of the social contexts in which the content of EDACS was examined and amended. The advantages and disadvantages of the Nominal Group process (NGP) and Delphi Survey (DS) in this context, are outlined in Chapter 5. I identified and invited suitable participants from diverse backgrounds, making use of formal and informal networks and contacts. The NHS Ethics committee, Research Governance

group, Project Team and my academic supervisory team provided invaluable additional vantage points to reflect upon and modify how I was potentially influencing outcomes.

My perceptions and conscious awareness were part of the process of the development of EDACS. I presented each new draft of EDACS for serial consideration at each of the Nominal Groups (NGP). I experienced the feedback and discussions directly and was able to revisit each group by listening to the tape recording and reading both the transcript for each group and the feedback notes transcribed during the group process. I examined the requests for change and I made all the alterations to each new draft of EDACS. I was clear that I needed to adopt a stance throughout the study of not defending the draft structure and subsequent iterations, not overtly influencing discussions within the NGPs by challenging opinions expressed, giving permission to disagree, enabling others to see the classification system as potentially for their use and allowing space for full comment and dissent within both the NGPs and DS. I had to allow the iterative process to unfold with no insistence that my proposed features of the system would continue through to the end of its development. I had to relinquish the classification system as my idea and acknowledge the hurt and upset when my ideas were rejected or challenged. I was not a neutral observer; however, it was essential to the process of the development of EDACS that my thoughts and feelings about EDACS were not fixed, were not rooted in dogma. I needed to be aware that my perceptions of reality were inevitably going to change as part of the research process.

I was acutely aware of the emotional experience of the development of EDACS, recorded more fully in Chapter 8. In the initial stages of sharing EDACS with groups of experts, I felt a mixture of excitement and anxiety, concerned that the ideas expressed in EDACS would be rejected or misunderstood. Other emotions that I experienced in following NGPs included joy and pleasure at the affirming experience of the groups alongside anger, frustration and resignation at the changes that were requested to what I considered a finished document. I was aware of the need to notice these emotions and not act upon them, to make use of the internal mental space that Mason (2002 p19) terms the “*inner witness*”, where internal and external events are noticed, whilst the need to act upon them, judge or dismiss them is resisted. When the emotions were at their highest points, I needed to put EDACS to one side for a few weeks before feeling able to translate suggestions for change into the next draft of EDACS.

I found it helpful to keep returning to the view of the researcher as someone who is aware of the perceptual flow of internal and external reality through the senses in order to describe the emerging structure of a phenomenon: Merleau-Ponty (1945 p viii) writes that

to describe it is the fundamental cognitive act: *“it is a matter of describing, not explaining or analysing”*. Mason makes explicit the need to use description, suggesting the researcher restricts themselves *“to describing only what others would recognise were they present, while avoiding explanations, judgements, theories and implicit assumptions”* (Mason 2002 p19).

The application of Merleau-Ponty’s ideas by others in a similar research context is of relevance here. Scheele (1975) discusses the different philosophical underpinnings that can be used in applying the DS and considers the construction of reality as a product of DS interaction following among others a system of enquiry based on the ideas of Merleau-Ponty. Scheele (1975) describes “reality” as the name given to the collection of tacit assumptions about different aspects of our lives – domestic realities, professional realities, organisational realities and stylistic realities among others. Scheele suggests that one important product of each DS panel is the “reality” that is defined through its interaction:

*“The Merleau-Pontyean enquiry system seems applicable to situations either where a redefinition of contextual reality can facilitate the generation of new options, or where the acceptance of a new reality must be negotiated to create the impetus for technical or social change”* (Scheele 1975 p 40-41).

For EDACS to be adopted by different clinical and research communities, it needs to be meaningful to a wide range of people. The NGP discussions and DS provide a means of externalising the assumptions of the evolving EDACS draft, that is the “local reality” of the Project Team, for examination by a group of interested others or “experts”. The success of EDACS will come from the level of clarity with which it *“[brackets an] idea out of the great din of experience”* (Scheele 1975 p40). The divisions that are created between the levels of eating and drinking ability within EDACS are not “true” in that further examination will produce a wealth of detail showing difference rather than similarity; however it represents a reality – a simplified classification of function - that has meaning for individuals with CP and their parents, as well as members of international clinical and research communities.

My emotional response to EDACS changed considerably throughout its development, and reflected my relationship with the ideas expressed within it. As I listened to the views of others and incorporated their views in to the system, EDACS felt less and less as if it belonged to me. With successive refinements, I lost the sense of the origins of its narrative content and it no longer felt like “my” idea; at that point I experienced a feeling of

emotional detachment. What I knew and understood about the functional aspects of eating and drinking for individuals with CP was challenged, reframed and expanded upon from contact with others. EDACS became a container for the views expressed by others. The information contained within it no longer represented my subjective reality but that it had a new social reality quite separate from me.

In order for EDACS to succeed as a classification system of use in clinical and research contexts, it is imperative that the ideas it encapsulates mean the same thing to a range of different people, at least in the short term until it is replaced by something that does the job better. However, it is not considered possible to develop a definitive classification system for eating and drinking that is time and context free (the nomothetic statements of a positivist stance – see Teddlie and Tashakkori 2009 p86). The original GMFCS, developed in 1997, was subsequently expanded and revised in 2007. The meaning contained within EDACS needs to be applicable across a whole population of individuals with CP, that is, it is nomothetic in its orientation. A classification aiming for widespread usage can draw from but cannot dwell in the unique experiences of eating and drinking for each individual, what would be termed ideographic.

I had a sense of the extent to which the meaning and subsequent utility of EDACS was appraised by the participants within the NGPs and DS. Some clinicians and parents were keen to use EDACS straight away as it matched their personal or clinical experience; others, typically the researchers and medically trained doctors, stressed the importance of reserving judgement until it had been tested empirically. The extent to which the meaning of EDACS was shared by expert users was examined using both statistical and discursive measures within the reliability studies.

### **3.5 Methodology – Mixed Methods**

In this section, I examine aspects of research design and strategy used in developing EDACS using methodological dimensions of contrast from Teddlie and Tashakkori (2009)

#### **3.5.1 Purpose of research**

The purpose of the study was both exploratory and confirmatory. The content of EDACS was co-created by the researcher and participants through exploratory research. The extent of agreement and reliability was examined through confirmatory studies.

### 3.5.2 Enquiry logic

The research paradigm selected within which to conduct research defines the theory or enquiry logic that is to be used, leading to an assessment of a study's validity or trustworthiness. Deductive and inductive logic are two types of enquiry logic.

Deductive logic, frequently associated with QUAN, makes use of reasoning from the general to the specific. Using a top down process, general premises are tested through a series of steps to reach objective conclusions about the generalizability of the data. The direction of reasoning is considered to be "top down" in that theory is examined or tested through the data collected.

In contrast, inductive logic, associated with QUAL, develops conclusions based on the exploration of how individuals experience and perceive the world. Reasoning is used from the specific to the general in a "bottom up" process. The starting point then is the data, concerned with specific events or phenomena. From the data, larger categories of phenomena or constructs may be identified and the researcher attempts to understand the relationships among them. In other words, the data is used to build theory.

MM research within a pragmatic paradigm involves the search for practical answers to questions of interest to the investigator, using the full array of both QUAL and QUAN methods. Decisions about the methods used depend upon the statement of the research question and the on-going phase of the inductive-deductive research cycle (Teddlie and Tashakkori 2009). Within the pragmatic paradigm, research on any question will fall at any point in time within the inductive-deductive research cycle. The decision about whether deductive reasoning or inductive reasoning would come first would depend on the level of development of the ideas connected to the phenomenon that is being studied. In relation to EDACS, there is a body of knowledge (observations, facts and evidence) connected to eating and drinking in CP. It has not however been arranged in a form that is ordered, from which a classification can be derived without some form of inductive reasoning.

If the original development paper of the GMFCS is examined closely (Palisano et al. 1997) it is evident that although the GMFCS was partly based or deduced from the theoretical framework and experience of using the Gross Motor Function Measure, another process was at work. There was some use of inductive logic, but there also appeared to be a creative leap from one existing schema to the new one. Rosenbaum and colleagues, the original authors of the GMFCS, write about the creation of the GMFCS which they consider to be a series of 'word pictures':



*“There were challenges in applying classical test theory to the development of the GMFCS. There was no criterion standard against which to validate the GMFCS. Although we used observations and descriptions of children’s motor performance to inform us about elements of motor function at various ages, the initial draft of the GMFCS was a conceptual exercise rather than a data-based system”*

(Rosenbaum et al. 2008 p 250).

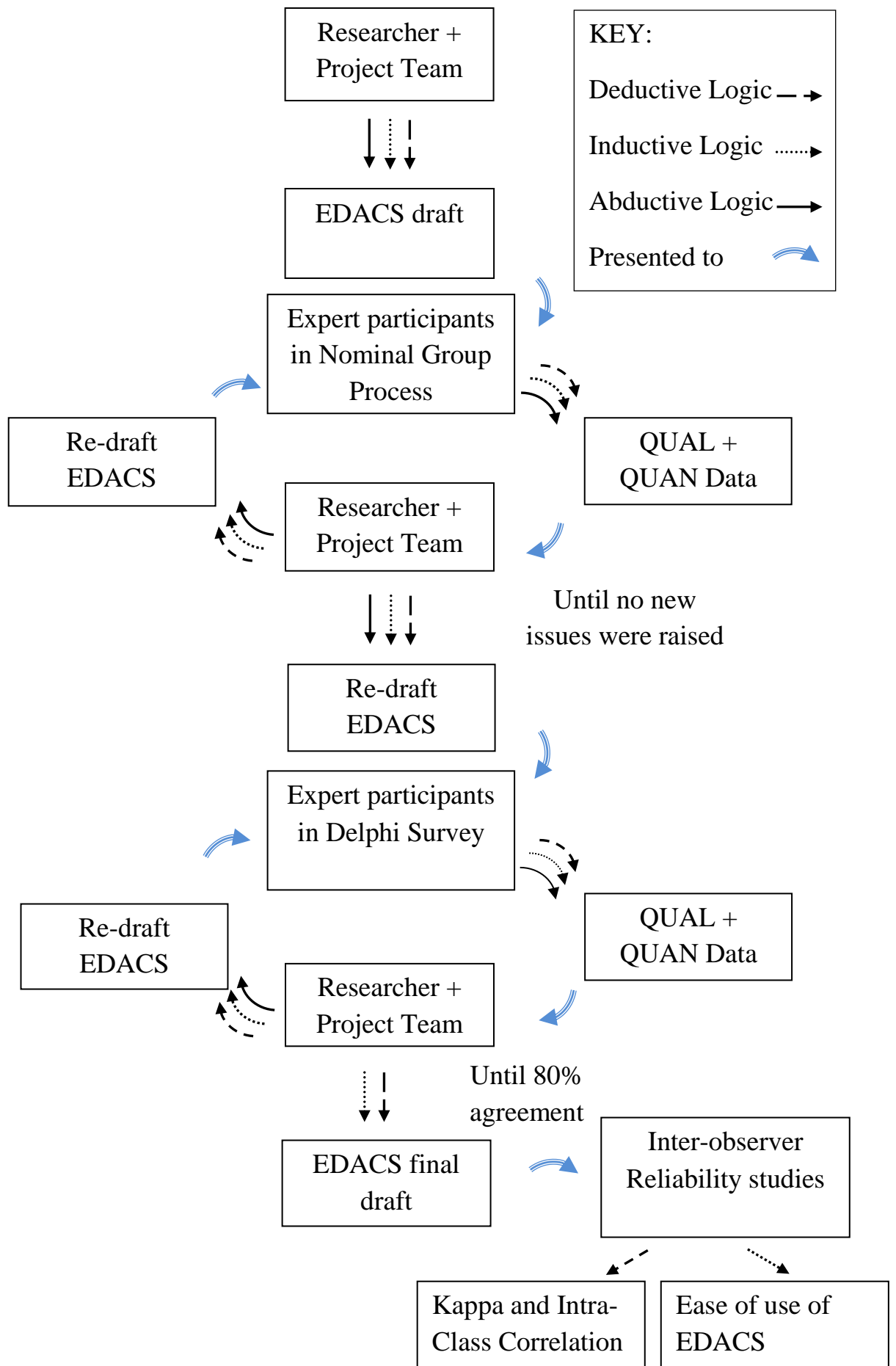
What is described here is a different process from that of inductive and deductive logic; it is conceptual, based on observed patterns within the data and involves the creation of a plausible hypothesis. Charles Peirce, one of the early advocates of pragmatism, described this third type of logic which he termed the “logic of abduction” (Peirce 1931). Teddlie and Tashakkori (2009) describe abduction as the process by which a researcher tries to determine what has caused a surprising event or unexpected pattern in the data. The researcher works back from an observed consequence to a probable antecedent or cause.

Wheeldon et al. (2012) further elaborate the process of abductive reasoning in the context of MM research, providing a useful definition. Whilst both deductive and inductive reasoning are included in the MM research process, abductive reasoning which encompasses the expertise, experience, and intuition of researchers is the key feature:

*“Associated with mixed-methods research, through the intersubjectivity of researchers and their understanding based on shared meaning, this approach to reasoning encourages testing intuitions theoretically and empirically”* (Wheeldon 2012 p117).

The development of EDACS made use of all three types of reasoning although a central part was the expertise, experience and intuition (abductive logic) of the researcher and the research participants. Figure 3-1 illustrates the use of all three types of logic in the development process. I made use of all three types of logic including my own experience, expertise and intuition as well as the experience and expertise of others as represented within the literature to create EDACS. This draft EDACS was then presented to a series of NGPs where participants had the opportunity to use all three types of logic to approve, reject and create different features of the proposed EDACS. Following this iterative process, the redrafted EDACS was presented to a group of experts participating in the DS. DS participants also had the opportunity to approve, reject and create different features of the proposed EDACS. The inter-observer reliability studies (IR) made use of deductive (QUAN) and inductive logic (QUAL) to examine the proposed system.

**Figure 3-1: Use of Abductive, Deductive and Inductive Logic in EDACS development**



### **3.5.3 Axiology**

Axiology refers to the role of values within the research process. My decision to develop EDACS was based on my personal value system. I conducted the study in a way that remained congruent with that value system and I included units of analysis and variables that I thought most likely to yield interesting results. This pragmatic approach contrasts with the value free approach of a positivist paradigm and the value bound enquiry of the constructivist paradigm, finding the middle ground between these two. Post-positivists attempt to reduce the influence of personal values and theoretical influences through methods whereby the internal validity and external validity of their conclusions can be enhanced. Researchers employing a pragmatic paradigm recognise that values play a role in conducting research and in drawing conclusions from their studies.

My motivation in identifying the need for an eating and drinking ability classification system for individuals with CP arose from my own frustrations and those of work colleagues about how ineffectually and inefficiently we communicated with one another about children's eating and drinking needs. I required a great deal of time to communicate all the carefully noted detail that I had observed about the children's eating and drinking needs to the dietitian and the paediatric consultant; my colleagues, in contrast, wanted speedily communicated, clear and essential information on which they could base their decisions to act. I was also frustrated about the absence of a framework or classification system to indicate to parents and professionals the level of concern I held about the limitations to eating and drinking ability of a particular child.

In addition to this, many who work with children with eating and drinking difficulties acknowledge that it can be highly emotionally charged. Many SaLTs have had experience of working with parents and individuals with CP who strongly disagree with a recommended course of action for mealtime management. SaLTs will be aware of safety concerns, recommending changes to usual mealtime practice. Some parents hold fast to normal experiences for their children around food and mealtimes, refusing to follow recommendations made to reduce risks to a child's health at mealtimes.

The lack of clarity about core facts can lead to a complicated mix of facts and values, often with little recognition of this by the parties involved. The anxieties associated with managing the risks linked to eating and drinking (choking / aspiration) can lead SaLTs to make management decisions to minimise risks with little reference to quality of life for the

person involved. When someone has been shown to aspirate on food or drink, often discussions follow about whether non – oral feeding should be considered with the placement of a feeding tube to maintain life. Parents can deny the significance of the evidence of a dynamic X-ray whilst health professionals can focus on a snap shot of the facts with little reference to quality of life. Parents can focus on the emotional experience of feeding their child even though the physical and sensory experiences of eating for their child might appear to be unpleasant or dangerous to health and limiting to survival.

I was keen that EDACS be similar in structure and form to the successful GMFCS, containing the same number of levels as the GMFCS and similar other classification systems to allow for an easier comparison. The name of EDACS was arrived upon as a way of marking its similarity with the other systems. I thought it was important to identify the key features of “*safety*”, “*life threatening*” and “*efficiency*” within the system prior to group consultation. In this way, I created the foundations of the system, establishing what I considered to be the centrality of air way protection during eating and drinking. EDACS version 1 is illustrated in Chapter 5, Figure 5-2.

The aim of the proposed classification system is to distil the observable facts of eating and drinking functional ability from the values, and to establish a simple and coherent way of talking about eating and drinking for individuals with CP. I thought that it would be possible to aim for agreement with the facts of eating and drinking function for individuals with CP across a heterogeneous group of interested participants. I thought that the values associated with eating and drinking would differ widely and would be challenging to classify in relation to the physical abilities and limitations associated with CP. Some participants thought it important to include enjoyment as a key feature of eating and drinking. I expressed the view that whilst enjoyment was an important feature of mealtimes, it was not something that could be generalised across different levels of ability. I challenged the assumption that enjoyment of eating went hand in hand with an ability to eat safely and efficiently: for example, someone able to bite and chew and swallow food with no limitations may not be particularly interested in the whole experience of eating – that is the pleasurable experience of eating is limited; someone with severe limitations to the oral skills required for safe eating may enjoy the experience of eating and drinking even though this might entail frequent episodes of coughing or choking, followed by regular inpatient stays or visits to the Accident and Emergency department. I was clear that

whilst the values associated with mealtimes are really important for the individuals concerned, it was not a feature of eating and drinking that EDACS was being designed to capture.

Another study could examine the emotional experience of eating and / or social participation issues linked to different eating and drinking abilities as measured by EDACS. I took note of comments made by participants concerning these aspects of eating and drinking but they were not included in the development of EDACS. This distinction was made explicit at the different stages of EDACS development (NGP and DS). The emphasis was always placed on the lack of a clearly defined and socially agreed measure of eating and drinking performance.

The establishment of an eating and drinking classification system would provide a neutral context for discussion between parents and health professionals.

#### **3.5.4 Mixed Methods - typology and function**

In this section, I will examine how QUAN and QUAL methods have been combined in the process of developing EDACS. Teddlie and Tashakkori (2009) describe a methodology continuum, placing the opposing methodologies of QUAL and QUAN at each end with a MM section in the centre of the continuum where the two separated and apparently incompatible entities of QUAL and QUAN are combined. It is important to consider all the different aspects of this “mixing”.

Alexander et al. (2007) write that by explicitly mixing both QUAL and QUAN methods associated with different paradigms, a fuller understanding of the social world which is inherently complex can be achieved. Issues arise, however, around mixing different types of data. The different ways of knowing arising from the data can be difficult to reconcile. If there is disagreement which form of data takes precedence? How can there be certainty that the interpretation of one form of data is actually compatible with the other? The other issue concerns which type of data or ways of understanding take precedence over the other. Some researchers may be more comfortable thinking in a particular way out of habit or out of a strongly held overarching theoretical position. If numeric and narrative data are mixed, which takes precedence? Alexander et al. (2007) wonder whether attention is given to the data that most usually occurs and is expected or is it the data which is easier to represent on

the printed page as text or a table. It is important then to make explicit how data is to be combined and utilised.

Teddlie and Tashakkori (2009) specify seven criteria that can be used to create different MM typologies. The first of these criteria is the theoretical perspective adopted by the study which I have already stated is pragmatism, discussed in Section 3.2. Taking each of the remaining six criteria in turn, a description of the MM research typology used for the development of EDACS will be outlined.

- **Criteria 1 - Number of methodological approaches used:**

EDACS was developed using different research strategies to collect both QUAL and QUAN data.

- **Criteria 2 - Number of strands or phases:**

QUAL and QUAN methods were combined in multiple phases making the development of EDACS a multistrand study.

- **Criteria 3 - Type of implementation process:**

The idea to develop an eating and drinking ability classification system along the lines of the GMFCS dictated the type and order of data collection methods to be used. QUAL and QUAN data collection methods occurred both sequentially and in parallel at different stages of the study. Data conversion occurred in the NGP stages when QUAL data was converted into QUAN data by participants, a process of “quantitising”. An element of multilevel mixed design took place in the early stages of the development of EDACS draft. By multilevel mixed design, Teddlie and Tashakkori (2009) mean QUAL and QUAN data is collected in different ways at different levels and then analysed and integrated to answer aspects of the same question or related questions. At the same time as the NGP stage where QUAL and QUAN data was collected in a prescribed way, I also shared the draft EDACS in an informal way with other experts to collect QUAL data through interviews with 4 eminent SaLTs recognised nationally in the UK for their expertise, an interview with an adult with CP and participation in a consultation group of young people with physical disabilities. The QUAL data obtained during these discussions was integrated into the narrative of the classification system which was presented and refined at subsequent NGPs and within the DS. The QUAL and QUAN data from all the methods utilised were

combined to create the narrative or text of EDACS. The clarity and meaning of this document was tested and refined throughout until the final testing stage determined the inference transferability of EDACS.

- **Criteria 4 - Stage of integration of approaches:**

Teddlie and Tashakkori (2009 p145) define distinct stages of research:

**Conceptualisation stage** – including the formulation of research purposes and questions.

**Experiential stage** – the experiential sphere where concrete observations and operations are made, including data generation and analysis.

**Inferential stage** – the sphere of inferences such as abstract explanations and understandings which include emerging theories, explanations, and inferences.

In the development of EDACS, the Conceptualisation stage took place in a clinical context where I work as a SaLT. Both QUAL and QUAN “data” were accumulated and combined as a result of my experience, academic study and reflexive practice which all contribute to my personal and professional knowledge. Eraut (2007) suggests that this professional knowledge is acquired partly through processes explicitly linked with learning but mainly as a by-product of working.

The NGPs and DS incorporated both Inferential and Experiential stages of the study in the iterative process, where both QUAL and QUAN data were collected and combined in order to create and refine the emerging classification system. Specific data was collected to determine within the DS when the process was finished. Once EDACS had moved through the development stages, it reached the final Experiential stage as a proposed new measurement tool. Both QUAL and QUAN data were collected in order to measure the inference transferability of EDACS.

- **Criteria 5 - Priority of Methodological Approach:**

Morse (2003 – in Teddlie and Tashakkori 2009 p143) developed a notational system to describe the different relationships between QUAL and QUAN data in MM research designs. It is useful to outline the system here in order to describe the priority given to each of the different approaches. The use of capital letters indicates the dominance or priority of one method, so for example “QUAL + quan” indicates that the qualitative results and

analysis take priority over the quantitative data and analysis. The arrow ( $\rightarrow$ ) indicates the sequence of methods and the plus sign (+) indicates simultaneity as discussed in criteria 3, concerning the type of implementation process.

Brannen (2007) outlines ways of combining QUAL and QUAN research methods. Simultaneous MM Designs would combine elements in any of the following ways:

QUAL + quan	QUAL + qual	QUAN + quan
QUAL + QUAN	QUAL + QUAL	QUAN + QUAN

Sequential Mixed Method Designs would combine elements in any of the following ways:

QUAL $\rightarrow$ qual	QUAN $\rightarrow$ quan	QUAL $\rightarrow$ quan	QUAN $\rightarrow$ qual
qual $\rightarrow$ QUAL	quan $\rightarrow$ QUAN	qual $\rightarrow$ QUAN	quan $\rightarrow$ QUAL
QUAL $\rightarrow$ QUAL	QUAN $\rightarrow$ QUAN	QUAL $\rightarrow$ QUAN	QUAN $\rightarrow$ QUAL

Using this same formulation, QUAL and QUAN methods were combined in the following format for the development of EDACS:

**Stage 1:** QUAL  $\rightarrow$  **Stage 2:** (QUAN + QUAL)  $\rightarrow$  **Stage 3:** (QUAN + QUAL)  $\rightarrow$  **Stage 4:** (QUAN + QUAL)

Where:

**Stage 1:** Creation of the initial EDACS draft

**Stage 2:** Nominal Groups

**Stage 3:** Delphi Survey

**Stage 4:** Reliability and Ease of use studies.

- **Criteria 6 - Functions of the Research Study:**

Greene et al. (1989) outlines the different functions that mixed methods within a research design can serve. She defines the functions of triangulation, complementarity, development, initiation and expansion which I will use to consider the functions and purposes of the mixed methods chosen for the development of EDACS.



The first, triangulation, is a term whose meaning has become rather lost in its overuse (Teddlie and Tashakkori (2009). Greene et al. suggest that:

*“Triangulation seeks convergence, corroboration, [and] correspondence of results from the different methods”. Its function is to “increase validity of constructs and inquiry results by counteracting or maximizing the heterogeneity or irrelevant sources of variance attributable to method bias but also to inquirer bias, bias of substantive theory, biases of inquiry context”.* (Greene et al. 1989 p259)

Convergence of opinion about the content of EDACS was sought from participants of different backgrounds within the first three stages of the study. The QUAL and QUAN data obtained from different sources, within informal discussions, the NGPs and the DS, all converged within the narrative of EDACS. QUAL info from NGP and DS were corroborated with the respective QUAN data collected at the same time from NGP and DS. Comments received in the NGP were corroborated with those comments received in DS. The face to face structured group process (NGP) was led in this instance by the researcher and creator of EDACS. The QUAL and QUAN data obtained in the NGPs therefore needed to be examined for the degree of convergence with the QUAL and QUAN data obtained in the DS where participants did not meet each other or the researcher face to face.

In this study, the statistical reliability measures (QUAN) were corroborated with the QUAL data of the professional focus group discussion and phone calls to parents.

The second function is that of complementarity where the results from one method are used to elaborate, enhance, illustrate and clarify the results from another method. The aim of complementarity is to increase the validity and trustworthiness of constructs and enquiry results *“capitalizing on inherent method strengths and counteracting inherent biases in methods and other sources”* (Greene et al. 1989 p259). Within the EDACS study design, the iterative development stages (NGP and DS), including both QUAL and QUAN data, enabled me to successively refine the meaning, interpretability and content validity of the classification system. The method strengths of the NGP and the DS were capitalised upon to counteract any biases in methods and other sources. The conversion of QUAL data to QUAN data by NGP participants aided me in making changes to the EDACS draft without degradation of the QUAL data. Tape recordings of NGP complemented the written records

of the NGPs. The QUAN data of the DS was supplemented with QUAL data to elaborate and enhance the levels of agreements expressed.

Development is the third function where the results from one method are used to develop or inform the other method. This might include sampling, implementation and measurement decisions with the aim to *“increase the validity of constructs and inquiry results by capitalising on inherent method strengths”* (Greene et al. 1989 p259). The EDACS draft was examined and redrafted as a result of each of the NGPs and DS – a product of development. The completion of one stage was necessary before the next stage of EDACS development could take place.

The term initiation is used in MM research to describe the exploration of paradox and contradiction within the results from one method with the results from another method in order to increase the breadth and depth of enquiry results by considering them from the different perspectives inherent in the different methods and paradigms. The QUAL and QUANT data within the NGPs and DS were analysed for contradiction and paradox. Any unanswered questions from one method were reframed and posed in a different format. An example of this is the assertion by some health professionals within the NGP and DS that some parents would not be able to accurately rate the eating and drinking abilities of their own children using EDACS. Parents and individuals with CP expressed satisfaction at the “word pictures” of the different levels within EDACS within the DS and NGPs and many were keen to have a system that could be used by them. The question about whether parents would rate their own children using EDACS in the same way as SaLTs was reframed and tested within the reliability studies.

Expansion refers to the function of MM research strategy where different methods are used for different enquiry components in order to extend the breadth and range of enquiry. The study made use of face to face discussion within the NGP. Participants within the NGP included people from many different backgrounds and included a group just for parents of individuals with CP. The breadth and range of enquiry was further expanded through the DS to include a wider international audience. The DS included the collection of QUAN data using a Likert scale to measure the levels of agreement; this was expanded and combined with the opportunity for participants to provide comments and suggestions for change. An expansion of QUAL data collection was made to include informal interviews

with young people with CP as well as expert practitioners prior to DS when agreement was explicitly measured.

In the final stage of examining the inference validity of EDACS, it was important to consider not only the numerical measure of reliability of EDACS but also to invite participants to comment on the process of using EDACS. The “truth” of Cohen’s Kappa includes the imprecise processing of information by the participants in the inter-observer reliability studies. The QUAL data provided a summary of the inter-subjective experience of using EDACS. The focus groups and discussions after the reliability data collection facilitated some insight into the process and experience of using EDACS.

### **3.5.5 Inference quality and inference transferability**

Inference quality is the term which refers to the standard for evaluating the quality of the conclusions that are made within research, whether the origins of the findings are QUAL or QUAN (Teddlie and Tashakkori 2009). Inference transferability is an umbrella term to describe the degree to which the conclusions from a study may be applied to other settings, people, time periods, contexts and so on, whether the findings are QUAL or QUAN.

Inference quality and inference transferability were important concerns in the development of EDACS in that both dimensions influence the extent to which EDACS will be accepted by the different communities that will potentially use the tool. By communities in this context, I am referring to groups of individuals engaged in clinical and research activity which include individuals with CP, their families and carers.

Different communities will have different strategies for measuring the usefulness of a new tool. Academic communities valuing the “truth” of QUAN methodology will examine the statistical measures employed; parents and to some extent clinicians will make a judgement about the “truth” of the tool by how closely it matches what they know to be “true”.

Conversations on this theme occurred regularly in the course of EDACS development: some individuals encountering the tool expressed their wish to use it before its reliability had been tested because they could imagine its utility based on their reading of the narrative content; other participants for whom numerical measures of the validity of a measurement tool were meaningful, asked about the procedures involved in testing the reliability of EDACS.

Different communities have their own conventions and language which need to be used in order to address issues of inference quality and transferability. Consideration will be given here to the inference process behind the development of EDACS. Teddlie and Tashakkori (2009) outline the dimensions of contrast between QUAL and QUAN methodology, drawing from the work of Lincoln and Guba. Table 3-2 shows the types of criteria for “trustworthiness” and the analogous QUAN concepts, as defined by Lincoln and Guba (1985), cited by Teddlie and Tashakkori (2009 p296).

**Table 3-2: QUAL and QUAN contrasts of Inference Quality and Transferability**

Qualitative Research	Quantitative Research
<b>Trustworthiness</b> - the extent to which the researcher can persuade audiences to pay attention to findings	<b>Validity</b> – the extent to which a study accurately reflects or assesses the specific concept that the researcher is attempting to measure.
<b>Transferability</b> - the transferability of inferences from the research context to other similar settings	<b>External Validity</b> - the generalizability of the results to other persons, settings or times
<b>Credibility</b> – the extent to which the research report is credible to the research participants	<b>Internal validity</b> – the degree to which plausible alternative explanations for the obtained results can be eliminated
<b>Dependability</b> – the extent to which variation in a phenomenon can be tracked or explained consistently using the instrument across different research contexts	<b>Reliability</b> - how accurate and consistent is the measurement that the instrument produces

In relation to the development of EDACS, a new classification system or measurement tool, the following questions arise within each of the dimensions described in Table 3-2:

**Transferability:** To what extent do the opinions of experts represented in the development of EDACS, represent the opinions of all those with some experience of the eating and drinking abilities of individuals with CP?

**External Validity:** To what extent can the results of EDACS be generalised to other persons, settings or times?

**Credibility:** Have I truly captured the participants' contributions to the development of EDACS? Have I truly captured the participants' views on the utility and ease of use of EDACS?

**Internal Validity:** To what extent is the content of EDACS representative of the key features of eating and drinking abilities of individuals with CP rather than any other construct?

**Reliability (QUAN)** – Does the use of EDACS produce consistent and reliable results?

**Dependability (QUAL)** – Does the use of EDACS produce dependable results across different contexts?

Table 3-2 belies the claim that there is not a one to one relationship between QUAL and QUAN dimensions in relation to inference quality and transferability. Additional dimensions of validity and trustworthiness are delineated within each of the different research traditions. Two types of validity, of relevance here in the context of the development of EDACS, drawn from the QUAN tradition are content validity and convergent validity. Content validity or the judgemental validation of an instrument by expert judges was used in the development of EDACS in both the NGP and the DS. A measure of the convergent validity of EDACS would be obtained by looking at the degree to which standard assessments of eating and drinking ability for a particular individual with CP agree with EDACS.

The inference quality of EDACS was determined by a combination of internal and external validity including content validity, transferability and credibility. The inference transferability for EDACS was determined by a measurement of reliability (QUAN) and dependability (QUAL):

QUAN: Inter-observer reliability – provides information about the degree to which ratings of two or more observers are consistent. The level of agreement between two sets of ratings produced by two individuals who rate an attribute in a group of individuals can be calculated using Cohen's Kappa (Cohen 1960) and the Intra-Class Correlation Coefficient (McGraw and Wong 1996).

QUAL: For categorical (or even unstructured QUAL) observations, dependability is determined by evaluating the degree of agreement of two observers observing the same phenomenon in the same setting.

The assessment of the reliability or dependability of EDACS was determined by both QUAL and QUAN means. EDACS provides “word pictures” or narrative categories to use to observe the same phenomenon. Observers were not given checklists or questions to pinpoint their observations; rather they were told to assign the level linked to the word picture which best described the eating and drinking ability of someone with CP they knew well. Although the measure of reliability is a statistical one (QUAN), the process of ascribing a category or EDACS level to the individual with CP was a QUAL one.

The psychometric (QUAN) properties of EDACS were represented by measures of validity and reliability. Validity refers to how well the scale measures the construct of interest and reliability refers to the consistency with which a scale measures the construct of interest. Psychometric properties refer to specific statistical measures. I strongly agree with the school of thought which stresses that whenever statistical (QUAN) measures are used, the underlying relationships within the data (QUAL) should also be considered. Cano and Hobart (2011) consider problems arising within the construction of tools designed to measure aspects of health. They cite examples where the psychometric properties or statistical measures of proposed health scales are falsely used to justify the content of the scales. Cano and Hobart also cite examples of rating scales in use that have little investigation of their psychometric properties. It is important in the development of a health rating scale that the psychometric properties of the system are tested. For newly created instruments to have some utility, it is essential that they measure the variable that has been targeted and that they provide data which is clinically useful, meaningful, and interpretable. Cano and Hobart (2011) argue that few scales that are currently in use meet these vital criteria, representing a ‘house of cards’ situation. If there is not clarity about the exact variables that a scale is measuring, it is challenging to know what to do with the information provided by the scales. Cano and Hobart suggest this fundamental issue has serious repercussions for the whole of health measurement. In order to achieve greater precision and clarity in the development of health measurement scales, Cano and Hobart advocate using MM, giving equal emphasis to both QUAL and QUAN information:

*“We would argue that greater use of qualitative assessments is vital, and should include evaluating the extent to which the items of a scale map out the construct to be measured, establishing the most appropriate item phrasing, structuring and context, and cognitive debriefing to ensure consistency in meaning” (Cano and Hobart 2011 p286).*

They warn that psychometric statistics, if considered in isolation, can be misleading.

*[Psychometric statistics] “cannot be expected to produce consistently meaningful results when considered apart from qualitative scale content evaluations .... establishing clinically meaningful content validity from the onset by defining, conceptualizing, and operationalizing the constructs intended to be measured is a vital step” (Cano and Hobart 2011 p288).*

The MM approach facilitates the use of both QUAL and QUAN measures of trustworthiness and validity, subsumed under the headings inference quality and inference transference. I was aware during the development of EDACS that at times views expressed through QUAL data were at odds with those within QUAN data – for example, participants within the DS indicated agreement on the Likert Scale and also offered a suggestion for improvement of EDACS. I was also aware that a few individuals disagreed with much of the content of EDACS in that it did not represent their experience – it was not trustworthy. The views of the majority were captured within EDACS, at the expense of a small minority opinion. I consider the artificiality of “consensus” that can be achieved within a DS in Chapter 5, Section 5.4 when the views of the non-participants are not considered or attention is not given to the opinions of those who disengage from the process. It is important to acknowledge that appraising trustworthiness and establishing validity are two distinct processes and at times are incompatible.

### **3.6 Summary**

In summary, I have adopted a pragmatic Mixed Methods approach to the development of EDACS within a post-positivist worldview. Details of the methods used are given in Chapter 5.





## **4 Chapter 4 Ethics**

### **4.1 Introduction**

The development of a new health measurement scale, such as EDACS, is considered to be medical research combined with clinical care or clinical research. All clinical research conducted within the National Health Service is subject to the ethical principles set out in the World Medical Association Declaration of Helsinki (1996 cited from NIHR 2011 version 2.1). The reason for the original declaration and subsequent revisions was to safeguard the rights of human subjects participating in medical research. Doctor Mengele's medical research conducted within Auschwitz prison camps on the powerless and dispossessed provide appalling and extreme examples of the abuse of human beings in the search for "truth" (Nyiszli 2011).

The basic principles of the declaration are:

1. Research involving human subjects must conform to generally accepted scientific principles and on a thorough knowledge of the scientific literature.
2. Design and performance of each experimental procedure should be formulated as a research protocol presented for consideration, comment and guidance to a specially appointed independent research ethics committee.
3. Research should be conducted only by suitably qualified persons who remain responsible for the human subjects participating within the research.
4. The research can only be conducted if the importance of the objective is in proportion to inherent risk to the subject.
5. Concern for the interests of the subject must always prevail over the interests of science and society, therefore a careful assessment of predictable risks and foreseeable benefits to the subject should be carried out.
6. The right of the subject to safeguard his or her integrity must always be respected. Every precaution should be taken to respect the subject's privacy, and minimize the impact of the study on the subject's personality, and mental and physical integrity.
7. Researchers should not engage in research involving human subjects if it exposes subjects to unpredictable hazards. Investigations should be terminated if the hazards are found to outweigh potential benefits.

8. The researcher should preserve the accuracy of results that are published and that research activity that violates the Helsinki declaration should not be accepted for publication.
9. Each potential research subject should be adequately informed of the aims, methods, anticipated benefits, potential hazards and the discomfort it may entail. Each subject should be informed that they are free to abstain from participation in the study or withdraw their consent to participate at any time. The subject's freely given informed consent should be obtained, preferably in writing.
10. Care should be taken when obtaining informed consent to be aware of the nature of the relationship between the researcher and the subject. If the subject is in a dependent relationship with the researcher, consent should be obtained from someone independent of the research and the official relationship.
11. Where a subject is not legally competent to give consent, consent should be obtained from the subject's legal guardian in accordance with national legislation. When the research subject is a minor, permission from the responsible relative replaces that of the subject in accordance with national legislation. Whenever a minor is able to give consent, it should be obtained in addition to the consent of the minor's legal guardian.
12. The research protocol should always contain a statement of ethical considerations and should indicate that the principles of the present declaration are complied with.

As a researcher within the National Health Service, I am required to attend Good Clinical Practice training on an annual basis (NIHR 2011). Good Clinical Practice, incorporating the Helsinki declaration, provides the required framework for what is considered best practice in research with human subjects. There is no legal obligation for it to be used, unless the research project involves investigational medicinal products. In addition to Good Clinical Practice training, I undertook regular supervision sessions with academic supervisors as part of the study for a PhD, as well as regular Project Team Meetings and Project Team consultations at each stage of the research study. I kept an account of sampling issues and concerns within the reflective journal.

In the following sections, I set out the details of the processes followed to ensure that the research project was conducted within the principles of the Helsinki declaration.

## **4.2 NHS Ethics and Research Governance process**

The Department of Health sets out the requirements for the conduct of research in the booklet “*Research Governance Framework for Research in Health and Social Care*” (2005). Research Governance defines the set of principles, requirements and standards for research and the mechanisms by which quality of research is assured, with reference to the Helsinki declaration. The Research Governance Framework (Department of Health 2005) identifies the roles and responsibilities of individuals and organisational bodies involved in the research process. These are given below with specific details for the conduct of the study.

- **Chief Investigator**

The Chief Investigator is the person taking overall responsibility for the design, conduct and reporting of a study with overall responsibility across sites if there is more than one site involved. In my role as the Chief Investigator for the study, I developed proposals that were scrutinised by the Research Design Service (NIHR) and the NIHR funding panel through the Research for Patient Benefit competition to ensure that they were scientifically sound and ethical. These proposals were subjected to independent expert review by the NIHR and by the local NHS Research Ethics Committee. In conducting the study, I adhered to the agreed protocol; changes made to the protocol were agreed with the funding body, and local Research Ethics Committee. I conducted the study in accordance with the legal requirements and Good Clinical Practice guidance (NIHR 2011) and accepted standards of good practice. I prepared and provided participant information and ensured their welfare whilst in the study. I made arrangements to make findings and data accessible following expert review through publication in scientific journals and through the final report for the NIHR. Feedback of EDACS development was given to research participants.

- **Employing Organisation / Organisation providing care**

Sussex Community NHS Trust, the organisation that employs me remains liable for my work and held the contract detailing the funding agreement with the NIHR for the study. Sussex Community Trust remained responsible for the management of the funds provided, overseeing the regular financial reports I provided to the NIHR. In addition it is the employing organisation’s responsibility to promote a quality research culture, ensuring that I understand and discharge my responsibilities as the Chief Investigator. The Head of

Research and Development within Sussex Community NHS Trust signed the original funding application form submitting the EDACS research proposals to the NIHR, and is required to ensure that studies are properly designed and submitted for independent review. Sussex Community NHS Trust also had the responsibility to ensure that the study was managed, monitored and reported as described and agreed in the protocol, taking action if misconduct or fraud was suspected.

- **Funder**

Funding for the EDACS study came from the NIHR through the Research for Patient Benefit programme. It was the funder's role to assess the scientific quality of the proposed research as well as establish whether the proposal represents value for money. Details of the research environment, including details of the experience and expertise of the Chief Investigator and key researchers within the Project Team were included for scrutiny in the extensive research funding application form. In addition, funding from the NIHR was dependent upon collaboration and inclusion of users of NHS services. The original Project Team was expanded at the request of NIHR to include a parent of a child with CP.

- **Research Ethics Committee**

The development and testing of EDACS involved research participants identified from their use of services for which UK Health Departments are responsible; research participants were also identified because of their status as relatives or carers of users of these services. For this reason, a Research Ethical Committee review was required. The local Research Ethics Committee is a group established to provide participants, researchers, funders, sponsors, employers, care organisations and professionals with an independent opinion on the extent to which proposals for a study comply with recognised ethical standards. The task of the local Research Ethics Committee, according to the NIHR is to *“safeguard the rights, safety and well-being of all trial subjects. Special attention should be paid to the trials that may include vulnerable subjects”* (NIHR 2011p25). All study documentation including the Project Outline, symbol version of the Project Outline, Participant Information sheets, letters inviting participation and data collection sheets were scrutinised as part of the process. Any changes to study documentation were submitted to the Research Ethics Committee for the necessary approvals.

- **Sponsor (Sussex NHS Research Consortium)**

The sponsor is the organisation with overall responsibility for securing the arrangements to initiate, manage and finance the EDACS study. The sponsor was responsible for confirming that everything was ready for the study to begin. This included ensuring that the research protocol, research team and research environment had all “passed appropriate scientific quality” and that the study had ethical approval. It also needed to be satisfied that arrangements were kept in place, in line with Good Clinical Practice, for monitoring and conducting the study, including prompt reporting of suspected unexpected serious adverse events or reactions. All study documentation was printed and filed within a comprehensive site file in order to facilitate inspection of the conduct of the study.

- **Participating Sites**

As part of the EDACS study, participants were invited from across the UK and internationally. When clinical opinion about specific users of health services were sought from practising SaLTs, local Research Governance agreement was required through Integrated Research Application System (IRAS) using Site Specific Information forms. The information contained with the Site Specific forms enabled participating organisations to ensure appropriate health or social care to patients and/or service users and carers participating in a study. Each participating organisation remained liable for the quality of care, and for their duty towards anyone who might be harmed by the study. Where the participating sites involved SaLTs employed by the NHS, Research Governance from the local NHS Research and Development departments was sought. The management teams of the participating independent schools provided the necessary Research Governance.

- **Principal Investigator**

The Principal Investigator was the person who was responsible for the conduct of the study at a particular site. For each of the schools participating in the reliability studies there was an identified Principal Investigator who signed the necessary Site Specific Information forms.

All permissions for relevant approvals for the study were sought through IRAS, a single online system for health and social care/community research in the UK. Requests for Ethical Committee approvals, including notices of substantial amendment, and local

Research Governance approvals for different sites involved in the study were conducted through IRAS. The details for EDACS were entered on to the IRAS system only once and used to complete separate application forms.

Appendix 1 contains copies of documents detailing the approval of the NHS Ethics Committee and Research Governance Consortium. The project outlines are contained in Appendix 3. Appendix 4 contains the invitation letters and consent form for the Nominal Group Process (NGP). Appendix 5 contains the invitation letter to the Delphi Survey (DS). Appendix 6 contains the information sheet, invitation letter, consent form and survey for parents to participate in the reliability studies. Appendix 7 contains the consent form, data collection sheets and an example of an invitation letter to a speech and language therapy team inviting their participation in the reliability studies.

### **4.3 Participant involvement**

The level of detail and scrutiny provided by the Research Governance framework ensured that I was sensitised to the viewpoints of others. All written materials were critically appraised by others. However, the manner in which I approached research participants required a level of sensitivity conveyed in writings about the Ethics of research in a social setting. For example, Bulmer writes:

*“Ethics is a matter of principled sensitivity to the rights of others. Being ethical limits the choices we can make in the pursuit of truth. Ethics says that while truth is good, respect for human dignity is better”* (Bulmer 2008 p146).

I endeavoured throughout to avoid harm, to act with great sensitivity to others and to be transparent in sharing information about the study with others. Whenever I invited someone to participate in the study, I was aware of the guiding principle of being open handed, with no hint of obligation or insistence that someone take part. Written material inviting participation was prepared with care to avoid coercive language.

It was important that individuals representing the backgrounds of all potential users of EDACS were invited, including individuals with CP. I made the deliberate decision not to approach young people with CP attending the special school where I also work as a speech and language therapist. I did this in order to avoid invitations to participate in the research project that were suffused with obligation and expectations arising because of my clinical

role within the school, not connected with my research role. I chose instead to consult with young people through an independent advocacy service (Triangle [www.triangle.org.uk](http://www.triangle.org.uk)) where issues of confidentiality, power and influence were addressed by experienced group leads. I joined the consultative group to discuss EDACS and chose to follow the usual format of the group, rather than insisting that the Nominal Group Process be followed. Participants for the Delphi Survey were recruited through Triangle and support was provided by the experienced staff team to enable the young people to complete the surveys anonymously.

The sampling strategies employed at each of the stages of the study were subjected to scrutiny by the NHS Research Ethics Committee. Processes were created to ensure that participants gave informed consent to participate in the study. I considered possible benefits and risks to the participants of taking part in the study, as part of the Ethics application. At each of the different stages of the study, participants were assured that confidentiality would be maintained throughout. Participants were informed at every stage of their right to withdraw from the study whenever they wanted.

Ward (1997) suggests that researchers can do more or less to redress the balance of power between them and those that they interview and engage in research. She suggests that the whole subject of disability research is receiving more attention than previously with the expectation that those affected by disability will be included within research.

#### **4.4 Patient and Public Involvement**

The source of funding received for the development of EDACS (NIHR RfPB) strongly encourages Patient and Public Involvement (PPI) at every level of the research design. In the development of the ideas for EDACS, I sought the views of the Chailey Research Advisory Group, a group of parents and individuals with physical disability willing to comment on research ideas and proposals. I included people with CP and their parents or carers in the development stages of EDACS, and later extended the reliability studies to include views of parents. The NIHR provided funding for a parent of a child with CP to be paid as member of the Project Team. The inclusion of the parent in the team ensured that there was one parent voice among the health professionals and researchers; it was also possible for other parents to contact a parent with inside knowledge about the project if they were considering participation and required further information.

The NIHR encourages the engagement of users of NHS services to become actively involved in the research process by setting research priorities, advising, assisting in the design, recruiting, carrying out the research and publicising the results. The active engagement of the public and users of the health service challenges the traditional role of research subjects.

#### **4.5 Summary**

The research project to develop and test the reliability of a new Eating and Drinking Ability Classification System for people with CP was conducted within the guidelines set out within Good Clinical Practice training (NIHR 2011). The necessary approvals within the Research Governance Framework (2005) were obtained using the IRAS online system in conjunction with the Sussex NHS Research Consortium, the sponsor for the study. All documentation pertaining to the study has been stored in paper form within the required Site File format for scrutiny by the NHS Research sponsor.

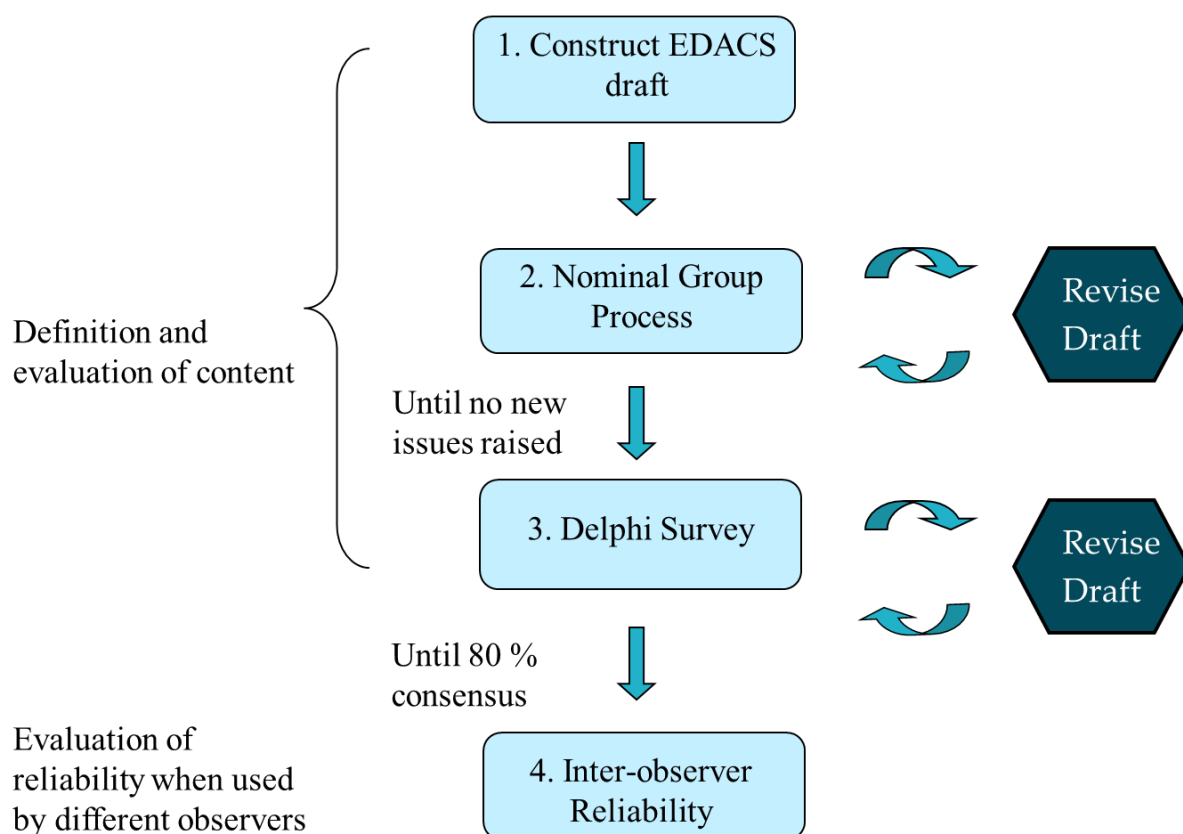


## 5 Chapter 5 - Research Methods

### 5.1 Introduction

The Eating and Drinking Ability Classification System (EDACS) was constructed using a multi-strand sequential Mixed Methods research strategy, detailed in Chapter 3. In this chapter, the methods used in each of the four different stages are outlined. The satisfactory completion of one stage was necessary before the commencement of the next stage. The draft of EDACS was central to each of the stages. The content of EDACS was redrafted and refined in the first three stages until the pre-set measure of consensus or agreement in the Delphi Survey (DS) was reached. The inter-observer reliability of the final version of EDACS when used by speech and language therapists and parents was tested in the final stage. Figure 5-1 illustrates the four stages of the development of EDACS.

**Figure 5-1: Stages involved in the development of the Eating and Drinking Ability Classification System**



In developing EDACS, a new health measurement scale, it was important to reference appropriate quality standards for its development. Terwee et al. (2007) define quality

criteria for assessing the measurement properties of health status questionnaires. The first three stages of EDACS development address issues of “content validity”, defined by Terwee et al. (2007 p35) as “*the extent to which the concepts of interest are comprehensively represented*”. In order to assign a positive rating to a health measurement scale, Terwee et al. propose that the following criteria be met:

- Measurement aim of the scale should be clearly stated
- Concepts that the scale is intended to measure should be stated within a clear frame work
- Target population should be clearly identified
- Target population should be involved in the selection of content for the scale
- The scale should not require reading skills beyond that of a 12 year old in order to facilitate understanding

Stage 4 of the study included an assessment of reproducibility or reliability when different observers used the scale to independently rate the eating and drinking ability of children with CP. Terwee et al. (2007) differentiate between “agreement” and “reliability”.

Agreement represents the absolute measurement error of a scale, captured for ordinal scales by kappa, a measure of chance corrected agreement (Cohen 1960). Reliability is defined as the extent to which a tool can distinguish between people, despite measurement error. Weighted kappa (Cohen 1968) or intra-class correlation coefficients (McGraw and Wong 1996) are typically used to assess this. Terwee et al. (2007) propose a minimum standard of a weighted kappa or ICC value of at least 0.7 in a sample size of at least 50 subjects.

The following sections detail the methods used to determine the content and assess the reliability of EDACS. Because of the sequential study design, the results of the NGP are reported in full in this chapter. The results of the DS necessary to proceed to the next stage are also reported; details pertaining to the DS panellists are reported in Chapter 6. The content of EDACS and the results of the reliability studies are reported in Chapter 6.

## **5.2 Construction of Eating and Drinking Ability Classification System**

The construction, deconstruction and reconstruction of the classification system draft proceeded throughout Stages 1, 2 and 3. The name Eating and Drinking Ability Classification System was introduced and tested in the Nominal Group Process (NGP).

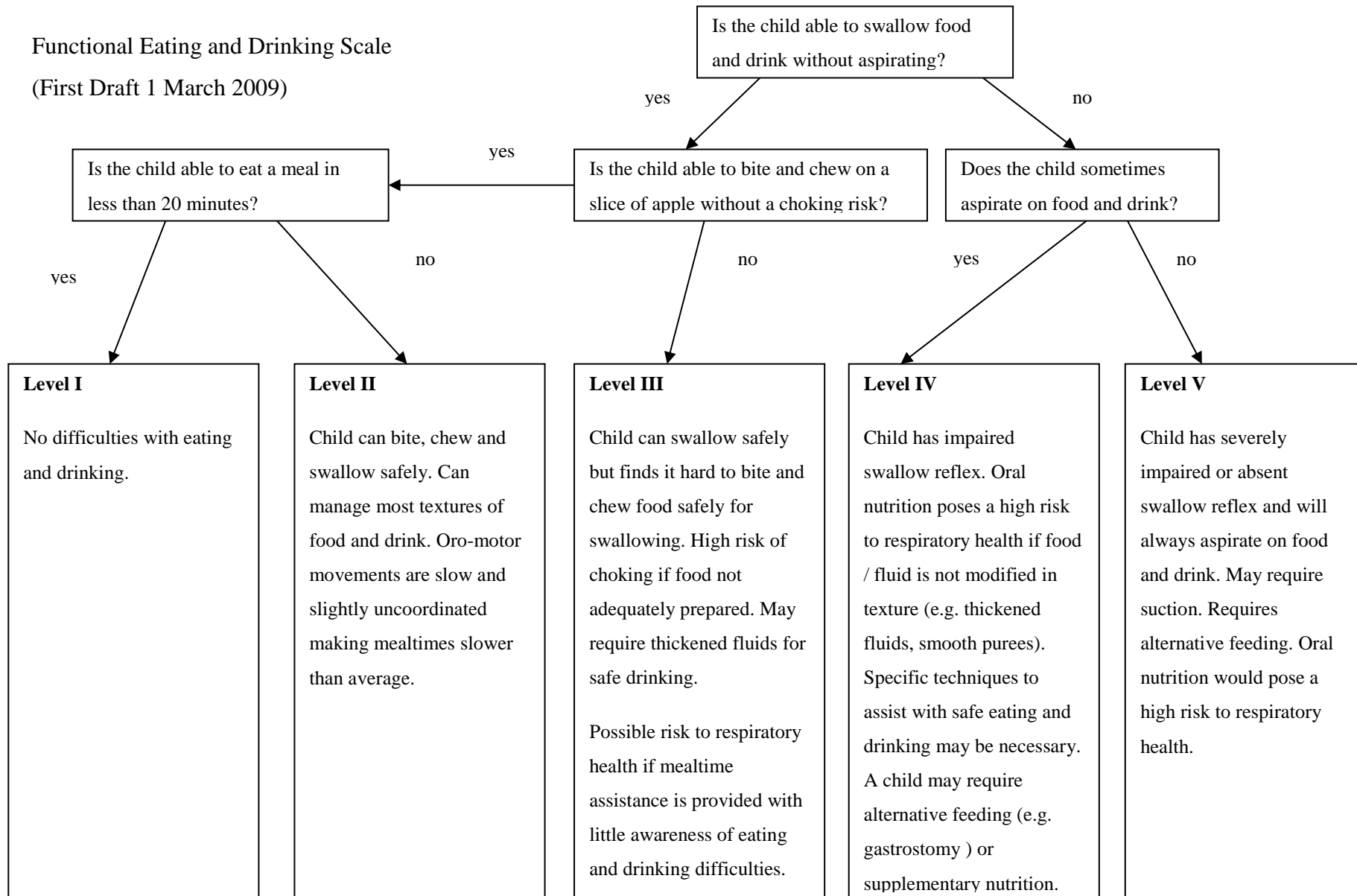
The name arose from the connections with the other classification systems, previously discussed (GMFCS Palisano et al. 1997, MACS Eliasson et al. 2006 and CFCS Hidecker et al. 2011), in order to signal it was part of the same family. The data derived from the NGP and the Delphi Survey (DS) contributed to the content and structure of the system. All versions of EDACS are included in Appendix CD1; versions 7, 13, 16 and 18 particularly demonstrate the extent of change to EDACS content and structure. Changes were made in response to requests or suggestions for improvement from NGP participants and DS panellists.

EDACS content was also modified as a result of interviews with five expert individuals and feedback from a consultative group of young people with physical disabilities, at the same time as the NGP. Information was drawn from the research literature and clinical experience. Members of the Project Team reviewed each set of results from the NGPs and DS and appraised the changes made to each new EDACS draft.

### **5.2.1 Original draft of Functional Eating and Drinking Scale**

The initial ideas for the content EDACS arose from a categorisation system developed by the author and currently in use at Chailey Heritage Clinical Services. Children's mealtime needs are coded depending upon **aspiration** and / or **choking risks**. The different codes or bandings for the children are useful in determining the training needs of staff assisting children at mealtimes, anticipating speech and language therapy needs of the children, as well as targeting scarce resources such as the specialist paediatric dietitian's and nutrition nurse specialist's time. These two critical features of eating and drinking connected to "airway protection" formed the basis of the initial decision making algorithm which was formulated as part of the original Ethics Committee submission. The feature of speed was also included to differentiate between Levels I and Levels II – see Figure 5-2. The branching structure, leading to five separate levels or descriptions of eating and drinking performance, was based on the underlying structure of the Communication Function Classification System (Hidecker et al. 2011) and the Manual Ability Classification System (Eliasson et al. 2006).

**Figure 5-2: First Draft of the Functional Eating and Drinking Scale 1.3.2009**



Prior to the first NGP, EDACS v1 was expanded to include details of the overall purpose, user instructions, definitions, descriptions of levels and distinctions between levels. The content and structure was developed following close study of the original Gross Motor Function Classification System (GMFCS Palisano et al. 1997) and the expanded and revised version of the GMFCS (GMFCS - E & R Palisano et al. 2007).

As EDACSv1 was redrafted into the version to be presented at the first NGP, the process of naming the different version numbers was still in development. The documents named EDACS v2 to EDACS v7 show only small changes between each version number; the decision was subsequently taken to create a new version number after each NGP or DS, with the number of redrafts of that version indicated in square brackets: for example, EDACS v8 [1] was the first redraft of EDACS following the first NGP; this was successively refined until EDACS v8 [10] which was presented to the second NGP.

New ideas for EDACS content were tested in the NGP with subsequent inclusion, refinement or rejection. In addition, the content of the EDACS levels was discussed with four highly respected speech and language therapists, three of whom took part in the NGP. Proposed changes were made directly to EDACS versions 11, 13 and 14 and were subsequently examined as part of the NGP and DS. An in depth interview with an individual with CP was conducted to examine the draft; suggestions made were included in EDACS v9. The transcript of the interview is in Appendix CD2. EDACS was also discussed with the author by the young people's consultative group at Triangle, an independent consultative and advocacy organisation based in Brighton for individuals with special needs including physical disabilities; suggestions for improvements were included in v17 (see Appendix CD2 for notes from meeting).

The EDACS draft was revised many times throughout the development process; further details of EDACS content are presented in Chapter 6, Section 6.3. EDACS v7 was presented to the first NGP (see Appendix CD1).

### **5.3 Nominal Group Process (NGP)**

The Nominal Group Process (NGP) or Nominal Group Technique has been used by researchers as a means of structuring face to face group interactions, particularly when idea generation is the target activity of the group (Delbecq et al. 1975). A NGP follows a prescribed series of steps, including a stage when participants are invited to consider the problem at hand in silence and independently within the group in order to generate ideas and opinion. This is the stage from whence the title “nominal” comes as the group

interaction or absence of verbal interaction does not follow that typical of a group – it is therefore a group only in name.

The original text by Delbecq et al. (1975), referred to throughout, provides the clearest description of the NGP method available. The stages of the NGP, as prescribed by the creators Delbecq et al. (1975), are:

**a) Formulation and presentation of the “problem” at hand**

The welcoming statement by the group leader sets the tone for the meeting and includes a warm welcome, and a statement about the importance of the group’s task. Emphasis is placed on the importance of each participant’s contribution to the problem at hand.

**b) Silent generation of ideas in writing by members of the group in response to the problem**

The group leader presents the “Question” for the group in a verbal and a written form, before instructing them to write their ideas in brief phrases or statements. The group is asked to work silently and independently, with the group leader and facilitators all modelling the behaviour expected by group members as working participants. The group leader needs to help participants work in silence and stay focussed on the task at hand.

**c) Round-robin feedback from group members without discussion or an attempt to evaluate the suggestions made**

All ideas voiced by the group are then recorded on a flip chart visible to the entire group. “Round-robin recording” means asking for one idea from one member at a time, moving round the table, and repeat this process until ideas are collected. Each idea is written on the flip chart before the next person in the group is asked for an idea. This process may stimulate another member to think of a new idea or say something previously not disclosed because it felt too challenging or risky. Duplicate ideas are not recorded. The ideas generated need to be presented in brief words or phrases to map out the thinking of the group as rapidly as possible.

**d) Group discussion of each idea for clarification and evaluation**

Each idea is discussed in turn for clarification, information sharing and a shared analysis behind judgements. Differences of opinion can be expressed without the need to argue the case for a particular idea. The process of listing makes it challenging for group members to remember which idea came from whom.

**e) Individual voting on priority ideas with group decision through rank ordering or rating**

The next stage involves the aggregation of judgements in order to determine the relative importance of individual items. Participants are invited to make independent judgements about the ideas generated, in a written form. These judgements are expressed numerically by rank ordering or rating items. The group's decision is represented by the mean value of independent judgements.

**f) Feedback of results, further discussion and voting**

The results of the individual voting are then fed back to the group with the opportunity for further clarification but without pressure toward artificial consensus. Group members are provided with a final opportunity to clarify their positions before a final vote is requested. This follows the same process as previous voting.

### **5.3.1 Background to Nominal Group Process**

The NGP was derived from social-psychological studies of decision making conferences, management science studies of aggregating group judgements and social work studies examining the problems that arise in public participation in government organisations (Delbecq et al. 1975). This section outlines some of the research involved in its creation and development.

The NGP was developed from research which showed that more ideas were produced by individuals "brainstorming" together in a group than were produced by the same number of individuals "brainstorming" independently (Delbecq et al. 1975). "Brainstorming" groups also generated more ideas than conventional discussion groups in problem solving situations. The ideas output from non-interacting or "nominal" groups were contrasted with that from interacting groups. Using measures such as the average number of unique ideas, the average total number of ideas and the quality of ideas produced, nominal groups were found to be significantly superior to interacting groups in generating information relevant to a problem. In creating the NGP, Delbecq et al. (1975) made use of the findings that increased creative thinking and ideas generation takes place when people work silently in the presence of others, writing ideas independently of one another but not talking about them.

Some key group process characteristics, addressed by the NGP, are detailed by Delbecq et al. (1975). Within a discussion group, individuals tend to direct attention towards social

roles such as friendship acts or task oriented roles such as judgement sharing or giving ideas. When an individual works alone, all attention can be given to the problem solving task. In a face to face group there is an interaction between the social-emotional dimension and the task oriented behaviour. Pressure to reach some sort of decision will lead to more attention being given to the social-emotional dimension than the generation of ideas. The NGP stimulates a balanced orientation among group members between social-emotional concerns and task focussed activity.

The separation of the investigation of a particular problem from the search for a solution ensures that the problem is more fully understood. The NGP counters the human tendency to seek solutions before a problem has been fully understood; speedy decisions are postponed with the promotion of investigating the problem rather than finding a solution. Delbecq et al. (1975) outline two distinct search processes: “reactive” and proactive”. A “reactive” process is when group members react to the opinions of others rather than generate their own ideas, typical of an interacting group. It is characterised by short periods of focus on the problem, tangential discussions, frequent interruptions, and high efforts to maintain social relationships. The NGP tends to elicit a “proactive” search process because participants are required to formulate their own ideas without the opportunity for other group members to react or evaluate.

Research on the behaviour of individuals within groups suggests that normative pressures to conform within conventional discussion groups tends to “*constrain the felt freedom and openness of members to express their ideas*” (Delbecq et al. 1975 p24) and inhibit creative decision making: for example, participants may experience covert judgements by other group members as critical of their ideas, status incongruities between participants may lead to the unhelpful adoption of ideas presented by high status participants, dominant personality types may bring undue influence upon the group and more knowledgeable members may be perceived as bringing with them the threat of sanctions against others.

The NGP was developed to reduce or minimise many of the conforming influences of face to face group meetings through the generation and expression of minority opinion and the toleration of conflicting and incompatible ideas when expressed in written form. All participants influence the direction of the final decision of the group and have equal opportunity to participate.

Delbecq et al. (1975) found that participation in interacting groups tended to decrease as group size increased above seven participants and with larger group sizes the more active



participants became increasingly active. NGP can accommodate larger numbers of participants, approximately nine members, without the limitations to performance of interacting groups. The NGP also facilitates group working by participants with disparate backgrounds and experiences which leads to a higher proportion of high quality and high acceptance solutions, whilst containing the potential for disagreement and conflict within a heterogeneous group.

Conflict or disagreement within groups can either lead to creative decision making or to emotional exchanges depending upon how it is controlled. It is important to separate individuals from the identified problems in order to prevent an attack on a problem being perceived as an attack on a person. In interacting groups, Delbecq et al. (1975) found that group cohesion and relationships developed around areas of agreement; areas of disagreement tended to be avoided or smoothed over. When disagreements did openly emerge on issues, there was a tendency for group members to become polarised on issues and remarks becoming polarised in the discussion. The NGP structures group interactions so that there is a separation between the ideas and the participants that contribute them, conflicting ideas being welcomed and recorded with equal status. Many different viewpoints can be viewed dispassionately.

Delbecq et al. (1975) identify limitations of the NGP, such as the need for extended preparation, difficulty in changing topics in the middle of a meeting, and that not all participants will feel comfortable conforming to the behaviour required of the structured format. The NGP is recommended by a number of authors as an egalitarian means of collecting and measuring opinion in a health care setting (Fink et al. 1984, Gallagher et al. 1993, Carney et al. 1996). All these authors recommend the technique on the basis of Delbecq et al.'s (1975) evidence and design; Delbecq et al. (1975) provide the clearest descriptions of the application and use of the NGP.

### **5.3.2 Nominal Group Process for EDACS**

The developers of the GMFCS (Palisano et al. 1997) and the CFCS (Hidecker et al. 2011) used the NGP in different ways. These differences were examined alongside the clear rationale and evidence presented by Delbecq et al. (1975). The NGP, developed to examine the content validity of EDACS, had the following features:

- The “problem” for each group to consider was the evolving EDACS draft.

- The content of the EDACS draft was revised in response to the voting of each of the groups until no new concepts were proposed and only wording changes were suggested.
- Participants examined the content of EDACS by responding to a series of statements which made the content explicit.
- The NGP as described by Delbecq et al. (1975) was used to structure group interactions.
- The five changes receiving the most votes by the group were incorporated in to the new draft.
- The composition of the different groups was both heterogeneous and homogenous. The definition of expert included individuals who have direct knowledge of eating and drinking with limited movement as a result of CP and their parents and carers as well as professional experts and researchers.
- Most groups were attended by members of the Project Team.
- The author led each of the groups but refrained from commenting or influencing the discussion in any way. The Research Assistant took care of recording and time keeping.
- Groups were held around the UK, closely linked to the localities associated with Project Team members to facilitate their participation; one group was held in London and another in Manchester in order to access the expert group of professionals based in those two cities.
- There were approximately 9 participants for each group.

The following sections detail the preparation required for the seven NGP groups that were held around the UK between October 2010 and May 2011.

### **5.3.3 Location**

Five different venues were identified within the UK as suitable locations for each of the NGPs. The venues and the reasons for selection are given in Table 5-1:

**Table 5-1: Venues and reasons for selection for Nominal Group Process**

<b>Venue</b>	<b>Reason</b>
Central London, Royal College of Speech and Language Therapists, Head Office	Central venue with easy access for expert clinicians from Great Ormond Street Hospital, Evelina Children's Hospital, Bobath Centre Finchley, Greater London area
Sussex, Chailey Heritage Clinical Services	Base for project with easy access for parents of children with CP, expert clinicians from local area, Project Team members from University of Brighton and Sussex Community Trust
Cerebra Research Unit, Peninsula Medical School, University of Exeter	Base of one Project Team member with easy access for parents of children with CP linked with Cerebra Research Unit, expert clinicians from a specialist residential school for children with physical disability, expert SaLT lecturer from a local college, community specialists working with children with CP from Devon and Cornwall
Royal Manchester Children's Hospital, Manchester	Base for paediatric eating and drinking specialist with easy access for therapists from regional specialist schools and colleges for children and young people with physical disabilities, experts with links to Manchester Metropolitan University SaLT department, community specialists working with children with CP
Newcastle University, Newcastle	Base for one of the Project Team members with easy access for expert community and neuro-disability paediatricians, therapists and parents from a regional specialist school for children with physical disabilities, community specialists working with children with CP

A suitable meeting room was arranged in each of the venues, large enough to accommodate 12 people comfortably, sitting in a round table meeting style. This ensured that participants could each see one another for the discussion and feedback sections of the NGP and also write independently during the silent examination of the EDACS draft.

There also needed to be space for a flip chart stand so that all could view the written material generated in the round-robin feedback session.

### **5.3.4 Recruitment**

Participants were invited to take part in the NGP once the locations had been determined.

Suitable “experts” were identified through many different sources:

- Recommendations by Project Team members
- London Paediatric Dysphagia Special Interest Group
- Leading writers and teachers in the UK, involved in the postgraduate training of speech and language therapists in paediatric eating and drinking difficulties
- Professionals working in regional specialist schools and colleges providing expert care for individuals with CP
- Recommendations by specialists identified in the different locations of colleagues or parents of children with CP
- Chailey Heritage Research Advisory Group – a group of children and parents interested in advising clinicians on all aspects of research studies
- AMAZE Brighton a charitable organisation working with parents of children with special needs
- SCOPE - the leading UK disability charity for children and adults with cerebral palsy (CP) who provided a list of their specialist centres in the UK.

Once individuals were identified, they were invited to participate in the appropriate group via e-mail or letter, followed up by a phone call if necessary. A copy of the letter (see Appendix 4) and the Project Outline (Appendix 3) sent to prospective participants have been included in the appendices. A number of different dates were offered to prospective participants in order to facilitate their attendance. Once a date had been agreed, details of the venue and timings of the meeting were sent out. Each participant was sent a consent letter for completion prior to meeting, giving their consent to make an audio recording of the discussion as well as providing details of their dietary requirements (see Appendix 4).

Of the 69 people who agreed to participate in the NGP, including 5 Project Team Members, 15 were unable to attend. All expressed an interest in participating in the DS. Table 5-2 gives the details of the backgrounds of the NGP participants.

**Table 5-2: Backgrounds of Participants in Nominal Group Process**

<b>Background</b>	<b>Number accepting invite to NGP</b>	<b>Number of participants able to attend NGP</b>
Speech and Language Therapists	28	21
Parents of children with CP	13	9
Community Paediatricians / Neuro-Disability Paediatricians	9	7
Nurses	6	5
Occupational Therapists	5	5
Physiotherapists	3	2 + 1 participant who is parent + physiotherapist
Dietitians	3	2
Health Researchers	2	2
Psychologist	1	1
<b>TOTAL</b>	<b>69</b>	<b>54</b>

Two of the seven groups were homogenous in composition. Both groups were held at Chailey Heritage Clinical Services, one being for parents of children with CP and the other for speech and language therapists from the local area with an expertise in paediatric eating and drinking difficulties. The participants in the homogeneous groups appeared to quickly find common ground in group discussions and parents in particular appeared to feel more confident to speak out about more contentious subjects. Two parents in one of the heterogeneous groups were also confident in making their contributions, although they were both experienced members of a group with the expressed purpose of encouraging parents to influence and contribute to research programmes. The NGP held for SaLTs from the local area sought to involve them in the project, and initiate some interest in EDACS across Sussex, a particular requirement of the Research for Patient Benefit funding stream.

### **5.3.5 Nominal Group Process – the meetings**

Careful planning and preparation prior to each of the NGPs was necessary to ensure smooth running of each of the groups and to limit the variability in presentation and participation. The following is a list of materials taken to each venue:

1. Introduction and Statement of the “Problem”
2. Latest draft of EDACS for each participant
3. List of statements to examine EDACS content for each participant
4. Copies of GMFCS and MACS development papers
5. Blank flipchart and flip chart pens
6. Blue Tack to stick completed flip chart sheets on the wall
7. Digital audio recording device with conference recording mode
8. Pens
9. Index cards for voting
10. Name badges
11. Travel claim forms

Suitable refreshments including hot and cold drinks, and either lunch or afternoon tea depending upon the time of day of the NGP, were arranged at each of the venues.

The first three items on the list require more explanation:

### **1. Introduction and Statement of the Problem**

A presentation was constructed which began by welcoming and thanking all participants for coming to the meeting and then stating the “problem” at hand. It was important to include a context for the development of EDACS as not all participants were familiar with the GMFCS and other functional classification systems; also not all participants were aware of the limited means available to measure the eating and drinking abilities of individuals with CP and the consequences of that in different health contexts. The significance of each of the participants’ contributions to the NGP was stressed in order to engage them fully with the process. The introduction included details of the meeting format and ground rules for participation.

Details of the script and information presented are given in Appendix CD2. The information was presented on a flipchart as a visual aid for the presentation rather than a computer based projected presentation in order to ensure consistency of presentation to all 7 NGPs. A computer based presentation might also contribute to the author being seen as the “expert” in the group rather than foster the desired interaction on an equal footing.

### **2. EDACS Drafts**

Details about the construction and content of EDACS are given in Section 5.2, and more fully in Chapter 6, Section 6.3. Participants were sent a copy of the version of EDACS to be examined at least one week prior to the NGP.

### **3. Statements to examine EDACS content**

Both the GMFCS and CFCS developers utilised a series of statements or questions to aid participants in examining the content of EDACS. A list of 37 statements was produced for the first NGP, making the content and the decisions contained in EDACS explicit. After each revision of the draft, the statement set was revised in order to reflect the new content. The statement set for the first NGP is included in Appendix CD2.

The statements were used to examine:

- Purpose of EDACS
- Aspects of eating and drinking that EDACS should measure
- Feasibility of classifying the eating and drinking abilities of individuals with CP
- Agreement with the key features of eating and drinking selected – i.e. safety and efficiency of eating and drinking
- Who would decide on the levels assigned to an individual
- Age limits of EDACS and whether to use age bands to represent the developmental dimension of eating and drinking
- Variability of performance – whether to use best, usual or worst performance
- Significant other factors involved in eating and drinking
- Clarity and appropriateness of the Definitions
- Whether other Definitions are required
- Clarity of the General Headings given
- Appropriateness of Descriptions given
- Whether the Distinction between the levels were well defined.

The statements were presented in a typed form as a list with a substantial space under each for participants to record their comments.

Prior to the arrival of participants for the group, each room was set up for the meeting. Copies of the EDACS draft and sets of statements were placed on the tables where each participant was going to sit, together with a pen should it be needed. Several copies of the GMFCS and MACS development papers were placed around the room for reference should participants chose to examine them. The flipchart stand was set up in a location so

that all participants could view it; the introduction and meeting was conducted close to the flipchart.

### **5.3.6 Data collection**

Everyone was welcomed to the group as they arrived. Whilst waiting for all group members to arrive, introductions were made between group members who did not know one another. Participants were helped to refreshments and asked to write their first names on a sticky label.

Once all participants had arrived and apologies given for those unable to attend, everyone was welcomed and thanked for coming. Housekeeping issues were dealt with. The author, research assistant and any Project Team member introduced themselves before an invitation to each participant to give their names and their backgrounds.

The information contained within the scripted introduction was delivered in a spontaneous manner to all of the participants of the NGP (see Appendix CD2).

- **Instructions**

At the end of the introduction, participants were invited to read the EDACS draft and comment on it using the statement sets. Participants were told that the statement set represented the content of EDACS and that the two documents needed to be looked at together. The importance of working in silence together for approximately one hour was emphasised. Participants were invited to help themselves to refreshments and take a break from the task should they need it but without disturbing others. The author and research assistant examined the EDACS document and statements at the same time as the group participants.

- **Recording**

An audio recording was made of the group discussion for each NGP. Participants had each agreed to this via signed consent forms returned either on the day or prior to the meeting. The digital audio recorder was set to conference mode.

- **Feedback**

The next stage of the NGP was introduced with a description of the process by which participants' views and comments would be collected in turn, moving around the table.



Someone was invited to volunteer to offer their views first on each of the statements.

Participants were encouraged to:

- Condense what they had to say into a short phrase to be written on the board
- Not restate what had already been said
- Pass if nothing to add but comment later on if something else occurred to them
- Contribute as quickly as possible
- Not attempt to find solutions to problems raised.

Participants were invited in turn to comment at least once for each statement, with an opportunity to add anything further after a completed circuit of the group. Participants' comments were written in a brief form on flip chart sheets, following some clarification, next to a number representing the statement that it referred to. As each flip chart sheet was completed, it was displayed around the room, in the order in which they had been written.

Although the intention for each of the groups was to clarify and discuss each item after all the responses had been collected, in practice each of the groups discussed and clarified comments made throughout the round-robin stage. In some groups it was not possible to go through all the statements so group members were invited to contribute anything else they wanted to say before moving on to the voting stage of the NGP. In some groups, participants were encouraged to focus on the later sections of EDACS in order that the first part of the document did not always receive the greatest amount of detailed attention from participants.

- **Rank ordering of ideas**

Each of the participants was then given 5 index cards. They were asked to consider the information collected during the round-robin feedback, displayed around them on the walls and select what they considered to be the five most important ideas or necessary changes. They were asked to write each of the ideas on each separate index card. The following instructions were then displayed on the Flipchart:

*You each have 5 votes. Please write a number on the flipchart next to the changes you would like to see.*

*Give 5 to the idea you think is most important*

*4 important but not as important as 5*

*3 important but not as important as 4*

*2 important but not as important as 3*

*1 important but not as important as 2*

Participants were asked to write a number on each of the five cards to assign a rank order to the ideas selected. It was stressed that what they considered to be the most important idea should be given the highest value of 5 and the least important a value of 1. The author and research assistant participated in the voting process.

The NGP was then brought to a close.

### **5.3.7 Data analysis**

Each NGP produced 3 separate sources of data:

- Flipchart recording - QUAL
- Voting cards - QUAL and QUAN
- Audio recording of group discussion and feedback - QUAL.

The flipchart comments collected during the NGP were typed out for ease of reference; an example from one of the groups can be found in Appendix CD2.

The ideas and necessary changes written on the voting cards and the rank order they received were transferred to Excel. The same ideas or suggestions for change were grouped together and the total score was calculated. The five ideas that received the highest score were used to amend the next draft of EDACS. Ideas which received a score of 5 or 4 from a single participant, but did not receive a high enough score to fall in the top 5, were considered for inclusion. It was possible that the high ranking of an idea by a lone individual might reflect specialist knowledge not shared with any other member of the group. If the group had been comprised of more participants with the same specialist knowledge, it is possible that that idea might have been selected more frequently and received a much higher score. Other ideas were included if they were considered useful. An example of the full set of results from one of the NGPs is given in Appendix CD2. Table 5-3 provides a summary of the top 5 requests for change identified in each of the 7 NGP.

**Table 5-3: Summary of top five changes to EDACS from Nominal Group Process**

<b>Top 5 Changes Requested</b>	<b>Votes received / total votes</b>
<b>London Group (n=9) EDACS v7</b>	
Acknowledge fluctuations in performance connected with different carers, environments, time of day, position, fatigue	35/135 (26%)
Impact of nutrition – differentiate feeding ability from nutrition adequacy	18/135 (13%)
Define “successful” eating and drinking and whether this means “safely”	13/135 (10 %)
Clear definitions of textures and consistencies needed	12/135 (9%)
Age limit of EDACS needs to be lower than 5 years	7/135 (5%)
<b>Parent Group (N=7) EDACS v8</b>	
Age Limit – needs to be older than 18 years and younger than 5 years	19/105 (18%)
Helpful to indicate whether child can feed self or requires assistance	12/105 (11%)
Needs classification of degree of help needed	9/105 (8.5%)
EDACS should cover eating and drinking for an individual’s lifetime	9/105 (8.5%)
Include environmental factors e.g. noise, sleep	8/105 (7.6%)
EDACS to be used by someone who knows the individual well	8/105 (7.6% )
<b>Exeter (N=12; only 10 set of votes) EDACS v9</b>	
Clarify meaning of “Safety” and that EDACS cannot assess safety alone	25/150 (17%)
Define “Safety” and “Efficiency”	23/150 (15%)
Improve consistency of terminology / language used	13/150 (9 %)
Reconsider Age Bands – introduced after parent group	13/150 (9 %)
Clarify levels of assistance – more levels needed	11/150 (7%)
<b>Manchester (N=11) EDACS v10</b>	
Clarify that EDACS is overall classification tool not a clinical assessment	34/165 (21%)
Include other features such as cutlery and adapted equipment	18/165 (11 %)
Specify clinical signs and symptoms of aspiration	13/165 (8%)
Define “tastes” in Level V more clearly	12/165 (7%)
Someone who knows the child well (parent) together with professional who knows about eating and drinking should complete the classification	11/165 (6%)
<b>Newcastle (N=10) EDACS v11</b>	
Make reference to nutritional requirements / needs	22/135 (16%)
Importance of posture / positioning needs to be highlighted	18/135 (13%)
Decide on primary clinical purpose for EDACS	18/135 (13%)
Consider evidence base for age levels and feeding skills	17/135 (12.6%)
Consider use of “harm” to further define safety as aspiration not always harmful	15/135 (11% )

<b>Top 5 Changes Requested</b>	<b>Votes received / total votes</b>
<b>Sussex Speech and Language Therapist Group (N=8) EDACS v12</b>	
Tabulate different levels so it is easier to compare	29/120 (24%)
Clarify who will use EDACS to assign a level	17/120 (14%)
Clarify the purpose of EDACS e.g. where and when will it be used	17/120 (14%)
Define “aspiration” and “silent aspiration” together with clinical indicators	10/120 (8%)
Consistency of terminology – use safety and efficiency as key markers	8/120 (7%)
<b>Multi-professional Group - Sussex (N=11) EDACS v13</b>	
Use language consistently	23/165 (14%)
Clarify who will assign levels	20/165 (12%)
Reconsider age bandings	20/165 (12%)
Acknowledge all variables that affect levels	18/165 (11%)
Clarify purpose of classification system	16/165 (10%)

**Table 5-3: Summary of top five changes to EDACS from Nominal Group Process**

After each group, the audio recording was transcribed by the research assistant. Each one was then checked by the author who completed any gaps and made necessary corrections. Each transcript was used to revisit the content of each of the discussions and aid a better understanding of what participants had said (see Appendix CD2). The NGP groups gave rise to a significant number of statements which were considered in depth. Because of the large volumes of information collected at each NGP, the decision has been made to provide only an overview of the changes requested. The data collected as part of the NGP was incorporated into each of the EDACS drafts.

### **5.3.8 Feedback to participants**

Once the changes had been made to the draft EDACS, from an analysis of the results, NGP participants were sent a copy of the new version of EDACS to which their NGP participation had contributed. In this way, feedback was given to each of the participants from the discussion and voting process in which they had participated. This was accompanied by a handwritten thank you card and a copy of the signed Consent Form.

### **5.3.9 Issues arising**

Chapter 3, Section 3.5.3 provides details of the role of values within the study. The Reflective account in Chapter 8 gives more detail of the experience of leading the NGPs. It

was important to refrain from influencing group feedback and defending the decisions made in constructing EDACS. Information and clarification were provided if requested.

One concern during the NGP was that the task of examining the content of EDACS became progressively more onerous as the length of the document increased from 2 sides of A4 to 16 pages. The details contained within the age bandings that were introduced after two NGPs were often only cursorily examined. Discussions about whether to represent eating and drinking abilities developmentally or not were present in each of the groups, without a clear consensus emerging.

The decision to discuss and clarify ideas at the same time as the round-robin feedback stage emerged during the group process. As a result of the expansion of the EDACS document, later groups had a considerable number of statements to respond to; there was not often sufficient time to separate out the ideas generation stage from the discussion and clarification stage. It was not always possible or helpful to convey feedback in just a few words because of the complexity of the ideas expressed. Participants wanted to discuss some of the ideas with the whole group. The structure of moving from one statement to the next facilitated the refocusing of the discussion on a different aspect of EDACS.

On some occasions the NGP over ran or some participants needed to leave before the voting stage was completed. In these cases, participants were invited to send their votes at a later stage. This was facilitated by sending them a copy of the typed up flipchart comments and instructions about the voting process. One participant did not contribute to the voting process.

The audio recording of the group for parents was lost before transcription was possible. This was due to corrupted software on the computer used to download the audio recording. Although notes were taken throughout, it was unfortunate because parents expressed strong views about wanting a tool that they could use. They also engaged strongly with the question of aspiration and diagnosis by videofluoroscopy. Many of the group had encountered difficult experiences with the procedure, feeling very dissatisfied that such a brief snap shot of their child's eating and drinking ability was used to decide whether oral feeding should continue.

One parent, whose first language was not English, was offered individual assistance in examining the statements and EDACS. Help was declined although it was evident that the levels of literacy and English language comprehension required for the task were challenging for that participant.

In some groups the decision was taken to focus the group on a particular aspect of EDACS such as the age levels or the stages at the end. If all groups always started at the beginning it would mean that the EDACS levels had less viewing and discussion time. The author used the feedback from previous sessions and her experiences and dilemmas in redrafting EDACS to guide where she invited groups to focus.

The round-robin feedback session often ran out of time so the author invited participants to contribute the most important concerns they had. Running out of time was connected with the extensive writing that was needed to collect all the ideas. Many pages of notes on flipchart paper were often posted around the walls for group members to peruse before deciding to vote.

Sometimes people did not fully comprehend what a classification system meant although it was set out in context at the beginning. This led to concerns being expressed that were later withdrawn once a better grasp of the purpose of the tool had been realised.

A conscious decision was made not to get involved in discussions and defend EDACS as the purpose was to collect participants' views on EDACS content. However, at times it may have been helpful to provide more information about the background and reasons for the development of EDACS, as well as the function of existing classification systems, in order to clarify and consequently limit the debate.

Serial consideration of EDACS content within the NGP was brought to an end when no new concerns or requests for change were made, and issues focussed on word changes or grammar rather than content. Following discussion with the Project Team, the decision was taken to present EDACS to a new group of experts through the DS.

## **5.4 Delphi Survey**

The creators of the NGP also examined the potential of the DS as a group technique.

Delbecq et al. (1975) recommend the DS when there is a need for:

- a pooled judgement in the context of a complex problem where there is no apparent acceptable solution to all parties
- ideas generation and evaluation
- group interaction that is not face to face, therefore not constrained by time, affective relationships and finance in bringing a large group together

- structured group interaction which facilitates equal participation by all no matter how large the respondent group and regardless of how assertive or submissive certain personalities within the group may be
- exploration and exposure of underlying assumptions or information which leads to different judgements
- information which may generate consensus within the respondent group
- correlation of informed judgements on a particular topic across a range of disciplines
- the possibility of anonymity of the group respondents
- education of respondent group about the diverse and inter-related aspects of topic.

The DS provided a means to interact with potential users of EDACS around the world. The cost in time and money of organising face to face meetings to examine the content of EDACS would have been prohibitive. Individual views were collected as part of the examination of content in a setting that was not face to face, providing anonymity for panellists. It also provided a structure for managing the interaction between experts.

The basic format of a DS is described by Mullen (2003). The Project Team or Monitoring Group send out a survey which may be structured or unstructured to the DS panellists or “Expert Panel” (Mullen 2003). The responses to the survey, which requests qualitative information alongside some quantitative rating (e.g. Likert scale or rank order) of ideas or statements, are then collated. The original or revised survey is then re-circulated accompanied by an anonymised summary of responses together with requested additional information. Panellists are then invited to confirm or modify their initial responses. This procedure is repeated for a specified number of rounds or until some pre-determined criteria has been realised such as “consensus” (i.e. levels of agreement among the panellists) or “stability” (i.e. absence of statistically different outcomes between two successive rounds).

#### **5.4.1 Background to Delphi Survey**

Fink et al. (1984 p980) write that formal consensus studies, such as the Delphi Survey, are *“intended to correct for the lack of conclusive data by putting the knowledge and experience of practitioners and other experts in touch with available information”*.

There is no agreement in the literature about the label applied to the method – Delphi, Delphi Technique, Delphi Survey and Delphi Method are all used interchangeably. There

is also no agreement about the method definition, limiting comparisons between studies (Mullen 2003).

Linstone and Turoff (1975), in their seminal text about the Delphi Method, acknowledge that any attempt to explicitly define this technique would inevitably be contradicted by other successful users. Both process and content of the DS can be adapted to meet the requirements of the research question, generating both narrative and numerical data. Linstone and Turoff (1975 p3) consider “*that in its design and use Delphi is more of an art than a science*”, limited only by the creative design of its users.

The DS was originally developed within the RAND Corporation to determine an unknown aspect of the future (Dalkey and Helmer 1963). It was used to answer a question important at the time to the American Military in the context of the Cold War with the Soviet Union. They pioneered the technique in order to arrive at an expert forecast of the number of A bombs needed from the viewpoint of the Soviet Union to drop on US industrial targets to reduce munitions output by the prescribed amount. This, as Helmer (1977 p18-19) subsequently wrote was “*in a domain of what might be called “soft data” and “soft laws” ... Standard operations research techniques have to be augmented by judgemental information*”.

#### **5.4.2 Criticisms of the Delphi Survey method**

Because the results of the DS are “*the product of a carefully designed and managed interaction and not answers to a set of abstract questions obtained through following prescribed methods*”, (Scheele 1975 p36) it is important to be aware of the impact on the results of the design and management. One major criticism of the DS technique would be the power of the Monitoring Group given that they are involved in the selection of the panellists, preparation of materials, interpretation of responses, integration of insights and presentation of results. Linstone and Turoff (1975) acknowledge that the imposition of Monitor views and the exclusion of contributions are common reasons for failure. Scheibe et al. (1975) give details of a study experimenting with the DS technique to investigate the effects on the results of the DS if false feedback was given to the panellists: unsurprisingly, false feedback given after the first round of the DS was incorporated by panellists and influenced subsequent opinions which moved away from the initial views expressed.

As with the NGP, the majority of papers providing a detailed critical analysis of the DS’s application date from the 1960s and 1970s when the technique was first developed. More recent papers detailing the use of the DS in a health setting cite the work of the original



authors as described here (Sinha et al. 2011, Mullen 2003, Cantrill et al. 1996, Fink et al. 1984).

#### **5.4.2.1 Expert Panel Selection**

Sackman (1974) provides numerous examples of the abuse of the technique by the Monitoring Group. He pays particular attention to way in which Expert Panels are selected, and considers the influence of political and power relationships in the selection of panellists.

Sackman (1974) asks the question what constitutes an “Expert” and states that few DS panels request detailed personal data from panellists for sampling profiles. He cites some DS studies where experts produce similar forecasts to non-experts. Mullen (2003) suggests that the assumption that “experts” are professionally qualified and / or with high status needs to be challenged and that an expert can be defined as anyone with a relevant input. In the field of health care, Cantrill et al. (1996 p69) suggest that “*the definition of [an expert] should include any individual with relevant knowledge and experience of a particular topic, including patients and carers*”.

Given the very loose definition of a DS, it is not surprising that there is no answer to the question about the optimal size of a panel. Cantrill (1996 p69) gives examples of panels in DS studies of health issues ranging from 4 to 3,000 members. The recommendation is that the size of the panel is governed by the needs of the investigation where sample size would be specified as part of a statistical process.

#### **5.4.2.2 Expert panel responses**

Sackman (1974) offers strong criticism about the tendency to treat panellists’ responses as considered and reflective of the task at hand. He reflects upon his own experiences in completing extensive DS questionnaires with limited time given to each question. He suggested that the demands of some questionnaires may well elicit snap decisions and stereotyped thinking. Sackman also suggested that the proposed anonymity of DS panellists may also contribute to irresponsible contributions because of the lack of accountability.

Linstone (1975) acknowledges that a most serious problem associated with the execution of a DS, which is difficult to remedy, is the basic lack of imagination by the designer and consequent poor design. Linstone (1975) writes that the designer needs to try and perceive

how different individuals may view the same problem and in response to this create opportunities within the design of the DS interaction for panellists to offer their responses.

A very significant criticism of the DS which requires careful consideration is that of forced consensus. There is the potential within a DS to apply covert pressure to change opinion in order to achieve “consensus” as outlined by Sackman:

*“By the time the third or fourth round occurs, the holdout individualist responses pose the threat of yet another tedious run through of the same items, and even die hards are inclined to yield to save everyone the dreary routine of another round.”*  
(Sackman 1974 p47-49).

Sackman points to conformity research which has demonstrated the tendency for individuals to conform to group opinion in relatively unstructured situations.

Writing with the same concerns, Linstone observes that:

*“A dogmatic drive for conformity, the “tyranny of the majority”, sometimes threaten to swamp the single maverick who may actually have a better insight than the rest of the “experts” who all agree with each other”.* Linstone (1975 p 567).

The panellists’ responses will be affected by all aspects of the design of the study; the results will be illusory if it is poorly thought through, insensitive to opinions expressed, or driven by the wish for consensus rather than to make explicit the underlying assumptions behind agreement or disagreement. The DS is a way of structuring group interaction and is much more than an opinion poll.

#### **5.4.2.3 Superficial analysis**

Another criticism levelled by Sackman (1974) was that in his experience, DSs paid little attention to the drop out patterns of panellists. He reported a study where the responses of people who dropped out from a particular DS were analysed: panellists who dropped out responded to fewer questionnaire items with responses that were far more critical of the overall study and the usefulness of the questionnaire items than non-dropouts (Sackman 1974 p 20). In other instances where panellists stick through the entire process, both positive and negative reasons may operate: for example, strong interest and motivation in the target area or personal acquaintances of the Monitoring Group may influence participation. If dissenters drop out from the process, this will contribute to an artificial consensus (Mullen 2003).

Sinha et al. (2011) offer guidance concerning methodology and reporting when using the DS based on a systematic review of existing studies. They suggest that patients and clinicians be involved and that researchers avoid imposing their views on panellists. They recommend that the attrition rate of panellists be minimised and that methodological decisions be clearly reported. Following this guidance, the DS for EDACS collected the following information:

- Size and composition of the DS panel: total number of panellists invited, number who completed Round 1, backgrounds of panellists, how panellists were identified
- Methodology of the DS: administration of questionnaires e.g. electronically or by post, information shared with panellists in Round 1, information shared in subsequent rounds, how were questions posed, level of anonymity between panellists, definition of consensus given, and inclusion of non-responders in subsequent rounds.
- Results: Number of panellists invited to each round, number who completed each round, results scored by panellists in each round with a measure of group response preferably with a measure of distribution, a comprehensive list of what the panellists agreed to.

#### **5.4.3 Delphi Survey as used by developers of GMFCS and CFCS**

The developers of the GMFCS (Palisano et al. 1997 and 2007) and CFCS (Hidecker et al. 2011) both used the DS to examine the content of each of the draft classification systems but in slightly different ways.

The GMFCS study involved 19 people in a DS conducted in three rounds, using a paper based survey. The expert panel was described by Palisano et al. (1997) as “homogenous” in composition in that physiotherapists and occupational therapists were invited to participate; the different backgrounds and theoretical viewpoints of these experts might be better described as “heterogeneous”. The draft GMFCS together with 38 statements, making the content of the system explicit, were sent to the panellists. Panellists were invited to rate their agreement with the statements using a 7 point scale where 1 signalled strong disagreement, 4 indicate indifference and 7 indicated strong agreement. Agreement was reached when each statement was given a score of 5 or more. 15 or more people out of 20 panellists had to agree with each statement for it to reach the required level of agreement or consensus (80%). In the final round, clinicians were asked to assign a level to children with CP known to them, giving feedback about how easy that was to complete.

In contrast the CFCS DS expert panel was much larger (n=112 for first round, n=69 for second round) and was heterogeneous in composition. It included individuals with CP, parents, paediatricians, speech and language pathologists / therapists, occupational therapists, physiotherapists and researchers. The DS was conducted in 2 different rounds with the draft CFCS being sent with a series of 36 questions that included 10 questions requiring a Yes or No answer. The answers to these 10 questions were used as a measure of agreement. The other questions were either concerned with the backgrounds of the panellists or open ended questions inviting comments on the draft. The responses to these questions were not included in the measurement of consensus. Consensus was arrived at when there were 80% “Yes” responses from all panellists. 9 of the 10 questions used to measure consensus received a “yes” response in the first round of the DS from 80% of the panellists. The second round involved a revised draft and a reduced survey with some open questions and the restating of the one consensus question that had failed to reach the required level of consensus in the first round. Authors of the CFCS were able to use computer based communication to access a wider range of people more quickly.

The function and meaning of the questions and statements posed to the DS panellists by the development teams of the CFCS and GMFCS were appraised. They aimed to assess the following for each classification system:

- Level of agreement with the aims and with the clinical distinctions made
- Clarity of the aims and the clinical distinctions made
- Feasibility of the aims and the clinical distinctions made
- Clarity of the Introduction, User Instructions, General Headings, Descriptions, Distinctions between Levels and Definitions
- Completeness of Definitions
- Appropriateness of General Headings, Descriptions and Distinctions between Levels
- Assessment of the scope of each system
- Open questions for comments

The majority of the questions for the CFCS concerned the clarity of wording used and whether aspects of the system made sense. There were few questions concerning the level of agreement with the content of the system itself. The open questions of the CFCS DS gave more space to the panellists to scrutinise the content in contrast to the more structured statements of the GMFCS DS. The two choices of either “yes” or “no” for the CFCS DS gave little scope for measuring the extent of disagreement or agreement although the box

for comments would provide the opportunity to show this. The rating scale of the GMFCS DS would allow discrimination of levels of agreement; however, the authors used the scale in a binary way by defining consensus as a score of 5 or more. The author and Project Team considered it helpful in the context of the DS to know by how much someone agrees or disagrees with the content of EDACS, as facilitated by the use of the Likert scale.

Neither study reported any examination of panellist responses if they dropped out from the study. The EDACS monitoring group gave careful attention to this aspect of DS design.

#### **5.4.4 Delphi Survey content for EDACS**

Following extensive discussion within supervision and the Project Team, the following decisions were made about the DS to examine EDACS content.

- Use a DS similar in design to that of the GMFCS DS in order to capture data providing both a graded numerical assessment of agreement and narrative suggestions for change
- Include some questions to elicit information about the backgrounds of the panellists
- Use a 7 point Likert Scale for levels of agreement - agreement with the statement defined as a score of 5 or more.
- Use the web based programme Survey Monkey to send out the survey electronically with the latest draft of EDACS; panellists have the option to participate using paper copies of the DS
- Tag each Survey in order to match responses in the different rounds of the DS. Although this meant that panellists' responses to the survey were not anonymous to the monitoring group, they were offered reassurances that only their anonymised responses would be shared with other panellists.
- Use new surveys in subsequent rounds in response to results received.

#### **5.4.5 Recruitment**

The selection of experts or individuals with relevant knowledge and experience was given careful consideration as was the backgrounds and the numbers of panellists to be invited to participate. A list of individuals with relevant knowledge and experience was compiled. A letter was either e-mailed or sent by post inviting them to participate in the DS (see Appendix 5). They were:

- Key individuals who have published work in relevant subject areas

- Individuals with relevant specialist knowledge expressing an interest in participating in the DS following presentations by the author at local, national and international conferences
- Suggestions by members of the Project Team including individuals with links to the Survey of Cerebral Palsy in Europe group (SCPE 2010) and researchers based in Europe and North America
- Individuals who responded to the authors requests for participation in the DS through networks within professional organisations, parent networks and other support and advocacy groups for individuals with CP. The author approached the British Dietetic Association Dietitians Interested in Special Children, Royal College of Speech and Language Therapists affiliated Paediatric Dysphagia Special Interest Groups around the UK, Royal College of Nursing, British Association of Occupational Therapists and SCOPE, the leading UK disability charity for children and adults with cerebral palsy
- Chailey Heritage Research Advisory Group – a group of children and parents interested in advising clinicians on all aspects of research studies
- Individuals who had agreed to participate in the NGP who had been unable to attend and had expressed an interest in giving their views through the DS
- Following personal communication with Mary Jo Cooley Hidecker, author of the CFCS, the author was sent a list of names of experts from North America and Australia who had expressed an interest in participating in the development of an eating and drinking classification system
- Individuals known to the author with expert knowledge
- Individuals with CP, approached through an independent advocacy organisation for individuals with special needs called Triangle. Triangle was able to provide communication support and a confidential space for individuals with CP to complete the surveys. The cost of this service was agreed in advance and payment made through the NIHR Research for Patient Benefit budget.

Only individuals who actively agreed to participate in the DS were sent the next letter giving them details of how to participate together with the link to the online survey. The author aimed to recruit around 60 people of varying backgrounds to the DS, in order to ensure a wide range of responses to EDACS content but without collecting too much data to process in the available time frame.

### 5.4.6 Delphi Survey design

The surveys sent out in each of the rounds of the DS alongside the EDACS draft were designed following close examination of those used by the developers of the GMFCS and CFCS. A mixture of closed and open questions were used throughout.

For both Delphi Survey Round 1 (DS1) and Delphi Survey Round 2 (DS2) the content of EDACS was represented by a series of statements to which panellists were asked to indicate the level of their agreement. A 7 point Likert scale of identical design to the GMFCS was used to do this. The decision to use scaled responses rather than a binary “agree” or “disagree” response was made in order to capture the extent to which an aspect of EDACS was being agreed or disagreed with. If an aspect of EDACS was strongly disagreed with it would be harder to alter EDACS in order to elicit agreement in subsequent rounds. In processing the results however, responses were codified as either AGREE or DISAGREE – see Section 5.4.8 for details of this.

For example:

6. EDACS should provide a systematic way of describing 5 different levels of performance to replace subjective terms such as “mild”, “moderate” and “severe”.

Do you ....

strongly disagree	disagree	slightly disagree	neither agree nor disagree	slightly agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any comments?

Each statement was followed by an open text box of unlimited size giving panellists an opportunity to give more detail about their response with the question “Any comments?”

Appendix CD2 includes a copy of the survey used in DS1.

A summary of the information content of the survey is given below:

- Level of agreement with the aims of EDACS
- Level of agreement with the key features of eating and drinking
- Level of agreement with the process of classification

- Clarity of the expression of the aims of EDACS
- Clarity of the expression of the key features of eating and drinking
- Clarity of the expression of the process of classification
- Clarity of the General Headings, Descriptions, Distinctions and Definitions
- Appropriateness of the General Headings, Descriptions, Definitions and Distinctions
- Assessment of the scope of the system.

The surveys were presented to the panellists using the Survey Monkey Gold package. This package was chosen because it allowed sufficient flexibility in design and storage of data. The colour of EDACS (purple at that time) was used as a header to each of the pages of the survey. The original intention to include the Chailey Heritage Clinical Services and Sussex Community Trust logos within the survey was rejected because the facility to include logos was limited within Survey Monkey Gold. It was decided that these logos be included at the top of the letter which included instructions about how to complete the survey.

Survey Monkey was set up in order to allow panellists to access the survey as many times as they wanted to answer questions in any order without any requirement that any question be answered. Within Survey Monkey, if a question is marked by the survey creator as requiring an answer, it is not possible for the participants to move on to other parts of the survey until a response to that question is given. The decision to make no restrictions to accessing the survey came about from the authors own frustrations in completing online questionnaires. It was important that the survey facilitated reflection on the part of the panellists, enabling them to return to questions that they were unable to answer. Panellists were told it would take about an hour to complete the survey; the design recognised that some people may not have an hour to complete the survey in one sitting.

The facility to complete the survey in a paper form was offered to panellists; any surveys returned in paper form were entered by hand into Survey Monkey by the author.

#### **5.4.7 Delphi Survey Round 1 – data collection**

Instructions for participation in the DS were brief and clear. A letter was composed explaining the process of the survey: for example, feedback from DS1 would be given to panellists anonymously and that it was important that panellists complete subsequent rounds of the survey (see Appendix 5). An electronic link to the survey with an individual number tag linked with each person's name was included in the letter along with the EDACSv16 draft. Other instructions were given about accessing the survey through the same computer on different occasions otherwise the responses would be lost.



The DS1 opened with four questions to elicit personal or professional backgrounds of each of the panellists, an indication of the area in the world that they had experience of the eating and drinking abilities of individuals with CP and the extent of their expertise. An open ended question was selected to explore the degree of “expertise” panellists had. This was “In your opinion, what are the significant features of eating and drinking for individuals with cerebral palsy?” Whilst there were no external criteria against which the degree of “expertise” could be measured, the responses given were appraised and analysed by the author, making use of her clinical knowledge and the literature as set out in Chapter 2, particularly Section 2.2, 2.5 and 2.6. Section 6.2.3 details the results from this question.

Panellists were instructed that the rest of the survey was about the content of EDACS v16 and to refer to the copy sent with the survey. They would be asked the extent to which they agreed with the series of statements that followed in the survey and that these statements represented the content. It was pointed out that each statement was followed with an open box for comments or suggestions for change.

These 42 statements were presented in sections and in an order relating closely to the content of the EDACS v16 so it would be relatively easy for panellists to find their way through the DS. The final item in the DS1 gave panellists the opportunity to make any other comments about EDACS v16.

The number of panellists agreeing with each of the 42 statements was taken as an indication of the level of agreement with EDACS content within DS1.

#### **5.4.8 Delphi Survey Round 1 - data analysis**

Both quantitative and qualitative data were examined and processed using Excel.

The Likert scale data for the 42 statements representing EDACS content were divided into two categories: responses 1 to 4 representing strongly disagree, disagree, slightly disagree and neither agree nor disagree were categorised as DISAGREE; responses 5 to 7 representing slightly agree, agree and strongly agree were categorised as AGREE.

In DS1, 80% or more of panellists agreed with 39 of the 42 statements representing EDACS content which meant that the majority of EDACS content reached the required level of agreement. Table 5-4 indicates the levels of agreement for DS1 including details of the three statements that did not meet the required levels of agreement:

**Table 5-4: Levels of agreement for Delphi Survey Round 1**

Statement	% agreement
39 / 42 statements	≥ 80%
<b>S22.</b> EDACS should classify the eating and drinking abilities of individuals with cerebral palsy from the age of three years	58.8%
<b>S30.</b> No other definitions are required	70.2%
<b>S31.</b> EDACS should contain 5 levels in line with other Functional Classification Systems	78%

All comments in the form of text data were read and codified at three different levels:

- Level 1 –whether the panellist’s comment expressed agreement, disagreement, and reservations or noted an omission in relation to the statement.
- Level 2 –whether they proposed the inclusion of more detail or less detail in EDACS, or whether there was some misunderstanding.
- Level 3 – details of suggestions for change to content, typing errors, word order and unclear language were recorded.

The comments received for Statements **S22**, **S30** and **S31** were examined for possible reasons why agreement levels were low.

**S22 - EDACS should classify the eating and drinking abilities of individuals with cerebral palsy from the age of three years.**

**S22** received 51 comments. 9 of these 51 comments expressed agreement with **S22**. 35 of the remaining 42 comments stated that EDACS should start at a younger age. Two further comments requested the rationale for the 3 year age limit.

One comment which summarises the other comments reads:

*“In its current form [EDACS] probably could not be used for smaller children. However in clinical practice it is often already with infants that one starts to worry about their oromotor skills, and potentially three years of silent aspiration is a constant health hazard and probably quite a long term respiratory health risk too.*

*Would it be possible to describe the levels separately for different age groups like the GMFCS does?”*

### **S31 - EDACS should contain 5 levels in line with other Functional Classification Systems.**

17% of panellists indicated that they “neither agreed nor disagreed” with **S31**. An examination of the qualitative data revealed that 5 of the 17 comments received expressed agreement with **S31**. 5 comments suggested that EDACS should contain 5 levels only if they represented eating and drinking ability fully. For example:

*“Why does it need to have the same number of levels as the others? It needs to be meaningful and make sense”* and

*“There should be as many levels as there need to be”.*

Two of the 17 comments requested further information about the other Functional Classification Systems as they were not familiar with them. On reflection, **S22** and **S31** did not accurately frame the content of EDACS. These were revised and expanded in DS2. The following section (Section 5.4.9) contains further details.

### **S30 - No other definitions are required**

Comments received in relation to **S30** and **S29 - All definitions are clear and appropriate** were suggestions about refinements and additions to the Definitions section. These were used by the author to refine and expand the Definitions section of EDACS. Comments suggested changes related to food texture descriptions and details about effects on breathing rate from aspiration. Some panellists wanted further detail about “Silent aspiration” – for example:

*“Under Signs of Aspiration, you might also add "Individuals with silent aspiration will not show signs of aspiration when eating or drinking." I just think this is an important point that cannot be overemphasized in providing care for individuals with CP”.*

Further analysis was made of the levels of agreement for panellists in groups according to their backgrounds (e.g., Speech and Language Therapists / Pathologists, Community Paediatricians, Nurses, Parents, Individuals with CP). The group “Other” was excluded from this analysis because of its heterogeneous membership. The profession Occupational Therapy was also excluded from this analysis because only one person indicated

occupational therapist as a profession; in this instance there was no group data to consider. It was important to consider whether there was disagreement for some aspects of EDACS content by a minority group which was masked by the majority. Table 5-5 shows details of the statements where the levels of agreement given by panellists who shared the same background were less than 50%.

Table 5-5: Statements receiving less than 50% levels of agreement by Delphi Survey panellists with the same background

Statement	Background	Level of Agreement
<b>S9.</b> The section "Introduction and Purpose" is clear.	Individuals with CP	17%
<b>S20.</b> Classification using EDACS should preferably be made by both a parent or carer AND a speech and language therapist	Paediatricians – Neurodevelopmental specialist	45%
<b>S22.</b> EDACS should classify the eating and drinking abilities of individuals with CP from 3 years	Individuals with CP	33%
<b>S28.</b> It is clear from the User Instructions how to determine which level most accurately represents an individual's present abilities and limitations.	Individuals with CP	33%
<b>S31.</b> EDACS should contain 5 levels, in line with other Functional Classification Systems (e.g. GMFCS, MACS and CFCS).	Individuals with CP	17%

Individuals with CP indicated in the comments section of these statements about the clarity of EDACS that the language used in EDACS was difficult for to understand (**S9** and **S28**).

For example:

*“Some of the language is difficult to understand.”*

*“Too long and "wordy" - use of bullet points/headings, different presentation???”*

This minority view, masked by the majority, would support the development of a version of EDACS which is constructed with simpler language, as has been done by the developers of the GMFCS for use by individuals with CP and their parents.

Discrepancies between high levels of agreement expressed numerically and disagreement or reservations made in comments were explored. For the most part there was agreement between QUAL and QUAN data. However, reservations about **S20 - Classification using EDACS should preferably be made by both a parent or carer AND a speech and language therapist** were expressed in 33 out of the 44 comments made. These comments convey the gist of the reservations given:

*“In the USA the professional involved with feeding is not always a speech-language pathologist. It is often an occupational therapist, but may be a specially trained/educated nurse or teacher. I think a professional should be involved, but not necessarily a SLP.”*

*“(a) The parent ought to be the world's expert on their child; and (b) there might not be an SLP around. The question of whether parents are reliable against SLPs is an empirical one that I assume you will explore once the EDACS is ready to be field tested.”*

The latter comment indicates the need to test the assumption expressed in **S20** empirically.

The analysed qualitative data was used to make further changes to EDACS. All comments were examined for potentially helpful suggestions about EDACS content and presentation, whether the statements reached the required level of agreement or not. Because the majority of the content had been agreed in DS1 it was important not to change the substance of EDACS. However, useful comments about organisation of the information, wording and typing errors were acted upon.

#### **5.4.9 Delphi Survey Round 2**

The results of DS1 were used to make amendments to EDACS v16 including some changes to wording, word order, better organisation of information within the different sections and the correction of typing errors.

The Definitions section of EDACS v16 was the only section that was substantially redrafted with inclusion of more detail suggested by panellists. This resulted in EDACS

v17. The three statements which had not reached 80% or more agreement together with the changes to EDACS formed the basis for the next survey for DS2.

Feedback about the changes that had been included in EDACS v17 was given to panellists in two different ways. Changes in the Definitions section were highlighted in EDACS v17. Feedback was also given in the Survey itself in a short paragraph prior to the statement of content being examined by panellists.

For example:

*58% of you agreed that EDACS should classify the eating and drinking of individuals with CP from 3 years. Many of you thought it should be used with children younger than 3 years. At the moment we do not have enough information about the development of eating and drinking for individuals with CP under 3 years to do this with EDACS. Delphi Survey 2 p2.*

The three statements from DS1 that required re-examination were represented by 6 new statements which were presented in the same format as DS1.

The statement **DS1 S22 - EDACS should classify the eating and drinking abilities of individuals with cerebral palsy from the age of three years** was replaced by two further statements to more accurately represent EDACS content:

**DS2 S1 - EDACS in its current form is valid to describe the eating and drinking abilities of individuals with CP from 3 years and above.**

**DS2 S2 - It would be helpful if EDACS was further developed to classify the eating and drinking abilities of children younger than 3 years of age.**

Changes made to the Definitions section were examined using the same DS1 statements:

**DS2 S3 -All definitions are clear and appropriate**

**DS2 S4 -No other definitions are required**

The statement **DS1 S31 - EDACS should contain 5 levels in line with other Functional Classification Systems** was replaced by two further statements to more accurately represent EDACS content:

**DS2 S5 - The range of eating and drinking ability for individuals with CP is covered by the five different levels of EDACS**

**DS2 S6 - The five levels of EDACS discriminate sufficiently between different levels of functional eating and drinking ability.**

These statements were followed by optional open ended questions about each of the sections of EDACS: for example, Question 7 was **Do you have any comments about the “Purpose” section?** The final item of DS2 survey was an invitation to panellists to try out EDACS followed by an open comments box to complete with reflections upon their experience. The full survey sent out for DS2 is included in Appendix CD2.

Given that 79% of the panellists in DS1 had agreed with more than 80% of EDACS content and many had made very positive comments, it was thought likely that some panellists may have little motivation to complete DS2. It was really important that panellists of DS1 complete the first six questions of the survey in order to assess the overall levels of agreement for EDACS. 80% or more agreement for all content was required before moving on to the next stage of the Project. It was therefore decided to strongly encourage panellists to respond to the first 6 statements and make the remaining 7 questions optional.

The DS2 survey was created in Survey Monkey in an identical way as for DS1 in order to facilitate ease of use, reflection and the possibility of revisiting and amending responses within the survey any number of times before submitting.

An e-mail was constructed giving brief feedback to panellists about DS1 and explaining how to participate in DS2. It was sent out to all the individuals who had agreed to participate in DS1 whether they had chosen to complete the survey or not, together with a link to the online survey and EDACSV17 (see Appendix 5). A hard copy of the letter and all the information required to take part in DS2 was sent to panellists who had previously requested it.

**5.4.10 Delphi Survey Round 2 – data analysis**

The QUAN and QUAL data from DS2 was analysed in exactly the same way as for DS1 using Excel spread sheets (see Section 5.48).

More than 80% of DS2 panellists agreed with five out of the six statements representing EDACS content. **DS2 S2 - It would be helpful if EDACS was further developed to classify the eating and drinking abilities of children younger than 3 years of age** received 77% agreement. With reflection, this statement was considered not to represent

actual content of EDACS but an examination of future aspirations for EDACS. It was therefore not included in the final consensus figures which are given in Table 5-6.

**Table 5-6: Levels of agreement for content of EDACS obtained in the Delphi Survey**

<b>Levels of Agreement</b>	<b>≥80%</b>	<b>&lt;80%</b>
<b>Delphi Round 1</b>	39 / 42 statements	3 / 42 statements
<b>Delphi Round 2</b>	5 / 5 statements	0 / 5 statements

As anticipated, the response rate for DS2 was not as high as DS1. However, some panellists who chose not to complete DS1 did complete DS2. Thirty out of 72 (42%) panellists in DS2 chose to answer only the first six questions.

Further details of the results from the DS, including an analysis of panellists' backgrounds, experience and patterns of response are given in Section 6.2 in Chapter 6.

#### **5.4.11 Completion of Delphi Survey Round 2**

Following the completion of DS2, an e-mail or letter was sent to all panellists thanking them for all their contributions to the DS. A brief report of the outcomes of DS2 was given alongside the conclusion that no further rounds of the DS were required because the necessary levels of agreement had been reached. A copy of the version of EDACS to be included in the next stage of the project was also included. Panellists were also asked to give consent to their names being used in a future publication detailing the process of EDACS development and the use of the DS. A record of those providing consent and those declining either through their response or by not responding to the request was made.

### **5.5 Inter-observer reliability studies**

#### **5.5.1 Introduction**

On completion of the DS, the fourth and final stage of the project was to examine the use of EDACS by different observers to rate the eating and drinking ability of children with CP. Statistical measures of reliability were used together with qualitative interviews with observers to understand their experience using EDACS.



### **5.5.2 Background**

An assessment of the reliability of a health measurement scale is considered necessary because of the awareness that the observer or rater is a potential source of measurement error. It is unlikely that EDACS will always be used in exactly the same way by all health professionals, even if they are identically trained eating and drinking specialists. In the UK, SaLTs traditionally take responsibility for the assessment and management of eating and drinking difficulties. In other parts of the world, other health professionals such as occupational therapists, physiotherapists, or speech language pathologists undertake the same task. EDACS has been developed as a tool which facilitates obtaining parental judgement about their children's eating and drinking ability. An investigation to compare use of the tool by parents and SaLTs was carried out.

Reliability studies are conducted to measure the level of observer variability that might be expected in using a particular tool to collect data. There may be differences in the way the same observer (intra-observer) uses a particular tool in a particular situation; different observers of the same subject (inter-observer) may also use the tool in different or similar ways (Landis and Koch 1977); different environments may impact upon the functioning of someone with CP. There is no "truth" about the functional eating and drinking ability for individuals with CP against which each observer's judgement can be compared to appraise its degree of accuracy. Some may consider that speech and language therapists with extensive training and experience in assessing eating and drinking performance by individuals with CP can provide judgements that might be considered to be more "objective" and most closely resemble the "truth". Some might consider parents' views to be the most accurate as they have extensive and expert knowledge about their own child, encompassing many different environments. A pooled judgement following a conversation between a parent and a SaLT or other specialist health professional might be considered to more closely approximate the "truth". Some might consider that judgements made using EDACS need to be compared with an objective instrumental measure of eating and drinking such as the Exeter Dysphagia Assessment Technique (Selley et al. 1990) or videofluoroscopic swallowing studies (Rogers et al. 1994).

The concept of "reliability" encompasses a number of different dimensions including the level of agreement between observers and the extent to which the measurement instrument reflects true differences among individuals. Any statistical measure of reliability obtained for use of EDACS by different observers does not constitute inherent unchanging properties of the scale, but rather a measure of the interaction between EDACS, the

observers, the child concerned and the situation in which observations are made. As Streiner and Norman point out:

*“Reliability is not an immutable, inherent property of a scale; it is an interaction among the instrument, the specific group of people taking the test, and the situation”* (Streiner and Norman 2008 p172-173).

Measures of “reliability” therefore refer only to the results obtained using the instrument and not the instrument itself. Here they were used to examine to what extent there was agreement between two observers when they use EDACS to rate the eating and drinking ability of the same child with CP. Any other use of the tool by different observers or on a different population such as individuals with Down syndrome would need to be empirically tested in the same way.

By discussing the experience of observers following use of EDACS to rate the eating and drinking abilities of children with CP, there was greater potential to ensure data quality and gain insights into measurement errors.

For EDACS to have any value as a measurement instrument it is essential that it can be used to differentiate between the eating and drinking abilities of individuals with CP and that all five levels of ability described by EDACS are used by observers. This is stressed by Streiner and Norman who write that:

*“At its root, the reliability coefficient reflects the extent to which a measurement instrument can differentiate among individuals, i.e. how well it can tell people apart, since the magnitude of the coefficient is directly related to the variability between subjects.”*(Streiner and Norman 2008 p170).

If EDACS is used to rate the eating and drinking abilities of a population of individuals with CP, it might be that observers consistently use only one of the five possible categories to describe all individuals. Although there would be perfect agreement between observers, EDACS would not be considered a reliable tool because it does not discriminate between cases.

As EDACS represents an external criterion against which individuals are rated, it was important to consider the absolute values assigned to each individual by the observers. Additionally, it was important to also examine the nature of the differences between observers, that is, the consistency with which the tool is used. Two measures of reliability were used to capture these differences: Cohen’s kappa ( $\kappa$ ), a measure of chance corrected

agreement between observers and the intraclass correlation coefficient (ICC) to examine consistency between observers.

### 5.5.3 Cohen's kappa

Streiner and Norman (2008) discuss the use of Cohen's kappa coefficient (Cohen 1960). They describe the statistical analysis to be concerned with whether there is simple agreement between two observers, explicitly dealing with the chance occurrence of two observations agreeing. In interpreting the value of kappa, the closer the value is to 1 the greater the level of agreement between observers. This is illustrated by a fictitious data set of two observers judgements as to whether a particular characteristic is "present" or "absent" (see Table 5-7).

**Table 5-7: Contingency table for two observers (Streiner and Norman 2008)**

		Observer 2		
		Present	Absent	TOTAL
Observer 1	Present	20	15	35
	Absent	10	55	65
	TOTAL	30	70	100

The figures outlined on the diagonal line indicate where the two observers agree with one another. This could be expressed as a percentage of absolute agreement – out of 100 ratings there was agreement 75% of the time. Cohen's kappa eliminates those agreements that might be expected by chance using the following formula where  $P_o$  is the proportion of observer agreements and  $P_e$  is the proportion expected by chance:

$$\text{Kappa } (\kappa) = \frac{P_o - P_e}{1.0 - P_e}$$

Where  $P_o$  is 75 / 100  
 and  $P_e$  is (35 x 30 / 100) + (70 x 65 / 100)

In the example given in Table 5-7 kappa would be:

$$\kappa = \frac{\left( \frac{75}{100} \right) - \left( \frac{10.5+45.5}{100} \right)}{1.0 - \left( \frac{10.5+45.5}{100} \right)} = 0.43$$

In interpreting the value of kappa, the closer the value is to 1 the greater the level of agreement between observers. Streiner and Norman (2008) cite three papers providing various interpretations of kappa which are given in Table 5-8.

**Table 5-8: Interpretation of kappa values - Streiner and Norman (2008 p188)**

<b>Kappa</b>	<b>Landis and Koch (1977)</b>	<b>Cicchetti and Sparrow (1981)</b>	<b>Fleiss (1981)</b>
< 0	Poor	Poor	Poor
0.00 – 0.20	Slight		
0.21 – 0.40	Fair		
0.41 – 0.60	Moderate	Fair	Fair to Good
0.61 – 0.75	Substantial	Excellent	Excellent
0.75 – 0.80			
0.80 – 1.00			

Following Terwee et al. (2007) and the authors of GMFCS (Palisano et al. 1997), a value of 0.7 for kappa when used by SaLTs to rate the same child was selected as the minimum requirement for EDACS to be considered reliable. A sample size of more than 50 is recommended by Terwee et al. (2007).

An examination of the relationship between observers' judgements, that is the consistency of judgements made, is not possible using kappa as it implicitly assumes that all disagreements are equally serious. A weighted kappa can be employed where the investigator specifies the relative seriousness of each kind of disagreement (Cohen 1968). Kappa is used with categorical data (nominal and ordinal scales) in contrast with continuous data (interval and ratio) where the intraclass correlation coefficient (ICC) is used. Fleiss and Cohen (1973) show the equivalence of weighted kappa and the intraclass correlation coefficient (ICC) where inter-observer judgements are based on continuous rather than nominal data.

#### **5.5.4 Intraclass correlation coefficient**

The ICC measures the relationship between two or more variables that measure the same thing (hence intraclass correlation) and is frequently used to assess the consistency between observers' judgements. Streiner and Norman (2008) discuss the relative merits of using kappa, weighted kappa and ICC. They consider that the measurement of absolute agreement corrected for chance using kappa is appropriate for binary decisions, where observers are deciding whether an observed phenomenon can be considered to be X or Y. They suggest that kappa is less appropriate where there are more than two options for observers to use as in the case of EDACS where observers have 5 possible options to use. The reason for this is that kappa considers only total agreement and does not provide partial credit for responses that differ only by one or two categories.

When observers use EDACS to describe the eating and drinking abilities of individuals CP they are imposing 5 separate categories upon what might be considered to be continuous data. Eating and drinking ability is not obviously divisible into distinct absolute categories; the development process of EDACS has proposed definitions of distinct categories. When an assessment is made of the reliability of an observer's use of an ordinal scale, where there are more than two choices, it is helpful to make some note about the extent of the disagreement between two observers. If two observers agree in the assignment of levels for 50% of cases and disagree by one level for the remaining 50% of case, the reliability of the use of the tool is very different from one where two observers agree on 50% of cases and that the remaining cases show disagreement from anywhere between 1 and 4 levels.

Streiner and Norman (2008) write that the weighted kappa can be used as a way of capturing the level of disagreement between observers, as it focusses on disagreement. However, they do not recommend the use of weighted kappa for any except the simplest 2

x 2 tables, preferring instead to use the ICC. They argue that it is superior to weighted kappa because it has the ability to isolate factors affecting reliability and is flexible in that it is possible to analyse reliability studies with more than two observers and more than two response options. ICC allows for the inclusion or exclusion of systematic differences between observers (bias) and can handle missing data. Streiner and Norman suggest that ICC provides a unifying framework that ties together different ways of measuring inter-observer agreement. This analytic approach of defining reliability is based on the statistical technique of Analysis of Variance (ANOVA). As repeated observations on each subject are made by different observers, the method used is called the repeated measures ANOVA.

There are different types of ICC stemming from the inferences behind each one, outlined by McGraw and Wong (1996). These inferences are represented within the decisions required to calculate the ICC in IBM SPSS Statistics (Nichols 1998).

The first decision required concerns whether the data are treated via a one way or two way ANOVA model. A one way ANOVA model would be adopted if there was a random association between the observers and the ratings made, as would be the case if a group of SaLTs were asked to use EDACS to make judgements about children with CP, not known to them, from video recordings of mealtime behaviour. EDACS is to be used by people who know the child well so the appropriate ICC would be two way ANOVA, recognising the parents and SaLTS as a second source of variance. The second decision required is whether the ICC is used to consider absolute agreement between observers or the consistency of the disagreements. Kappa was calculated to examine absolute agreement corrected for chance; the appropriate ICC to explore the nature of the differences in judgements made is therefore the one that calculates “*consistency*” rather than “*absolute agreement*” between observers.

In this study a comparison was made between single judgements made by pairs of observers, not an average of judgements made; within SPSS, single measures were therefore noted. SaLTs from different schools rated the eating and drinking ability of one or more children and parents only rated their own children; a random model was therefore selected as the same set of observers did not all rate the same children. Using McGraw and Wong’s (1996) definitions, ICC (C,1) two-way random effects single measures consistency with 95% confidence interval was selected within SPSS.

Unlike kappa, there are not such clear guidelines for interpreting ICC values. Morris et al. (2006) examined the differences between professional and family report of GMFCS levels

and made use of both kappa and ICC. Two different levels of reliability for values of ICC were given: coefficients exceeding 0.9 are regarded as reliable for use clinically with individuals; coefficients exceeding 0.7 are commonly regarded as reliable for population based research (p22 Fitzpatrick et al. 1998, Morris et al. 2006 p676). As previously stated, Terwee et al. (2007) consider reliability of a health assessment scale to be positive where there is at least a value of 0.7 for ICC or kappa for a population of 50 or more.

The use of kappa facilitates a direct comparison between the reliability of EDACS and the GMFCS as reported in the original development paper (Palisano et al. 1997). The ICC also allows for a direct comparison of observers use of EDACS in contrast with the use of GMFCS by professionals and families (Morris et al. 2006).

### **5.5.5 Inter-observer reliability studies for the GMFCS and CFCS**

The original GMFCS development paper (Palisano et al. 1997) reported the value of kappa (chance corrected agreement) when 26 physiotherapists and 25 occupational therapists used the tool to rate the gross motor function of 77 children with CP, known to them. The two groups of therapists were treated as a homogenous group in terms of their knowledge of the child for the purposes of the assessment. Later studies compared use of the tool by parents with physiotherapists (n=129) ICC = 0.92 (95% confidence interval [CI] 0.90 to 0.93) and parents with paediatricians ICC=0.90.(95% CI 0.88 to 0.92) (Morris et al. 2006)

Inter-observer studies for the CFCS reported weighted kappa for judgements made by different health professionals (n=61) and parents (n=68) familiar with the communication performance of 69 children. When judgements made by two health professionals were compared weighted kappa=0.66 (95% confidence interval [CI] 0.55-0.78); when judgements made by parents were compared to those made by health professionals, weighted kappa =0.49 (95% CI 0.4-0.59).

### **5.5.6 Sampling strategy and recruitment for reliability studies.**

Health professionals working with individuals with CP in the UK tend to specialise in different areas of function; as a result of this not all health professionals are familiar with the eating and drinking ability of people with CP. In the UK, specialist dysphagia trained speech and language therapists take responsibility for the assessment, treatment and management of eating and drinking difficulties. In other parts of the globe this role is fulfilled by other health professionals such as occupational therapists and nurses.

Following the NGP and DS, the User Instructions of EDACS state that:

*“To identify the level of eating and drinking ability of an individual with cerebral palsy, it is necessary to involve someone who knows that person well such as a parent or carer. Some aspects of eating and drinking are not possible to see, so it may also be helpful to assign a level together with a professional who has knowledge about the necessary skills for safe and efficient eating and drinking.”*

The recommendation is to arrive at a combined judgement between a health professional familiar with manifestations of limitations to eating and drinking skills and parents who know the person with CP well. Reliability studies connected with the GMFCS and CFCS have compared judgements made by these two groups of individuals. It was considered necessary to identify health professionals with sufficient knowledge about a child’s eating and drinking skills to make an independent judgement using EDACS. The assumption was that parents would know their own children well.

Consideration was given to settings where two or more SaLTs with specialist dysphagia training would have comprehensive knowledge about the eating and drinking skills of the same set of children with CP, and therefore able to give independent ratings of eating and drinking ability using EDACS. Five schools providing specialist education for individuals with physical disability in the South of England were identified as having the required SaLT provision. Three of these five schools agreed that they would send letters to parents of children attending these schools on the researcher’s behalf, inviting them to provide judgements about their children’s eating and drinking abilities using EDACS. In addition, judgements of children’s eating and drinking ability using EDACS by lone specialist trained SaLTs, working in five other special schools, were also sought to compare with judgements provided by the children’s parents.

Speech and language therapists working in the schools were asked to identify children with CP across the whole range of ability; confidential details such as names and addresses were not passed on to the research team. Cases were included if the individual had CP, no matter what the level of eating and drinking ability, was attending the school or college and was known to the SaLT(s) participating in the study.

In summary, the following sampling strategies were used to recruit participants:

- Purposive convenience cluster sampling strategy was employed where specific schools catering for individuals with physical disability in the South of the UK were approached to take part.



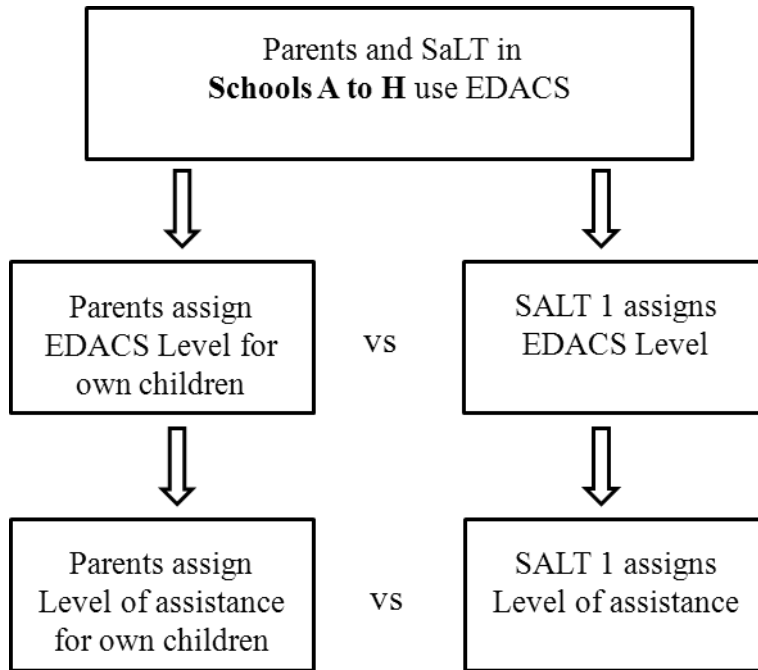
- The lead SaLT working in each special school was a volunteer in this convenience sample; depending upon the level of consultation within the team, other SaLTs were either captive or volunteer subjects.
- Parents were recruited using a purposive sampling technique in that SaLTs working in eight of ten special schools sent invitations from the research team to participate to all parents of children with CP.
- Children rated by SaLTs alone were identified using purposive convenience sampling by the SaLTs working within the schools. A sub-group of children from this purposive convenience sample came from parents who responded to the invitation to participate.

Recruitment to the study was subject to ethical scrutiny by the NHS Ethics committee and research governance as detailed in Chapter 4. The NHS Ethics committee agreed that it was acceptable for SaLTs to make judgements about children's eating and drinking ability using EDACS without seeking consent from all parents, because it was based on the SaLTs existing knowledge of the children. All parents and SaLTs who accepted the invitation to participate in the inter-observer reliability studies did so with signed consent (see Appendix 6 and 7).

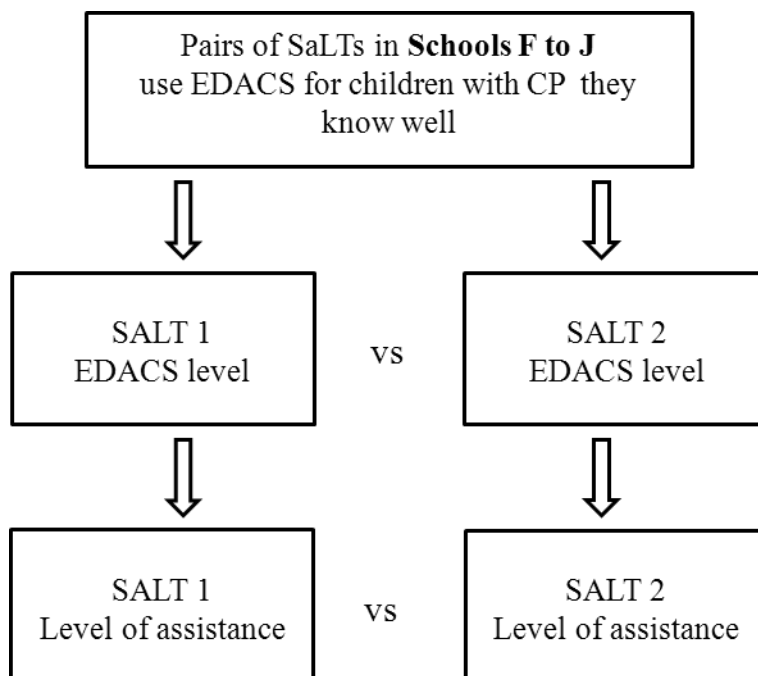
### **5.5.7 Design**

The research design was set up in order to obtain pairs of judgements about the eating and drinking ability of a group of children with CP. The judgements to be compared were either parents vs. specially trained SaLTs or SaLTs vs. SaLTS. Figures 5-3 and 5-4 set out how these pairs of judgements were obtained. The judgements of single specialist SaLTS who worked in schools A to H were compared to judgements made by parents. Pairs of specialist SaLTs who knew the eating and drinking abilities of the same children worked in schools F to J. Schools I and J did not wish to invite parents to participate in the reliability study.

**Figure 5-3: Pathway for obtaining judgements from parents and speech and language therapists using EDACS**



**Figure 5-4: Pathway for obtaining judgements from pairs of speech and language therapists using EDACS**



The identity of each of the schools is recorded and held in the confidential records of the study. In schools A-H, where there was agreement to parental involvement, an invitation pack was sent out by SaLTs to parents on behalf of the researcher. Postal costs were

covered from the research budget. The invitation packs included all information required to take part:

- Invitation letter (Appendix 6)
- Consent form(Appendix 6)
- EDACS levels v18 on single sheet of A3, excluding Purpose, Background, Key Features, User Instructions and General Headings (see Appendix CD1)
- EDACS Survey for parents(Appendix 6)
- Invitation to provide contact details in order for the researcher to phone to discuss their experiences using EDACS (Appendix 6)
- Stamped and addressed envelope for survey to be returned directly to the researcher.

If parents provided contact details, agreeing to further contact with the researcher, a phone call was made to discuss their experience using EDACS using the following topic guide:

1. How clear were the directions given?
2. How easy was the task?
3. Was the clinical algorithm easy to use?
4. Are each of the level descriptions clear?
5. Are the distinctions between each of the levels clear?

A date was arranged for data collection within a month of information being sent out to parents, allowing a maximum of 3 hours for data collection and discussion. In Schools F to J where pairs of SaLTs were to use EDACS, the SaLTs were asked to identify a list of 20 children whose eating and drinking ability was well known by both SaLTs. The researcher informed Schools F to H of those children whose parents had provided an EDACS rating.

On visiting the schools, the researcher took the following materials:

- Consent forms (Appendix 7)
- EDACS v18 (Appendix CD1)
- Data collection sheet 1 (Appendix 7)
- Data collection sheet 2 (Appendix 7)
- Topic Guide for discussion
- Digital tape recorder
- Cake and fruit for refreshment
- Pens

Where data was collected by telephone, all relevant documents were sent electronically. Consent forms were completed by all participating SaLTs. SaLTs were asked to use EDACS to independently assign levels to children known to them. Following completion of the rating task, SaLTs were invited to comment on their experience using EDACS using the same topic guide as that used with parents. The digital recording of the discussion was made and later transcribed.

### **5.5.8 Data collection**

The researcher collected and checked surveys completed by parents to ensure that all the necessary details were present. Lists of children whose parents had completed the survey were compiled for each of the participating schools (A-H). Telephone interviews were conducted with parents if they provided contact details and indicated a willingness to discuss their experiences using EDACS. Some of the interviews were digitally recorded; notes were taken in others.

The researcher visited eight of the participating schools in person; in Schools A and B, data was collected in a telephone interview.

The SaLT teams at Schools F –J were asked to compile a list of approximately 20 children with CP whose eating and drinking abilities were known to pairs of SaLTs within the team. Schools F to H included all the children on that list whose parents had returned the survey and were clearly identified by name; the remaining children were identified on Data Collection Sheet 2 only by their initials and ages in order to maintain confidentiality. The SaLT participants were able to cross refer to a list of names held by the SaLT teams.

Demographic information about the identified children was collected using Data Collection Sheet 2. Children whose diagnosis was not CP were not included in the inter-observer reliability studies. The following information for each of the children was collected on Data Collection Sheet 2:

- Subject number
- Age
- Gender
- Subtype of CP – Spastic Unilateral, spastic bilateral, dyskinetic, ataxic, non-classifiable. (SCPE collaborative group 2000 – see Appendix 2). Children with a diagnosis of Worster-Drought syndrome were identified
- Gross Motor Function Classification System Level (Palisano et al. 1997)

- Presence of a feeding tube such as gastrostomy
- Presence of seizures
- Initials of SaLT who knew child best – designated SaLT1
- Initials of second SaLT who knew child – designated SaLT2 – were added to Data Collection Sheet 2.

In schools F to J where pairs of SaLTs were providing a rating, a discussion took place to decide which SaLT would provide the second rating. A photocopy of Data Collection Sheet 2 and the master list held by SaLT team was made in order that each of the SaLTs independently knew which children's eating and drinking they were rating.

The researcher then introduced EDACS v18 and gave the SaLTs the opportunity to read it. All SaLTs were then asked to use EDACS to complete Data Collection Sheet 1 for each of the children using the following information:

- Child's initials
- Subject number
- SaLTs name
- Date form completed
- Indication of level of eating and drinking ability using EDACS levels I to V
- Indication of levels of assistance required: independent, requires assistance, totally dependent
- Comments if required

The researcher emphasised that the task was not a test of memory but rather their knowledge of the children. SaLTs referred to case notes and other documents detailing eating and drinking ability.

For schools F-J, the researcher ensured that there were two ratings for each subject number during the visit, and that the data sheet was completed. Cases where SaLTs disagreed were considered briefly, with comments inserted on Data Collection Sheet 1 to elaborate reasons given. This also provided an opportunity to make corrections associated with human error such as when two subjects who shared the same name initials were misidentified by the SaLTs providing the rating.

Data collected from the parents was not shared with the SaLTs.

After data collection was completed, SaLTs and parents were asked to comment on their experiences using EDACS using the topic guide outlined in Section 5.5.7.

Thank you cards were sent to all participants together with a copy of the signed consent forms. Cards to parents were sent via their child's SaLTs.

### **5.5.9 Data analysis**

All collected data was entered into IBM SPSS Statistics program Version 20. Details of the data variables and data set are given in Appendix 8. As detailed in Sections 5.5.3 and 5.5.4, measures of reliability of the EDACS levels and Levels of assistance required were assessed using a measure of absolute agreement, Cohen's kappa (Cohen 1960) and ICC (McGraw and Wong 1996) for pairs of ratings made by two SaLTs and pairs of ratings made by SaLT1 and parents.

The association between EDACS levels and GMFCS levels was investigated using Kendall's tau, a rank correlation coefficient (Kendall 1938). Kendall's tau, a non-parametric test, is used to investigate whether two variables may be regarded as statistically dependent. If two variables are independent of one another, the value of Kendall's tau would be zero. A value of  $-1$  would indicate a perfect negative association and a value of  $+1$  would indicate perfect positive association.

Transcripts were made of the audio recordings of discussions that took place after different observers had used EDACS. These were organised within Excel under each of the different questions from the topic guide. Comments and responses made were compared to establish different "fuzzy categories"; these categories were further refined into larger categories with the emergence of key themes (Pope et al. 2000 p114).

## **5.6 Summary**

The development of EDACS proceeded through the four stages identified in Figure 5-1, using the methods outlined here, over a period of three years. Data collected within the NGP and some of the DS have been considered in this chapter. Further details of the DS, including panellists' backgrounds, level of expertise and patterns of participation are considered in Chapter 6. Details of the development of the content of EDACS and the results from the inter-observer reliability studies are also given in Chapter 6.

## **6 Chapter 6 - Results**

### **6.1 Introduction**

A multi-strand sequential Mixed Method study design was utilised to create the Eating and Drinking Ability Classification System (EDACS). The satisfactory completion of one stage was required before the commencement of the next stage; therefore some results are reported in Chapter 5. The results from the Nominal Group Process (NGP) are reported in Section 5.3.7. Some of the results from the Delphi Survey (DS) are reported in Sections 5.4.8 and 5.4.10 where results were required to proceed from one stage to the next, that is, Delphi Survey Round 1 (DS1) to Delphi Survey Round 2 (DS2) and from the DS to the inter-observer reliability studies.

In this chapter, additional results from the DS are reported, including details about DS panellists' backgrounds and levels of experience. The development of EDACS, as a result of data collected, is reported in detail. The final section outlines the results from the reliability studies when EDACS was used by speech and language therapists and parents of children with CP.

### **6.2 Delphi Survey – additional results**

#### **6.2.1 Backgrounds of Delphi Survey panellists**

The content validity of EDACS was examined by potential users of the system from a variety of backgrounds. Table 6-1 summarises the backgrounds of study participants, contributing to and commenting on the content of EDACS. Backgrounds of participants in the NGP, whilst already reported in Chapter 5, have been included in the table for comparison.

**Table 6-1: Backgrounds of participants in Nominal Group Process and Delphi Survey**

<b>Backgrounds</b>	<b>NGP n= 57 ( % )</b>	<b>DS1 n=87 ( % )</b>	<b>DS2 n= 72 ( % )</b>
Individuals with neuro-disability	3* (5%)	7 (7%)	8 (10%)
Parents of individuals with CP	9 (16%)	4 (4%)	6 (7%)
Speech and Language Therapists / Pathologists	21 (37%)	46 (46%)	35 (42%)
Community paediatricians and neuro-developmental specialists	7 (12%)	16 (16%)	12 (14%)
Nurses	5 (9%)	4 (4%)	5 (6%)
Dietitians	2 (4%)	5 (5%)	5 (6%)
Occupational therapists / Physiotherapists	8 (14%)	3 (3%)	1 (1%)
Researchers / epidemiologists	2 (4%)	10 (10%)	6 (7%)
Other	1 (2%)	6 (6%)	5 (6%)
<b>TOTAL BACKGROUNDS</b>	58	101	83

\*denotes two participants from the Triangle Consultative group and one participant who made contributions in an interview.

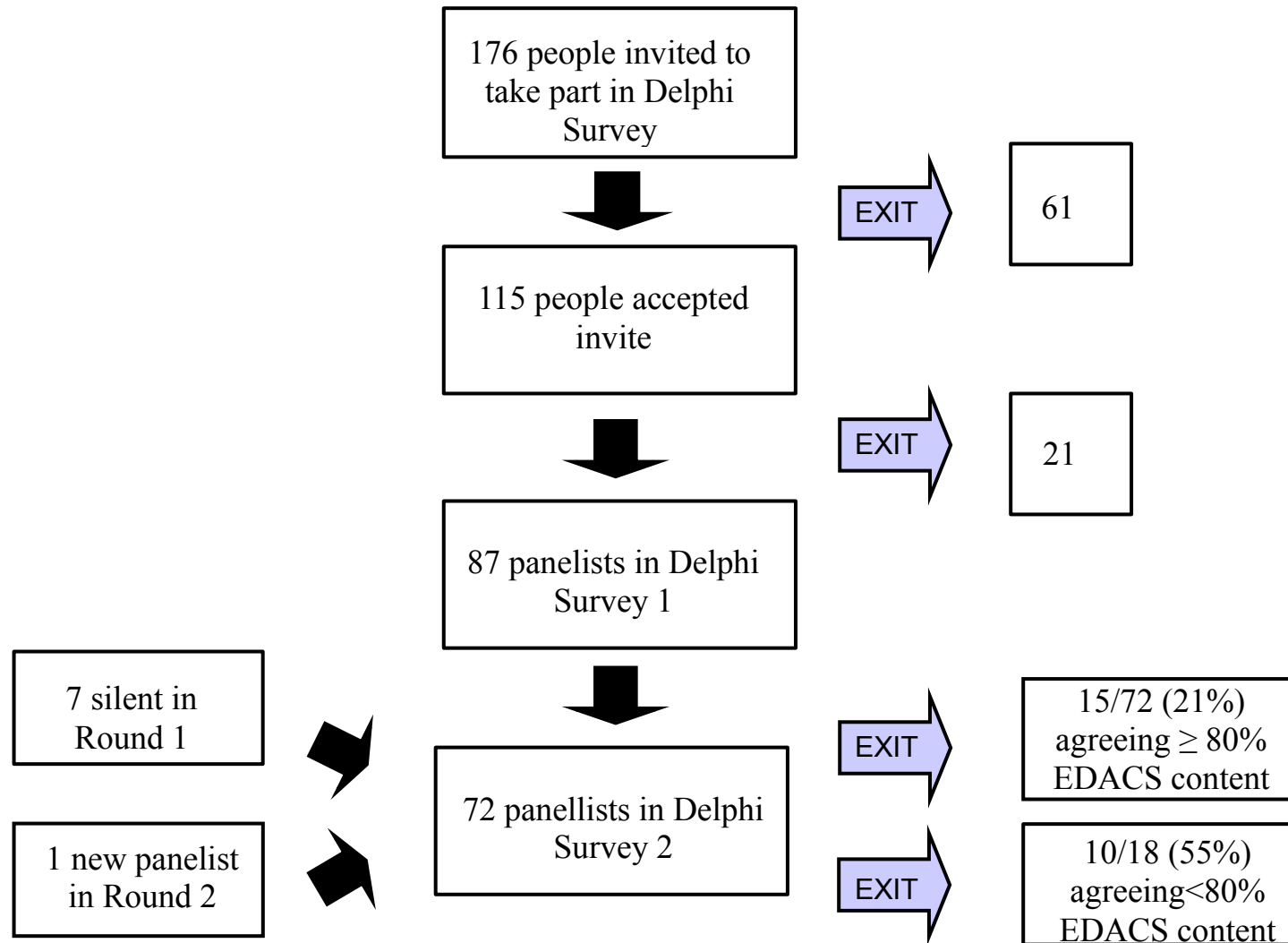
Table 6-1 shows the backgrounds of panellists in DS1 and DS2, indicating that fewer people participated in DS2. Some of the panellists in DS2 who did not participate in DS1 did not complete the necessary background information which was elicited only in DS1. These individuals were approached at the end of the survey by e-mail to supply the necessary details.

### **6.2.2 Participation in Delphi Survey**

Closer examination of overall participation in the DS is required to gain an impression about how successful the survey was in encouraging participation. It was also important to consider whether panellists who disagreed with EDACS content in DS1 were more likely to choose not to complete DS2, thereby contributing to an artificial consensus as discussed in Section 5.4.2.3. Following Sinha et al. (2011), details of new panellists or non-responding panellists are included. Figure 6-1 provides an overview of the numbers of individuals invited to participate in the DS and subsequent participation.



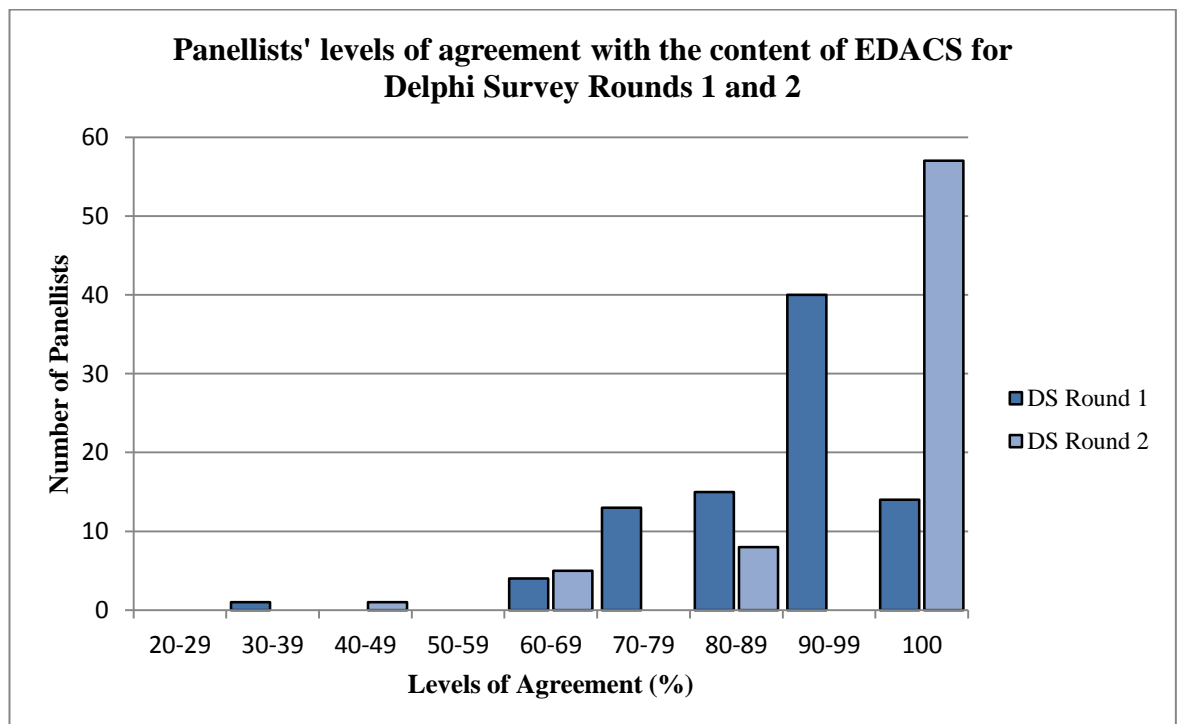
**Figure 6-1: Number of panellists at each stage of the Delphi Survey**



As shown in Figure 6-1, 10/18 panellists (55%) who agreed with less than 80% of the content of EDACS in DS1 chose not to participate in DS2. A close examination of the survey responses of these 10 panellists revealed no consistent patterns in the disagreements expressed other than those already given in Section 5.4.8. Fifteen out of 72 panellists (21%) who agreed with more than 80% of EDACS content in DS1 chose not to participate in DS2. One panellist (BB), who wrote extensively in DS1 criticising EDACS, chose not to participate in DS2. A detailed reply was sent to this panellist, answering some of the questions posed and clarifying the purpose of EDACS. No further correspondence was received. The script of the reply is included in the Appendix CD2.

When the overall responses of the panellists in DS1 and DS2 are considered, very few panellists disagreed with much of the content of EDACS. See Figure 6-2 for the frequency distribution of panellists' responses for different levels of agreement with EDACS statements by DS panellists.

**Figure 6-2: Panellists' level of agreement with the content of EDACS for Delphi Survey Rounds 1 and 2**



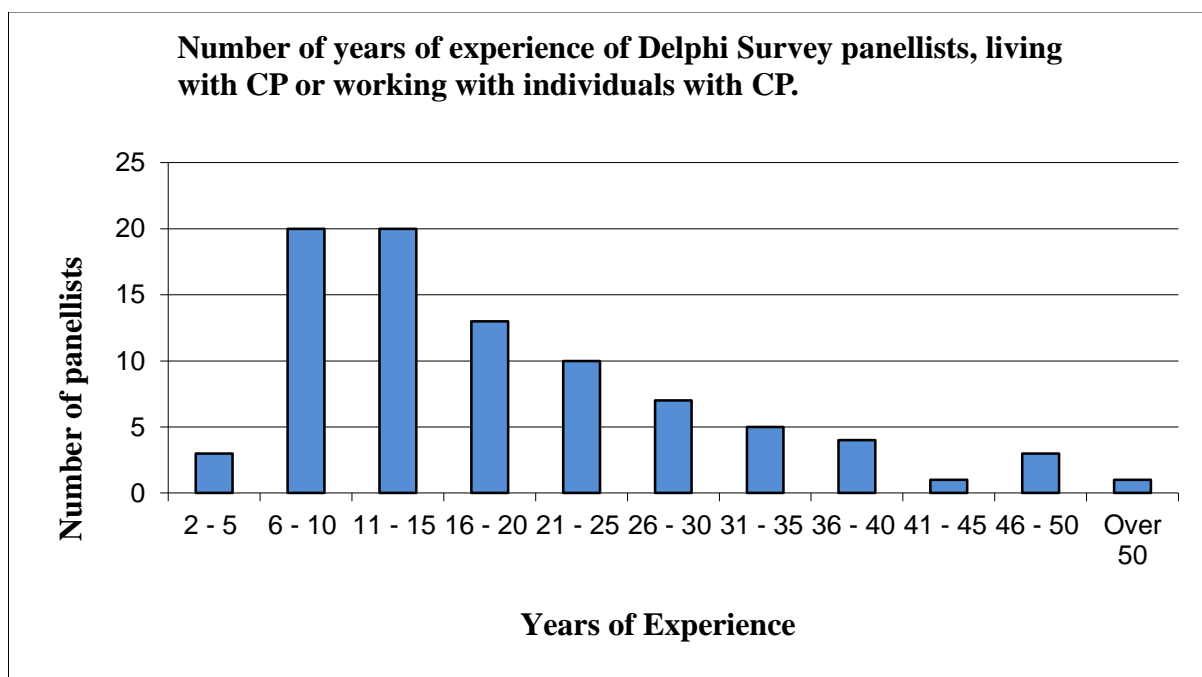
The comments made by panellists were reviewed and codified using a similar schema to that used in DS1 (see Section 5.4.8). Details of these responses are given in Appendix CD 2. Any suggestions regarding spelling mistakes or typing errors were amended within the EDACS draft, if thought appropriate. No further changes to the content of EDACS v17 were made.

### 6.2.3 Experience of Delphi Survey panellists

In DS1, information was collected about the backgrounds, experience and views on the important features of eating and drinking for people with CP, in order to investigate the questions posed in Section 5.4.2.1 about what constitutes an “expert” member of a DS panel.

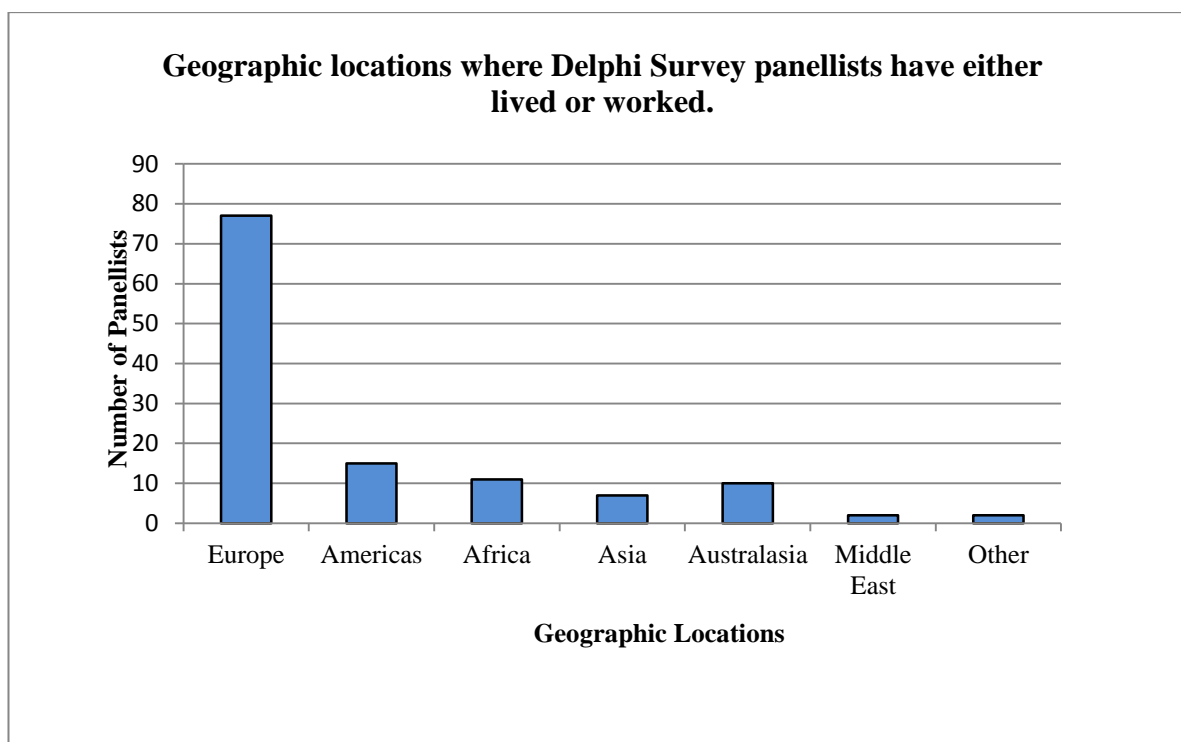
Panellists were asked “**How many years of experience do you have with cerebral palsy?**” The range was from 2 years to 50 years; the median number of years’ experience was 15 years. The results are displayed graphically in Figure 6-3.

**Figure 6-3: Number of years of experience of DS panellists, living with CP or working with individuals with CP.**



Panellists were asked “**Please indicate the parts of the world where you have experience of the eating and drinking difficulties associated with CP. Tick all that apply.**” Panellists’ responses are illustrated in Figure 6-4.

**Figure 6-4: Geographic locations where Delphi panellists have either lived or worked**



The majority of panellists had spent time living and / or working in Europe; from the author’s knowledge of the DS panellists, at least 17 people living and / or working in European countries other than the UK were included.

As a means of gauging the level of expertise brought to the DS, panellists were asked “**In your opinion, what are the significant features of eating and drinking for individuals with cerebral palsy?**” Panellists’ responses were read and coded; no panellist’s response to this question suggested the need for excluding his or her responses in the DS because of lack of expertise, as appraised by the author based on her clinical knowledge and her understanding of the literature. Key features identified by panellists were included in EDACS content.

Following the inductive process set out by Pope et al. (2000), the features suggested by panellists were eventually grouped in to nine different categories: Mouth and tongue movements, Safety, Whole body factors, Nutrition, Health Issues, Quality of life concerns, Efficiency, Family and individual concerns, and Environment. Table 6-2 shows the percentage of panellists’ responses under each of these different headings.

**Table 6-2: Overarching themes of panellists responses to question "In your opinion, what are the significant features of eating and drinking for individuals with cerebral palsy?" in percentages**

<b>Overarching themes:</b>	<b>Frequency of response:</b>
<b>Mouth movements</b> including drinking, biting, chewing, swallowing	156 (24%)
<b>Safety</b> including airway protection, aspiration, choking,	152 (23%)
<b>Whole body factors</b> including positioning, co-ordination, severity and type of CP	88 (13%)
<b>Nutrition</b> including hydration, supplementary feeding, poor growth	68 (10%)
<b>Quality of Life</b> including pleasure, trust, fear, stress, no enjoyment	64 (10%)
<b>Health Concerns</b> including respiratory health, reflux, seizures	46 (7%)
<b>Efficiency</b> including prolonged feeding time	41 (6%)
<b>Family and Individual Concerns</b> including conflicting advice, social participation at mealtimes, poorly understood issue	25 (4%)
<b>Environment</b> including techniques, equipment, experience of carers	18 (3%)

### **6.3 Eating and Drinking Ability Classification System**

Eighteen different version numbers of the draft Eating and Drinking Ability Classification System were created within the development stages, each new version passing through as many as ten incremental redrafts. Each set of changes were tracked and saved within Microsoft Word. Rather than report all the changes that were made to the EDACS drafts in extended sequential detail, the decision was taken to report the most significant and enduring changes made to EDACS. These changes are recounted in the following sections, the headings of which represent the different sections of EDACS v18, produced after the final round of the DS (see Appendix 9). Successive EDACS drafts are shown in Appendix CD1. EDACS v7, 13, 16 and 18 show the significant changes in structure and content.

### **6.3.1 Purpose**

Successive participants of the NGPs and the DS requested a clear statement of the purpose and focus of EDACS, to distinguish it from more familiar clinical assessment or diagnostic tools that would look in detail at the component parts of eating and drinking. It was challenging for some participants and panellists to understand what the purpose of EDACS was initially, particularly among SaLTs, given that it did not conform to the usual clinical measures available to SaLTs. EDACS v18 contains the following statement:

*“The purpose of the Eating and Drinking Ability Classification System (EDACS) is to classify how individuals with cerebral palsy eat and drink in everyday life using distinctions that are meaningful. EDACS provides a systematic way of describing an individual’s eating and drinking in five different levels of ability.”*

The focus was placed on the functional activities of eating and drinking such as sucking, biting, chewing, swallowing and keeping food or fluid in the mouth and included references to required adaptations to food textures and fluid consistencies, techniques used and some other features of the environment. It was clearly stated that EDACS classifies overall performance in eating and drinking, including both motor and sensory elements, from the age of 3 years.

The properties of the 5 level ordinal scale were described. It was stated that the distances between the levels are not equal and individuals with CP will not be distributed equally across the levels.

### **6.3.2 Background**

The section of EDACS entitled “Background” clarifies the focus of attention on usual performance whilst eating and drinking rather than what can be done to the best of individual’s ability, with an acknowledgement of variability in performance. The many factors that will influence eating and drinking performance were identified in this section including the impact of different settings, personal factors, the skill and familiarity of the carer, and other environmental features. Overall physical ability was also acknowledged in this section:

*“The way an individual balances, controls head movements and sits upright influences their oral skills whilst eating and drinking. Some individuals will require close attention to positioning in sitting, standing and lying, and adapted equipment*

*to optimise their eating and drinking abilities. The manner and degree of postural management required by individuals will depend upon their gross motor abilities.”*

A list of other factors influencing eating and drinking performance was also outlined. This included epilepsy and disturbances to cognition, communication, and sensation including touch sensation, vision and hearing. Other factors to be considered include illness, tiredness, pain or medication, as well as personal factors including social, emotional and behavioural issues. Features of the environment may also have an influence such as the familiarity of a new carer, background or sudden noises, quality of lighting and sudden movements. If an individual requires assistance with eating and drinking, a highly significant feature will be the quality of the relationship between the individual and the carer, including how well they each communicate with the other.

Acknowledgement was also given to the disturbances of the digestive system that frequently occur in individuals with CP such as gastro-oesophageal reflux or constipation, which will have an impact upon appetite and interest in food.

### **6.3.3 Key Features**

The key features of “safety” and “efficiency” emerged in the process of EDACS development, having been loosely represented in EDACS v7 by terms such as “easily”, “safely”, “slower performance” and “successfully”. The full definitions of these terms, as used in EDACS v18, are given here:

*“**Safety** refers to the risks of **choking** and **aspiration** associated with eating and drinking.*

***Choking** occurs when a piece of food becomes lodged in the airway; this may be connected to limitations in chewing and biting as well as co-ordinating the movement of food in the mouth with swallowing.*

***Aspiration** occurs when food or fluid enters the lungs; this may be connected to limitations in co-ordinating breathing and swallowing, controlling food or fluid in the mouth or an impaired swallow reflex. Some aspects of eating and drinking are impossible to observe, especially swallowing. Even if you know someone really well it is not always easy to notice the **signs of aspiration**; this is known as **silent aspiration**.*

*Aspiration* may trigger respiratory illnesses and is potentially harmful. If *aspiration* is suspected, it is helpful to seek further assessment from a suitably qualified professional such as a speech and language therapist.

*Efficiency* refers to the length of time and effort required to eat or drink, as well as whether food or drink is kept in the mouth without loss. Limitations to the quality and speed of movement of the different parts of the mouth will affect how efficiently food and drink is consumed. The amount of effort required for eating and drinking will have an impact upon how quickly an individual tires during a meal.

The *efficiency* with which someone uses the parts of the mouth to eat and drink has an impact upon the amount of food and fluid they are able to consume. This is one of a number of factors that influence whether an individual is able to take in enough food and drink to grow and remain in good health. It is considered good practice to assess individual nutrition and hydration requirements and decide whether these are being met adequately.”

Participants and panellists agreed with the central importance of these features and the decision was taken to stress the importance of safety before efficiency.

#### **6.3.4 User Instructions**

Users of EDACS are instructed to find the level that best describes an individual’s overall usual performance when eating and drinking. The question about who should use EDACS to describe an individual’s eating and drinking arose in the development stages. Some professionals expressed concern about the tendency by some parents to underestimate the difficulties their children have with eating and drinking. Conversely, some parents considered the views of some professionals to be overly cautious about eating and drinking. The User Instructions of the final version includes the following statement:

*“To identify the level of eating and drinking ability of an individual with cerebral palsy, it is necessary to involve someone who knows that person well such as a parent or carer. Some aspects of eating and drinking are not possible to see, so it may also be helpful to assign a level together with a professional who has knowledge about the necessary skills for safe and efficient eating and drinking.”*

Users of EDACS were also instructed to assign the level describing the greater level of limitation in borderline cases, in order not to underestimate the risks to health.



Instructions were also given about supplementing the eating and drinking ability level with a description of the level of assistance required to bring food or drink to the mouth.

### **6.3.5 Definitions**

The Definitions section in EDACS v18 was expanded considerably as new terms were introduced and more detailed information was requested. Full definitions for each of these terms are provided in this section: *Age appropriate food textures, Aspiration, Breathing changes, Choking, Fluid Consistency, Food textures, Gastrostomy, Oesophagus, Postural Management Programme, Signs of Aspiration, Silent Aspiration, Suction, and Tube Feeding*. Reference should be made to EDACS v18 in Appendix CD1 for further detail about the majority of these terms. However, more detailed consideration will be given to the terms related to aspiration, and food textures and fluid consistencies in the following two sections.

### **6.3.6 Aspiration**

Aspiration and its consequences to health were discussed in Chapter 2, Section 2.5.2 together with the phenomena of silent aspiration and associated “respiratory illness”. Concerns about aspiration and the oro-pharyngeal stage of swallowing are generally investigated using a dynamic X-ray (VFSS), where the invisible and critical features of swallowing are made apparent. Although the different stages of swallowing are not referred to explicitly within EDACS, that is the oral stage and the oro-pharyngeal stage, the different levels describe limitations arising at the different stages. All levels show limitations to some degree or other at the oral stage of eating and drinking. Limitations to the oro-pharyngeal stage of swallowing are captured within Levels IV and V where there is an explicit mention of aspiration risk, the latter level being associated with harm arising from impairments to swallowing function leading to aspiration. Level III also contains a reference to aspiration risk, associated with drinking.

Some participants within the NGP and DS expressed concern about the development of EDACS because of these invisible and critical features of swallowing. Professionals, trained to assess eating and drinking difficulties, will look out for clinical signs from which aspiration can be deduced or suspected; a referral for VFSS is often made to confirm or refute suspicions of aspiration. Some professionals were concerned that parents were often unaware of the clinical signs that professionals had been trained to notice. Other professionals, particularly paediatricians, expressed concern that critical management decisions for individuals with CP, to restrict oral intake for example, were based on a

snapshot VFSS assessment without reference to that individuals overall health and well-being. Section 2.5.2 contains more detailed discussion of these concerns, particularly Cass et al. (2005). The pragmatic decision was taken to report risks of “aspiration” and the “clinical signs of aspiration” in plain English within EDACS. The final Level V contains explicit mention of “harm” from aspiration, as well as descriptions of possible clinical interventions in order to keep the airway clear and provide nutrition via tube feeding. The term “harm” replaced the more alarming “significant threat to life” which was used in the early EDACS versions.

The clinical descriptors relating to aspiration and breathing changes, previously outlined in Chapter 2 were included in the Definitions section of EDACS (Parrot et al. 1992, Reilly et al. 2000, Weir et al. 2009). The definitions of *Breathing changes*, *Signs of Aspiration* and *Silent Aspiration* are given here in full:

*“Breathing changes might be noticed during eating or drinking which might suggest difficulty clearing food or fluid away from the airway and throat. The changes observed may be linked to the sound of the breathing (wheezy, rattly, noisy or wet) or may be linked to changes to the way someone breathes (e.g. changes to the rate of breathing or laboured, effortful breathing.”*

*“Signs of Aspiration are clinical observations that have been linked to Aspiration: coughing, wet sounding voice, breathing changes (sound of breathing as well as the rate and manner of breathing), changes in skin colour, whole body reactions, eye widening or watering, or panic reactions evident in facial expression.”*

*“Silent Aspiration is the term given when aspiration takes place but that outward signs of aspiration such as coughing do not occur. Other Signs of Aspiration such as eye widening or watering, or panic reactions evident in facial expression may be observed.”*

### **6.3.7 Food textures and fluid consistencies**

Considerable attention was given to the descriptions of food and fluid textures in the Definitions section, which were referred to throughout the “word pictures” describing different levels of ability. The physical properties of food and fluid elicit different movement patterns in the anticipatory and oral stages of eating and drinking (see Section 2.5.2). The most difficult to manage foods are those marked as hazardous, particularly for neurologically impaired individuals and young children, in the recent policy statement to

prevent choking (American Academy of Pediatrics 2010). The food texture descriptors used in EDACS made use of information detailed in Section 2.5.3, avoiding technical language. The challenge in setting out a range of textures was to include examples from the easiest to eat to the most demanding of strength, stamina and skilled oral movement. The descriptions, as for every aspect of EDACS were successively refined, added and clarified throughout the development stages. The description of food textures and fluid consistencies, leading to the reliable replication of the appropriate textures and consistencies, is one that continues to challenge professionals specialising in the management of eating and drinking difficulties (See Dysphagia Diet Food Texture Descriptors 2012 and Cichero et al. 2007).

A comment made early on in an interview with an individual with CP (see interview with Jodi p.4 Appendix CD2) was that it was important not to connect a particular food texture or fluid consistency with a particular food or drink in case someone really did not like that food or fluid. The challenge then was to describe food textures and fluid consistencies broadly enough for them to be meaningful to a wide range of people who might use EDACS in the future. As the focus of a speech and language therapist is often on modifications to diets, it took some considerable reflection and exploration to arrive at the more challenging textures described. A range of different food texture examples were included in response to Jodi's observations. Reference was also made to the "Guide to Food and Drink Textures", compiled by the London based Paediatric Dysphagia Special Interest Group (Cockerill et al. 2010).

EDACS also needed to contain an acknowledgement that most foods and fluids could be modified to change the texture to one that was easier to manage, so that tough meats could be blended and large pieces could be cut into smaller pieces, for example.

The final version of EDACS refers to the following food textures:

*“Firm bite and effortful chew textures which are the most challenging to eat e.g. tough meats, molluscs, hard nuts, crunchy fibrous fruit and vegetables.*

*Mixed textures when different food textures and fluid consistencies are combined (e.g. lumps of food in a thin soup, watery puree which separates into fluid and food, meat and salad sandwich) or slippery textures of food are particularly challenging to control in the mouth and eat safely.*

*Sticky foods can cause problems if an individual has difficulty clearing the mouth: e.g. nut butters, halva, tahini and toffee.*

*Hard chew textures e.g. raw fruit and vegetables, meat, crackers, crusty bread.*

*Soft chew textures e.g. well cooked non fibrous vegetables, very ripe peeled fruit without seeds, well cooked pasta and soft cake require less effort, strength and co-ordination to eat.*

*Well mashed foods require very little chewing e.g. well cooked meat mashed with potato or well cooked vegetables, well cooked pasta or cake mashed with cream.*

*Puree is a smooth uniform consistency which requires no chewing.”*

EDACS refers to different fluid consistencies that change the speed at which fluid moves, having an impact on how safely a drink can be swallowed. The Definitions section of the final version of EDACS contains the following description:

*“Thin fluids are fast flowing and require quick co-ordination of the movements of swallowing and breathing. Smooth thicker fluids flow more slowly and may be used by individuals with slower movements during swallowing in order to reduce the risk of fluid entering the airway or lungs, and / or to reduce loss of fluid from the lips. Thick fluids may be prepared by using diluted yoghurts or thick soups; thin fluids may be thickened using commercially available thickening agents.”*

### **6.3.8 General headings**

Each of the levels of eating and drinking ability are summarised by a General Heading, following the design of the GMFCS, MACS and CFCS. These headings or brief summaries were all developed to contain some formulation in relation to the key features of “safety” and “efficiency”. The changes that emerged as EDACS was successively redefined are evident in these General Headings. Table 6-3 gives details of the changes to the General Headings for EDACS together with the version number when the change took place; the final formulation of the General Heading for each of the levels has been highlighted:

**Table 6-3: Different formulations of the General Headings for each EDACS level together with the version number where changes were made.**

Level	General Heading Changes with EDACS version number
<b>Level I</b>	v7 Eats and drinks easily and successfully v8 Eats and drinks efficiently and safely <b>v12 Eats and drinks safely and efficiently</b>
<b>Level II</b>	v7 Eats and drinks with some limitations to quality and speed of movement v8 Eats and drinks safely with some limitations to efficiency because of quality and speed of movement v9 Eats and drinks safely but with some limitations to efficiency because of quality and speed of movement <b>v10 Eats and drinks safely but with some limitations to efficiency</b>
<b>Level III</b>	v7 Eats and drinks but needs some changes to food and fluid textures to eat or drink successfully v8 Eats and drinks but needs some changes to food and fluid textures to eat or drink efficiently and safely v11 Eats and drinks but changes to food and fluid textures are needed to eat or drink efficiently and safely <b>v14 Eats and drinks with some limitations to safety; there may be limitations to efficiency</b>
<b>Level IV</b>	v7 Eats and drinks with significant limitations; may need supplementary tube feeding v8 Eats and drinks with significant limitations to safety and efficiency; may need supplementary tube feeding v10 Eats and drinks with significant limitations to safety; tube feeding to supplement oral nutrition may be considered <b>v14 Eats and drinks with significant limitations to safety</b>
<b>Level V</b>	v7 Cannot eat or drink – will need tube feeding to sustain life v8 Cannot eat or drink safely - will need tube feeding to sustain life v9 Cannot eat or drink safely – will need tube feeding to obtain nutrition v10 Cannot eat or drink safely – tube feeding may be considered to provide nutrition <b>v17 Unable to eat or drink safely – tube feeding may be considered to provide nutrition</b>

The General Headings do not provide sufficient information to determine the level of eating and drinking ability for an individual with CP. Users are directed to the full descriptions or “word pictures” describing eating and drinking performance.

### 6.3.9 Levels of assistance

An additional dimension that emerged in the NGP was the introduction of the categorisation of levels of assistance required at mealtimes. The initial formulation of two levels (Independent and Requires Assistance) was expanded to three:

*“Independent (Ind) indicates that individuals are able to bring food and drink to their own mouth without any assistance. It does not indicate that individuals are able to modify food to the required texture for safe and / or efficient eating and drinking. It also does not indicate that individuals are able to sit independently.*

*Requires Assistance (RA) indicates that an individual needs help to bring food or drink to the mouth, either from another person or through the use of adapted equipment. Help may be needed loading the spoon, placing food in the hand or guiding the individual’s hand to the mouth, holding a cup steadily, providing close supervision or verbal prompts.*

*Totally Dependent (TD) indicates that an individual is totally dependent upon another to bring food or drink to the mouth”.*

For the reasons outlined in Section 2.5.5, the functional ability of bringing food and drink to the mouth was kept separate from the oral skills involved in biting, chewing and swallowing. The examples provided in the EDACS document serve to illustrate the importance of separating these different dimensions from each other:

*“An individual’s eating and drinking ability will be expressed as a number followed by an indication of the degree of help needed at mealtimes. For example, a child who is able to eat safely with some limitations to efficiency and requires assistance in loading the spoon or steadying a cup would be EDACS Level II Requires Assistance (RA); a child who has an unsafe swallow and is able to bring food and drink to the mouth would be EDACS level V Independent (Ind).”*

### 6.3.10 Descriptions of different EDACS levels

As discussed in Chapter 2, Section 2.10, the process of classifying entails the grouping of people into classes according to common characteristics (Eliasson et al. 2006). The key features of eating and drinking for individuals with CP have also been outlined in Chapter 2, Section 2.5. Significant dimensions of contrast emerged in order to create the series of “word pictures”, describing limitations to eating and drinking ability in different classes.

The GMFCS details overall ability for sitting, standing and lying and limitations that may occur with CP. It also provides brief details about the impact of these limitations, the adaptations that may be made to facilitate movement and the extent to which the environment influences movement. Similar headings were identified within which to organise different dimensions of contrast for each of the Levels of EDACS:

- Eating ability or performance (tongue, jaw, lip movements and swallowing ability)
- Food textures
- Limitations or challenges linked to eating performance
- Drinking ability (tongue, lip, jaw movements and swallowing ability)
- Fluid consistencies
- Limitations or challenges to drinking performance
- Safety - impact or consequences (aspiration, coughing, choking, changes to breathing, harm)
- Efficiency (speed of eating and drinking, duration of meal, food or fluid loss)
- Adaptations (techniques, equipment)
- Environment (positioning, modifications required)

Although not explicitly mentioned, details related to these headings are included in each of the descriptions of the different levels.

In developing EDACS, the descriptions or “word pictures” were always viewed as descriptions of function whilst eating and drinking and not as descriptions of discrete oral movements which can sometimes be emphasised in clinical assessments. The rhetorical question, “Would anyone who knows an individual with CP well recognise that person’s usual eating and drinking performance in the EDACS “word picture” was held in mind.

The discrete physical movements required for eating and drinking ability are well described in the Schedule for Oral Motor Assessment (SOMA - Reilly et al. 2000). The development of the SOMA involved the selection of features of oral ability that discriminated between infants with oral motor dysfunction and children with normal oral motor ability. Those features that were found by Reilly and colleagues to be useful in discriminating “abnormal” oral ability for eating and drinking were examined for inclusion into EDACS. These include the following items when eating puree, semi-solid, solid food or a cracker and drinking from a bottle trainer cup and cup:

- Upper and lower lip movement – closure around the spoon, drawing food from the spoon, closure during swallow, closure during bite or chew, firm contact around teat or nipple, lip movement to assist in cleaning lips and teeth
- Tongue protrusion – minimal, considerable, beyond incisors, beyond lips
- Tongue asymmetry
- Jaw movement – internal jaw stability, variable stability, external stability, vertical movements, wide vertical excursions, small vertical movements, head movements associated with jaw movements, graded jaw opening neither too wide or too narrow, vertical movement
- Bite – controlled or sustained bite, mouthing only
- Food or fluid loss – profuse or marked
- Sequences of movement – smooth rhythmic sequence
- Swallow – gagging, panic reactions observed on face and whole body, no swallow observed, uses head extension and gravity to assist, numerous attempts to initiate swallow, choking.

The standardised observations of the SOMA focus on specific movements and do not convey a range of ability or overall function. The final score obtained from the SOMA determines whether or not an individual has “Oral Motor Dysfunction”. The emphasis within EDACS is on overall function, that is eating and drinking performance or a description of what actually happens. Observations from the SOMA were utilised as a starting point to describe the full range of eating and drinking ability for individuals with CP. For example, the thirteen different patterns of lip movement detailed by Reilly and colleagues (Skuse et al. 1995) were considered in terms of their overall contribution to eating and drinking performance, particularly food and fluid loss. More detail about tongue movement was included, particularly speed of movement, the functional ability of drawing food or fluid to the centre of the mouth, pushing food to the sides of the mouth for chewing and clearing food and fluid from different areas of the mouth.

Table 6-4 shows the differences between EDACS levels categorised by the functional movements of the individual parts of the mouth and connection with eating and drinking performance. It is important to be aware, however, that no individual part of the mouth functions separately from another.



**Table 6-4: Differences between EDACS levels categorised by the functional movements of parts of the mouth**

<b>Tongue Movement</b>	
Level I	<ol style="list-style-type: none"> <li>1. Tongue moves food to the sides of the mouth for chewing and draws food to the centre of the mouth ready for swallowing.</li> <li>2. Slight limitations to the range of movement - far corners of the mouth and outer tooth surfaces are difficult to clean with tongue.</li> <li>3. Tongue is able to retain bolus (food or fluid) in its centre, giving time to co-ordinate swallowing and breathing.</li> <li>4. Tongue moves at reasonable speed with no impact on mealtime duration.</li> </ol>
Level II	<ol style="list-style-type: none"> <li>1. Some limits to the range of tongue movement although able to reach sides and front of mouth, and draw food to centre of mouth.</li> <li>2. Limits to using tongue to retrieve food debris, particularly front tooth surfaces and between teeth and gums or if food is sticky.</li> <li>3. Tongue able to retain food in its centre, giving time to co-ordinate swallowing and breathing; may be some limitations to holding fluid bolus especially if large quantity of fluid is taken into mouth.</li> <li>4. Tongue movement slower than typically developing peers leading to longer mealtimes.</li> </ol>
Level III	<ol style="list-style-type: none"> <li>1. Limitations to range of tongue movement available, particularly to the sides, back corners of the mouth and front surfaces of the teeth.</li> <li>2. Some lateral movement of tongue although not sufficient to retrieve food and fluid from between teeth and gums, from front surfaces of teeth and possibly from roof of mouth.</li> <li>3. Ability of the tongue to hold food or fluid in the centre of the mouth until breathing and swallowing can be co-ordinated may be limited; fluid will present greater challenges than soft food textures.</li> <li>4. Mealtimes will be prolonged if food is challenging requiring a great deal of processing in the mouth.</li> </ol>

<b>Tongue Movement (continued)</b>	
Level IV	<ol style="list-style-type: none"> <li>1. Movement is limited in range to anterior and posterior movements, with no controlled sideways and vertical movement.</li> <li>2. Tongue movement to retrieve food from around mouth and tooth surfaces is not possible.</li> <li>3. Limited ability to hold bolus of food or fluid in the centre of the tongue until breathing and swallowing can be co-ordinated; food and fluid will often fall to the back of throat in uncontrolled way.</li> </ol>
Level V	Similar or even greater limitation than IV – “harm” from eating and drinking evident.
<b>Lip Movement</b>	
Level I	<ol style="list-style-type: none"> <li>1. Slight limitations to lip closure during eating might lead to slight loss of food or fluid during meals, particularly for challenging textures.</li> <li>2. Effective lip seal formed on a range of drinking receptacles, including a straw.</li> </ol>
Level II	<ol style="list-style-type: none"> <li>1. Some limitations to lip closure when chewing, leading to some food or fluid loss.</li> <li>2. Can form a lip seal around most drinking receptacles, including a straw.</li> <li>3. Speed of movement will be affected.</li> </ol>
Level III	<ol style="list-style-type: none"> <li>1. Lip closure is challenging as jaw, leading to some food and fluid loss from the mouth.</li> <li>2. Lip seal around drinking receptacle may not be strong enough to eliminate fluid loss whilst drinking; lip seal around a straw may not be possible; tongue may be used to form a seal instead of lips.</li> </ol>
Level IV	<ol style="list-style-type: none"> <li>1. Lip closure will be limited, leading to significant loss of food and fluid from the front of the mouth.</li> <li>2. Lip seal around a drinking receptacle will be challenging.</li> </ol>
Level V	Similar or even greater limitation than IV – “harm” from eating and drinking evident.

<b>Jaw Movement</b>	
Level I	<ol style="list-style-type: none"> <li>1. Vertical and sideways jaw movements are present making the strong, repeated rotary chewing of challenging food textures possible.</li> <li>2. Some foods requiring very firm biting and repeated chewing may be avoided.</li> </ol>
Level II	<ol style="list-style-type: none"> <li>1. Vertical and sideways jaw movement possible, enabling rotary chewing movements.</li> <li>2. Speed of movement will be affected, as well as stamina and strength.</li> </ol>
Level III	<ol style="list-style-type: none"> <li>1. Vertical jaw movement is possible; may be some restrictions to sideways jaw movement limiting rotary chewing ability.</li> <li>2. Foods requiring strong controlled jaw pressure and complex jaw movements to bite and chew will be too challenging to manage and may present a choking hazard (this is also linked to limitations to tongue movement).</li> <li>3. Mouth opening may be slow and there may be limitations to graded jaw opening.</li> </ol>
Level IV	<ol style="list-style-type: none"> <li>1. Jaw movement is likely to be uncontrolled; vertical jaw movements will be present with limited or no controlled sideways movements.</li> <li>2. Unable to bite and chew food – choking hazard.</li> <li>3. Limitations to graded jaw opening; delays and mis-timings of mouth opening and closure.</li> </ol>
Level V	Similar or even greater limitation than IV – “harm” from eating and drinking evident.
<b>Swallowing</b>	
Level I	<ol style="list-style-type: none"> <li>1. Slight limitations to swallowing may be evident when individual is distracted, tired or challenged, leading to coughing or gagging.</li> <li>2. Able to organise movements and co-ordinate breathing in order to drink using consecutive swallows.</li> </ol>
Level II	<ol style="list-style-type: none"> <li>1. Some limitations to swallowing may be evident when individual is distracted, tired or challenged, leading to coughing or gagging.</li> <li>2. Able to organise movements and co-ordinate breathing in order to drink using consecutive swallows.</li> </ol>

<b>Swallowing (continued)</b>	
Level III	<p>1. Movements of swallowing are effective although sometimes compromised by limitations to lip, tongue and jaw movements, leading to coughing and occasional aspiration; most noticeable when drinking fluids and eating challenging food textures; some risk of choking.</p> <p>2. Consecutive swallows when drinking may be possible although it may need time to swallow repeatedly between sips of drink.</p>
Level IV	<p>1. Challenging to co-ordinate swallowing and breathing with the occurrence of some signs of aspiration, coughing and gagging, with choking if lumps of food are eaten.</p> <p>2. Likely that swallowing repeatedly when eating and drinking will be necessary in order to clear the back of the throat.</p>
Level V	<p>1. Individual is unable to swallow food or drink safely due to limitations in range and co-ordination of movement for swallowing and breathing; aspiration and choking are very likely if the individual eats and drinks.</p> <p>2. “Harm” from aspiration is evident.</p> <p>3. Swallowing may be so limited that individual is unable to swallow their own secretions to keep airways clear.</p>

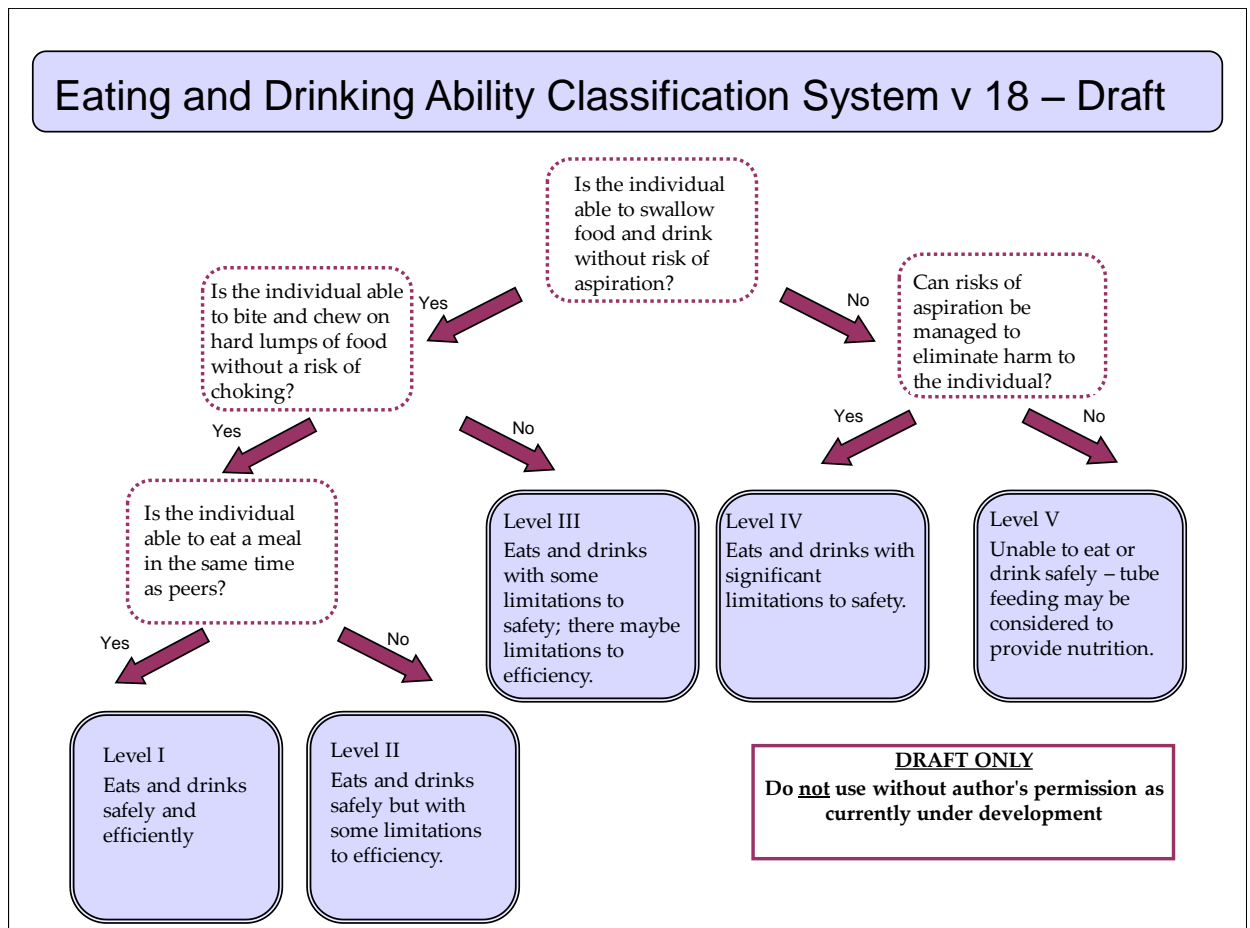
**Table 6-4: Differences between EDACS levels categorised by the functional movements of parts of the mouth**

### 6.3.11 Distinctions between the levels

Located between each of the descriptions of the different levels of ability in EDACS v18, are four different “Distinctions” between the levels in order to aid the user to make a decision. The “Distinctions” contain information derived from the underlying framework of EDACS v1 which evolved in to the decision algorithm of EDACS v18, represented in Figure 6-5. An example of one of these Distinctions is given here:

*“Between Levels I and II: Compared with Level I, individuals in Level II will have some limitations with more challenging food textures. Eating and drinking will take longer for individuals at Level II.”*

**Figure 6-5: Decision making algorithm underlying EDACS v18**



### **6.3.12 Developmental dimension of eating and drinking ability**

The final section focusses on the developmental dimension of eating and drinking performance that was not included in the first or final versions of EDACS, but was present in EDACS versions 9 to 14.

The GMFCS (Palisano et al. 1997 and 2007) describes gross motor function as “word pictures” for each of the five different Levels, in distinct age bands. There are different descriptions for individuals with CP before the 2<sup>nd</sup> Birthday, between the 2<sup>nd</sup> and 4<sup>th</sup>, 4<sup>th</sup> and 6<sup>th</sup>, 6<sup>th</sup> and 12<sup>th</sup> and 12<sup>th</sup> and 18<sup>th</sup> Birthdays. The descriptions of function within the age bands for the GMFCS were based on the detailed gross motor development curves of the Gross Motor Function Measure (Russell et al.1989).

EDACS v7 was proposed to describe the eating and drinking performance of individuals with CP from 5 years of age. This was done deliberately in order to avoid the need to include the developmental changes that take place in all children under 5 years of age. Participants in the first and other groups suggested that a lower age limit would be useful. No such detail about the development of eating and drinking for individuals with CP has yet been collected and no one assessment tool has been developed in order to do this (see Benfer et al. 2012d). Using the Developmental Milestones for typically developing children outlined by Arvedson et al. (2002 – see Section 2.5.4), different age bands for eating and drinking ability were developed and examined by 5 NGPs. The age bands continued through EDACS versions 9 to 14 (see EDACS v13 in Appendix CD1). Whilst some participants agreed with the content of the levels, others expressed concern about the evidence base for the levels. As a result of the NGP, the decision was taken to discard the age bandings for EDACS and to develop “word pictures” that potentially described the eating and drinking ability for individuals with CP from age 3 years to 18 years. The term “age appropriate food textures” was introduced to accommodate developmental differences for younger children.

### **6.3.13 Summary of development of the EDACS draft**

EDACS v18 (see Appendix 9) represents the final version of EDACS following the development in 3 distinct stages including the NGP and DS. The content of EDACS v18 received the required level of agreement from the DS panellists. EDACS v18 was taken forward to the final inter-observer reliability stage of the project to examine the use of the new tool by parents and SaLTs with children they know well. Table 6-5 illustrates the

relationship between the general summary headings of the GMFCS, EDACS levels and EDACS levels of assistance.

**Table 6-5: General summary headings for GMFCS, EDACS and EDACS Levels of Assistance**

<b>Levels</b>	<b>GMFCS</b>	<b>EDACS</b>	<b>EDACS Levels of Assistance</b>
<b>I</b>	Walks without limitations	Eats and drinks safely and efficiently	Independent
<b>II</b>	Walks with limitations	Eats and drinks safely but with some limitations to efficiency	Requires assistance
<b>III</b>	Walks using a handheld mobility device	Eats and drinks with some limitations to safety; there may be limitations to efficiency	Totally dependent
<b>IV</b>	Self-mobility with limitations; may use powered mobility	Eats and drinks with significant limitations to safety	
<b>V</b>	Transported in a manual wheelchair	Unable to eat and drink safely – tube feeding may be considered to provide nutrition	

## **6.4 Inter-observer reliability studies**

The results from the inter-observer reliability studies are reported in full in this section.

### **6.4.1 Participant and subject demographic information**

Participants in the reliability study comprised 26 SaLTs working with children with CP, using specialist knowledge of limitations to eating and drinking ability, and 48 parents of children with CP. The survey was sent to 233 parents giving a return rate of 20.6%. Parents rated their own children. SaLTs rated children who were well known to them as part of their clinical caseloads.

Table 6-6 contains details of the number of people with CP (subjects), together with the number of participating SaLTs and parents for each school site. The SPSS variable site code is given for each school.

**Table 6-6: Number of subjects, participating SaLTs and parents for each school site, and SPSS variable code**

School Code	Number of subjects	Number of participating SaLTs	Number of participating parents	SPSS Variable Site Code*
A	1	1	1	4
B	3	1	3	11
C	10	2	10	9
D	4	1	4	10
E	5	2	5	2
F	18	3	6	1
G	20	3	4	6
H	31	7	15	3 and 12
I	17	3	0	8
J	20	3	0	7
<b>TOTAL</b>	<b>129</b>	<b>26</b>	<b>48</b>	----

\*SPSS Variable Site Code 5 not used as associated with school where no parents responded to invitation to participate.

EDACS was used to classify the eating and drinking ability of 129 children and young people with CP (age range 4y - 22y; median age 14y; mean age 14y, SD 4.27). Other demographic information, as detailed in Section 5.5.8, is given in Table 6-7.



**Table 6-7: Demographics of children and young people with CP, subjects of the inter-observer reliability studies.**

Demographic	Data
<b>Ages:</b>	
Range	4y -22y
Median	14 y
Mean	14y SD 4.29
<b>Gender:</b>	
Males	78/129 (60%)
<b>GMFCS Level:</b>	
I	7 (5%)
II	10 (8%)
III	12 (9%)
IV	33 (25.6%)
V	66 (51.2%)
TOTAL	128*
<b>SCPE CP Subtype:</b>	
Spastic unilateral	5 (4%)
Spastic bilateral	69 (54%)
Dyskinetic	37 (29%)
Ataxic	4 (3%)
Worster-Drought syndrome	8 (6.2%)
Unclassifiable	5 (4%)
<b>TOTAL</b>	128*

\*Denotes missing data for one subject

Details about the subjects' use of feeding tube and presence of seizure activity are given in Table 6-13.

#### **6.4.2 Results of inter-observer reliability studies**

Following the methods detailed in Section 5.5.3 absolute agreement and chance-corrected agreement (kappa, Cohen 1960) were calculated between observers. Using the interpretation provided by Landis and Koch (1977), reported in Table 5-8, kappa values of 0.41-0.6 indicate moderate agreement, 0.61-0.80 substantial agreement and values between

0.81 and 1.00 indicate almost perfect agreement. Section 5.5.4 details the methods used to calculate Intraclass Correlation Coefficients for the data set (ICC, two way random effects single measures consistency). Interpretation of ICC values is provided by Fitzpatrick et al. (1998) who consider that values of 0.7 or higher are acceptable for measures in groups, and ICCs exceeding 0.9 are regarded as reliable for use clinically with individuals.

Table 6-8 and Table 6-9 show the results of the inter-observer reliability studies when pairs of SaLTs (n=19) used EDACS to rate the eating and drinking ability of 100 children (age range 4 to 22 years; median 15y; mean 14.41y, SD 4.3 years). When EDACS levels were assigned, the value of absolute agreement was 78% and chance corrected agreement or kappa was 0.72, indicating substantial agreement. (Landis and Koch 1977) The SaLTs used EDACS with a high level of consistency as indicated by the value of the ICC which was 0.93 (95% CI 0.90 to 0.95); where there was disagreement it was only by one level, with one exception (see Table 6-8). When pairs of SaLTs assigned the level of assistance required to the children known to them, absolute agreement was 87%, kappa was 0.80, and the ICC value was 0.92 (95% CI 0.88-0.94) indicating excellent agreement and reliability (see Table 6-9).

**Table 6-8: Inter-observer reliability: EDACS levels I-V SaLT1 vs. SaLT2. Absolute agreement=78%; chance corrected agreement k=0.72; ICC=0.93 95% CI 0.90-0.95**

	SaLT 1					
SaLT 2	I	II	III	IV	V	Total
I	9	3	1	0	0	13
II	1	21	5	0	0	27
III	0	4	12	2	0	18
IV	0	0	3	14	1	18
V	0	0	0	2	22	24
Total	10	28	21	18	23	100

**Table 6-9: Inter-observer reliability: EDACS Levels of assistance SaLT1 vs. SaLT2. Absolute agreement=87%; chance corrected agreement  $k=0.80$ ; ICC=0.92 95% CI 0.88-0.94**

	SaLT 1			
SaLT2	Independent	Requires assistance	Totally dependent	Total
Independent	29	5	0	34
Requires assistance	4	15	2	21
Totally dependent	0	2	43	45
Total	33	22	45	100

Speech and Language Therapists (n=20) and parents (n=48) used EDACS to rate 48 children (age range 4y–17y; median age 13y; mean 12.08y, SD 3.84). When EDACS levels were assigned to the children, absolute agreement was 58%, chance corrected agreement or kappa was 0.45 and ICC was 0.86 (95% CI 0.76 to 0.92) (see Table 6-10). Parents either agreed with the SaLT, or assigned a level one higher than that assigned by the SaLT; that is some parents rated their children as more able. When EDACS levels of assistance were assigned, absolute agreement was 79%, kappa 0.64, ICC=0.77 (95% CI 0.62 to 0.87), indicating moderate to substantial agreement and good to excellent reliability. Patterns of disagreement were less predictable when parents and SaLTs assigned levels of assistance.

**Table 6-10: Inter-observer reliability: EDACS levels I-V SaLT1 vs. Parents. Absolute agreement=58%, chance corrected agreement  $k=0.45$ ; ICC 0.86 95% CI 0.76-0.92**

	SaLT 1					
Parents	I	II	III	IV	V	Total
I	1	2	0	0	0	3
II	1	5	5	1	0	12
III	0	1	5	7	0	13
IV	0	0	0	11	3	14
V	0	0	0	0	6	6
Total	2	8	10	19	9	48

**Table 6-11: Inter-observer reliability: EDACS Levels I-V SaLT1 vs. Parents. Absolute agreement=79%; chance corrected agreement  $k=0.64$ ; ICC 0.77 95% CI 0.62-0.87**

	SaLT 1			
Parents	Independent	Requires assistance	Totally dependent	Total
Independent	6	1	0	7
Requires assistance	3	8	3	14
Totally dependent	1	2	23	26
Total	10	11	26	47

### 6.4.3 Associations between EDACS and other markers of functional ability

The association between eating and drinking difficulties and overall gross motor function for individuals with CP was explored in Section 2.5.6, with the conclusion that prevalence rates varied depending upon the definitions used. There is wide international consensus about the use of GMFCS as a severity rating scale of gross motor function. In some instances it is used as a measure of overall function in the absence of other suitable markers of function, including eating and drinking ability (e.g. Day et al. 2007). It is therefore important to examine the extent to which limitations to gross motor ability are

associated with limitations to eating and drinking ability. This was done by using Kendall's tau to examine the association between GMFCS level and EDACS level as recorded by SaLT1.

The association between EDACS level and level of assistance required at mealtimes was also examined using Kendall's tau.

There was a significant positive correlation between EDACS level and level of assistance required to bring food and fluid to the mouth (Kendall's Tau = 0.69,  $p < 0.01$ ). Table 6-12 shows a comparison between GMFCS levels and EDACS levels recorded for all subjects; there was a significant but moderate positive correlation between the EDACS and the GMFCS (Kendall's Tau=0.5,  $p < 0.01$ ) challenging the assumption that individuals with the most severe overall movement difficulties will have the greatest limitations to eating and drinking.

**Table 6-12: Comparison of EDACS levels and GMFCS levels with significant but moderate positive correlation between EDACS and GMFCS (Kendall's Tau=0.5,  $p < 0.01$ )**

	EDACS (SaLT 1)					
GMFCS	I	II	III	IV	V	Total
I	0	7	0	0	0	7
II	2	7	0	1	0	10
III	3	3	5	1	0	12
IV	6	8	11	6	2	33
V	1	7	15	20	23	66
Total	12	32	31	28	25	128

**Table 6-13** shows the presence of feeding tube and seizure activity in subjects, associated with EDACS levels.

**Table 6-13 Presence of feeding tube and seizure activity by EDACS level**

EDACS Level	Feeding tube present	Seizure activity present
Level I	1/12 (8%)	2/8 (25%)
Level II	1/32 (3%)	8/27 (30%)
Level III	5/31 (16%)	12/26 (46%)
Level IV	12/28 (43%)	16/25 (64%)
Level V	25/26 (96%)	19/25 (76%)
TOTAL	44/129 (34%)	57/111* (51%)

\*Denotes missing data – seizure activity data not available for 18 children.

#### **6.4.4 Ease of use**

All SaLTs in schools C , and E to J participated in an audio recorded interview after they had used EDACS to categorise the eating and drinking abilities of children known to them. SaLTs at schools A and B provided information in telephone conversations that were not recorded. No recording was made at School D as the SaLT had already answered the questions before the tape machine could be set up; she found EDACS unequivocally clear and easy to use.

Telephone contact was successfully made with five parents who indicated they were willing to be contacted on their returned EDACS survey; telephone messages were left and not returned for two other parents. Transcripts of a recorded discussion from one of the schools, a recorded phone conversation with a parent and notes from a telephone conversation with a parent are included in Appendix CD2.

A topic guide was used to structure conversations but not restrict discussions with participants after they had used EDACS. The responses are summarised below:

##### **1. How clear were the directions given?**

Participants commented that the directions were clear and easy to follow. One SaLT commented that it was possible to use EDACS on first receiving the hardcopy of the document, without further training.

*“Very clear .... I think I would have felt confident to have a go without your kind of.....verbal direction, so it is written out very clearly, I think, in there.”* SaLT1 School E.

## 2. How easy was the task?

Parents commented that it was easy to find their children in the classification system:

*“I found it quite straightforward, ummm, I didn’t have any problems with it, ummm, I just needed...you just need to obviously read through all the different categories, and that was really what prompted my sort of questioning.”* Parent 2.

*“Ummm, yes, I mean, it was all very straightforward and ummm, yeah, there weren’t many problems with that.”* Parent 1.

In an unrecorded telephone interview, Parent 3 commented that the first thing he did was to look for his son in the information given. He could find his son in EDACS which he liked.

Parent 2 found the task challenging because of the complex nature of her child’s difficulties. She thought that he fell somewhere between Levels IV and V. Her son had taken the decision to limit his oral intake, relying on his gastrostomy for nutrition. The parent acknowledged that whilst there was a significant risk of aspiration, if carefully managed her son was able to take small tastes of food and drink if he wanted to without “harm”. It might be that the avoidance of oral intake by the young person is directly connected with the lack of “harm” associated with aspiration.

*“...it means that he must only be given a drink by those who know him well and, you know, that have been shown what to do and what to look out for and how to respond to a potential aspiration situation.”* Parent 2.

The responses by SaLTs to this question suggested they found the task easy for most children, especially when they knew the child well. The task was more challenging when the SaLT was not so familiar with the child:

*“I found it easy to use on people I know well.”* SaLT School G.

*“When I knew the child well I found it a lot easier.”* SaLT School J.

*“And the extremes were very quick and easy.”* SaLT School J.

*“I think the extreme, like when it was level V it was easy, when it was ...Level I and II it was easy, I found it hard differentiating in between Levels III and IV.”* SaLT School H.

*“I think that generally the level of assistance required was quite easy to fill in...where I struggled or had to think a bit more was when, between totally dependent and requiring assistance, because the particular student, I mean, probably 95, maybe 99% of the time it is totally ‘dependant’, totally ‘independent’, sorry. Independent, but there are occasions when he needs help in loading the spoon.”*  
SaLT School H.

Some SaLTs commented on the unusual nature of the task in that often only one SaLT knows a child’s eating and drinking really well. The second SaLT rating was provided by one of the senior therapists working in the schools overseeing complex dysphagia cases or another therapist who had worked with that child recently. Some children attending schools F to J could not be assigned an EDACS level by pairs of therapists because they were only known well by one SaLT.

Some SaLTs and parents commented that EDACS prompted them to think in more detail about a child’s eating and drinking:

*“Easy ... Yeah. I think it was testing enough to make you really think about the descriptors.....and how they apply to each one, so enough thought. Not too simple but...”* SaLT School E.

*“Helped me find a place in my brain to put the information.”* Parent 5.

SaLTs from five schools (C,F,H,I,J) commented that EDACS was similar to systems they already had in place to manage the eating and drinking needs of their students.

One SaLT commented that she found the task challenging for young people who were choosing to take more risks with eating and drinking than she considered safe. She was not sure whether to select an EDACS level describing what actually happened or what she thought should happen. She cited an example of a young person at risk of aspiration, who continued to eat and drink larger quantities of food and drink, placing himself at risk of harm. She considered that the evidence of “harm” was building but that it was not sufficient for the young person or his parents to revise their decisions.

*“Yeah, and I find it hard when someone is doing something that maybe isn’t what would have been our recommendation so... an example is that somebody who is a high risk and probably should be Level V, but actually he has decided that he kind of wants to be Level IV, I think.”* SaLT School H.



Another SaLT described a similar dilemma for a young person who had died shortly after his parent had returned the EDACS survey. During the planned telephone discussion, the SaLT found it upsetting to consider rating this young person's eating and drinking as she had received the news of his unexpected death the previous day. The SaLT recounted that a VFSS assessment had indicated no aspiration when this young person swallowed which supported a continuing tastes programme, suggesting a rating of level IV, in spite of the risk of aspiration; during the conversation she said that she did not want to decide on an EDACS level to represent his eating and drinking ability. The child's parent had selected EDACS Level IV, Totally Dependent to represent her child's eating and drinking ability. At a later date, this SaLT sent the EDACS levels for this young person, assigning EDACS Level V, Totally Dependent. Information about the cause of death was not given and not asked for as it fell outside of the remit of the research.

### **3. Was the clinical algorithm easy to use?**

Speech and language therapists were asked to comment on the clinical algorithm illustrated in Section 6.3.11, Figure 6-5. This algorithm does not form part of the EDACS document that was shared with parents. Some SaLTs found the diagram useful to find their way through the extensive information of the EDACS levels:

*"For some of the more challenging ones I found this diagram quite useful to consider."* SaLT School I.

*"Yeah. I do like the flow chart as well, because you can just pick it up."* SaLT School F.

The SaLT used the algorithm to direct herself to the appropriate descriptors. *"But the detailed descriptions, sometimes I was getting quite bogged down in because there is such a lot of information on there."* SaLT School J.

One SaLT commented that the algorithm highlighted the distinction between safety concerns associated with choking from those associated with aspiration; she had not been aware of this distinction on first reading EDACS.

Some SaLTs did not find the clinical algorithm useful, finding the narrative of the EDACS document easier to follow:

*"I actually found this version easier than looking at [the algorithm] .... But somehow visually...The EDACS document easier than the flowchart one."* SaLT School G.

#### 4. Is each of the level descriptions clear?

Parents who were interviewed found the descriptions clear and easy to follow:

*“They were because I read them through and I thought, this is someone who clearly knows exactly.....the issues we have with, when food becomes a problem and when it can differentiate between choking and uncomfortable and messy and whatever, so I thought the descriptions were very good.”* Parent 1.

One parent was interested to note that the descriptions contained information that she thought were only relevant for her child:

*“I thought it was may be just Paul, but it is obviously quite a common thing because somewhere in your notes you have said about not feeling comfortable eating or drinking in public.....and ummm, and that certainly is Paul. I mean, when we are out with him, even if it is us out with him, he really doesn’t want to actually drink anything when we are out and about, if it is snack time or lunch time, he is very clear about that. And the only explanation I could come up with was that he is not comfortable doing that in public.”* Parent 2.

The comments from SaLTs indicated they thought the descriptions of the levels were clear:

*“Level Is and Level Vs [is clear]; ummm, between II and III and III and IV is obviously a bit more problematic but doable though.”* SaLT School J.

*“Really clear ... I think that the reason I am checking is because I haven’t seen the child, not because of the classification, it is more..... that I haven’t seen the child.”* SaLT School E.

*“I like the description for the independent versus the... requires assistance.”* SaLT School F.

One therapist commented on the potential confusion arising from similarities between the bullet points in the different levels:

*“I think sometimes that can be a little bit confusing because you have got very similar bullet points in two different sections, but then that is because some people are gonna have things that are similar aren’t they?”* SaLT School G.

Some SaLTs commented that for some children there were features in two different levels that described a child’s eating and drinking ability. In the absence of a precise marking

scheme to use to assign levels, some therapists noticed the requirement for more active thinking arising from the user instructions:

*“And I think it was a bit of a judgement call about whether the majority of it is in there or whether there are features in there which make you think...”* SaLT School I.

Where there was uncertainty, SaLTs used the information in the distinctions between levels to inform their decisions.

### **5. Are the distinctions between each of the levels clear?**

Both parents and SaLTs found the distinctions between levels clear to understand.

*“I think they did help, when I was deciding between a couple.”* SaLT School J.

*“I used the thing in the box where it says about the distinctions... [to make choice between levels].”* SaLT School I.

*“They were really useful when you were just querying one or the other.”* SaLT School I.

*“the bit that I found helpful then was the actual box that says the distinction...so then I could see the difference because otherwise they are quite similar.”* SaLT School F.

One SaLT commented on the need to read the information closely because of the apparent similarity on first reading:

*“I think there were a couple of times when I kind of thought they were at so and so level ... And when I looked at the next level up or down, I thought well actually that sounds quite right, and sometimes the distinctions helped... but I think there was one or two ... where I kind of had to really read the distinctions a couple of times as I thought they still sounded quite similar.”* SaLT School F.

### **6. General comments on EDACS**

There were some other comments made by SaLTs and parents about the overall system.

Several parents commented on the utility of EDACS in providing a shorthand way of conveying their children’s eating and drinking ability:

*“ you know a young person that is coming into the hospital situation, you can say, well they are category IV eating and drinking and they are category V for [GMFCS]*

*then it means something, and then there is something for people to go and look up exactly... ..to get a whole instant sort of feel for what that young person's needs and disabilities and abilities are...To get to the same answer...without having to go through an hour of medical history ((laughs).)" Parent 2.*

Parent 3 thought it was a good way to help objective understanding such as when his son goes to hospital; everyone would know roughly what to expect.

Another parent expressed relief that there was an acknowledgement of an area of difficulty for her child that was rarely discussed:

*"Yeah, I hadn't even thought of it because it is just one of the things that I just, I was like, my little thing that I just had to get on with by myself, it was only when you sent the form through I thought, oh my god, yes that would be so helpful. I was so kind of keen on it, because I have had so many learning issues along the way." Parent 1.*

She later stated that her child had severe speech and language difficulties but that

*"there is never anything in there about eating and drinking ((laughs))It has never been part of his diagnosis, it has never been talked about medically, or anything, and actually something that he has to do constantly every day to live." Parent 1.*

The SaLTs commented on the utility of EDACS to aid communication, to plan within a school setting and use something that is widely understood:

*"I think it is great. And it would be so much easier for us with kids coming from different areas of the country and if there is something like this that could go with them." SaLT School C.*

*"I think it is really useful... I think you automatically try to do this as you're working anyway... in your head, I know we have, when we have tried to group children as to how much support they should get, but, nothing so specific as this really." SaLT School F.*

*"I think it gives you a nice ball park figure in a way.... a shared communication around a ball park figure, that everyone understood." SaLT School E.*

*"if you took something like this with you, I think that would give you a really clear framework." SaLT School H.*

One SaLT expressed concern at the amount of information contained within EDACS for processing and wondered how easy a task that would be for parents to complete:

*“I guess from a parents point of view, there is quite a lot of information, I think for us who are used to doing assessments, I think we can almost kind of flick through it, and think oh yeah, yeah, I know what that means, and focus on this bit. I think if I was to give this to somebody, a parent or you know, a member of the public who hadn’t seen something like this before, I think, even for me, I think, if I had never seen this before, I would have to read it very carefully... and that would be very time consuming I guess.”* SaLT School G.

Some other SaLTs commented on the potential confusion arising from the interactive nature of eating and drinking difficulties. Some therapists identified children who were potentially independent at mealtimes but required mealtime supervision in order to reduce risk of aspiration and choking associated with their limited awareness of their difficulties, or the presence of seizure activity:

*“...and what made me put him on a IV was because if I wasn’t there, and we weren’t supporting it, and then it would be a very unsafe mealtime... because he would be in III just on face value, but if I wasn’t there, then, or if an adult wasn’t there, then he would be a IV, because he would be at more risk of aspiration, irrespective of the independence.”* SaLT School E.

Following discussion with her senior colleague, the SaLT revised the level assigned to III. Another SaLT commented:

*“I thought that with Johnathan as well as I thought, well actually, his dysphagia, you know, once all his food is managed he eats quite well, but when he suffers with lots of seizures and you can’t feed him.”* SaLT School G.

## **7. Views on level of agreement between parents and speech and language therapists**

The author asked some of the therapists whether they thought they would be in agreement with parents of children they knew; some parents were asked if they thought they would agree on their children’s levels of ability with SaLTs who knew their child well.

Parent 3 commented that for the most part they agreed with SaLTs especially as their son was now at such a good school. When he first started Toby’s mother went into school to

make sure that everyone knew how to feed Toby and what techniques should be used and what food textures he should be given. She made sure she covered all the different staff in different shifts.

Speech and language therapists thought there would be reasonable levels of agreement between them and the parents of the children they knew. They thought that some parents might take greater risks with their children than SaLTs would consider appropriate in a school setting:

*“I think we have had a couple of parents that are much more willing to take risks than we would, and, one particular... That they are willing. Yes, and we’ve, ummm, I am thinking about Lucy’s student in college, Lucy sent, well I did when he was in school, and Lucy sent even more information since he has been in college, and parents are incredibly happy with that information so that is great, and that is what you do in school, but at home we do this, to an extent they are happy to send them to A and E in an ambulance when they do have incidents, and that has happened a couple of times.”* SaLT School F.

*“We might have parents be more umm adventurous than we are.”* SaLT School C.

*“It is the school environment I think in a very busy, noisy hall he gets easily distracted so we are having to err on the side of caution with the textures we are giving him.”* SaLT School C.

One SaLT thought parents might challenge their children less at home than they are challenged at school”:

*“I wasn’t sure about one because the parents have chosen, ummm, for that student to, or to have a more cautious approach, whereas actually, they might manage a bit more...”* SaLT School H.

Some SaLTs acknowledged that there might not be agreement between parents and SaLTs but that EDACS was potentially useful as a framework for discussing differences of opinion and arriving at decision about a child’s eating and drinking ability:

*“And also, this is a little bit more objective, because I think we might actually agree if you looked at specific information ... we might perceive that as being quite problematic so our limitations to safety, whereas a parent might say, oh yeah we*

*have got all these things going on, but actually it is not a problem, we manage it.”*  
SaLT School G.

*“But it can therefore also work as a really good tool if you have got someone coming in new, it is a good way of agreeing together, with a parent, where you think that child is at.....so you would have agreement then, and hopefully you would have a sort of agreement, or at least be all talking the same language, whether there is agreement or not.”* SaLT School G.

Other SaLTs agreed about the potential to use EDACS with parents as part of the process of getting to know their child:

*“You could do it with a child that you don’t know particularly well, particularly if you are doing it in conjunction with the parent.”* SaLT School H.

## **8. Views of why few parents returned the EDACS survey**

Some parents and SaLTs were asked for views on the low return rate of the EDACS survey by parents.

Parent 3 commented that he tended to lose his appetite for forms after a while as you are approached for information from so many directions. Parent 4 thought parents were not replying because in her case the deadline had been quite short. For this particular school there was a delay in sending out the survey letters to parents because of school holidays. Although Parent 4 knew she had missed the deadline she thought she would send the information in anyway as she wanted to help.

The SaLTs at School C were surprised at how few parents had responded to the request to participate, particularly those of the more physically able children. The SaLTs wondered whether parents had not responded because they had no particular working relationship with the SaLT team, as their children had few speech and language issues.

## **6.5 Summary**

The results and data analysis are given in this chapter. Appendix 8 outlines data processes used to analyse the numerical data collected. Appendix CD2 contains examples of raw data. These results and their implications are considered in the Chapter 7.





## 7 Chapter 7 - Discussion

The following chapter includes a discussion about the findings of the research study, which aimed to develop a new classification system or social convention to describe limitations to the eating and drinking abilities of people with cerebral palsy (CP). Limitations to the study are also discussed. Future directions for research connected with the Eating and Drinking Ability Classification System (EDACS) will be considered.

### 7.1 Overview of EDACS

The prompt to develop EDACS came from the awareness that there was no valid and reliable tool available to classify the eating and drinking abilities of people with CP, in a clinical and research context. Ordinal scales are used in medicine to aid planning and systematize clinical description, an example being the staging and grading systems used to describe tumours. In order to systematize clinical descriptions of limitations to gross motor function, the developers of the Gross Motor Function Classification System (GMFCS Palisano et al. 1997) devised a five level ordinal scale. The five levels standardized the descriptions of increasing limitations to function, replacing apparently meaningful but imprecisely defined terms such as “mild”, “moderate” and “severe”.

The need for a new classification system of eating and drinking was confirmed by a systematic review of ordinal scales used to classify the eating and drinking abilities of people with CP (see Section 2.9.1 and Appendix 9, Sellers et al. 2013a). EDACS was developed in the context of other functional classification systems for people with CP, particularly the GMFCS and CFCS, against the backdrop of the quality standards for health measurement scales set out by Terwee et al. (2007).

The system describes the functional eating and drinking abilities of people with CP in five distinct levels, from the age of three years. The key features of *safety* and *efficiency* are used to identify the EDACS levels, linked with limitations to oral skills required for biting, chewing and swallowing. *Safety* refers to the likelihood of choking and aspiration; *efficiency* refers to the time taken to eat in relation to typically developing peers and the loss of food and fluid from the mouth. The scale also includes information about a person’s ability to bite, chew and swallow, the different food or fluid textures that can be managed, the breath changes associated with eating and/or drinking, and risk due to aspiration or choking. Following the GMFCS, CFCS and MACS, the different levels of the ordinal scale

were indicated by Roman numerals I to V. The use of Roman numerals deliberately marks the scale as ordinal, preventing use of the scale as if it presented interval data.

A separate three category ordinal scale describes the levels of assistance required at mealtimes by people with CP: *independent*, *requires assistance* and *totally independent*.

Attention was given to both the content validity and reliability of EDACS, as defined by Terwee et al. (2007).

## **7.2 Content validity**

The content of EDACS was carefully developed using a multi-strand sequential Mixed Methods research strategy, as detailed in Chapter 5. An appraisal of the content validity of EDACS is considered here with reference to the quality standards defined by Terwee et al. (2007).

A clear statement of the measurement aims of EDACS is contained in the first section of the EDACS document, entitled “Purpose” (see Section 6.3.1). The purpose of EDACS is to classify how people with CP eat and drink using five distinct descriptions to convey the whole range of ability in a systematic way. It is distinguished from detailed clinical assessments and diagnostic tools that clinicians will be familiar with using to look in detail at the component parts of eating and drinking. Users are informed that the classification system has properties associated with other ordinal scales in that people with CP will not be distributed equally across the levels and that the distances between the levels are not to be considered equal.

The clarity with which the measurement aims were stated was examined and refined by the participants in the Nominal Group Process (NGP) and Delphi Survey (DS), reaching the required level of agreement in the first round of the DS.

The EDACS document contains statements about the concepts the scale intends to measure, setting them out in a framework that has been used successfully in other contexts (GMFCS Palisano et al. 1997, MACS Eliasson et al. 2006 and CFCS Hidecker et al. 2011). In the section entitled “Purpose”, it is stated that the focus of EDACS is on the functional activities of eating and drinking such as sucking, biting, chewing, swallowing and keeping food or fluid in the mouth; the descriptions of the levels and distinctions between them make reference to the required adaptations to food textures and fluid consistencies, techniques used and some other features of the environment.

The section entitled “Key Features of Eating and Drinking” (see Section 6.3.3) further outlines the concepts contained within EDACS. Participants in the NGP and DS examined and refined the key concepts of EDACS, including the clarity with which concepts were stated. The required level of agreement with the concepts set out in EDACS was met within the first round of the DS.

A clinical algorithm representing the clinical decisions underlying EDACS is provided on the EDACS website to guide users if required (see Figure 6-5). This does not form part of the EDACS document.

The target population for EDACS v18 is clearly identified: people with CP from the age of 3 years. At certain stages within the NGP, EDACS included descriptions of eating and drinking performance of children younger than 3 years of age. However, the evidence base for these descriptions was considered to be insufficient for their inclusion in the final version of EDACS presented to panellists within the DS. The age at which EDACS should classify children’s eating and drinking was the focus of the greatest level of disagreement in the first round of the DS, with only 58% of panellists agreeing that EDACS should classify the eating and drinking performance of children from age three years. The majority of the comments received in response to this assertion suggested that EDACS should start at a younger age. In DS2, panellists agreed that EDACS in its current form was valid to use from age 3 years and above. Twenty three percent of panellists were uncertain about the feasibility of extending EDACS for use with children younger than 3 years.

The target population of potential users of the system was identified, with the suggestion that someone who knows the child well such as a parent or carer of a child with CP should identify the level of eating and drinking ability, in conjunction with a health professional who has knowledge about the necessary skills for safe and efficient eating and drinking.

The target population and potential users of the system were involved in the selection of content for the scale. People with CP were involved in the selection of content in the Delphi Survey, Consultative Group at Triangle (Appendix CD2) and the individual interview with Jodi (Appendix CD2). With hindsight, the inclusion of someone with CP on the Project Team would have been helpful; the insights provided by the parent member of the Project Team were invaluable. Other potential users of EDACS were included in the NGP and DS: parents of children with CP, a range of health professionals with extensive experience of eating and drinking abilities of people with CP, and researchers. The NGP and DS were used in order to facilitate equal participation, making use of the benefits of

group activity whilst building in opportunities to think and reflect separately from the group.

Terwee et al. (2007) state that reading skills beyond that of a 12 year old should not be required to understand the health measurement scale. Although the reading skills to understand EDACS have not been explicitly measured, it has been scrutinised by a range of lay people and health professionals. As far as is possible, EDACS was written without jargon; definitions of essential technical words were provided and refined as requested within the development process. Further changes to the Definitions section of EDACS were requested in DS1; more than 80% of panellists in DS 2 agreed that all definitions were clear and appropriate and that no other definitions were required.

As discussed in Section 5.4.8, some people with CP found the wording challenging. Some of the young people with CP were dependent upon a facilitator to access the written material of EDACS, because of limitations in reading the written word.

The reading comprehension age levels were not assessed for any of the study participants.

Using the quality standards detailed by Terwee et al. (2007), the content validity of EDACS would be appraised positively.

### **7.3 Reliability**

The quality standards proposed by Terwee et al. (2007) are also used here to appraise the measures of reliability made in the inter-observer reliability studies for EDACS. As previously stated, “agreement” between observers and the “reliability” of use of the scale by different observers need to be considered separately. “Agreement” represents the absolute measurement error of a scale, captured for ordinal scales by kappa, a measure of chance corrected agreement (Cohen 1960). “Reliability” is the extent to which a tool can distinguish between people, despite measurement error. Terwee et al. (2007) propose a minimum standard of a weighted kappa or intra-class correlation coefficient (ICC) value of at least 0.7 in a sample size of at least 50 subjects. In the context of health measurements scales, Fitzpatrick et al. (1998) also consider that ICC values of 0.7 or higher are acceptable for measures in groups; additionally ICCs exceeding 0.9 are regarded as reliable for use clinically with individuals.

Pairs of specialist trained Speech and Language Therapists (SaLTs) used EDACS to rate the eating and drinking ability of 100 subjects, that is children with CP known to them; the levels of assistance required were also rated. Using the interpretation of kappa provided by

Landis and Koch (1977), the measures of agreement are “substantial” when therapists used five EDACS levels to classify children’s eating and drinking ability. Therapists assigned the same EDACS level or disagreed by one level only for all but one child, where disagreement was by 2 levels. There was almost “perfect” agreement when SaLTs used the three level scale detailing level of assistance required at mealtimes; where there was disagreement, it was only by one level.

Measures of the reliability of EDACS when used by SaLTs, representing the interaction between the two parts of the classification system, the specific group of people using EDACS and the situation, were captured using ICCs. The ICC values when SaLTs used the EDACS levels (ICC=0.93) and levels of assistance scales (ICC=0.92) to rate the eating and drinking ability of children they knew well, were both greater than 0.9. The high ICC values indicate that EDACS can reliably differentiate between the eating and drinking abilities of individuals with CP, when used by SaLTs who know a child well, and can be considered useful in a clinical context (Fitzpatrick et al. 1998). All five levels of ability described by EDACS and all three levels of assistance required are used by the SaLT observers to classify children’s eating and drinking ability.

There are differences in the ways that parents and SaLTs used EDACS to rate the eating and drinking of 48 subjects, as indicated by lower agreement: agreement between SaLTs and parents, as indicated by kappa, is interpreted as “moderate” (Landis and Koch 1977). Parents, however, appear generally consistent in the way they use the scale compared to SaLTs, assigning either the same level or one level higher indicating a greater level of ability. The strong pattern of consistent differences in use of the scale is captured in the high value of ICC (0.86). The value of kappa when parents and SaLTs assigned levels of assistance required, was higher, indicating “substantial” agreement. However, the lower value of ICC (0.77) is indicative of greater inconsistency in the use of the levels of assistance scale by SaLTs and parents. Although the ICC values met quality standards (Terwee et al. 2007), the sample size of 48 subjects rated by parents and SaLTs was marginally below the recommended size of 50 or more.

It is unclear from the study as to whether the differences in use of EDACS by parents and SaLTs are associated with children’s different abilities in different environments with familiar and unfamiliar carers. Some feedback received from parents and SaLTs during the ease of use discussions in the reliability studies (see Section 6.4.4) suggested that some differences were linked to different levels of risk that children were exposed to. SaLTs considered it their professional responsibility to ensure mealtime safety of children within

the school environment, limiting exposure of individuals with CP to food and fluid textures that increased risks of choking and aspiration. Some parents were willing to work at the edges of their children's abilities even if this entailed emergency interventions. This highlights the potential importance of professionals asking parents to classify their child's eating and drinking ability in order to have a fuller understanding of their performance across environments.

#### **7.4 EDACS - associations with other areas of function**

The EDACS levels assigned to 129 subjects by SaLT1, who knew the child well in each of the school settings, were used to examine the association between eating and drinking ability and the level of assistance required at mealtimes. The association between eating and drinking ability and the ability to bring food and drink to the mouth was significant but moderate, supporting the need for these skills to be considered separately.

The EDACS levels assigned by SaLT1 were used to examine the association between EDACS and gross motor ability, expressed using the GMFCS (see Section 6.4.3). The significant but moderate association between the EDACS and the GMFCS highlights the need for eating and drinking ability to be considered separately from gross motor function. Limitations to eating and drinking ability will be present for individuals across the full range of gross motor ability; individuals who experience great limitations to gross motor ability (GMFCS levels IV and V) may have few limitations to eating and drinking function.

As might be expected, the incidence of tube feeding increased with increasing limitation to eating and drinking ability, although feeding tubes were used by some children classified at EDACS level I to III. There is an increased incidence of seizure activity with increasing limitations to eating and drinking ability, a marker perhaps of the extent of damage to the developing brain sustained at the beginning of life.

#### **7.5 Limitations**

As discussed in Chapter 3, EDACS was developed within a post-positivist world view, with the acknowledgement of a changing subjective, imperfect and incomplete view of reality. In the following section, the limitations of the study are considered.

### **7.5.1 Limitations of Nominal Group Process**

The issues arising in the use of the NGP are recounted in Section 5.3.9. It was challenging for NGP participants to examine all content of the EDACS document as it grew in length from 2 pages of A4 paper to 16 pages. The NGP facilitates the generation of ideas and the feedback from each of the groups was extensive, and at times rather dispersed. The voting process provided the means to separate out the key ideas from the views expressed.

However, because of the time pressures to create a new draft of EDACS before the next NGP, it was not always possible to consider the audio transcripts of the discussion in detail. The flipchart recordings of ideas expressed were considered and further exploration of these ideas was made if thought necessary.

One out of 56 participants chose not to vote because of strong disagreement with the concepts behind EDACS.

The loss of the audio recording of the parent group NGP discussion, before a transcription could be made, was considerable. Parents engaged strongly with the question of aspiration and diagnosis by videofluoroscopy; several parents described difficult experiences with the procedure, feeling dissatisfied about the use of a snap shot of their children's eating and drinking ability to decide whether oral feeding should continue. The themes of conflict within parental thinking presented by Craig and Scambler (2006) were also evident within the parent group. All parents expressed the view that EDACS should be a tool for them to use. Further study needs to be made of the decision making process for parents concerning their children's eating and drinking ability, assessment of safety and risk to health and the introduction of tube feeding (Morrow et al. 2008 and Craig and Scambler 2006).

### **7.5.2 Limitations of the Delphi Survey**

Attempts were made in designing the DS to address some of the criticisms raised by Sackman (1974) and others (see Section 5.4.2) and attention was paid to reporting guidelines set out by Sinha et al. (2011). As described in Section 6.2.2, 10 out of 18 panellists (55%) who agreed with less than 80% of the content of EDACS chose not to participate in DS2. The reasons for their discontinued participation were not explored. An examination of their responses in DS1 revealed no themes which connected each of the participants. Although the overall levels of agreement in DS1 were high, the loss of potentially critical voices in DS2 was noted.

One panellist (BB), who wrote extensively in DS1 criticising EDACS, chose not to participate in DS2; a detailed reply was made to the questions posed by this panellist in

DS1, in an attempt to keep that person engaged with the process. No further correspondence was received (see Appendix CD2).

There was some masking of minority opinion by the majority voice as detailed in Section 5.4.8 (see Table 5-5). It would have been helpful to include more people with CP in the DS in order to better represent their views.

### **7.5.3 Limitations of inter-observer reliability studies**

Some of the SaLTs who participated in the inter-observer studies commented on the artificiality of the task of recording the eating and drinking ability of a large group of children. Sometimes the second of the SaLT pairs, who had less frequent contact with the target child, found the task challenging because assigning a rating was based on rather old knowledge. One SaLT who had recently returned from an extended period of sick leave was particularly out of step with her colleagues; the levels of agreement between therapists in that particular school were lower than the other schools. Several SaLTs commented that using EDACS was very easy when considering children they knew well.

A major limitation to the inter-observer reliability studies was the small percentage of parents (20%) who completed the EDACS survey. Although the survey was sent out to all parents of children with CP attending schools A to H, very few parents of children whose eating and drinking was minimally affected (EDACS level I) returned the survey. Reduced variability in the sample influences the assessment of reliability (Streiner and Norman 2008). A discussion with parents who chose not to return the survey would have helped in elucidating possible reasons for the low return rate, although this was not undertaken.

The author has noticed, in working with parents of children with CP, that parents are often greatly stretched with the demands of caring for their children. This surmise was supported by the “return” of one survey, promised by one parent: the survey envelope contained the signed consent form but no survey giving EDACS levels for their child; the envelope was stained with mark from a tea or coffee cup and the parent had unnecessarily affixed a stamp, not noticing the FREEPOST address on the envelope. One of the parents participating in a telephone discussion expressed the view that sometimes parents receive a large number of requests for information. One parent indicated that the deadline for returning the survey had been too close to her receiving the information; better co-ordination with the participating SaLTs would have avoided this issue.



Another comment made by SaLTs in one school, surprised at the absence of response by parents of children who had few limitations to eating and drinking, suggested that the motivation to respond to the survey was closely linked to the relationships between parents and the SaLTs. Where children received very little input from SaLT services, parents may not be aware of the services offered or feel motivated to respond to a request for information from an unknown source. Parents who disagree with the management strategies employed by SaLTs for their children may not have been willing engage in a task associated with them. One parent sought reassurance before she was willing to participate that her use of EDACS to rate her child's eating and drinking ability was not going to be communicated with her child's SaLT.

The interviews conducted with SaLTs and parents as part of the inter-observer reliability study invited comments on ease of use. A wealth of qualitative data was generated in the form of interview transcripts which might have been more fully analysed. The data analysis presented in Section 6.4.4 is limited to answers given to the original topic guide.

#### **7.5.4 Limitations of EDACS**

As outlined in Section 2.5, eating and drinking ability is affected by a number of interacting factors that have the potential to profoundly affect eating and drinking performance. For example, if an individual with CP requires close attention to positioning because of limitations to head and trunk control, inadequate postural management will lead to unnecessarily compromised oral skills. The section of EDACS entitled Background provides details of significant factors that influence eating and drinking but that fall outside of the classification system itself. The impact of the environment on eating and drinking performance is evident if the opportunities that a person with CP is given are considered. One panellist from the DS wrote of experiences of working with children in Bangladesh, where children with CP were frequently deemed incapable of managing food textures other than smooth purees; the limited experience influenced the restricted development of oral skills. EDACS only classifies eating and drinking performance, what a person actually does, not capacity, what a person is capable of doing.

Whilst the inter-observer reliability studies suggested that EDACS could be used reliably to classify the eating and drinking ability of children with CP, there were some expressed concerns relating to the concept of "harm" associated with aspiration. For some individuals with CP, the evidence of "harm" linked to aspiration when eating and / or drinking is beyond doubt because of recurrent chest infections and compromised respiratory health.

For others, although there may be a suspicion of aspiration when an individual eats and drinks (e.g. trace aspiration seen on a videofluoroscopy assessment), the effects of that aspiration may not be apparent in the short term. For some parents, limiting their child's oral intake of food and fluid constitutes greater "harm" than the future possibility of compromised respiratory health. The dilemmas detailed in the paper presented by Cass et al. (2005) are present when assigning an EDACS level. The presence of clinical uncertainties and the clash of parent views, the views of people with CP and professional views will not be changed by the development and adoption of EDACS. It may help the concerned parties by providing a shared context for discussion.

Concerns were expressed within the NGP about the dangers of limiting thinking about eating and drinking ability to EDACS. Users of EDACS have described how it prompts them to further thinking and assessment, however, it is important to recognise the very significant limits to its clinical utility. It is a helpful tool for communication between professionals, parents and people with CP; it has the potential to aid planning and point to the need for further assessment. It is an adjunct to the usual clinical assessment of eating and drinking, not a replacement.

Participants in the NGP and DS suggested the need for regular review of EDACS levels assigned to children with CP because compromised eating and drinking skills may have an effect on the safety of mealtimes. There was concern that an assigned EDACS level would lead to complacency in the management of eating and drinking difficulties. Some participants thought it important to review the assigned classification at regular intervals. In the absence of research evidence, EDACS does not currently contain any guidance about how frequently the level should be reviewed.

It is important to be aware that even though EDACS is similar in appearance to other functional classification systems, it cannot be assumed to have the same attributes. Classification of gross motor function using the GMFCS provides some indication of prognosis for future development, because of the extensive research evidence base associated with it, following its development (Palisano et al. 2006).

Whilst EDACS has been developed for people with CP, some participants in the NGP and DS were interested to know if EDACS could be used for people with other conditions which affected eating and drinking, arising in childhood such as Down syndrome or Rett syndrome. It was reported that the measures of content validity and reliability are not transferable to a different population.

Some participants noticed that the feelings and related behaviours associated with eating and drinking were not represented within EDACS. An exploration of personal experiences associated with eating and drinking would be informative but falls outside of the scope of the current study.

### **7.5.5 Use of EDACS by parents**

Some might consider the moderate agreement (indicated by kappa  $k=0.45$ ) between parents and SaLTs when using EDACS as evidence to support the view that parents underestimate or minimize their children's eating and drinking limitations (see Section 2.7). It is helpful to compare the findings of the EDACS inter-observer reliability studies with those associated with the GMFCS. The reliability of the original GMFCS was tested by comparing the judgements made by what were described as a "homogeneous" group of physiotherapists and occupational therapists. At a later date, a comparison was made between the use of the system made by expert health professionals and parents (Morris et al. 2006).

Morris et al. (2006) outlines the differences and similarities with which the GMFCS is used by health professionals and parents. Parents and health professionals did not always agree when assigning a GMFCS level to their child but that there was consistency in the way that the GMFCS was used. For research purposes, some may prefer to use the view of professionals based on the assumption that it is more "objective". A pragmatic approach is advocated: if measures of reliability and consistency associated with a particular instrument are known for different groups of observers, an explicit statement within the methods is required about who has been asked to assign the level of ability. When parents' views are sought by health professionals, there is recognition of their expert knowledge of their child, which can contribute to better health care outcomes (King et al. 1996). Morris et al. (2006) suggest that by asking parents for an opinion of their child's gross motor ability using the GMFCS, parents may feel empowered such that their opinion matters. Disagreement could be discussed within the consultation to elucidate the source of difference of opinion.

There is no "gold standard" against which the judgements of parents or SaLTs can be compared which is why measures of consistency are of interest. There is a consistency in the way that EDACS is used by parents and SaLTs. A similar approach to the GMFCS may be adopted in using EDACS, with an explicit statement about who has been asked to assign the level of eating and drinking ability. Following King et al. (1996), by seeking the

views of parents using EDACS, there is recognition of their expert knowledge of their child. By sharing the same framework, it may be possible to elucidate the nature of the disagreement. The strength of feeling expressed by parents in the NGP, that EDACS should be considered as a tool for use by parents and health professionals, would support this point of view (see Section 5.3.9).

### **7.5.6 Use of EDACS by people with cerebral palsy**

Some people with CP found the full EDACS instruction leaflet difficult to understand and requested a shorter version in plain English. The decision was taken at the end of the NGP that whilst this would be a potentially useful future development, it fell outside of the remit of the current study. Whilst the content would be connected to the original document, the reliability of a simplified version of EDACS would need to be examined separately. Specific questionnaires have been developed to enable parents and people with CP to use the GMFCS and have been found to be reliable (Morris et al. 2004a; Morris et al. 2006).

The research project may have been enhanced by greater involvement by people with CP; future projects should consider the inclusion of someone with CP as a member of the Project Team.

### **7.5.7 EDACS for children with CP aged three years or younger**

Participants in the NGP and DS identified the need for the development of descriptions of eating and drinking ability for children with CP younger than 3 years. As set out in Section 6.3.12, EDACS versions 9 to 14 included descriptions of different levels of eating and drinking ability, arranged within different age bands, including information for children younger than three years – see EDACS v13 in Appendix CD1. Whilst some participants agreed with the content of the levels, others expressed concern about the evidence base for the levels. At the end of the NGP, the decision was taken to discard the age bandings for EDACS and to focus instead on descriptions of eating and drinking ability for individuals with CP from age 3 years to 18 years. An acknowledgement was made within DS2 that there was insufficient research data to outline the developmental progression of eating and drinking ability for children with CP under 3 years. The term “age appropriate food textures” was introduced to accommodate developmental differences for younger children.

Statement 2 in DS2 probed panellists for their views on the development of EDACS for children younger than three. Seventy seven per cent of panellists agreed with the statement that “*It would be helpful if EDACS was further developed to classify the eating and*

*drinking abilities of children younger than 3 years of age*". Panellists' responses were considered to reflect support for future development of EDACS.

## **7.6 Dissemination**

The process of dissemination of research findings was planned, giving attention to potential target audiences and settings. The following section outlines details of this plan.

- **Graphic Design**

Following the completion of the reliability studies, the decision was taken to consider the appearance of the finished classification system, an important feature in communicating with a wider audience. A logo for EDACS was developed. A graphic designer was employed to place the content of EDACS into a consistent and appealing graphic frame.

- **Website (EDACS.org.uk)**

EDACS has been developed as a classification system that will be available for use free of charge, following the same path as the GMFCS, MACS and CFCS. To facilitate easy access to the document and information associated with EDACS, dedicated webpages have been established within the Sussex Community NHS Trust website. A domain name has been purchased ([www.EDACS.org](http://www.EDACS.org)) and linked to the NHS website in order to facilitate access to EDACS through different internet search engines. The Project Team decided that it was necessary to publish the details of the development of EDACS in a scientific journal in order to clearly identify the intellectual property associated with the work. Following publication, EDACS will be made available for downloading on this website. Visitors to the site who request to download EDACS will be required to complete a simple online form providing contact details and reasons for downloading EDACS, with an option to indicate interest in future research using EDACS.

- **Publication of Research findings**

The development and reliability of EDACS has been described in an original article, and published by *Developmental Medicine and Child Neurology*, a leading scientific journal (Sellers et al. 2013b - see Appendix 9). Whilst publication in a scientific journal is an essential first step, it is important to consider other platforms to communicate with others.

The UK based Royal College of Speech and Language Therapists publishes a monthly Bulletin, circulated to member speech and language therapists. It would be helpful to

submit an article describing the development and reliability of EDACS for publication in the Bulletin to interact with SaLTs who may not access scientific journals regularly.

- **Presentation at conferences**

In the process of the development of EDACS, potential users of the system were engaged with at a number of conferences (Sellers et al. 2011, 2012a, 2012b, 2012c).

Future plans include presentation of the completed tool to the following audiences:

- Brighton and Sussex Medical School, Paediatric and Neonatal Research Symposium, September 2013 – accepted for oral presentation
- Oral Motor Symposium, St Gallen, Switzerland, September 2013 – invited oral presentation
- British Academy of Childhood Disability, South West Region Group, Exeter, October 2013 – invited oral presentation
- European Academy Childhood Disability Conference in Newcastle, October 2013 – accepted for poster presentation
- UK Swallowing Research Group Conference, February 2014 – invited oral presentation

Opportunities to present EDACS to other audiences will be explored.

- **Provide feedback to people who have expressed interest in EDACS**

Following publication of EDACS, the intention is to send details of the development paper and the web address to all people who participated in the research project and all those who have expressed an interest in hearing more about the system.

## **7.7 Future developments**

EDACS has the potential to be used across clinical and research contexts, by professionals, people with CP and their parents. In a clinical context, it provides a professional or parent with an overview to understand limitations to a particular individual's functioning. More broadly, it provides the means to plan for the needs of individuals attending a particular clinical, educational or social care setting, ensuring that risks associated with someone's eating and drinking are adequately managed; it also can ensure that someone's eating and drinking ability is communicated clearly and systematically between settings. At a macro level, it has the potential to be used in large scale surveillance studies exploring the stability and change of eating and drinking ability over time for people with CP. Data

collected in population studies using EDACS would contribute to the body of evidence that can be sensitively shared by professionals in their consultations with people with CP and their families. Some future developments outlined here are possible with minimal extra funding; the more expansive plans require substantial new financial backing.

- **Use of EDACS by local teams**

An important first step is to introduce EDACS to local teams providing clinical care to children with CP. The development of EDACS has already been discussed in a county-wide Paediatric Dysphagia Support Group for SaLTs, with many therapists expressing an interest in using the tool in their clinical practice. The suggestion will be made to local SaLTs to consider using the tool to collect parents' opinions about their children's abilities. Any difficulties encountered by SaLTs in using EDACS can be discussed in the regular meetings. A comparison between different markers of functional ability for each child would be possible using the GMFCS, MACS, CFCS and EDACS.

It would be helpful to seek the views of parents about the use of functional classification systems, such as EDACS, in the management of their children. The medical team within Chailey Heritage Clinical Services are planning to hold a focus group with parents to consider how classification systems could be best used, leading to the delineation of a clear process for use of EDACS and other systems across the organisation.

- **Involvement with other research teams**

Requests have been received to translate EDACS into four different languages. A protocol has been developed, with reference to existing processes defined by the developers of the GMFCS, MACS and CFCS, for the translation of EDACS into other languages.

Developers of the translated tool will be required to share the back translation of the document with the author of EDACS; on completion the translated version of EDACS will be available for downloading on the EDACS website.

Other international research teams have expressed an interest in using EDACS; possible collaboration with those teams will be considered.

- **Extend reliability studies**

The data set comparing use of EDACS by parents and SaLTs had significant limitations, as outlined in Section 7.5.3. Further assessment of the reliability of EDACS when used by parents and SaLTs is warranted. Future studies could explore the cognitive processes by

which parents and professionals use classification systems like EDACS. The use of the tool by other health professionals, such as dietitians, nurses and paediatricians in conjunction with parents, should be explored.

- **EDACS for children with CP aged three years or younger**

Continued development of EDACS to describe levels of ability for children with CP under 3 years should be considered, to address limitations as discussed in Section 7.5.7. A research group in Australia is currently engaged in a longitudinal cohort study of oropharyngeal dysphagia in pre-school children with CP, a potential source of information about the development of eating and drinking for children with CP between the ages of 1 and 3 years (Benfer et al. 2012a).

- **Stability of eating and drinking ability as measured by EDACS**

The GMFCS has been used to explore how gross motor function changes in a large population of children with CP (Palisano et al. 2006). The evidence arising from this study allows a level of prediction of gross motor function in that the level of the GMFCS assigned to a young child with CP is likely to remain the same; if change does take place it is likely to be by just one level. An exploration of the stability of eating and drinking ability for a population of children with CP would be possible using EDACS, following a similar study design to that employed by Palisano et al. (2006).

- **Associations between EDACS, respiratory health and nutritional adequacy**

EDACS has been developed as a tool suitable for use both in clinical and research settings. There is the potential to use EDACS to explore associations within populations of people with CP between eating and drinking ability and markers of respiratory health. The concerns regarding “harm” as a consequence of aspiration, as discussed in Section 7.5.4, could be examined using EDACS. The classification system would also be useful to explore associations between eating and drinking ability and measures of nutritional adequacy, health and growth.

- **Version for people with CP**

As detailed in Section 7.5.6, development of a simpler, plain English version of EDACS should be considered.

- **Use of EDACS for other conditions arising in childhood**



It would be necessary to examine the content validity and reliability of EDACS if it was to be used to classify the eating and drinking abilities of individuals with other conditions arising in childhood, associated with limitations to oral skills (e.g. children with Down syndrome, Moebius syndrome, Rett syndrome).

## **7.8 Conclusion**

In conclusion, EDACS offers a new system for classifying eating and drinking ability that is distinct from detailed clinical assessments and guidelines for mealtime management. It provides a means to recognise and distinguish different levels of functional performance to aid communication between people with CP, their parents and different health professionals. It provides a context, describing the whole range of ability, for parents to consider and understand their own child's eating and drinking ability. It has the potential to be used in population studies to explore the stability, progression or regression of eating and drinking ability for individuals with CP, as well as associations with compromised hydration and nutrition, respiratory illness and other health concerns.

EDACS contributes another dimension to the growing family of classification systems describing functional performance within daily life for people with CP. EDACS is designed for use by parents and professionals, and could facilitate working in partnership. It has the potential to enable more robust clinical and population-based research.

EDACS has been shared with a wide audience of potential users, in the context of its development as well as presentation to others at conferences. Presentations of EDACS at international conferences have led to expressions of interest in the system from eminent health professionals and researchers.

The potential of EDACS as a clinical and research tool has been recognised prior to its official publication, as evidenced by the number of requests received to use EDACS in both clinical and research contexts. A number of international research teams have asked for permission to use EDACS in epidemiological studies. Permission and the team's participation in translating EDACS into four different languages has also been sought. On publication of the paper detailing the development of EDACS in a scientific journal (paper submitted in July 2013), the new system will be available to download, without cost, from [www.EDACS.org](http://www.EDACS.org)).



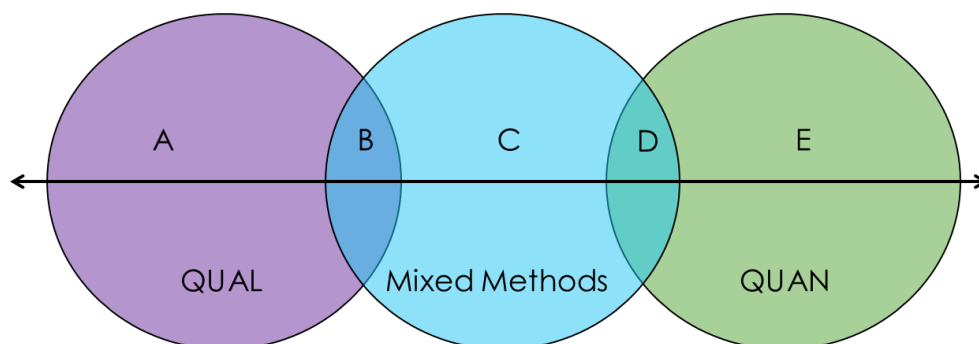
## 8 Chapter 8 - Reflection Chapter

### 8.1 Introduction

In this chapter I describe my self-reflective process whilst conducting the research project to develop the Eating and Drinking Ability Classification System (EDACS). The last three and half years have provided me with many opportunities to change, to challenge deeply held assumptions about myself and the world around me and to adjust to new ways of thinking and being. The material for this chapter comes from the self-reflective journal recorded over three years. I am aware that my capacity to reflect upon and record my internal experience has been greatly enhanced by the opportunity to share it with people around me, in academic, professional and personal settings.

In reading my journal in preparation for this chapter, it became obvious to me that there have been some significant changes as I have developed as a researcher. There are different and inter-connecting themes that emerged as I developed new skill sets, new mind sets, a new eye for small important details and a willingness to be immersed in one thing for an extended period of time. All of the identified themes are unified under the one overarching theme of change. I found it helpful to consider the changing themes in the context of the research paradigm chosen for the study. The pragmatic paradigm views knowledge as being both constructed and based on the reality of the experienced and lived in world where there will inevitably be tensions and conflict between different theories and perspectives. Through the experience of collecting and analysing data in order to construct EDACS, I have been aware of the conflict, discrepancies and tensions both within myself and within the research participants and data collected.

The Mixed Methods research strategy can be represented schematically as a research continuum as outlined by Teddlie and Tashakkori (2009) and shown in Figure 8-1:



**Figure 8-1: QUAL-Mixed Methods-QUAN Research Continuum from Teddlie and Tashakkori (2009 p28)**

The apparent simplicity of the model belies the tensions and contradictions that can occur between two theoretical paradigms (QUAL and QUAN) that do not overlap but are combined within a Mixed Methods study. My experience of mixing QUAL and QUAN methods includes both the constructed, emotional dimension and the emotionally neutral statistical and procedural dimensions. In the following sections, I will explore some of my experiences whilst engaged in what Teddlie and Tashakkori (2009 p74) term the “*naturalistic and process-orientated organism-environment transaction*” by which change comes about.

## **8.2 Transition from clinician to researcher**

In Chapter 3, Section 3.3, I outlined my academic experiences as a trainee speech and language therapist within a positivist tradition, where the values of the researcher and the subject under investigation were excluded as part of the process of study. This contrasted with my more recent academic study at the Tavistock Clinic in London which facilitated my development as an observer both of the emotional lives of others as well as my own. It became obvious to me in the process of observing that I was not a neutral observer of what was happening around me but that my own values interacted with those of the individuals I was observing, always filtering and colouring in some way what I thought I saw and experienced. In my work as a speech and language therapist, I have considerable experience integrating the subjective and objective observations that I make. As a clinician, I experience considerable satisfaction from changes to the subjective experiences of others, either because of change derived from therapeutic interventions or improved understanding as result of my work.

As a novice researcher, I experienced the beginnings of the project to be full of emotions connected to stepping out of my familiar and practised clinical role. I experienced anxieties about what felt to be a challenging, if not impossible task, reinforced by conversations with other speech and language therapy colleagues: one highly respected SaLT at the first Nominal Group commented that if it was possible to create a classification system for eating and drinking for people with CP, someone would have done it already. In contrast I was surprised at my temerity to even embark on such a project and experienced excitement about being able to focus exclusively on a research project for three years. I was acutely aware of the gaps in my research skills and academic knowledge at the QUAN end of the

continuum having spent my Masters studying within a constructivist paradigm; I was also aware of unknown terminology and processes associated with QUAL research methods.

As a new PhD student at the University of Brighton, I was required to attend a series of lectures and workshops contributing to my development as a researcher. One of the workshops, led by a senior lecturer from the Education department, captures the essence of my experience. The lecturer used a poem from an article by McCrary Sullivan (2000) to describe the phenomenon of changing perception in the context of research, as outlined in Chapter 3, Section 3.3. My experience of learning to give attention to the complexities of surface detail and to attend to what lies beneath those surfaces, has shown me never to assume “*that what one sees in the moment is what one will always see*” (McCrary Sullivan 2000 p221). This simple truth allowed me to make many revisions of the EDACS draft, to study and revise the content repeatedly, to let the feelings of frustration or resentment fall away as I noticed something I had previously missed. I learnt the patience of research which McCrary Sullivan closely links to the aesthetic vision of the artist that pays attention to detail, just as her mother did as the researcher “*observing, noticing, discovering patterns, making sense*” (McCrary Sullivan p221).

It has been my experience throughout the project that my perceptions and understanding of all things related to the classification system have changed as the project has progressed. Comments and alternative viewpoints expressed by members of the Project Team and participants in the research process have not always made immediate sense to me and I have not always been able to hear what has been said. I noted in my journal that when I listened back to the audio recording and the written transcript of the first Nominal group held in London that it showed me how incomplete my perceptions of the group had been. It has been important to make use of all forms of data throughout the study in order to broaden and clarify my perceptions.

In working closely with experienced academic researchers within my PhD supervisory team and the EDACS Project Team, I have had many opportunities to learn, explore ideas and receive constructive feedback and criticism. The academic supervisors and Project Team members would offer guidance and critical review of the ideas and materials I presented, often with suggestions of other areas of fruitful study. In the early stages of the project, I sometimes found the experience of being the sole person driving the project forward difficult to manage. As I experienced success in recruiting participants, running the Nominal Group Process (NGP), collecting and analysing data, and revising the EDACS

draft I began to take ownership of the project. I began to really enjoy the opportunities to discuss the project with involved others and look in detail at unexplored dimensions.

A significant change in my subjective experience of the world that allowed that transition was the letting go of my anxiety about receiving criticism from others. I generated considerable internal tension early on in the project in my belief that each new draft of EDACS would receive few requests for change from NGP participants because I had given so much time and attention to it. In the first few groups, my personal motivation for giving intense focus to each new EDACS draft was to avoid critical feedback from others in the NGP. It quickly became apparent that this was not going to be possible and most certainly was not desirable. With hindsight it demonstrated my very limited view at the time of the process of validating the content of EDACS. I was very closely identified with the fledgling ideas of the new EDACS draft and to some extent experienced critical review as a direct measure of my personal worth.

I wrote extensively in the journal after the Exeter NGP in reaction to my subjective experience of the group which was that my ideas had been completely shredded, giving rise to feelings of anger and defensiveness. The clear structure of the NGP, contained my subjective experience of running the group although I remember feeling considerable discomfort at the conflict between my emotions and what I actually said in leading the group. As I reassured NGP participants that it was fine to criticise the EDACS draft and that was the purpose of the meeting, I was aware of strong feelings that were completely at odds with those statements. Whilst I was able to state that the content of EDACS needed to be refined with input from people who may potentially use it in the future, that EDACS was not **my** baby, I was so frustrated and angry after the group that I was unable to look at the EDACS draft or the data collected until my emotions had calmed down. With a clearer mind, I was able to see that the criticisms made had rarely been directed at the ideas expressed but the inconsistent use of language, although my intense reaction highlighted the need for closer examination of my relationship to the EDACS draft and my response to criticism in general.

It became apparent to me that I needed to examine my resistance to allowing space for feedback in general in many situations, not just in relation to EDACS. By not allowing space for criticism, I was in effect blocking any kind of feedback and limiting my capacity to search or research. With the inclusion of suggestions from the Exeter group, the realisation emerged that the document was considerably improved through the insights of others. My relationship to the project began to shift along the research continuum,

becoming more dispassionate and open to outside possibilities other than those occurring within the confines of my mind. By being part of the research process, my subjective experience and relationship to critical feedback has changed. I noted in the journal after the Newcastle NGP that at times the group felt rather like a pack of dogs pulling apart a new toy as they criticised EDACS but that I was able to remain more distant from the process. Although I clearly felt perturbed by the strength of opinion being expressed, I was more able to stand by and witness the discussion. I commented in the journal that I did not feel personally under attack although acknowledged that I would have found that NGP difficult to manage if it had occurred earlier on in the series of groups.

By allowing space for feedback without interpreting views expressed as a personal attack, I experienced a reduction in internal tension when I engaged in the various learning opportunities available at the university. For example, I was able to enrol on a statistics for health research course and stay engaged with the process of learning in spite of finding it extremely challenging. Although I struggled to conceptualise what some of the statistical methods showed, I was able to work my way through what felt like a very dark forest with the help of key texts and course tutors. It was a revelation to me that on close examination of some peer reviewed papers that incomplete understanding of the concepts of the statistical methods used was apparent by the authors of the papers as well as members of the health statistics group. I was not alone in my struggle to grasp the concepts.

With an increasing confidence in my capacity to learn, investigate and find my way through each new set of challenges with the help of the research literature and people around me, I have settled in to the new role of researcher. My clinical work has benefitted too from a research mind set. The last four years has been filled with the experience of sharing many different pieces of work with others, including written submissions for articles, PhD thesis chapters, documents relating to EDACS, conference presentations and posters, and receiving critical feedback. It is a process I have learnt to trust and actively enjoy. To return to McCrary Sullivan's analogy, I now really enjoy the experience of noticing more as I peer in to rock pools with others. I no longer perceive the need for help, guidance and insights from others as a reflection of my lack of capacity. I have developed an increased capacity to keep looking, certain in the knowledge that there is always more to be seen.

### 8.3 Development of EDACS

In the previous section, I recounted my changing emotional and cognitive experiences of receiving feedback within the NGP. The EDACS document has been at the centre of the research project and my relationship to the ideas expressed within it have changed considerably.

My relationship to the embryonic ideas for EDACS was undeveloped. Rather like an unborn child, I was unaware of many of its attributes and considered only future possibilities. The EDACS draft filled one page of A4 paper (see Figure 5-2, Section 5.2.1) and I was able to speak about the project very briefly and only in relation to other proven and well developed ideas such the Gross Motor Function Classification System (GMFCS Palisano et al. 1997). I remember feeling very exposed as I placed EDACSv7 on the tables in front of the first NGP expert participants. In my journal account of the first NGP, I noted my satisfaction at witnessing the intense scrutiny being applied to the document by expert participants. I felt slightly apologetic about presenting EDACS to them, aware of the considerable skills and reputations of the people in the room who had agreed to participate.

As I analysed the data and made changes to EDACS, the document expanded considerably as did my emotional investment in the tool. I described in the previous section the fruitful investigation of my emotional reactions to criticism, associated with identification with EDACS as “my baby”. With internal processing and better understanding of my emotional world, together with continued scrutiny of EDACS content by others, I began to view EDACS more dispassionately. By including comments and suggestions from others, EDACS became a container for expert opinion collected and refined in the NGP.

After the seventh and final NGP, I was left with feelings of dissatisfaction that EDACS had not received a ringing endorsement from the group, but that similar concerns had been voiced again about layout, inconsistent use of language, and lack of clarity about purpose as well as concern about the developmental stages of eating and drinking ability represented within age bands. Supervision and a Project Team meeting helped me with the process of seeing the contents of the EDACS document more clearly, encouraging me to trim the document considerably. I remember feeling resistance to taking the age bands out of EDACS, having spent considerable mental effort in delineating them; the grief about the radical trimming passed quickly with the creation of the new leaner EDACS draft.

My capacity to view EDACS at more of an emotional distance was enhanced by the Delphi Survey (DS) where numerous opinions were provided by international experts. It was



exciting to receive comments and suggestions for change. The quantified measures of collective opinion provided by the Likert scales served to show me the extent to which EDACS had the potential to work as a classification system. In perusing the narrative data, it was very easy for me to become caught by opinions expressing disagreement. Even though only one participant expressed strong disagreement with many of the statements about the content of EDACS, it was helpful to notice how much time I spent considering that person's viewpoint and justifying my own. A work colleague helped me realise that the same pattern of resistance to criticism was at work in my reactions to the extensive comments made by this DS participant; the colleague pointed out the less critical aspects to the participant's responses that I had overlooked. I considered that an individual response to this DS participant was necessary because of the questions posed within her extensive contribution and the important points raised. It was helpful to consider each of the participant's comments in detail in my reply, in order to diffuse my emotional response to criticism. Inviting comments from others to my reply also helped with this process.

I experienced a feeling of great satisfaction at the successful completion of the inter-observer reliability studies. The numerical assessment of the reliability of EDACS, when used by different observers, had a precise value that could be compared to quality standards accepted by the wider scientific community in relation to health measurement scales (Terwee et al. 2007). I was relieved at the strength of this statistical marker, whilst being aware that its strength was determined by the detailed examination of narrative data as the content of EDACS was defined. At the other end of the research continuum, I found the comments received by people who used EDACS to be satisfying: several parents said they were able to recognise their children in the different EDACS levels; one parent commented that it had helped her obtain a better understanding of her child's eating and drinking; SaLT thought that it was easy to use and most expressed a wish to use it in their clinical work.

I was surprised that after so many revisions and so much scrutiny, there were still tiny inconsistencies in the use of punctuation and language in the final version of EDACS that was sent to the graphic designer. There was still more to be seen and changed in EDACS when viewed through the expert eyes of the designer.

#### **8.4 Holding clear boundaries on the research continuum**

The Mixed Methods circle in Figure 8-1 occupies a central position on the research continuum. The letters A to E represent the different positions that can be taken on the

research continuum when mixing QUAL and QUAN methods. The letter B, for example, represents research which is primarily QUAL in orientation with a QUAN component, whilst the letter E represent research which is exclusively QUAN in orientation. As stated in Chapter 3 (Section 3.5.4), EDACS was developed and tested using both QUAL and QUAN methods, falling within zone C of Figure 8-1. However, the process of distilling the observable facts of eating and drinking functional ability from the values inclined the study towards the QUAN end of zone C (see Section 3.5.3).

I needed to be very clear about the boundaries of the Mixed Methods circle within the development of EDACS. In inviting comment and engaging with participants in each of the stages of the project, there was always the possibility of moving beyond the remit of the classification system. As a clinician, my orientation is often the subjective experiences of the children and families I work with. In the development of EDACS, my orientation needed to be different. I remember occasions on which people with CP, fellow health professionals and parents wanted EDACS to include an emotional dimension associated with eating and drinking performance: participants commented on the importance of enjoyment, social embarrassment around eating, fear and anxieties as well as food refusal experienced by people with CP at mealtimes. As a clinician, I would consider this information to be clinically relevant in relation to decision making around mealtime practices. In defining the central task of the classification of eating and drinking performance for people with CP, it was important to set to one side personal experiences that were not specifically associated with limitations to eating and drinking ability. Individuals that I have worked with who have no limitations to the ability to bite, chew and swallow may have little enjoyment in eating; others, able only to have the tiniest of tastes of food because of compromised swallowing, enjoy these limited experiences. Some young people with CP reported no social embarrassment at eating in public places whilst another person deliberately avoided eating in public because of embarrassment about messy eating.

At one NGP, a parent who was struggling with her child's emotional and behavioural reactions to eating and drinking, found it upsetting that what she considered to be important was not represented within the EDACS levels. I was aware of how dissatisfied she felt with EDACS within the NGP which she demonstrated in the group discussion and by choosing not to contribute to the voting process. I experienced considerable tension as the roles of clinician and researcher collided. As a clinician, I would have explored the parent's concerns; as a researcher I held the boundaries of the NGP. The Project Team member, present at the group, was able to help me understand what my role was. I

remained sensitive to the parent's unmet concerns which I acknowledged in a thank you card. The emotional and behavioural dimensions were acknowledged within the list of additional features that needed consideration in the "Background" section of EDACS (see a Section 6.3.2), whilst remaining clear about the key features of eating and drinking represented within the classification system.

I experienced a strong pull towards the QUAN end of the continuum as the DS was being constructed. There was the possibility of following the survey structure set up by Hidecker et al. (2011) in the development of the CFCS, where agreement was indicated by "yes" or "no" rather than a Likert scale; the questions asked by Hidecker et al. pertained to the clarity of expression of ideas used within the CFCS rather than an investigation of the levels of agreement for the ideas themselves. The simpler survey design was appealing in that the desired levels of agreement looked more attainable than in the more detailed focus of the DS used by the developers of the GMFCS (Palisano et al. 1997). By holding the central position on the research continuum, with encouragement from one of my academic supervisors skilled in survey design and statistical methods, I considered it necessary for participants of the DS to evaluate EDACS statement by statement using both Likert scales and free text. The QUAL dimension of the Likert scale contributed to an impression of the extent of disagreement, and therefore the likelihood of change of opinion if the EDACS draft was changed.

I was impressed by the strength of the research methods used to consult with participants, each sitting comfortably in the middle of the research continuum. The DS and NGP facilitated focussed attention on the EDACS document. I struggled initially in the application of the structured NGP, when I required participants to study EDACS in silence for an hour and feedback their views in a prescribed format, when I am more familiar with looser discussions around particular themes. Participants often joked about the experience feeling rather like exam conditions. It was a helpful skill to learn to direct, contain and facilitate the collection of group opinion. I also found the detailed deliberations concerning the setting up of the DS to be extremely helpful.

The need to hold clear boundaries in the middle of the research continuum within the inter-observer reliability studies was also apparent to me. I was aware that I needed to be very focussed and precise as I collected data in order to help participants carry out the task they were required to do. I first collected inter-observer data from the clinical team of SaLTs at my place of work. I remarked in the journal that the familiarity between work colleagues meant that some of them were not as focussed on the task in hand as they needed to be and

that I needed to be clearer about what was required. It was at that point that I realised I needed to use the prompt to SaLT colleagues that the information I was collecting was not a test of their memories but rather a summation of their knowledge about each child's eating and drinking taken from their memories and case notes. I also needed to be alert to the possibility of human error in the QUAN data collection and analysis.

## **8.5 Summary**

It is challenging to summarise my experience of this absorbing journey as a fledgling researcher. The extended periods of time spent in isolation, studying and writing, contrast greatly with the high social demands of presenting EDACS in face to face settings, such as in the NGP, reliability studies and at conferences. The process of "noticing" more (Mason 2002) has been incredibly rewarding, whether that be at the level of data analysis or at the level of insight into my own emotional and mental processes. The staged approach to the development of EDACS has mirrored my own staged development. I accepted each new challenge with a mixture of excitement and trepidation, always uncertain about the final outcome.

I am encouraged by the considerable interest in EDACS even before its official publication. The interest provides an indication of the extent to which I have captured an "idea out of the great din of experience" (Scheele 1975 p40) and the potential EDACS has as a new social convention for referring to eating and drinking ability of people with CP.

The ability to take food and fluid into the body is essential for survival; limitations to this ability can be associated with premature and preventable death. It is my hope that EDACS will be used as a shared framework to think clearly about the eating and drinking needs of people with cerebral palsy, by those closely involved in their care and by those conducting research in a wider context to ameliorate the quality of their lives.

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<b>APPENDIX 1 – ETHICS PERMISSIONS:</b>	<b>PAGE</b>
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## National Research Ethics Service

### Brighton West Research Ethics Committee

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16 December 2009

Mrs Diane Sellers  
Speech and Language Therapist,  
Clinical Lead Eating and Drinking Difficulties  
South Downs Health NHS Trust  
Chailey Heritage Clinical Services  
North Chailey, Nr Lewes  
East Sussex  
BN8 4JN

Dear Mrs Sellers

**Study Title:** To Develop a Functional Classification System of Eating and Drinking Abilities for Children and Young People with Cerebral Palsy.  
**REC reference number:** 09/H1111/66  
**Protocol number:** 1

The Research Ethics Committee reviewed the above application at the meeting held on 14 December 2009. Thank you for attending the meeting.

#### Ethical opinion

The Committee thought that your research aim was very relevant, as eating and drinking constituted a major undertaking for children with cerebral palsy and there was no scoring system in existence.

The Committee thought that a standardised method for understanding the various levels of disability in feeding would be advantageous. They felt that the risks of the scheme were that it dealt with a sensitive topic, however, they agreed with you that this was offset by participants wishing to take an interest in the project.

The Committee commented that you were not seeking consent from the child, only from the speech and language therapist. However, they are assured with your explanation that the child's information would be known to the therapist and there would be no additional interaction between the therapist and the child.

The "functional eating and drinking scale" was very comprehensive and understandable and the Committee questioned whether this in effect answered the research aim and therefore you had done ninety percent of the work already. However, they understand from the explanation you gave at the meeting that the project was a novel area for participants to think about, there would be three years of discussion and development, and therefore the scale would most likely change.

This Research Ethics Committee is an advisory committee to South East Coast Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England*



The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Written clarification requested**

There were a couple of amendments required that the Committee seek written clarification on as below:

1. The Committee thought that there was an error between level 4 and 5 and the yes and no arrows. It was initially thought these were the wrong way round. However you explained the meaning behind the yes and no arrows and the committee requested that this be confirmed in writing.
2. The Committee noted that if a participant chose not to be recorded in the group discussion, then they would effectively be self excluding themselves from the group discussion as a whole. Therefore the invitations to participate in group discussion, consent and assent forms needed to be amended to reflect this issue.
3. The consent forms should include the standard paragraph below. It may be adapted accordingly in terms of whether reference to medical records apply and whether the consent is an "assent form" etc. This is a requirement from NRES as they have received complaints from NHS R&D and the MHRA that where this paragraph has been omitted from consent forms it precludes them from inspection at research audits/GCP inspections.

"I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from (company name), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records"

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC application	2	16 November 2009
Protocol	1	27 August 2009
Investigator CV		27 August 2009
Participant Information Sheet: draft classification system	1	11 November 2009
Participant Information Sheet: project outline	1	12 November 2009
Participant Information Sheet: project outline in symbols	1	13 November 2009
Participant Consent Form: nominal groups	1	12 November 2009
Letter of invitation to participant (nominal group)	1	12 November 2009
Letter of invitation to participant - delphi group	1	12 November 2009
Letter of invitation to participant - nominal group children	1	12 November 2009
Participant Consent Form: parents nominal groups	1	12 November 2009
Participant Consent Form: children assent form	1	12 November 2009
Interview Schedules/Topic Guides (nominal group and inter-rater reliability studies)	1	12 November 2009
Letter re. Research for Patient Benefit funding		23 November 2009

### **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### **After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of

changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

09/H1111/66

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

  
Dr Andrew Nayagam  
Chair

Email: [michelle.roman@bhcpct.nhs.uk](mailto:michelle.roman@bhcpct.nhs.uk)

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments  
"After ethical review – guidance for researchers"*

Copy to: *Ms Helen Evans  
[Manager of R&D office for NHS care organisation at lead site]*



**Brighton West Research Ethics Committee**

**Attendance at Committee meeting on 14 December 2009**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Jill Adams	GP	Yes	
Dr Duncan Angus	Consultant Psychiatrist	Yes	
Dr John Bull	Consultant Physician	Yes	
Prof. David Candy	Paediatric Gastroenterologist	Yes	
Mr Gerard Cronin	Lay Member (Business Development Manager)	Yes	
Mr Dipak Duggal	Chief Pharmacist	Yes	
Mrs Janie Foote	Lay Member (publishing consultant)	No	
Mr Stuart Heatherington	Lay Member/Statistician (Chartered Mathematician)	Yes	
Dr Andrew Nayagam	Consultant in GU/HIV Medicine	Yes	
Dr Jeremy Quiney	Consultant Chemical Pathologist	Yes	
Ms Michelle Roman	Committee Co-ordinator	Yes	
Dr Pauline Shute	Consultant Community Paediatrician	Yes	
Dr Richard Venn	Consultant in Anaesthesia and Intensive Csre	Yes	
Mrs Susan Waton	Lay Member (School Librarian)	Yes	



## National Research Ethics Service

### Brighton West Research Ethics Committee

NHS Brighton & Hove  
1st Floor, Prestamex House  
171-173 Preston Road  
Brighton  
East Sussex  
BN1 6AG

Telephone: 01273 545371  
Facsimile: 01273 545372

25 January 2010

Mrs Diane Sellers  
Speech and Language Therapist, Clinical Lead Eating and Drinking Difficulties  
South Downs Health NHS Trust  
Speech and Language Therapy,  
Chailey Heritage Clinical Services  
North Chailey, Nr Lewes East Sussex  
BN8 4JN

Dear Mrs Sellers

**Full title of study:** To Develop a Functional Classification System of Eating and Drinking Abilities for Children and Young People with Cerebral Palsy.  
**REC reference number:** 09/H1111/66  
**Protocol number:** 1

Thank you for your letter of 14<sup>th</sup> January 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 14 December 2009. Please note these documents are for information only and have not been reviewed by the committee.

#### Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Information for children with parents consent form	2	13 January 2010
Covering Letter		
Children's assent form	2	13 January 2010
Invitation to nominal group and consent	2	04 January 2010
Parent consent form	2	04 January 2010
Functional Eating and Drinking Classification	2nd draft	10 January 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**09/H1111/66**

**Please quote this number on all correspondence**

Yours sincerely

This Research Ethics Committee is an advisory committee to South East Coast Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England



**Ms Michelle Roman**  
**Committee Co-ordinator**

E-mail: michelle.roman@bhcpct.nhs.uk

Copy to: *Ms Helen Evans,*  
*[R&D office for NHS care organisation at lead site]*

Research Consortium Office  
 Worthing Hospital  
 Lyndhurst Road  
 Worthing  
 West Sussex  
 BN11 2DH

Tel: 01903 285027  
 Fax: 01903 209884  
 www.sxrc.nhs.uk

Ms Diane Sellers  
 Speech and Language Therapist: Clinical Lead  
 Speech and Language Therapy  
 Chailey Heritage Clinical Services  
 Beggars Wood Road  
 North Chailey  
 BN8 4JN

05/05/2010

Dear Ms Sellers,

**Our ID: CSP 28187**

**TITLE: To Develop a Functional Classification System of Eating and Drinking Abilities for Children and Young People with Cerebral Palsy.**

Thank you for your application to the Sussex NHS Research Consortium for research governance approval of the above named study.

I am pleased to inform you that the study has been approved, and so may proceed. This approval is valid in the following Organisations:

- **South Downs Health NHS Trust – Diane Sellers**

The final list of documents reviewed and approved is as follows:

FILENAME	DOCUMENT CATEGORY	TYPE	VERSION
TP CV.pdf	Investigator's CV	CV	Terry Pountney CV
18144 - Mrs Diane Sellers.pdf	Funding agreement	Funding	NIHR funding agreement letter
DS IRAS CV_Document[3].pdf	Investigator's CV	CV	SOUND CI CV
Project Protocol IRAS 27.8.09.pdf	Protocol	Other documents	SOUND Protocol v1
Rec Formcopy submitted 16.11.09.pdf	Application	Ethics	REC form signed by sponsor
Topic Guide V1.pdf	Questionnaire/Survey tool	Other documents	SOUND
Project Outline V1.pdf	Other study-related documentation or correspondence	Other documents	SOUND
Parent Consent Form V2.pdf	Patient Informed Consent Form including biological and quality of life consent forms	Patient Related	SOUND
Invitation to questionnaire V2.pdf	Letter to Patient	Patient Related	SOUND





Invitation to nominal group and consent V2.pdf	Patient information sheet and Consent Form (combined)	Patient Related	SOUND
Children's Information V2.pdf	Patient Information Sheet	Patient Related	SOUND
Draft Framework V2.pdf	Other study-related documentation or correspondence	Other documents	SOUND
Children and Young People's Assent Form V2.pdf	Patient Informed Consent Form including biological and quality of life consent forms	Patient Related	SOUND
REC confirmation of compliance with approval conditions letter.pdf	Acknowledgement	Ethics	SOUND
symbol project outline nominal group 13.11.09.pdf	Other study-related documentation or correspondence	Other documents	
Ethics letter 16Dec2009.pdf	Approval letter subject to specific conditions	Ethics	
Signed SSI Form.pdf	SSI Form	R&D (Local)	SOUND
27Jan10 Classification System of Eating and Drinking Abilities for Children and Young People with Ce	Other study-related documentation or correspondence	Other documents	SOUND
NhsSsiForm.pdf	Other study-related documentation or correspondence	Other documents	SOUND
21Jan10 NIHR CSP - Ref. 28187 - SSI Form Amendment Required.pdf	Other study-related documentation or correspondence	Other documents	SOUND
NIHR CSP - Ref. 28187 - RD Form Confirmation.msg	Acknowledgement	R&D (Local)	
NhsRdForm.pdf	Application	R&D (Local)	
NIHR CSP - Ref. 28187 - RD Form Amendment Required.msg	Rejection	R&D (Local)	
PortfolioAdoptionForm.pdf	[NOT SET]	[NOT SET]	

Your research governance approval is valid providing you comply with the conditions set out below:

1. You commence your research within one year of the date of this letter. If you do not begin your work within this time, you will be required to resubmit your application.
2. You notify the Consortium Office should you deviate or make changes to the approved documents.
3. You alert the Consortium Office by contacting me, if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction.
4. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of research governance approval.
5. You comply fully with the Department of Health Research Governance Framework, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.



6. You ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act. Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Good luck with your work.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'E. Peskett', with a stylized flourish at the end.

**Miss Emma Peskett**  
Research Governance Officer

Email: [emma.peskett@wshh.nhs.uk](mailto:emma.peskett@wshh.nhs.uk)  
Tel: 01903 285222 Ext 4781  
Fax: 01903 209884

cc: Lorraine Southby, R&D Manager, South Downs Health NHS Trust



**NRES Committee South East Coast - Brighton and Sussex**

Charing Cross Hospital REC Centre  
Room 4W/12, 4th Floor  
Charing Cross Hospital  
Fulham Palace Road, London  
W6 8RF

Tel: 020 33 110106  
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10 November 2011

Mrs Diane Sellers  
Speech and Language Therapist, Clinical Lead Eating and Drinking Difficulties  
South Downs Health NHS Trust  
Speech and Language Therapy,  
Chailey Heritage Clinical Services  
North Chailey, Nr Lewes East Sussex  
BN8 4JN

Dear Mrs Sellers

**Study title:** To Develop a Functional Classification System of Eating and Drinking Abilities for Children and Young People with Cerebral Palsy.  
**REC reference:** 09/H1111/66  
**Amendment number:** Am01  
**Amendment date:** 21 October 2011

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

Members of the sub-committee did not raise objections to the amendments made to the invitation letter on ethical grounds

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Invitation to participate in the Delphi Survey	2	20 October 2011
Project Outline	5	20 October 2011
Notice of Substantial Amendment (non-CTIMPs)	Am01	21 October 2011
Covering Letter		24 October 2011

**Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an Advisory Committee to South East Coast Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>09/H1111/66:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely



*pp* **Dr Simon Walton**  
**Chair**

E-mail: [ncherodian@nhs.net](mailto:ncherodian@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to:* Helen Evans  
Research Governance Manager  
Sussex NHS Research Consortium  
Research & Innovation Department  
Western Sussex Hospitals NHS Trust  
Worthing Hospital  
Lyndhurst Road, Worthing  
BN11 2DH  
(Sponsor and on behalf of lead site)

This Research Ethics Committee is an Advisory Committee to South East Coast Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

**NRES Committee South East Coast - Brighton and Sussex**

**Attendance at Sub-Committee of the REC meeting on 10 November 2011**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr John Bull	Consultant Physician (retired)	Expert
Mr Stuart Heatherington	Mathematician (retired)	Lay Plus

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Nischinth Cherodian	Co-ordinator

This Research Ethics Committee is an Advisory Committee to South East Coast Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England



## Health Research Authority

NRES Committee South East Coast - Brighton and Sussex

Health Research Authority  
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80 London Road  
London  
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14 August 2012

Mrs Diane Sellers  
Speech and Language Therapist, Clinical Lead Eating and Drinking Difficulties  
South Downs Health NHS Trust  
Speech and Language Therapy,  
Chailey Heritage Clinical Services  
North Chailey, Nr Lewes East Sussex  
BN8 4JN

Dear Mrs Sellers

**Study title:** To Develop a Functional Classification System of Eating and Drinking Abilities for Children and Young People with Cerebral Palsy.  
**REC reference:** 09/H1111/66  
**Amendment number:** 3 Modified  
**Amendment date:** 30 July 2012

Thank you for submitting the above amendment, which was received on 09 August 2012. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 17/07/2012 refers).

The modified amendment has been considered on behalf of the Committee by the Vice-Chair who chaired the meeting.

### Ethical opinion

The Chair under delegated authority was satisfied that you had responded adequately to the issues raised in the amendment

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved are:

Document	Version	Date
Participant Consent Form: Parent	2	30 July 2012
Participant Information Sheet: Patent	3	30 July 2012

Protocol	3	30 July 2012
Modified Amendment	3 Modified	30 July 2012
Covering Letter		14 July 2012
Pathway 2 Dysphagia Trained SLT	2	30 July 2012
Pathway 1 Dysphagia Trained SLT	2	30 July 2012
Proposed amendment to IRR study	8 modified	30 July 2012
Eating and drinking ability classification system	2	
Invitation letter to parents for inter rater reliability study	3	30 July 2012
Questionnaire: GMFCS Family report questionnaire 6 to 12 years	1	30 July 2012
Questionnaire: for patents for inter rater reliability study	1	06 June 2012
Questionnaire: GMFCS Parent report questionnaire 12 to 18 years	1	30 July 2012

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H1111/66:	Please quote this number on all correspondence
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Yours sincerely

PP 

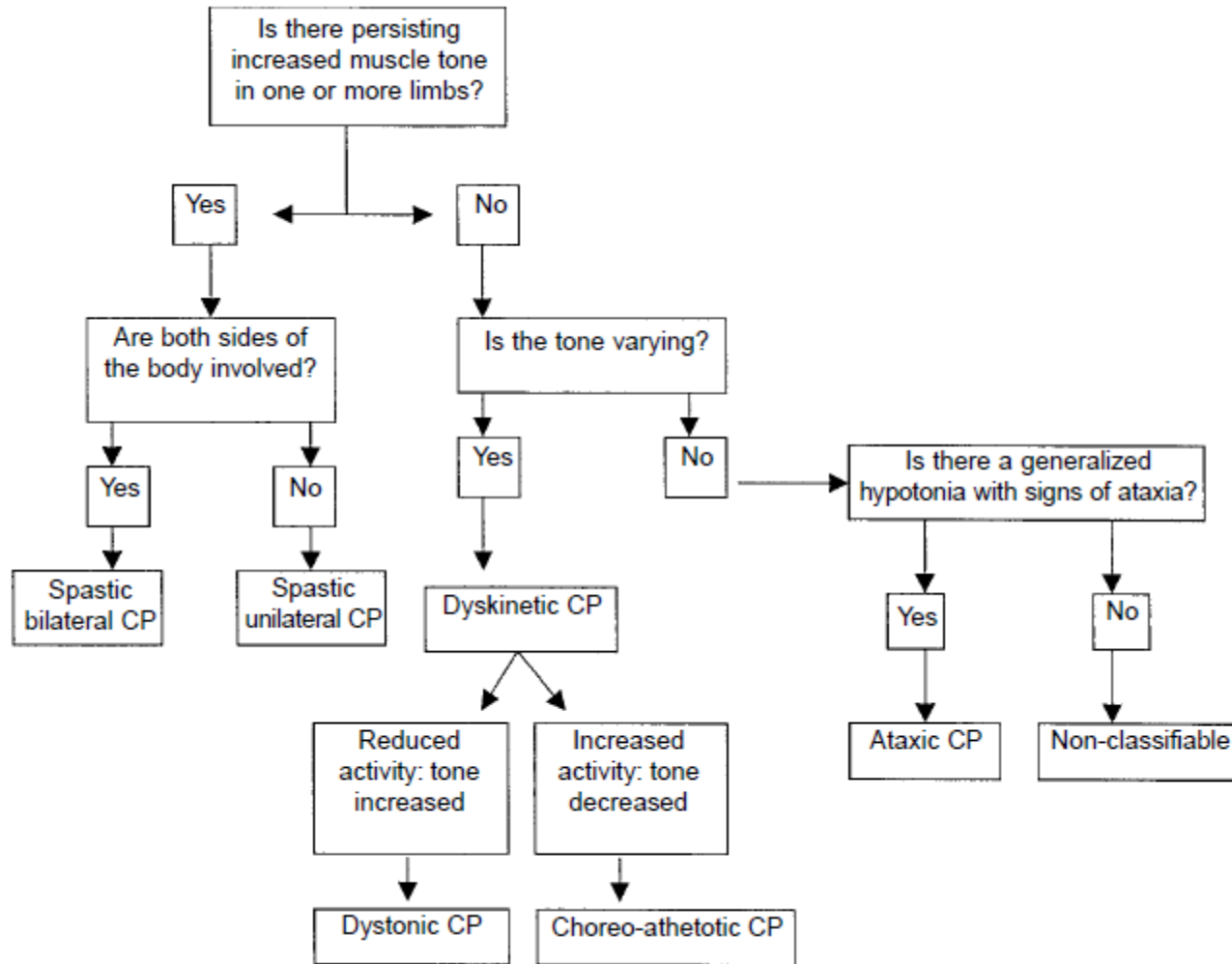
**Dr John Bull**  
Chair

E-mail: [NRESCCommittee.SECOast-BrightonandSussex@nhs.net](mailto:NRESCCommittee.SECOast-BrightonandSussex@nhs.net)

Copy to: Sarah, Sussex Community NHS Trust

Ms Helen Evans

<b>APPENDIX 2 – DEMOGRAPHIC INFORMATION:</b>	<b>PAGE</b>
Survey of Cerebral Palsy in Europe – Hierarchical classification tree of CP Subtypes from SCPE (2000).....	262
GMFCS Expanded and Revised version.....	263



SCPE Hierarchical classification tree of CP Subtypes from SCPE (2000) p821





CanChild Centre for Childhood Disability Research  
Institute for Applied Health Sciences, McMaster University,  
1400 Main Street West, Room 408, Hamilton, ON, Canada L8S 1C7  
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## **GMFCS – E & R**

# **Gross Motor Function Classification System**

## **Expanded and Revised**

GMFCS - E & R © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007  
*CanChild Centre for Childhood Disability Research, McMaster University*

GMFCS © Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997  
*CanChild Centre for Childhood Disability Research, McMaster University*  
(Reference: Dev Med Child Neurol 1997;39:214-223)

### **INTRODUCTION & USER INSTRUCTIONS**

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to 18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

## OPERATIONAL DEFINITIONS

**Body support walker** – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

**Hand-held mobility device** – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

**Physical assistance** – Another person manually assists the child/youth to move.

**Powered mobility** – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

**Self-propels manual wheelchair** – The child/youth actively uses arms and hands or feet to propel the wheels and move.

**Transported** – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

**Walks** – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

**Wheeled mobility** – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

## GENERAL HEADINGS FOR EACH LEVEL

<b>LEVEL I</b>	-	Walks without Limitations
<b>LEVEL II</b>	-	Walks with Limitations
<b>LEVEL III</b>	-	Walks Using a Hand-Held Mobility Device
<b>LEVEL IV</b>	-	Self-Mobility with Limitations; May Use Powered Mobility
<b>LEVEL V</b>	-	Transported in a Manual Wheelchair

## DISTINCTIONS BETWEEN LEVELS

**Distinctions Between Levels I and II** - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

**Distinctions Between Levels II and III** - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

**Distinctions Between Levels III and IV** - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

**Distinctions Between Levels IV and V** - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.

## Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

### BEFORE 2<sup>ND</sup> BIRTHDAY

**LEVEL I:** Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

**LEVEL II:** Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

**LEVEL III:** Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

**LEVEL IV:** Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

**LEVEL V:** Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

### BETWEEN 2<sup>ND</sup> AND 4<sup>TH</sup> BIRTHDAY

**LEVEL I:** Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

**LEVEL II:** Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

**LEVEL III:** Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

**LEVEL IV:** Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

**LEVEL V:** Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

### BETWEEN 4<sup>TH</sup> AND 6<sup>TH</sup> BIRTHDAY

**LEVEL I:** Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

**LEVEL II:** Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

**LEVEL III:** Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

**LEVEL IV:** Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

**LEVEL V:** Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations. © Palisano, Rosenbaum, Bartlett & Livingston, 2007 Page 3 of 4



## BETWEEN 6<sup>TH</sup> AND 12<sup>TH</sup> BIRTHDAY

**Level I:** Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

**Level II:** Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

**Level III:** Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

**Level IV:** Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

**Level V:** Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

## BETWEEN 12<sup>TH</sup> AND 18<sup>TH</sup> BIRTHDAY

**Level I:** Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

**Level II:** Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a hand-held mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

**Level III:** Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

**Level IV:** Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

**Level V:** Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

© Palisano, Rosenbaum, Bartlett & Livingston, 2007 Page 4 of 4

**APPENDIX 3 – PROJECT OUTLINES:**

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Project Outline – Symbol Version..... 270

**Project Outline:**

**Eating and Drinking Ability Classification System for Children with Cerebral Palsy**

Diane Sellers, Research Speech and Language Therapist or Sarah Ford, Research Assistant  
Chailey Heritage Clinical Services  
Beggars Wood Road North Chailey Lewes BN8 4JN  
Tel: +44 1825 724720 [diane.sellers@nhs.net](mailto:diane.sellers@nhs.net) or [sarah.ford5@nhs.net](mailto:sarah.ford5@nhs.net)

Children with cerebral palsy (CP) cannot use the range of physical movement available to most of us. Difficulties may occur in the development of walking, speech and hand function. The movements involved in biting, chewing and swallowing are frequently affected. Children with CP who cannot move their mouth muscles to eat and drink efficiently, are likely to have problems eating enough food to grow and to stay healthy. Some of them will have problems with frequent chest infections because particles of food or drink enter their lungs when they swallow. These difficulties continue throughout their lives.

Currently there is no agreement about how to rate the severity of a child's eating and drinking difficulty, i.e. the child's ability to move muscles to bite, chew and swallow. The words "severe", "moderate", and "mild" are all used without an agreed definition. For some researchers, a "severe" difficulty is when a child cannot feed themselves. Others have mistakenly assumed that only children with more severe general movement difficulties have problems with eating and drinking.

Other scales have already been developed to rate a child's ability to walk and move (Gross Motor Function Classification System), and to use their hands (Manual Ability Classification System). These are both extremely useful and are increasingly widely used. We have received funding from the NIHR (Research for Patient Benefit) to develop an eating and drinking classification system for children with CP by consulting with parents, children and experts both nationally and internationally.

Once developed, the system will be tested to see how easily and reliably it can be used. There are many benefits to children and families within the NHS and other healthcare systems that would come from such a rating system. They include:

- Increasing awareness of the mouth movements necessary for efficient and safe eating and drinking and distinguishing them from other types of movement.
- Enabling clear and efficient communication about a child's eating and drinking skills between professionals (e.g. children can fear hospital stays because of misunderstandings that have occurred at mealtimes).
- Providing a method by which limited resources can be directed (e.g. dietitian's time) to those children with the most severe difficulties, highest risk of malnutrition and therefore the greatest need
- Increasing awareness and thereby reducing the risks to health whenever a child eats or drinks (e.g. particles of food and drink entering the lungs whenever a child eats, choking)
- Contributing to the identification of treatment needs of children with CP (alternative feeding methods, intensive movement therapy to improve skills etc)

- Providing a means to communicate clearly about appropriate formulation of prescribed medication – e.g. not fluids or cannot swallow tablets etc
- Enable the prediction of levels training and experience needed by care staff
- Facilitating research into this area

There are four distinct phases of the project which will take place over approximately 3 years:

- Construct a draft of the initial eating and drinking classification system
- Discuss the draft with a group of invited experts (Speech and Language Therapists, Parents, Young People with CP, Nurses, Paediatricians, Occupational therapists etc) using Nominal Group Process until consensus is reached about the classification system
- Extend the discussion to a wider group of experts (including parents and young people with CP) using a Delphi Group Survey with Questionnaires until a pre-defined consensus has been reached.
- Conduct inter-rater reliability studies for the system, comparing the ratings of individuals' eating and drinking abilities by different Speech and Language therapists

If you are interested in taking part in any of the project, we would be happy to hear from you.

**Project Team:**

Mr Mike Carter, Parent of Young Person with CP

Ms Sarah Ford, Research Assistant, Chailey Heritage Clinical Services

Dr Matthew Hankins, Senior Lecturer in Public Health, University of Southampton

Dr Anne Mandy, Reader, University of Brighton, Sussex

Dr Chris Morris, Cerebral Research Unit, Peninsula Medical School, University of Exeter

Dr Lindsay Pennington, Research Fellow, University of Newcastle

Dr Terry Pountney, Head of Research and Development, Sussex Community Trust

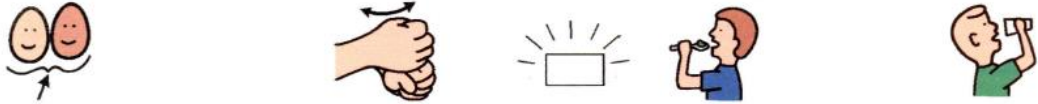
Ms Diane Sellers, Research Speech and Language Therapist, Chailey Heritage Clinical Services

20th October 2011



Project Outline – Symbols:

We want to make a new eating and drinking



leaflet. This is to help people understand about



eating and drinking when body, mouth and



tongue movements are difficult.



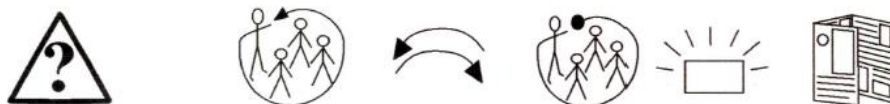
Can you tell us what you think is important



in a group with young people like you?



How can we change our new leaflet?



Thank you - Diane Sellers Speech Therapist.





<b>APPENDIX 4 – NOMINAL GROUP PROCESS (NGP):</b>	<b>PAGE</b>
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██████████  
Speech and Language Therapy  
Eating and Drinking Team

Diane Sellers  
Research Speech and Language Therapist  
Research Department  
Chailey Heritage Clinical Services  
tel: 01825 722112 ext 7796  
[diane.sellers@southdowns.nhs.uk](mailto:diane.sellers@southdowns.nhs.uk)

26<sup>th</sup> May 2010

Dear ██████████

I am writing to you about a new research project based at Chailey Heritage Clinical Services, as I understand that you are the speech and language therapist who is part of the eating and drinking team at ██████████ School.

The project, which has funding for 3 years through the National Institute of Health Research, aims to develop a functional classification system of eating and drinking ability for children and young people with cerebral palsy. I enclose a brief project outline for your information. If you or your colleagues are familiar with the Gross Motor Function Classification Scale or the Manual Ability Classification Scale you will have some idea of the direction we are heading in. It is **not** a new assessment or a therapy outcome measure, but more a tool to communicate the degree to which a child's eating and drinking skills have been affected by cerebral palsy.

A critical part of the project is to collect opinions of people like you and your team who will hopefully be using the tool in the future, following its development. We will be holding a nominal group discussion in ██████████ early in the New Year (2011) and I was wondering whether you and plus one member from the eating and drinking team would be interested in joining us. The group will have about 10 members and will take place over half a day. We will be providing lunch and will cover travelling costs.

As yet I do not have a firm date for the nominal group. Once I have expressions of interest we will arrange a date that can accommodate as many of the invited people as possible.

If you would like to discuss the project further and your involvement with it, I would be really happy to do so. The contact details to ring or write to me are given at the top and bottom of this letter.

I look forward to hearing from you

With good wishes

Yours sincerely

Diane Sellers  
Research Speech and Language Therapist

Research Department  
Chailey Heritage Clinical Services  
Beggars Wood Road  
North Chailey BN8 4JN  
01825 724721  
[www.sussexcommunity.nhs.uk/chailey](http://www.sussexcommunity.nhs.uk/chailey)  
[diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)

Name and address

Date

Dear

**Re: Nominal Group Discussion - Eating and Drinking Classification System for Children and Young People with Cerebral Palsy**

I am writing to you to confirm details of the group discussion to look at the draft Eating and Drinking Classification System.

We are meeting on 12<sup>th</sup> October 2010 from 9.30 -12.30 at **Royal College of Speech and Language Therapists Headquarters, 2 – 3 White Hart Yard, London. SE1 1NX, Tel: 020 7378 1200.** I have enclosed a map for your information.

Lunch and refreshments will be provided. We will reimburse your travel costs.

I would be grateful if you would please complete and return the attached form. Audio tape will be used to record all of the group discussion. In order to participate in the group discussion, you will need to give your consent to the use of audio tape. If you would prefer not to participate in the group discussion but would like to contribute to the research, please indicate your interest on the form.

We look forward to hearing from you.

Kind regards

Yours sincerely

**Diane Sellers BA MA MRCSLT**  
**Specialist Speech and Language Therapist (Eating and Drinking Difficulties)**

**Research Project to Develop an Eating and Drinking Classification Scale for Children and Young People with Cerebral Palsy**

**Invitation to Participate in Group Discussion**

Name: .....

Please delete the phrases which do not apply:

- 1) I **\*am able** / **\* am not able** to take part in the Group on 12th October 2010 at RCSLT Headquarters, 2 – 3 White Hart Yard, London. SE1 1NX
- 2) I **\*give my consent** / **\* do not give my consent** to my contributions being recorded on audio tape
- 3) I **\*would like** / **\*would not like** to participate in future phases of the research (E.g. Questionnaire Survey)
- 4) I understand that data collected during the study may be looked at by individuals from Chailey Heritage Clinical Services Research Department, from regulatory authorities or from the NHS Trust. I **\*give** / **\*do not give** permission for these individuals to have access to my records.
- 5) Please let us know if you have specific needs to make participation in the group discussion possible (E.g. hearing aid loop, large print needed for documentation, communication support)

.....  
.....

- 6) Please let us know of any specific dietary requirements

.....  
.....

Any Comments: .....

Signed: ..... Date: .....

Please return in envelope provided to Diane Sellers, Research Department, Chailey Heritage Clinical Services, Beggars Wood Road, North Chailey, Nr Lewes, East Sussex, BN8 4JN

NHS REC REF 09/H1111/66

Research Department  
Chailey Heritage Clinical Services  
Beggars Wood Road  
North Chailey BN8 4JN  
01825 724721  
[www.southdowns.nhs.uk/chailey](http://www.southdowns.nhs.uk/chailey)  
diane.sellers@southdowns.nhs.uk

Name  
Address

Date

Dear

**Re: Development of Eating and Drinking Classification System for Children with Cerebral Palsy**

Thank you for agreeing to take part in the Group discussion in \*\*\*\* on \*\*. We thought it would be helpful to give you some more detail about what will happen during the meeting and the significance of your participation.

We are following a similar approach to that used to develop other classification systems such as the Gross Motor Function Classification System. The different phases of the project include writing a draft, consulting experts about the content of the draft and then looking at how reliably the system can be used.

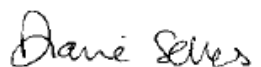
We have completed a \*\*\* draft of the system but need to obtain views of experts like you on its wording and content. The group we are holding in \*\*\*\* will involve group participants looking in detail at the draft, raising concerns or suggestions for change and then voting on the most significant changes that need to go forward into the next draft. The system will be considered by a series of similar groups around the country with different expert members until there is consensus about the content. Participation in the face to face group discussions will give you the opportunity to influence the system in its very early development.

At a later stage, a wider group of experts (national and international) will be invited to scrutinise the content of the system through a survey. Invitations to participate in this survey will also be sent to those who have taken part in the face to face group discussions.

Please find attached a copy of your signed Consent form, together with a Project Outline for your records.

Please let me know if you would like any additional information.

With good wishes



Diane Sellers  
Research Speech and Language Therapist  
Chailey Heritage Clinical Services



<b>APPENDIX 5 – DELPHI SURVEY:</b>	<b>PAGE</b>
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Research Department  
Chailey Heritage Clinical Services  
Beggars Wood Road  
North Chailey  
East Sussex BN8 4JN  
United Kingdom  
tel: +44 1825724720  
XX<sup>th</sup> XXXXXXXX 2011

Dear XXXXX

**Re: Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy**

I am writing to you to invite your participation in an international research project based at Chailey Heritage Clinical Services in the UK.

\*I understand that XXXX has spoken about the Project with you and that you were interested in giving your views on the classification system OR \*You expressed an interest in giving your views on the classification system when we met at XXXXX OR \*I have read your work on XXXX and was keen to seek your views on the classification system OR \*XXXXX from the Project Team suggested that I contact you as you might be interested in giving your views on the classification system (\*delete as appropriate – there might be some other link to the person being contacted but these cover scenarios encountered so far).

I have attached an outline of the project for your information.

We would like to invite you to take part in a Delphi Survey to look in detail at the content of the proposed classification system. A Delphi Survey is a way of bringing together views of people like you with considerable experience and expertise about a particular topic without actually meeting face to face. The opinions expressed in the first round of the survey will be summarised and conveyed anonymously to all participants of the Delphi. The views will be used to make changes to the current draft of the classification system. The revised draft will be sent out again for examination by the same group of people. The process is repeated until we establish the level of group consensus about the system.

We are planning to start the Delphi process at the beginning of December 2011 when we will e-mail the latest draft of the classification system together with the survey to be completed online. If you would like to participate but would prefer to complete the survey in conversation with someone or have a paper copy of the survey posted to you, please let the research team know.

Please could you confirm that you are interested in participating in the Delphi Survey and that you would be available to give your views on at least two occasions between 1<sup>st</sup> December 2011

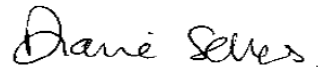


and 31<sup>st</sup> March 2012.

We look forward to hearing from you.

Kind regards

Yours sincerely

A handwritten signature in black ink that reads "Diane Sellers". The signature is written in a cursive style with a period at the end.

**On behalf of the Project Team:**

- Mr Mike Carter, Parent of Young Person with CP
- Ms Sarah Ford, Research Assistant, Chailey Heritage Clinical Services ([sarah.ford5@nhs.net](mailto:sarah.ford5@nhs.net))
- Dr Matthew Hankins, Senior Lecturer in Public Health, University of Southampton
- Dr Anne Mandy, Reader, Clinical Research Centre for Health Professions, University of Brighton
- Dr Chris Morris, Senior Research Fellow in Child Health, Peninsula Cerebra Research Unit, Peninsula Medical School, University of Exeter
- Dr Lindsay Pennington, Principal Research Associate, Institute of Health and Society, Newcastle University
- Dr Terry Pountney, Head of Research and Development, Sussex Community Trust
- Ms Diane Sellers, Research Speech and Language Therapist, Chailey Heritage Clinical Services ( [diane.sellers@nhs.net](mailto:diane.sellers@nhs.net) )

Chailey Heritage Clinical Services  
Date

Dear

We are pleased to send you the information you need to take part in the Delphi Survey for the proposed Eating and Drinking Ability Classification System (EDACS) for individuals with cerebral palsy. We estimate that it will take approximately an hour of your time to complete the survey.

We have included:

- A link for the survey – please follow the link.  
[Survey link to be given here.](#)
- A PDF copy of the latest draft of the classification system
- A PDF copy of the survey.

**Helpful Tips:**

You can go in and out of the survey as many times as you like before submitting it. All your responses will be saved as long as you **always use the same computer**. Please use the navigation buttons at the bottom of the page and the slide / scroll bar on the right hand side of the screen. If you use your internet browser button to move between the pages, your responses may be lost.

The first page of questions in the survey concerns your background and experience. The next section of the survey concerns the content of the classification system. **Please indicate the level of your agreement with all the statements given in the survey** as we are basing the measurement of consensus on these. The boxes after each statement give you the opportunity to make comments or suggestions should you wish to do so.

You will not be identified to other participants in the survey. Each survey has been given a number linked with your name in order that we can ensure the quality of the data collection process. You may be sent a reminder if the survey has not been submitted by 9<sup>th</sup> **January 2012**. Your responses will be combined with all the other responses in the analysis and will not be identified with your name.

Please get in touch with either Diane or Sarah if there are any concerns or if anything is not working as it should.

We would like to thank you for agreeing to take part in the Delphi Survey. We look forward to hearing from you.

With very good wishes

*Diane Sellers*

Diane Sellers      [diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)

Sarah Ford      [sarah.ford5@nhs.net](mailto:sarah.ford5@nhs.net)

Chailey Heritage Clinical Services  
Beggars Wood Road, North Chailey BN8 4JN  
tel: + 44 1825 724720

Dear

Many thanks for participating in the first round of the Delphi Survey to examine the content of EDACS, a proposed new classification system of the functional eating and drinking ability of individuals with cerebral palsy.

More than 90 of you, from a variety of different backgrounds, participated in the survey. Between you, there was a range of 2 to 52 years experience, with an average of 19 years experience within the group.

In the first round of the Delphi Survey, more than 80% of you agreed with 39 out of the 42 different statements we presented to you about EDACS v16. We have made some changes and are asking you to look again at the three statements for which agreement was relatively lower. We also looked closely at the comments you made. We have incorporated many of your suggestions to improve the wording and presentation of EDACS without changing the meaning.

- Here is the link to Round 2 of the Delphi Survey:  
<https://www.surveymonkey.com/s/7JXPRMJ?c=021>
- A PDF copy EDACS v17
- A PDF copy of the Delphi Survey Round 2

This time there are only 6 questions we would really like you to answer about EDACS v17 and 7 optional questions if you would like to offer further comment.

#### Helpful Tips:

It is fine to ignore questions that you feel unable to comment on.

You can go in and out of the survey as many times as you like before submitting it.

All your responses will be saved as long as you always use the same computer.

Please use the navigation buttons at the bottom of the page and the slide / scroll bar on the right hand side of the screen. If you use your internet browser button to move between the pages, your responses may be lost.

You will not be identified to other participants in the survey. Each survey has been given a number linked with your name in order that we can ensure the quality of the data collection process. Your responses will be combined with all the other responses in the analysis and will not be identified with your name. We would be grateful if you can complete the survey as soon as possible.

Please get in touch with either Diane or Sarah if there are any concerns or if anything is not working as it should.

We would like to thank you for agreeing to take part in the Delphi Survey. We look forward to hearing from you.

With very good wishes

*Diane*



<b>APPENDIX 6: INTER-OBSERVER RELIABILITY STUDIES</b>	<b>PAGE</b>
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Research Department  
Chailey Heritage Clinical Services  
Beggars Wood Road  
North Chailey  
Nr Lewes BN8 4JN  
tel: 01825 724720  
[diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)

xx<sup>th</sup> XXXX 2012

Dear Parent

**Re: Eating and Drinking Ability Classification System**

I am writing to invite you to take part in a research project based at Chailey Heritage Clinical Services in Sussex. Your child's speech and language therapist at XXXXX School is sending this information to you on our behalf.

We have developed a new way of talking about how children with cerebral palsy eat and drink. We would like to invite you to try it out and let us know what you think about it. We will be asking the speech and language therapists at your child's school to do the same.

We have sent you all the information you need to take part. In this envelope you will find:

- An information sheet for parents
- A consent form
- An A3 version of the Eating and Drinking Ability Classification System
- A copy of the Gross Motor Function Classification System
- A short questionnaire for you to complete
- An envelope for you to return the consent form and questionnaire to us.

If you would like to take part, please could you let me know within 2 weeks of the date of this letter.

If you have any questions about taking part, please ring me or contact me via e-mail. My contact details are given at the top of the letter. If you would prefer to speak with another parent of a young person with cerebral palsy, please contact M. C. (tel: [redacted] or [m.\[redacted\]@\[redacted\].com](mailto:m.[redacted]@[redacted].com))

With thanks and very good wishes

Yours sincerely

Diane Sellers  
Research Speech and Language Therapist  
Chailey Heritage Clinical Services

---

Chairman Susan Sjuve, Chief Executive Bob Deans  
Trust Headquarters: Brighton General Hospital, Elm Grove, Brighton, BN2 3EW

**Information Sheet for Parents:**  
**Eating and Drinking Ability Classification System for Children with Cerebral Palsy**

Diane Sellers, Research Speech and Language Therapist or Sarah Ford, Research Assistant  
Chailey Heritage Clinical Services  
Beggars Wood Road North Chailey Lewes BN8 4JN  
Tel: +44 1825 724720 [diane.sellers@nhs.net](mailto:diane.sellers@nhs.net) or [REDACTED]

M [REDACTED] C [REDACTED] Tel: [REDACTED] or [m \[REDACTED\] @ \[REDACTED\].com](mailto:m[REDACTED]@[REDACTED].com)

If you would like to speak to someone about the project please contact Diane or Sarah. If you would prefer to speak to a parent of a young person who has cerebral palsy, please contact M [REDACTED] C [REDACTED].

**Background:**

Children with cerebral palsy (CP) are limited to varying degrees in their physical movement ability. The movements involved in biting, chewing and swallowing are frequently affected to some extent. Sometimes it can be challenging for someone with cerebral palsy to eat enough food to grow and to stay healthy. Some people with CP may have frequent chest infections because particles of food or drink enter their lungs sometimes when they swallow.

Currently there is no agreement about how to rate the severity of a child's eating and drinking difficulty, i.e. the child's ability to move muscles to bite, chew and swallow. The words "severe", "moderate", and "mild" are all used differently by different people. For some people, a "severe" difficulty is when a child cannot feed themselves. Others assume that only children with the most severe movement difficulties have problems with eating and drinking.

Classification systems have been developed to rate a child's ability to walk and move (Gross Motor Function Classification System), and to use their hands (Manual Ability Classification System). These are both extremely useful and are increasingly widely used. We have received funding from the National Institute for Health Research (Research for Patient Benefit) to produce an eating and drinking classification system for children with cerebral palsy.

**Research:**

We have developed descriptions for each of five levels of the new Eating and Drinking Ability Classification System (EDACS). We did this by consulting with parents, individuals with cerebral palsy and professionals with expert knowledge both nationally and internationally.

We now need to test this system to see how easily it can be used and how reliable it is. We are inviting you as a parent of a child with cerebral palsy to try out the system to assign a level of eating and drinking ability to your child.

We have sent you a copy of EDACS, together with a questionnaire and a consent form for you to complete if you wish to take part in the research. If you choose to take part, we will then compare the information you give us in the questionnaire with the level assigned to your child by a suitably trained speech and language therapist who knows your child well.

If you give your consent, we will also be asking therapists from your child's school to describe your child's ability to move using the Gross Motor Function Classification System. We would like to compare your child's level of eating and drinking ability with his or her overall movement ability. I have included a copy of this classification system for your information.

The questionnaire we have sent you also includes space for your feedback about your experience using the classification system.

**Benefits:**

We think there are many benefits to children and families within the NHS and other healthcare systems that would come from such a rating system. They include:

- Increasing awareness of the mouth movements necessary for efficient and safe eating and drinking and distinguishing them from other types of movement.
- Enabling clear and efficient communication about a child's eating and drinking skills between professionals (e.g. children can fear hospital stays because of misunderstandings that have occurred at mealtimes).
- Providing a method by which limited resources can be directed (e.g. dietitian's time) to those children with the most severe difficulties, highest risk of malnutrition and therefore the greatest need.
- Increasing awareness and thereby reducing the risks to health whenever a child eats or drinks (e.g. particles of food and drink entering the lungs whenever a child eats, and choking).

We would be pleased to hear from you if you are interested in taking part.

**Project Team:**

Ms Diane Sellers, Research Speech and Language Therapist, Chailey Heritage Clinical Services

Dr Terry Pountney, Head of Research and Development, Sussex Community Trust

Ms Sarah Ford, Research Assistant, Chailey Heritage Clinical Services

Mr Mike Carter, Parent of Young Person with CP

Dr Matthew Hankins, Senior Lecturer in Public Health, University of Southampton

Dr Anne Mandy, Reader, University of Brighton, Sussex

Dr Lindsay Pennington, Research Fellow, University of Newcastle

Dr Chris Morris, PenCRU, Peninsula Medical School, University of Exeter

25<sup>th</sup> July 2012



**PARENT CONSENT FORM**

**Research Title: Eating and Drinking Ability Classification System for Children with Cerebral Palsy**

**Chief Investigator: Diane Sellers**

Please read the following statements and initial the corresponding box if you **AGREE** with the statement.

- |   | Please initial the<br>box if you agree<br>with the<br>statement |
|---|---|
| 1. I confirm that I have read and understand the information sheet provided for the above titled research.  | <input type="checkbox"/>  |
| 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.  | <input type="checkbox"/>  |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.  | <input type="checkbox"/>  |
| 4. I agree to take part in the above study.   | <input type="checkbox"/>  |
| 5. I agree to therapists at my child's school using their knowledge about my child to take part in the above study.   | <input type="checkbox"/>  |
| 6. I consent to the storage including electronic, of personal information for the purposes of this study. I understand that any information that could identify me or my child will be kept strictly confidential and that no personal information will be included in the study report or other publication. | <input type="checkbox"/>  |

If you have initialled all the boxes and you would like to take part in the research please sign your name below. A copy of this form will be given to you to keep.

Name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

SCHOOL CODE \* 1,  2,  3,  4,  5,  6 (\*delete as appropriate – depending upon school child is attending)

1) Please tell us your child's name and age:

Name: \_\_\_\_\_ Age: \_\_\_\_\_

2) Read the descriptions of the different eating and drinking levels in the enclosed leaflet called Eating and Drinking Ability Classification System or **EDACS**. There are some definitions of some of the terms used on the back of the leaflet. Please circle which description or level best fits how your child eats and drinks:

Level I                      Level II                      Level III                      Level IV                      Level V

3) Read the descriptions of the level of assistance needed to eat and drink on page 5. Please circle the category which best fits how much help your child needs when eating and drinking.

Independent                      Requires Assistance                      Totally Dependent

4) Have you had any discussions with your child's speech and language therapist about eating and drinking in the last 12 months?

Yes                      No

5) If you are interested in talking to someone about this questionnaire and the Eating and Drinking Ability Classification System, please write down your name and telephone contact details:

Name: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Many thanks for your help.

Diane Sellers, Research Speech and Language Therapist  
Chailey Heritage Clinical Services, Beggars Wood Road  
North Chailey, Nr Lewes BN8 4JN  
tel: 01825724720  
[diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)

---

Chairman Susan Sjuve, Chief Executive Bob Deans  
Trust Headquarters: Brighton General Hospital, Elm Grove, Brighton, BN2 3EW

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■■■■■  
Speech and Language Therapy  
School

7<sup>th</sup> June 2012

Research Department  
Chailey Heritage Clinical Services  
Beggars Wood Road  
North Chailey  
nr Lewes  
BN8 4JN  
[diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)

Dear ■■■■

I hope you are well and that half term has brought you some rest and recuperation time. I am writing to you about the ongoing project at Chailey to develop an eating and drinking classification system.

About three years ago, you agreed to participate in the final phase of the project when we examine how reliable the system is when used by different people. I am writing to check whether it is still possible, and whether you are still interested!

We would also like to include a new dimension to the reliability studies in that we would like parents to also be involved although we have to submit this new proposal to the local Ethics committee. I would appreciate your thoughts on the feasibility of this in the context of ■■■■. Our current proposal is for you to send an information pack and questionnaire to parents of all the young people attending ■■■■ who have cerebral palsy. You and a colleague would be asked to rate the eating and drinking ability of all the young people whose parents have returned the questionnaire directly to us, plus any more on your caseload to make up the number to 20 children in total. I hope that makes sense to you!

I would find it helpful to arrange a time to talk through what we would like to do, if you are in agreement. With our current timescales, it is likely to take place in the autumn term. I have enclosed the latest version of EDACS as it is now called so you can see how it has developed.

Could you suggest a good time for me to ring you?

I look forward to speaking to you.

With thanks and good wishes,

Diane Sellers  
Research Speech and Language Therapist.

---

Chairman Simon Turpitt Chief Executive Andy Painton  
Trust Headquarters: Brighton General Hospital, Elm Grove, Brighton, BN2 3EW



Research Project to Develop an Eating and Drinking Classification Scale for Individuals with Cerebral Palsy

Consent to participate in the reliability data collection and group discussion for the Eating and Drinking Ability Classification System (EDACS).

Name: .....

Please delete the phrases which do not apply:

1) I \*am able / \* am not able to take part in the Group on Nth Month 2012 in Town, County

2) I \*give my consent / \* do not give my consent to my contributions being recorded on audio tape

3) Please let us know if you have specific needs to make participation in the group discussion possible (E.g. hearing aid loop, large print needed for documentation, communication support)

.....  
.....

4) Please let us know of any specific dietary requirements

.....  
.....

Any Comments:

.....

Signed: ..... Date: .....

Please return to Diane Sellers, Research Department, Chailey Heritage Clinical Services, Beggars Wood Road, North Chailey, Nr Lewes, East Sussex, BN8 4JN

Inter-rater Reliability Professional Consent Form. Version 1. 25.10.12

### Data Collection Sheet 1

Subject Number (Name if parents involved):

SLT Initial:

Date:

You will need to familiarise yourself with the content of the Eating and Drinking Ability Classification System (EDACS).

1) Please circle which description or level best fits how this child / young person eats and drinks:

Level I                      Level II                      Level III                      Level IV                      Level V

2) Please circle the category which best fits how much help this child needs when eating and drinking.

Independent                      Requires Assistance                      Totally Dependent

Comments:

---

Chairman Susan Sjuve, Chief Executive Bob Deans  
Trust Headquarters: Brighton General Hospital, Elm Grove, Brighton, BN2 3EW

T:\Chailey\_Research\Eating and Drinking Scale\supporting documents\Version 1\Data Collection Sheet 1 SLT  
14.11.12 v1.doc

Data Collection Sheet 2

Name of School:				Date:				
Subject Number:	Child Initials only. Child's name if parent involvement	gender	age - years	CP type	GMFCS level	Gastrostomy Y / N	seizure disorder Y / N	Key SLT initials (if parent involvement)
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								
13								
14								
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<b>APPENDIX 8 – INTER-OBSERVER RELIABILITY STUDIES:</b>	<b>PAGE</b>
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The data variables set up within IBM SPSS Statistics were:

- ID – a unique subject number was given to each of the children
- Initials – initials of child's name
- Gender where 1=male, 2=female
- Age – age in years at time of inter-observer reliability studies
- CP subtype where 1=spastic bilateral, 2=spastic unilateral, 3=dyskinetic, 4=ataxic, 5=Worster Drought syndrome, 6=unclassifiable
- GMFCS - Levels I-V represented by numbers 1-5
- Gastrostomy where 1 = yes gastrostomy or feeding tube present, 2= no feeding tube
- Seizure where 1=yes seizure activity present, 2=no seizure activity
- Site where number 1-12 represents school site .
- R1\_Edacs – SaLT1 rating using EDACS levels I to V represented by numbers 1-5
- R2\_Edacs – SaLT2 rating using EDACS levels I to V
- R3\_Edacs – parents rating using EDACS level I to V
- R1\_Asst – SaLT1 rating using levels of assistance required where 1=independent, 2=requires assistance, 3=totally dependent
- R2\_Asst – SaLT2 rating using levels of assistance required
- R3\_Asst – Parents rating using levels of assistance required

IR data 14.5.13.sav [DataSet1] - IBM SPSS Statistics Data Editor

File Edit View Data Transform Analyze Graphs Utilities Add-ons Window Help

	Name	Type	Width	Decimals	Label	Values	Missing	Columns	Align	Measure	Role
1	ID	Numeric	8	0	ID	None	None	8	Right	Nominal	Input
2	initials	String	8	0		None	None	8	Left	Nominal	Input
3	Gender	String	8	0	Gender	{1, male}...	None	8	Left	Nominal	Input
4	Age	Numeric	8	0	Age	None	None	8	Right	Scale	Input
5	CPtype	String	8	0	CP type	{1, spastic ...	None	8	Left	Nominal	Input
6	GMFCS	Numeric	8	0	GMFCS	{1, GMFCS ...	None	8	Right	Ordinal	Input
7	Gastrostomy	String	8	0	Gastrostomy	{1, yes}...	None	8	Left	Nominal	Input
8	Seizure	String	8	0	Seizure	{1, yes}...	None	8	Left	Nominal	Input
9	Site	String	8	0	Site	{1, CHS}...	None	8	Left	Nominal	Input
10	R1_Edacs	Numeric	1	0	S1_Edacs	{1, EDACS I...	None	8	Right	Ordinal	Input
11	R2_Edacs	Numeric	1	0	S2_Edacs	{1, EDACS I...	None	8	Right	Ordinal	Input
12	R3_Edacs	Numeric	1	0	Parent_Edacs	{1, EDACS I...	None	8	Right	Ordinal	Input
13	R1_Asst	Numeric	1	0	S1_Asst	{1, Independ...	None	8	Right	Ordinal	Input
14	R2_Asst	Numeric	1	0	S2_Asst	{1, Independ...	None	8	Right	Ordinal	Input
15	R3_Asst	Numeric	1	0	Parent_Asst	{1, Independ...	None	8	Right	Ordinal	Input
16											
17											
18											
19											
20											

Appendix 8 Figure I: Data variable view within IBM SPSS Statistics v20 for inter-observer reliability studies

IBM SPSS Statistics Data Editor window showing a dataset named "64 : R3\_Asst". The table contains 25 rows of data with the following columns: ID, initials, Gender, Age, CPtype, GMFCS, Gastrostomy, Seizure, Site, R1\_Edacs, R2\_Edacs, R3\_Edacs, R1\_Asst, R2\_Asst, and R3\_Asst.

ID	initials	Gender	Age	CPtype	GMFCS	Gastrostomy	Seizure	Site	R1_Edacs	R2_Edacs	R3_Edacs	R1_Asst	R2_Asst	R3_Asst
1	1 CA	1	15	3	2	2	1	1	2	1	.	1	1	.
2	2 JA	1	18	5	1	2	1	1	2	2	.	1	1	.
3	3 JB	1	17	2	1	2	1	1	2	2	.	1	1	.
4	4 WG	1	10	5	1	2	2	1	2	2	.	1	1	.
5	5 BH	2	16	5	2	2	2	1	2	2	.	1	1	.
6	6 RF	1	15	5	2	2	1	1	4	4	3	1	1	1
7	7 GK	1	17	5	2	2	2	1	2	2	.	1	1	.
8	8 GM	1	13	6	1	2	1	1	2	2	2	1	1	2
9	9 CM	1	18	1	4	2	2	1	2	2	.	1	1	.
10	10 EO	1	14	6	2	2	2	1	2	2	.	1	1	.
11	11 CR	1	15	5	1	2	2	1	2	2	.	1	1	.
12	12 SR	1	15	2	2	2	1	1	2	2	2	1	1	1
13	13 SS	1	15	6	1	2	2	1	2	2	2	1	1	1
14	14 KY	2	11	5	2	2	2	1	2	2	.	1	1	.
15	15 LC	1	13	4	4	2	2	1	3	1	.	2	1	.
16	16 BM	2	12	5	5	2	2	1	2	2	1	1	1	1
17	17 MM	2	12	2	1	2	2	1	2	1	.	1	1	.
18	18 CK	2	14	1	2	2	1	1	1	2	2	1	1	2
19	19 FP	2	12	3	4	2	1	3	3	3	3	3	2	2
20	20 AF	2	4	6	5	1	1	3	4	4	4	3	3	3
21	21 HH	2	17	3	5	2	1	3	4	.	4	3	.	3
22	22 HH	1	6	1	4	1	1	3	5	5	5	1	1	3
23	23 HM	2	6	3	5	2	2	3	4	4	4	3	3	3
24	24 MD	1	17	1	5	1	1	3	5	5	5	3	3	3
25	25 TF	1	17	3	5	1	1	3	5	4	4	3	3	3

Appendix 8 Figure II: Data set within IBM SPSS Statistics v20 for inter-observer reliability studies

### Calculation of absolute agreement and kappa (k):

Within SPSS the following process was followed to calculate value of absolute agreement and kappa for EDACS levels:

- Select **Analyze > Descriptive Statistics>Crosstabs**
- Select variables **R1\_Edacs(SaLT1)** and place in **Rows** and either **R2\_Edacs(SaLT2)** or **R3\_Edacs(SaLT3)** and place in **Columns**
- Select **Statistics>** tick **Kappa>** select **Continue**
- Select **OK** to produce output tables including value of kappa.

### Calculation of absolute agreement:

$$\frac{\text{Total number of identical scores (across diagonal)}}{\text{Total number of cases}} \times 100$$

### Calculation of intraclass correlation coefficient (ICC):

Intra-class correlation coefficients for ratings (SaLTs vs SaLTs, SaLTs vs parents) were calculated using the following process:

- Select **Analyze>Scale>Reliability analysis**
- Select pairs of ratings to be compared e.g. variables **R1\_Edacs** and **R3\_Edacs**
- Select **Statistics>**tick **Intraclass correlation coefficient** box
- Select **Model “Two way random”, Type “consistency”, Confidence Interval 95%**
- Select **OK** to produce output tables – value of ICC is that given for **Single Measures** with upper and lower limits for confidence interval.

### Calculation of Kendall's tau:

The Kendall Tau-b coefficient is defined as:

$$\tau_B = \frac{n_c - n_d}{\sqrt{(n_0 - n_1)(n_0 - n_2)}}$$

where

$$n_0 = n(n - 1)/2$$

$$n_1 = \sum_i t_i(t_i - 1)/2$$

$$n_2 = \sum_j u_j(u_j - 1)/2$$

$n_c$  = Number of concordant pairs

$n_d$  = Number of discordant pairs

$t_i$  = Number of tied values in the  $i^{th}$  group of ties for the first quantity

$u_j$  = Number of tied values in the  $j^{th}$  group of ties for the second quantity

### Kendall's tau (Agresti 2010)

Kendall's tau was calculated within IBM SPSS Statistics using the following process:

- Select **Analyze>Descriptive Statistics>Crosstabs**
- Select variable **GMFCS** and place in **Rows**, select **R1\_Edacs** and place in **Columns**
- Select **Statistics>tick Kendalls tau-b>select Continue**

Select **OK** to produce output tables where value for Kendall's tau is given with level of significance.

## **APPENDIX 9 – PUBLICATIONS:**

EDACS – available to download from [www.EDACS.org](http://www.EDACS.org)

Sellers D, Mandy A, Pennington L., Hankins M and Morris C. (2013b). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine and Child Neurology*. doi:10.1111/dmcn.12352

Sellers D, Pennington L, Mandy A and Morris C (2013a). A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy. *Developmental Medicine and Child Neurology*. doi:10.1111/dmcn.12313



# EDACS

## EATING AND DRINKING ABILITY CLASSIFICATION SYSTEM

---

### PURPOSE

---

The purpose of the Eating and Drinking Ability Classification System (EDACS) is to classify how individuals with cerebral palsy eat and drink in everyday life using distinctions that are meaningful. EDACS provides a systematic way of describing an individual's eating and drinking in five different levels of ability.

The focus is on the functional activities of eating and drinking such as sucking, biting, chewing, swallowing and keeping food or fluid in the mouth. The different parts of the mouth include the lips, jaw, teeth, cheeks, tongue, palate and throat. The distinctions between the different levels in the EDACS are based upon functional ability, the need for adaptations to the texture of food and drink, the techniques used and some other features of the environment. It classifies overall performance in eating and drinking, which includes both motor and sensory elements.

The system provides a broad description of different levels of functional ability. The scale is ordinal. The distances between the levels are not equal and individuals with cerebral palsy will not be distributed equally across the levels.

EDACS is not an assessment tool to look in detail at the component parts of eating and drinking. It does not provide the comprehensive mealtime guidance required by some individuals with cerebral palsy to eat and drink safely and efficiently.

Changes to eating and drinking performance occur as someone grows as a result of physical development and experience. This current version of EDACS describes the eating and drinking abilities of children with cerebral palsy from the age of 3 years.



### BACKGROUND

---

EDACS classifies an individual's usual performance rather than what can be done to the best of their ability. The focus of EDACS is to determine which level most accurately represents an individual's present abilities and limitations. An individual may eat and drink differently in different settings, be influenced by personal factors and the skill and familiarity of the carer, and other environmental features.

The way an individual balances, controls head movements and sits upright influences their oral skills whilst eating and drinking. Some individuals will require close attention to positioning in sitting, standing and lying, and adapted equipment to optimise their eating and drinking abilities. The manner and degree of postural management required by individuals will depend upon their gross motor abilities.

We encourage users of EDACS to be aware of how other factors associated with cerebral palsy can influence an individual's performance whilst eating or drinking. These might include seizures and disturbances to cognition, communication, sensation, vision and hearing, as well as behaviour. Illness, tiredness, pain or medication will also have an effect. A wide range of personal factors and social, emotional and behavioural issues can become associated with eating and drinking. Features of the environment may also have an influence such as a familiar or new carer, background or sudden noises, quality of lighting and sudden movements. If an individual requires assistance with eating and drinking, a highly significant feature will be the quality of the relationship between the individual and the carer, including how well they each communicate with the other.

Disturbances of the digestive system such as gastro-oesophageal reflux or constipation will have an impact upon appetite and interest in food.

---

### KEY FEATURES OF EATING AND DRINKING

---

Key features of the process of eating and drinking are **safety** and **efficiency**.

**Safety** refers to the risks of **choking** and **aspiration** associated with eating and drinking.

**Choking** occurs when a piece of food becomes lodged in the airway; this may be connected to limitations in chewing and biting as well as co-ordinating the movement of food in the mouth with swallowing.

**Aspiration** occurs when food or fluid enters the lungs; this may be connected to limitations in co-ordinating breathing and swallowing, controlling food or fluid in the mouth or an impaired swallow reflex. Some aspects of eating and drinking are impossible to observe, especially swallowing. Even if you know someone really well it is not always easy to notice the **signs of aspiration**; this is known as **silent aspiration**.

**Aspiration** may trigger respiratory illnesses and is potentially harmful. If **aspiration** is suspected, it is helpful to seek further assessment from a suitably qualified professional such as a speech and language therapist.

**Efficiency** refers to the length of time and effort required to eat or drink, as well as whether food or drink is kept in the mouth without loss. Limitations to the quality and speed of movement of the different parts of the mouth will affect how efficiently food and drink is consumed. The amount of effort required for eating and drinking will have an impact upon how quickly an individual tires during a meal.

The **efficiency** with which someone uses the parts of the mouth to eat and drink has an impact upon the amount of food and fluid they are able to consume. This is one of a number of factors that influence whether an individual is able to take in enough food and drink to grow and remain in good health. It is considered good practice to assess individual nutrition and hydration requirements and decide whether these are being met adequately.

---

## USER INSTRUCTIONS

---

From the different descriptions given below, choose the level that best describes an individual's overall usual performance when eating and drinking.

To identify the level of eating and drinking ability of an individual with cerebral palsy, it is necessary to involve someone who knows that person well such as a parent or carer. Some aspects of eating and drinking are not possible to see, so it may be helpful to assign a level together with a professional who has knowledge about the necessary skills for safe and efficient eating and drinking.

In borderline cases the level of the EDACS which describes the greater level of limitation should be assigned.

Different degrees of assistance will be needed when eating or drinking depending upon age and the ability to bring food or drink to the mouth. The level of assistance required may change throughout life, beginning with the total dependence of the young infant. The EDACS level assigned to an individual is supplemented with an indication of whether an individual is Independent whilst eating and drinking, Requires Assistance in bringing food and drink to the mouth or is Totally Dependent.

### DEFINITIONS

---

**Age appropriate food textures** refers to textures of food typically given to a particular age group (e.g. in some cultures, nuts and tough meats are not given to young children).

**Aspiration** is defined as the entry of material (e.g. food or fluid) into the airway or lungs below the vocal cords. This may occur when there is weak or uncoordinated movement of food or fluid from the mouth to the oesophagus whilst eating. This is usually accompanied by coughing, breathing changes and other signs of aspiration; the term **silent aspiration** is used if outward signs of aspiration such as coughing are not obvious when a person aspirates. Aspiration may cause harm by contributing to respiratory illness and chronic respiratory diseases.

**Breathing** changes might be noticed during eating or drinking which might suggest difficulty clearing food or fluid away from the airway and throat. The changes observed may be linked to the sound of the breathing (e.g. wheezy, rattly, noisy or wet) or may be linked to changes to the way someone breathes (e.g. changes to the rate of breathing or laboured, effortful breathing).

**Choking** is the partial or complete blocking of the airway due to a foreign object becoming lodged in the throat or windpipe. The blockage may be relieved by coughing. If not, the individual will require assistance (e.g. UK Resuscitation Council recommendations).

**Fluid Consistency** refers to how thick or thin a fluid is. Fluid consistency changes the speed at which fluid moves. It may mean the difference between fluid being swallowed safely and fluid entering the airway or lungs. Thin fluids, such as water, are fast flowing and require quick co-ordination of the movements of swallowing and breathing. Smooth thicker fluids flow more slowly and may be recommended to individuals with slower movements during swallowing in order to reduce the risk of fluid entering the airway or lungs, and / or to reduce loss of fluid from the lips. Thick fluids may be prepared by using diluted yoghurts or thick soups; thin fluids may be thickened using commercially available thickening agents.

**Food textures** will affect how easy it is to eat something. Different foods have a range of qualities requiring different degrees of effort, strength and co-ordination to eat. Features to consider include the shape and size of the food, how hard it is to bite and chew the food into small enough pieces ready for swallowing and what happens once bitten – foods can dissolve, splinter, crumble or lump together. Most foods can be modified to change the texture to one that is easier to manage (e.g. mixed textures can be mashed down, tough meats blended, large pieces cut into smaller pieces). Some individuals may need to avoid certain foods if they cannot be modified.

**EDACS** refers to:

- **Firm bite and effortful chew textures** which are the most challenging to eat (e.g. tough meats, molluscs, hard nuts, crunchy fibrous fruit and vegetables).
- **Mixed textures** where different food textures and fluid consistencies are combined (e.g. lumps of food in a thin soup, watery puree which separates into fluid and food, meat and salad sandwich).
- **Slippery textures** of food are particularly challenging to control in the mouth and eat safely (e.g. melon or grapes).
- **Sticky foods** can cause problems if an individual has difficulty clearing the mouth (e.g. nut butters, halva, tahini and toffee).
- **Hard chew textures** require effort, strength and co-ordination to eat (e.g. raw fruit and vegetables, meat, crackers, crusty bread).
- **Soft chew textures** require less effort, strength and co-ordination to eat (e.g. well cooked non fibrous vegetables, very ripe peeled fruit without seeds, well cooked pasta and soft cake).
- **Well mashed foods** require very little chewing (e.g. well cooked meat mashed with potato or well cooked vegetables, well cooked pasta or cake mashed with cream).
- **Puree** has a smooth uniform consistency which requires no chewing.
- **Tastes or Flavours** may be offered when eating or drinking is not safe. **Tastes** are a minute amount of puree to be swallowed. A **flavour** has nothing of substance to be swallowed (e.g. what remains on a finger dipped in fluid with the drips shaken off).

**Gastrostomy or PEG (Percutaneous Endoscopic Gastrostomy)** is a surgical opening into the stomach usually for the long term placement of a feeding tube.

**Oesophagus** is the name of the tube which connects the mouth and back of the throat to the stomach.

**Postural Management Programme** is a planned approach encompassing all activities and interventions which impact on an individual's posture and function. Programmes are tailored specifically for each child and may include special seating, night time support, standing supports, orthotics, active exercise, surgery and individual therapy sessions.

**Signs of Aspiration** are clinical observations that have been linked to Aspiration: coughing, wet sounding voice, breathing changes (sound of breathing as well as the rate and manner of breathing), changes in skin colour, whole body reactions, eye widening or watering, or panic reactions evident in facial expression.

**Silent Aspiration** is the term given when aspiration takes place but outward signs of aspiration such as coughing do not occur. Other Signs of Aspiration such as eye widening or watering, or panic reactions evident in facial expression may be observed.

**Suction** is when secretions are cleared from an individual's airway through the use of a specifically designed suction pump.

**Tube Feeding** is when a tube is passed through the nose (or mouth) or through a surgical incision into the body (e.g. naso-gastric tube or gastrostomy). Medication, fluid or a liquid feed may be passed down this tube.

## GENERAL HEADINGS

---

<b>Level I</b>	Eats and drinks safely and efficiently.
<b>Level II</b>	Eats and drinks safely but with some limitations to efficiency.
<b>Level III</b>	Eats and drinks with some limitations to safety; there may be limitations to efficiency.
<b>Level IV</b>	Eats and drinks with significant limitations to safety.
<b>Level V</b>	Unable to eat or drink safely – tube feeding may be considered to provide nutrition.

---

Fuller descriptions of the levels are given below along with distinctions between the levels. These are to assist in determining the level that most closely resembles an individual's current eating and drinking ability.

## LEVEL OF ASSISTANCE REQUIRED

---

An individual's eating and drinking ability will be expressed as a level I-V followed by an indication of the degree of help needed at mealtimes. For example, a child who is able to eat safely with some limitations to efficiency and requires assistance in loading the spoon or steadying a cup would be **EDACS Level II Requires Assistance (RA)**; a child who has an unsafe swallow and is able to bring food and drink to the mouth would be **EDACS Level V Independent (Ind)**.

**Independent (Ind)** indicates that individuals are able to bring food and drink to their own mouth without any assistance. It does not indicate that individuals are able to modify food to the required texture for safe and / or efficient eating and drinking. It also does not indicate that individuals are able to sit independently.

**Requires Assistance (RA)** indicates that an individual needs help to bring food or drink to the mouth, either from another person or through the use of adapted equipment. Help may be needed loading the spoon, placing food in the hand or guiding the individual's hand to the mouth, holding a cup steadily, providing close supervision or verbal prompts.

**Totally Dependent (TD)** indicates that an individual is totally dependent upon another to bring food or drink to the mouth.

## DESCRIPTIONS OF DIFFERENT LEVELS

### Level I Eats and drinks safely and efficiently

- Eats a wide range of different texture foods that are age appropriate.
- May be challenged by some very firm bite and chew foods.
- Moves food from one side of the mouth to the other; may close lips whilst chewing.
- Drinks thin or thick fluids from range of cups with consecutive swallows, including through a straw.
- May cough or gag for very challenging textures.
- Eats and drinks at a similar speed to peers.
- Retains most food or fluid in the mouth.
- Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth.

**Distinctions between I and II:** Compared with Level I, individuals in Level II will have some limitations with more challenging food textures. Eating and drinking will take longer for individuals at Level II.

### Level II Eats and drinks safely but with some limitations to efficiency

- Eats a range of food textures that are age appropriate.
- Challenged by some firm bite, effortful chew, mixed and sticky textures.
- Moves food slowly from one side of the mouth to the other using the tongue.
- May chew with lips open.
- Drinks thin or thick fluids from most cups with consecutive swallows; may drink through a straw.
- Coughs or gags on new or challenging textures or when tiring.
- May sometimes cough if fluid is fast flowing or large quantity taken in the mouth.
- May tire if textures challenging and mealtimes will take longer than for peers.
- Loses small amounts of food or fluid especially challenging textures.
- Some foods will collect on some tooth surfaces and between cheeks and gums.

**Distinctions between II and III:** Individuals in Level II manage most age appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified in order to reduce risk of choking.

### Level III Eats and drinks with some limitations to safety; there may be limitations to efficiency

- Eats puree and mashed food and may bite and chew some soft chew food textures.
- Challenged by large lumps, firm bite and effortful chew textures which may lead to choking and reduced efficiency.
- It is challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating.
- Eating and drinking performance is variable and depends upon overall physical ability, positioning or assistance given.
- May drink from an open cup but drinking from cup with a lid or spout may be required to control the flow of fluid.
- May drink thickened fluids more easily than thin and may need time between sips.
- May choose to drink only in certain situations such as with a trusted carer or with no distractions.
- Specific food textures and positioning of food in mouth are required to reduce the risk of choking.
- May cough or aspirate if fluid is fast flowing or large quantity taken in the mouth.
- May tire whilst eating if food requires chewing and mealtimes will be prolonged.
- Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums.

**Distinctions between III and IV:** Individuals at Level III manage to chew soft lumps. Individuals at Level IV will need close attention given to a number of different factors to swallow food and drink safely because of the significant aspiration and choking risk.

### Level IV Eats and drinks with significant limitations to safety

- Eats smooth purees or well mashed food.
- Challenged by food that requires chewing; choking may occur if lumps are eaten.
- May at times be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.
- It is challenging to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.
- May swallow lumps whole.



- May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking.
- May choose not to drink fluids or to drink only in certain situations such as with trusted carer.
- Likely to need time between mouthfuls to swallow repeatedly before continuing.
- Will require specific food textures, fluid consistency, techniques, skilled carers, positioning and modified environment to reduce risks of aspiration and choking and increase efficiency.
- May tire whilst eating and mealtimes are likely to be prolonged.
- Significant food and fluid loss from the mouth.
- Food may become stuck on tooth surfaces, roof of the mouth and between teeth and gums.
- Supplementary tube feeding may be considered.

**Distinctions between IV and V:** Individuals at Level IV are able to swallow safely only if close attention is given to food texture and fluid consistency as well as the way in which food or drink is offered. Individuals at Level V cannot swallow safely so that taking food or drink in to their mouths will cause harm.

### **Level V** Unable to eat or drink safely – tube feeding may be considered to provide nutrition

- May manage very small tastes or flavours.
- Ability to manage small tastes and flavours will be affected by positioning, personal factors and environmental features.
- Unable to swallow food or drink safely due to limitations to the range and co-ordination of movement for swallowing and breathing.
- It is likely to be challenging to control mouth opening and tongue movement.
- Aspiration and choking are very likely.
- Harm from aspiration is evident.
- May require suction or medication to keep airway clear of secretions.
- Alternative means of providing nutrition such as tube feeding may be considered.



### **Project Team**

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# Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy

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## ABBREVIATIONS

EDACS	Eating and Drinking Ability Classification System
NGP	Nominal group process
SaLT	Speech and language therapist

**AIM** The aim of this study was to develop a valid classification system to describe eating and drinking ability in people with cerebral palsy (CP), and to test its reliability.

**METHOD** The Eating and Drinking Ability Classification System (EDACS) was developed in four stages in consultation with individuals with CP, parents, and health professionals: Stage 1, drafting informed by literature and clinical experience; Stage 2, modification by nominal groups; Stage 3, refinement in an international Delphi survey; and Stage 4, testing of agreement and reliability between classifications made by speech and language therapists (SaLTs), and between SaLTs and parents.

**RESULTS** Seven nominal groups involved 56 participants; 95 people participated in two rounds of the Delphi survey. Using the version of EDACS produced from this process, SaLTs in pairs classified 100 children. The rate of absolute agreement was 78% ( $\kappa=0.72$ ; intraclass correlation coefficient [ICC]=0.93; 95% confidence interval [CI] 0.90–0.95). Any disagreement was only by one level, with one exception. SaLTs and parents classified 48 children. The rate of absolute agreement was 58% ( $\kappa=0.45$ , ICC=0.86; 95% CI 0.76–0.92). Parents either agreed with SaLTs or rated their children as more able by one level.

**INTERPRETATION** The EDACS provides a valid and reliable system for classifying eating and drinking performance of people with CP, for use in both clinical and research contexts.

People with cerebral palsy (CP) are affected by a range of activity limitations, attributed to non-progressive disturbances occurring in the developing fetal or infant brain.<sup>1</sup> The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.<sup>1</sup> Impairments can limit the oral skills required for eating, drinking, and swallowing, with consequent risks of respiratory problems linked to direct aspiration of food and fluid into the lungs,<sup>2–4</sup> and inadequate nutrition and hydration.<sup>5,6</sup> Activity limitations also affect the ability to bring food and drink to the mouth. The degree to which a person with CP can control the posture and movement of the trunk and head has a direct impact on the efficient use of the muscle systems which support feeding and breathing.<sup>7,8</sup>

The prevalence of eating and drinking difficulties in individuals with CP is unclear.<sup>9</sup> Estimates depend on the definitions and tools used, ranging from 27%<sup>10</sup> to 90%.<sup>11</sup> Prevalence has been proposed to be related to severity of motor impairment,<sup>12</sup> although eating and drinking problems have also been reported to occur in individuals at Gross Motor Function Classification System (GMFCS)

levels I and II.<sup>13,14</sup> There is no agreement in the literature about the definition of the terms mild, moderate, and severe in relation to limitations to eating and drinking ability, or whether focus should be at the level of body functions and structures, activity, and/or participation. A recent systematic review identified the lack of a valid and reliable ordinal scale to classify the eating and drinking abilities of people with CP in both clinical and research contexts.<sup>15</sup>

The purpose of this study was to develop the Eating and Drinking Ability Classification System (EDACS) for people with CP, and evaluate its validity and reliability, making use of defined quality standards. Content validity is considered positive if there is a clear statement of purpose of the assessment and clear identification of the target population and concepts being measured. Content should be identified with input from the target population as well as experts and investigators. Reliability is considered satisfactory if the intraclass correlation coefficient (ICC; or weighted kappa) is at least 0.7 in a sample size of at least 50 patients.<sup>16</sup>

The EDACS is analogous and complementary to the GMFCS,<sup>17</sup> the Manual Ability Classification System (MACS)<sup>18</sup> or the Communication Function Classification System (CFCS).<sup>19</sup> Thus, the intention is for the EDACS

to be of use in both research and clinical contexts, by health care professionals and parents.

## METHOD

Development of the EDACS involved four distinct stages, derived from the process set out by the developers of the GMFCS, MACS, and CFCS. The original draft for the EDACS was constructed from the literature and clinical experience. The draft was examined and revised using several iterations of a Nominal Group Process.<sup>20</sup> Further examination and revision to the EDACS took place within two rounds of an online Delphi survey<sup>20,21</sup> until agreement about the content was reached. The final stage assessed reliability between speech and language therapists (SaLTs) and between SaLTs and parents. Ethics approval for the research was granted by National Research Ethics Service Brighton West Research Ethics Committee, REC reference 09/H1111/66; Research Governance was provided by Sussex National Health Service Research Consortium.

### Stage 1: Drafting of the eating and drinking ability classification system

The initial draft was constructed based on reviews of the literature,<sup>3–5,7,8,22–24</sup> clinical experience, and discussion with members of the nutrition team at Chailey Heritage Clinical Services (a SaLT with specialist paediatric dysphagia training, a neurodevelopmental paediatrician, a specialist paediatric dietician, and a nutrition nurse specialist) and Chailey Heritage Research Advisory Group. A hierarchical algorithm model was used to define five levels of eating and drinking ability with reference to the key features of ‘safety’ and ‘efficiency’. ‘Safety’ referred to food or fluid textures that a person with CP could manage to bite, chew, and swallow without risk of harm, choking, aspiration, coughing, or changes to breathing. ‘Efficiency’ referred to loss of food and fluid from the mouth as well as the range and speed of oral movements associated with eating and drinking.

### Stage 2: Nominal group process

#### Participants

The nominal group process (NGP) included 56 invited participants from the UK. Literacy and communication support was available where needed. See Table I for backgrounds of participants.

#### Procedures

The NGP was developed to enable investigation of a particular problem within a face-to-face meeting, to provide a means of aggregating group judgements, and to examine levels of consensus.<sup>20</sup> Seven NGP groups were created in different locations around England where participants examined the content of the EDACS and suggested changes. Two or more members of the project team attended every group meeting, and all members of the project team participated in at least one group; the first author facilitated the groups. At least 1 week before each group

## What this paper adds

- The EDACS provides a valid and reliable system for classifying eating and drinking performance of people with CP.
- The EDACS describes the whole range of ability from age 3 years, providing a context for parents to consider their own child’s eating and drinking.

meeting, participants were sent the latest version of the EDACS. During the session, participants were given time to read the EDACS in silence, and comment individually and in turn on each detail of the system prompted by a series of statements. The statements examined the purpose, content, appropriateness, and clarity of the EDACS draft; participants were encouraged to suggest changes. Feedback from all participants was collated and discussed. At the end of each group, participants were invited to independently select and rank in order of importance five of the suggested changes to the EDACS.

## RESULTS

The EDACS draft was revised progressively throughout the NGP using feedback from group participants. The scores given by participants to the suggestions for change were aggregated for each group; the five most popular suggestions were incorporated into the next draft. Attention was also given to other suggestions, particularly if individuals had ranked them as first or second in order of importance; this ensured that views held by solitary specialists within groups were considered. The revised EDACS draft was presented to the next NGP until no new substantive issues emerged, and only text changes were suggested.

A substantial change to the EDACS draft was the emergence of a separate three-level ordinal scale detailing the level of assistance required at mealtimes. There were differences of opinion among participants about the lower age

**Table I:** Backgrounds of participants in nominal group process and Delphi survey

Background	Nominal group, n=56 (%)	Delphi survey round 1, n=87 (%)	Delphi survey round 2, n=72 (%)
Individuals with neurodisability	2 (4)	7 (7)	8 (10)
Parents of individuals with cerebral palsy	9 (16)	4 (4)	6 (7)
Speech and language therapists/pathologists	21 (37)	46 (46)	35 (42)
Community paediatricians and neurodevelopmental specialists	7 (12)	16 (16)	12 (14)
Nurses	5 (9)	4 (4)	5 (6)
Dieticians	2 (4)	5 (5)	5 (6)
Occupational therapists/physiotherapists	8 (14)	3 (3)	1 (1)
Researchers/epidemiologists	2 (4)	10 (10)	6 (7)
Other	1 (2)	6 (6)	5 (6)
Total	57	101	83

GMFCS, Gross Motor Function Classification System; EDACS, Eating and Drinking Ability Classification System.

limit from which a classification of eating and drinking ability using the EDACS could be made. Mixed views were expressed about whether the EDACS was appropriate to be used by parents, all health care professionals, or only specialists with expert knowledge about eating and drinking.

### **Stage 3: Delphi survey**

#### **Participants**

The first author invited participation in the Delphi survey through specialist networks for people with CP, parents and professionals, as well as by directly approaching people with expert knowledge recognized through publication. Ninety-five international participants, with expert knowledge of CP acquired across five continents, were recruited to take part in the Delphi survey. Participants all had more than 2 years' experience of living with CP, caring for or working with someone with CP (range 2–52y; median 16y; mean 19.6y; SD 11.8y). All participants were asked to identify significant features of eating and drinking for individuals with CP as a means of gauging their level of expertise; no participant's contributions were excluded from the survey because of their response to this question. Hard copies of the survey and literacy and communication support were made available where required. Eighty-seven participants took part in the first round of the Delphi survey; 64 also completed round 2. There were seven participants who participated in the second round who had not responded in first round; one new participant joined in round 2. See Table I for backgrounds of participants.

#### **Procedures**

Delphi surveys provide a means of structuring group interaction, facilitating equal participation, with the potential to preserve the anonymity of participants who contribute their opinions.<sup>20,21</sup> Feedback from each round is given to participants until stability of group opinion or consensus emerges. Participants were asked to examine the content of the EDACS represented in a series of statements, using both open-ended questions and seven-point Likert scales (where 1=strong disagreement, 4=neither agree nor disagree, 7=strong agreement). Surveys were completed either online or on hard copy. The survey was repeated until there was more than 80% agreement for all statements representing the EDACS content. The EDACS was modified after each round using free-text feedback, and returned to all participants with a summary of the group responses and relevant revisions. The conduct of the Delphi survey followed recommended good practice.<sup>25</sup>

### **RESULTS**

More than 80% of participants agreed with 39 out of 42 statements representing the content of the EDACS in round 1, selecting a score of 5 or more on each Likert scale. In the case of the remaining three statements, the levels of agreement were, for statement 22 (EDACS should classify the eating and drinking abilities of individuals with CP from the age of 3y), 58% agreement; for

statement 30 (No other definitions are required), 70% agreement; and, for statement 31 (EDACS should contain five levels, in line with other functional classification systems), 78% agreement.

Changes made to the EDACS following round 1 included revisions to the definitions of terms used and a clearer layout of information presented. Where participants commented on their disagreement with statement 22, 37 out of 41 suggested that classification should take place from diagnosis of CP or at a younger age than 3 years. The EDACS draft was further revised and five statements representing content yet to reach the required level of agreement were sent out for consideration in round 2. These five statements concerned the content and clarity of definitions used, whether the five EDACS levels covered the range of eating and drinking ability, the clarity of the distinctions between the levels, and the validity of the descriptions of eating and drinking ability for people with CP from 3 years of age. All statements received the required level of agreement in round 2.

Fifteen of the 69 participants who agreed with more than 80% of the content of the EDACS in round 1 did not complete the second round of the Delphi survey; 10 out of 18 participants who agreed with less than 80% of the EDACS content did not complete the second round. Overall, 86 out of 87 participants in round 1 and 71 out of 72 participants in round 2 agreed with more than 60% of the content of the EDACS.

The key features of 'safety' and 'efficiency' of eating and drinking, with reference to a range of food textures and fluid consistencies, in five levels of ability, were endorsed. Individuals at level I were agreed to have few limitations to eating and drinking, and individuals at level V are unable to eat and drink. Three levels indicating degree of assistance required when eating and drinking were also defined. The EDACS was agreed to be appropriate from age 3 years. Table II shows general summary headings for the five EDACS levels and three levels of assistance required, alongside the five levels of the GMFCS. The EDACS has been included in Appendix SI (online supporting information) and can be downloaded from the EDACS website ([www.EDACS.org](http://www.EDACS.org)).

### **Stage 4: Reliability**

#### **Participants**

Participants in the reliability study comprised 25 SaLTs with specialist knowledge about eating and drinking and CP, working in special schools in the UK, and 48 parents of children with CP who attended these schools. Although no parent was excluded from the reliability study, participation was dependent upon understanding written English in order to read EDACS and complete the postal survey. The EDACS was used to classify the eating and drinking ability of 129 children and young people with CP (age range 4y–22y; median age 14y; mean age 14y, SD 4y 3mo). Other demographic information collected for the children and young people included sex, GMFCS level,

**Table II:** General summary headings for GMFCS, EDACS, and EDACS levels of assistance

Level	GMFCS	EDACS	EDACS levels of assistance
I	Walks without limitations	Eats and drinks safely and efficiently	Independent
II	Walks with limitations	Eats and drinks safely but with some limitations to efficiency	Requires assistance
III	Walks using a hand-held mobility device	Eats and drinks with some limitations to safety; there may be limitations to efficiency	Totally dependent
IV	Self-mobility with limitations; may use powered mobility	Eats and drinks with significant limitations to safety	
V	Transported in a manual wheelchair	Unable to eat and drink safely – tube feeding may be considered to provide nutrition	

CP subtype, presence of feeding tube, and presence of seizure activity (Tables III and VII).

### Procedures

Pairs of SaLTs who both knew the same child or young person with CP well were asked to classify their eating and drinking performance and levels of assistance required, using their knowledge of the child, case notes and written mealtime guidance. SaLT1 was identified as the therapist who knew the child best and was working with the child on a regular basis; SaLT2 was another therapist who was familiar with the child's eating and drinking ability. Parents of children with CP known to the SaLTs were invited to participate in a postal survey, by rating the eating and drinking ability and levels of assistance required using the EDACS. The survey was returned by 48 of 233 of parents invited (20.6%). The EDACS levels assigned by parents were compared with those assigned by SaLTs ( $n=19$ ) familiar with the child. Neither parents nor SaLTs received any training in using the EDACS; classification was based on instructions provided in the document.

**Table III:** Demographics of children and young people with cerebral palsy (CP) included in reliability studies

Age	
Range	4–22y
Median	14y
Mean	14y (SD 4.3y)
Sex: Males/Females	78/51
GMFCS level, $n$ (%)	
I	7 (5)
II	10 (8)
III	12 (9)
IV	33 (25.6)
V	66 (51.2)
Total	128 <sup>a</sup>
SCPE (CP subtype, $n$ (%))	
Spastic unilateral	5 (4%)
Spastic bilateral	69 (54)
Dyskinetic	37 (29)
Ataxic	4 (3)
Worster-Drought	8 (6.2)
Unclassifiable	5 (4)
Total	128 <sup>a</sup>

<sup>a</sup>Data missing for one participant. GMFCS, Gross Motor Function Classification System; SCPE, Surveillance of Cerebral Palsy in Europe.

Absolute agreement and the extent to which agreement exceeded chance ( $\kappa$ )<sup>26</sup> were calculated between twinned independent observers. Kappa values of 0.41–0.6 indicate moderate agreement, 0.61–0.80 substantial agreement, and values between 0.81 and 1.00 almost perfect agreement.<sup>27</sup> ICCs (two-way random effects single measures consistency) were calculated to assess reliability;<sup>28</sup> an ICC of 0.7 or higher is considered acceptable for measures in groups, and ICCs exceeding 0.9 are regarded as reliable for use clinically with individuals.<sup>29</sup> Kendall's tau was calculated to examine the association between EDACS level and level of assistance required at mealtimes, and the association between EDACS and GMFCS levels.

### RESULTS

Tables IV and V show the results of the reliability studies. When pairs of SaLTs ( $n=19$ ) used the EDACS to rate 100 children (age range 4–22y, mean 14y, SD 4y 3mo), absolute agreement was 78% ( $\kappa=0.72$ , indicating substantial agreement).<sup>27</sup> There was a high level of consistency in

**Table IV:** Reliability measures associated with use of EDACS by speech and language therapists (SaLTs). (a) Reliability of EDACS levels I to V, SaLT1 versus SaLT2. (b) Reliability of EDACS levels of assistance, SaLT1 versus SaLT2

SaLT2	SaLT1					Total
	I	II	III	IV	V	
I	9	3	1	0	0	13
II	1	21	5	0	0	27
III	0	4	12	2	0	18
IV	0	0	3	14	1	18
V	0	0	0	2	22	24
Total	10	28	21	18	23	100

SaLT2	SaLT1			Total
	Independent	Requires assistance	Totally dependent	
Independent	29	5	0	34
Requires assistance	4	15	2	21
Totally dependent	0	2	43	45
Total	33	22	45	100

Values shaded in grey indicate agreement between observers.

(a) Absolute agreement 78%;  $\kappa=0.72$ ; ICC 0.93 (95% CI 0.90–0.95).

(b) Absolute agreement 87%;  $\kappa=0.80$ ; ICC 0.92 (95% CI 0.88–0.94); EDACS, Eating and Drinking Ability Classification System.



**Table V:** Reliability measures associated with use of EDACS by speech and language therapists and parents. (a) Reliability of EDACS levels I to V, SaLT1 versus parents. (b) Reliability of levels of assistance, SaLT1 versus parents

Parent	SaLT 1					Total
	I	II	III	IV	V	
I	1	2	0	0	0	3
II	1	5	5	1	0	12
III	0	1	5	7	0	13
IV	0	0	0	11	3	14
V	0	0	0	0	6	6
Total	2	8	10	19	9	48

Parent	SaLT 1			Total
	Independent	Requires assistance	Totally dependent	
Independent	6	1	0	7
Requires assistance	3	8	3	14
Totally dependent	1	2	23	26
Total	10	11	26	47

Values shaded in grey indicate agreement between observers. (a) Absolute agreement 58%; kappa=0.45; ICC 0.86 95% (CI 0.76–0.92). (b) Absolute agreement 79%; kappa=0.64; ICC 0.77 (95% CI 0.62–0.87).

the use of the EDACS by SaLTs (ICC=0.93; 95% CI 0.90–0.95); where there was disagreement it was only by one level, with one exception. When pairs of SaLTs assigned the degree of assistance required, absolute agreement was 87% (kappa=0.80; ICC=0.92; 95% CI 0.88–0.94), indicating excellent agreement and reliability.

When SaLTs and parents used the EDACS to rate 48 children (age range 4–17y, mean 12y, SD 3.84y), absolute agreement was 58% (kappa=0.45; ICC=0.86; 95% CI 0.76–0.92); for degree of assistance, absolute agreement was 79% (kappa=0.64; ICC=0.77; 95% CI 0.62–0.87), indicating moderate to substantial agreement and good to excellent reliability. Parents either agreed with the SaLT or assigned a level one higher than that assigned by the SaLT, that is, some parents rated their children as more able.

There is a significant positive correlation between EDACS level and level of assistance required to bring food and fluid to the mouth (Kendall's tau=0.69,  $p<0.01$ ). Table VI shows a comparison between GMFCS levels and EDACS levels; there was a statistically significant but only moderate positive correlation between the EDACS and the GMFCS (Kendall's tau=0.5,  $p<0.01$ ), challenging the assumption that individuals with the most severe overall movement difficulties will have the greatest limitations to eating and drinking. Table VII shows the presence of a feeding tube and seizure activity associated with EDACS levels.

## DISCUSSION

The EDACS has been carefully developed using a staged approach, including review of the research literature and clinical experience, NGP, and an online Delphi survey to

**Table VI:** Comparison of EDACS and GMFCS levels<sup>a</sup>

GMFCS level	EDACS level (SaLT1)					Total
	I	II	III	IV	V	
I	0	7	0	0	0	7
II	2	7	0	1	0	10
III	3	3	5	1	0	12
IV	6	8	11	6	2	33
V	1	7	15	20	23	66
Total	12	32	31	28	25	128

<sup>a</sup>Significant but moderate positive correlation between the Eating and Drinking Ability Classification System (EDACS) and Gross Motor Function Classification System (GMFCS); Kendall's tau=0.5,  $p<0.01$ .

**Table VII:** Presence of feeding tube and seizure activity by EDACS level

EDACS level	Feeding tube present, <i>n</i> (%)	Seizure activity present, <i>n</i> (%)
I	1/12 (8)	2/8 (25)
II	1/32 (3)	8/27 (30)
III	5/31 (16)	12/26 (46)
IV	12/28 (43)	16/25 (64)
V	25/26 (96)	19/25 (76)
Total	44/129 (34)	57/111 <sup>a</sup> (51)

<sup>a</sup>Denotes missing data – seizure activity data not available for 18 children. EDACS, Eating and Drinking Ability Classification System.

engage the collective expert knowledge and opinions of a wide range of participants, and reliability testing. We have demonstrated evidence of the content validity of the EDACS, and that classification is broadly reliable.<sup>16</sup> The system describes functional eating and drinking ability in people with CP from the age of 3 years. The EDACS identifies the key features of safety (choking and aspiration risk) and efficiency (time taken in relation to peers and loss of food and fluid from the mouth) linked with limitations to oral skills required for biting, chewing, and swallowing. The level of assistance required at mealtimes is described in a separate scale. The five distinct levels of ability include information about biting, chewing, and swallowing ability, food and fluid textures that are managed, breath changes associated with eating and/or drinking, and risk due to aspiration or choking.

When specialist trained SaLTs use the EDACS to rate the eating and drinking ability of children with CP known to them, measures of agreement and reliability are 'substantial'; measures of agreement for the scale measuring level of assistance required are 'almost perfect'.<sup>27</sup> SaLTs assigned the same level or disagreed by only one level for all but one child, for whom disagreement was by two levels. There are differences in the ways that parents use the EDACS, as indicated by lower agreement. Parents, however, appear generally consistent in the way they use the scale compared with SaLTs, assigning either the same level or one level higher, indicating a greater level of ability. It is unclear from this study whether differences are associated with children's different abilities in different

environments with familiar and unfamiliar carers or whether they arise from different levels of awareness of the risks associated with eating and drinking, such as silent aspiration.<sup>2-4</sup> Feedback during the reliability studies from parents and SaLTs suggested that some differences were linked to different levels of risk that children were exposed to: school environments often limit the exposure of children with CP to food and fluid textures that increase the risks of choking and aspiration, whereas parents are willing to work at the edges of their children's abilities even if this entails emergency interventions. This emphasizes the potential importance of professionals asking parents to classify their child's eating and drinking ability in order to have a fuller understanding of their performance across environments.

The significant but moderate association between the EDACS and the GMFCS highlights the need for eating and drinking ability to be considered separately from gross motor function. The association between eating and drinking ability and the ability to bring food and drink to the mouth is also significant but moderate, supporting the need for these skills to be considered separately. As might be expected, the incidence of tube feeding increases with EDACS levels although feeding tubes were used by some children at EDACS levels I to III. There is, also, an increased incidence of seizure activity with increasing limitations to eating and drinking ability.

The EDACS offers a system for classifying eating and drinking ability that is distinct from detailed clinical assessments and/or guidelines for mealtime management. It provides a means to recognize and distinguish different levels of functional performance to aid communication between people with CP, their parents and different healthcare professionals working in different settings. It provides a context, describing the whole range of ability, for parents to consider and understand their own child's eating and drinking ability. It has the potential to be used in population studies to explore the stability, progression, or regression of eating and drinking ability for individuals with CP, as well as associations with compromised hydration and nutrition, respiratory illness, and other health concerns.

There are limitations to the study in that a large number of parents invited to take part in the reliability studies chose not to return the survey. There were very few responses from parents of children rated by SaLTs as EDACS level I. Reduced variability in the sample can influence assessment of reliability.<sup>28</sup> Some individuals with

CP found the full instruction leaflet difficult to understand and requested a shorter version in plain English. Specific questionnaires to enable family report for the GMFCS have been found to be reliable.<sup>30,31</sup> Future studies could explore the cognitive processes by which parents and professionals use classification systems like the EDACS, and further assessment of the reliability between parents' and professionals' classifications using the EDACS is warranted.

Participants in the NGP and Delphi survey identified the need for the development of descriptions of eating and drinking ability for children with CP younger than 3 years; sufficient research data to outline the developmental progression of eating and drinking ability for children with CP under 3 years were not available when the EDACS draft was under construction. Continued development of the EDACS to describe levels of ability for children with CP under 3 years should be considered.

The EDACS contributes another dimension to the growing family of classification systems (GMFCS, MACS, CFCS) describing functional performance within daily life for people with CP. The EDACS is designed for use by parents and/or professionals, and could facilitate working in partnership, and enable more robust clinical and population-based research.

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## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

**Appendix SI:** Full EDACS documents.

**Appendix SII:** Participants of the Delphi survey who gave consent to the publication of their names.

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# A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy

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## ABBREVIATIONS

ICF	International Classification of Functioning, Disability and Health
PEDI	Pediatric Evaluation of Disability Inventory

**AIM** The aim of this review was to examine systematically the scope, validity, and reliability of ordinal scales used to classify the eating and drinking ability of people with cerebral palsy (CP).

**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 World Health Organization 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.

**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. Eight scales used the terms mild, moderate, and severe (with varying definitions) to describe different aspects of eating and drinking impairment. There was an assessment of either content validity and/or reliability for five scales; however, none met the recommended psychometric quality standards.

**INTERPRETATION** Currently, there is a lack of evidence of the validity and reliability of ordinal scales of functional eating and drinking abilities of people with CP.

Individuals with cerebral palsy (CP) experience activity limitations including limitations in sitting, standing, walking, handling objects, and speaking. Impairments can also interfere with the 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 loss of both food and fluid from the mouth; this can lead to insufficient food and fluid intake to ensure growth and good health,<sup>3-7</sup> as well as adverse respiratory consequences such as episodes of choking and aspiration.<sup>1,8-10</sup>

The prevalence of eating and drinking difficulties in individuals with CP is unclear.<sup>11</sup> Estimates range from 27%<sup>12</sup> to 90%,<sup>13</sup> depending on the definitions and measurement tools used. It has been proposed that prevalence is related to the 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 the measures of eating, drinking, and feeding difficulties.<sup>3,20,21</sup> A survey of international CP surveillance registers revealed that, in 2009, 13 out 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 the prevalence of feeding disorders, and of associations between the severity of eating and drinking limitations and other health indicators 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 in children with neurodevelopmental disabilities.<sup>21</sup> The aim of the current review was to examine the evidence for the validity and reliability of descriptive ordinal scales used to classify the eating and drinking ability of individuals with CP. These scales could then potentially be adopted in clinical and population-based research.

## METHOD

### Search strategy

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 (online supporting information). The searches were conducted up to 14 June 2013. Additionally, forward chasing of citations of key texts (listed in Table SII, online

supporting information) was tracked through Web of Knowledge and Scirus; backward chasing (two generations) of references cited in these key texts was also performed.<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. An 'ordinal scale' was identified when descriptions of eating and drinking ability were placed in three or more ordered categories. Ordinal scales were eligible whether they were derived from clinical or technical assessments, surveys, or 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 that appeared 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

Candidate measures were checked to ensure that they met the requirements of ordinal scales.

Each identified measure was classified according to its type:<sup>26</sup> (1) clinical measures – clinician-administered assessments and checklists; (2) technical measures such as the dynamic fluoroscopic imaging of swallowing (videofluoroscopy), electromyography, flexible endoscopic evaluation of swallowing, or measures of respiration; or (3) patient-reported measures such as patient and/or proxy questionnaires.

### 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 the World Health Organization International Classification of Functioning, Disability and Health (ICF;<sup>30</sup> Table I).

Content validity was considered satisfactory if the purpose of assessment, the target population, and the concepts being measured were clearly identified; content should have been identified with input from the target population as well as experts and investigators. Construct validity was 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

### What this paper adds

- Currently, no valid and reliable scale exists to classify the functional eating and drinking abilities of people with CP.
- Validity and reliability need to be evaluated when classifying eating and drinking in both clinical and research contexts.

reference to kappa<sup>25,31</sup> and intraclass correlation coefficients (ICCs).<sup>28</sup> Reliability was considered satisfactory for population-based research if the ICC (or weighted kappa) was 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. After screening, 722 full-text papers were obtained, of which 464 papers were excluded. In total, 254 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 (Fig. 1). Agreement between reviewers was 98% (kappa=0.95).

Overall, 13 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 gathered in interviews or questionnaires from parents of children with CP or developmental disabilities.<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 Inventory (PEDI).<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 participants 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 utilizing three to six 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 these were 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 the level of assistance required by the child to eat or drink.<sup>6,20,35,40</sup> Three measures made use of the time taken or the duration in order 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>

**Table I:** World Health Organization International Classification of Functioning, Disability and Health (ICF) domains and categories relating to eating and drinking

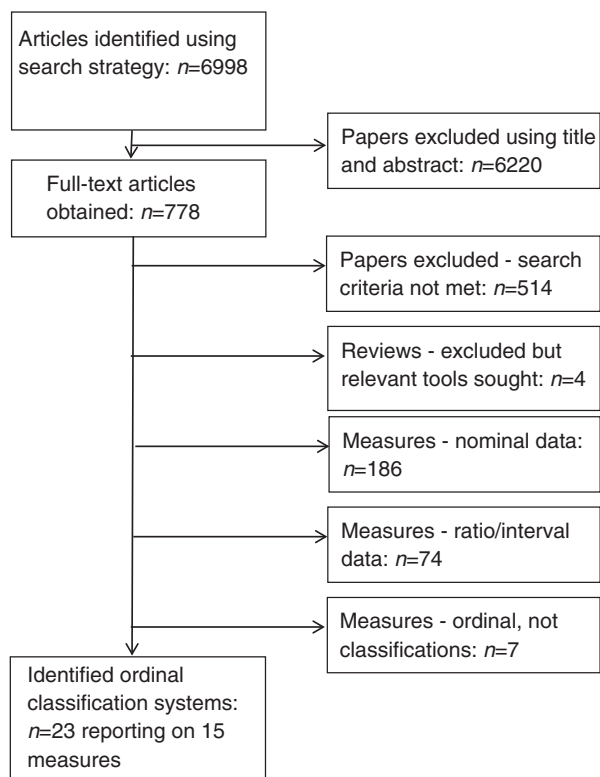
ICF domain	Categories
Body structure (s)	s320: Structure of mouth including teeth
Body function (b)	b510: Ingestion functions. Functions related to taking in and manipulating solids or liquids through the mouth into the body including b5100, sucking; b5101, biting; b5102, chewing; b5103, manipulation of food in the mouth; b5104, salivation; and b5106, regurgitation or vomiting b5105: Swallowing. Functions of clearing the food and drink through the oral cavity, pharynx, and oesophagus into the stomach at an appropriate rate and speed b535: Sensations associated with the digestive system b539: Functions related to the digestive system, including feeding tube b440: Respiration functions. Functions of inhaling air into the lungs, the exchange of gases between air and blood, and exhaling air, including aspiration b450: Additional respiratory functions. Additional functions related to breathing, such as coughing, sneezing, and yawning b126: Temperament and personality functions including attention and 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 b130: 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 b152: Emotional functions. Specific mental functions related to the feeling and affective components of the processes of the mind
Activity (d)	d550: 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 d560: 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 d660: Assisting others with their learning, communicating, self-care, movement, within the house or outside; including self-care, movement, nutrition and health
Participation (d)	d9205: Socializing. Engaging in informal or casual gatherings with others, such as visiting friends or relatives or meeting informally in public places
Environmental factors (e)	e110: Products or substances for personal consumption. Any natural or human-made object or substance gathered, processed, or manufactured for ingestion e1151: Assistive products and technology for personal use in daily living e340: Personal care providers and personal assistants e410: Individual attitudes of immediate family members e5800: 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

The number of constructs assessed to assign a classification category in the different measures ranged from 1, such as the level of assistance required<sup>35</sup> or number of chest infections,<sup>8</sup> to 15.<sup>38</sup> The content assessed by the included measures were coded with reference to the 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 who also received some of their nutrition by tube would not be easily categorized. 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>

The available evidence of the validity and reliability of the different scales is summarized 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 that the source of content for the ordinal scale is laboratory-based studies. Eating curves were developed for the typically developing population based on the 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.<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 ( $r=-0.18$  to  $0.46$ ). In the case of the remaining 11 measures, content validity was not reported.<sup>6,8,13,20,33,35–40</sup> For only one scale<sup>40</sup> were measures of reliability when used by different observers reported ( $n=30$ ; kappa values= $0.43 - 0.61$ ).

Eleven of these measures were found only in peer-reviewed publications by 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



**Figure 1:** The process of identification of ordinal scales used to classify eating and drinking abilities of people with cerebral palsy.

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 only 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. Eight of the scales utilized the terms mild, moderate, and severe; however, each measure defined these terms in different ways. 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 the ability to bite, chew, and swallow. There appears to be a dearth of evidence to support the validity and reliability of any of the published scales.

Attempts to provide simple objective measures of the severity of limitations to eating and drinking, such as mealtime duration, have been challenged because of the multidimensional nature of the activity.<sup>52,53</sup> Some of the included measures use no more than two constructs, such as time taken, food texture, or the ability to self-feed, to clearly define the distinct categories of the 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. By limiting the number of constructs used, scales suitable for use in population studies have been positively applied.<sup>8,20,34,35</sup> However, significant information related to the safety of eating and drinking is omitted from these scales. It may be possible to categorize 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 but experience regular respiratory illnesses associated with primary aspiration, while someone else may be able to ingest 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 categorized 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 to bring food and drink to the mouth but have the oral skills required to bite, chew, and swallow a full range of foods. The reverse can also be observed, most notably in the case of people with Worster-Drought syndrome, in whom the oral skills required to bite, chew, and swallow safely are limited but who suffer no limitations in 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> The most comprehensive measure is derived from a clinical assessment tool for use only by clinicians who have attended certification workshops.<sup>38</sup> Disagreements

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

Scale/author	Scale	User	Sampling frame	ICF category	Content validity	Reliability
Da Graca Andrada et al. <sup>40</sup> – Portuguese survey of CP in Europe scale	Five-level ordinal scale (I–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 4–7y; 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; kappa=0.61 speech and language therapists vs healthcare professionals None reported
Calis et al. <sup>32</sup> – DSS	Four levels linked to DDS <sup>46</sup> part 2 scores: (1) no dysphagia; (2) mild dysphagia; (3) moderate to severe dysphagia; and (4) profound dysphagia (nil by mouth)	Clinician/researcher qualified to use DDS	Individuals with CP; n=166; GMFCS level IV or V; age range 2y 1mo–19y 1mo, mean age 9y 4mo; attending specialized 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	Five-point ordinal scale (1) independent; (2) in need of some assistance; (3) totally dependent upon assistance not tube feeding; (4) partly tube fed; and (5) mainly tube fed. Levels 1 and 2 are children with no 'feeding problems'; levels 3–5 are children with 'feeding problems'	Paediatric neurologist with parents using registration form	Children with CP; n=661; GMFCS levels I–V; age range 3y 8mo – 10y 5mo; on Norwegian CP surveillance register	Total=2: b539 tube feeding; d550/d560 assistance required	None reported	None reported
Erkin et al. <sup>33</sup>	Four 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 level I to V; age range 2–18y; attending Ankara Physical Medicine and Rehabilitation Education and Research Hospital	Total=5: s320 structure of the mouth; b510 ingestion 'feeding difficulty'; b5105 swallowing; b539 tube feeding; e110 food consistencies	None reported	None reported



**Table II:** Continued

Scale/author	Scale	User	Sampling frame	ICF category	Content validity	Reliability
Fung et al. <sup>3</sup> – North American growth questionnaire	Four levels defined by food textures managed: normal, mild, moderate, or severe feeding dysfunction	Clinician/researcher from parent questionnaire	Children with CP; n=230; GMFCS level III to V; age range 5–14y; recruited from six centres in the 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 fluid consistencies	None reported	None reported
Gisel and Alphonse <sup>34</sup> Classification System	Three 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 range 2–16y; 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, age range 2–8y)	None reported
Haley et al. <sup>41</sup> – PEDI	Four levels defined by food textures managed: (1) pureed/blended; (2) ground/lumpy; (3) cut up/chunky; and (4) all food textures	Clinician/researcher from parent report	Children with CP; n=170; GMFCS level I–V; age range 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
Hung et al. <sup>35</sup>	Three levels defined by level of assistance: (1) totally dependent upon caretaker; (2) partially dependent (some help required); and (3) totally independent in feeding	Clinician/researcher from parent report	Children with CP; n=75; age range 5mo–10y; quadriplegia vs hemi- vs diplegia, wheelchair bound vs community walker; attending rehabilitation centre, Chang Gung Memorial Hospital, Kaohsiung Taiwan	Total=1: d550/d560 level of assistance	None reported	None reported
Morton et al. <sup>8</sup>	Three levels defined by respiratory illness: (1) no respiratory infection; (2) minor respiratory infections requiring one course of antibiotics; and (3) recurrent respiratory tract infections with two or more courses of antibiotics	Clinician/researcher	Children with CP; n=26; spastic quadriplegia, unspecified severity; age range 7mo – 16y; attending Derbyshire Children's Hospital	Total=1: b440 respiratory illness	None reported	None reported
Reilly et al. <sup>36</sup>	Four levels defined: (1) no apparent feeding problem; (2) mild swallowing/feeding difficulty; (3) moderate swallowing or feeding difficulty; and (4) severe swallowing and feeding problems	Clinician/researcher	Children with CP; n=30; spastic or athetoid, unspecified severity; age range 4y 4mo – 17y 11mo; 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

**Table II: Continued**

Scale/author	Scale	User	Sampling frame	ICF category	Content validity	Reliability
Reilly et al. <sup>13</sup>	Four 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 range 1–6y; 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	Five 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; and (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; age range 1–18y, mean age 8y 7mo; attending Feeding and Swallowing Advisory Centre at Vranch House Special School, Exeter	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	Five levels: (1) no symptoms; (2) mild; (3) moderate; (4) severe; and (5) 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; e340 special techniques; e5800 management strategies	None reported	None reported
Sullivan et al. <sup>9</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; and (6) self-feeds	Clinician/researcher from parent questionnaire	Children with neurological impairment; n=100; mild, moderate, severe CP; age range 4–13y, mean age 9y SD 2y 5mo; 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>	Three groups defined: (1) minimal or no risk of aspiration; (2) moderate risk of aspiration; and (3) no oral feeding owing to excessive risk of aspiration	Clinician/researcher	Children with CP; n=11; unspecified severity or type of CP; age range 11mo–13y; attending C.S. Mott Children's Hospital, Michigan, USA	Total=3: b440 aspiration; b5105 safety; e5800 special techniques	None reported	None reported

ICF, International Classification of Functioning, Disability and Health; CP, cerebral palsy; DSS, Dysphagia Severity Score; GMFCS, Gross Motor Function Classification System; PEDI, Pediatric Evaluation of Disability Inventory.

**Table III:** Frequency of International Classification of Functioning, Disability and Health (ICF) categories associated with constructs of identified ordinal scales

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

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</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> Categorization of eating and drinking ability on the basis of questionnaire data collected from parents was successfully applied in two large-scale population studies.<sup>3,6</sup> None of the identified measures allow for a direct comparison between ratings made by people themselves or by 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>54</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>1,9,55</sup> 'Silent aspiration', aspiration that takes place without the usual outward signs such as coughing, has also been documented.<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>

There are limitations to this systematic review in that only those scales that had been produced or translated into English were included. Evidence of measures of reliability and validity of the included scales was considered only if it had been published in peer-reviewed studies. Scales used within CP surveillance registers<sup>22</sup> were included only 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 Dysphagia Disorders Survey<sup>46</sup> suggests that 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>56</sup> but data emerging in the review were too limited to warrant the approach.

## Conclusion

None of the scales identified in this review can be considered as valid and reliable ordinal classification systems of eating and drinking ability for people with CP. This systematic review supports the development of a new system to classify eating and drinking through rigorous and robust methods, as have been applied to other classification systems.<sup>16-19</sup> The Gross Motor Function Classification System and other functional classification systems have had a profound impact upon research and clinical practice.<sup>16-18</sup> A valid and reliable classification system of eating and drinking ability would enable more rigorous investigation of prevalence and an exploration of associations between limitations to eating and drinking ability and other health-related concerns. Development of classification systems and measures should include consultation with potential users to ensure content validity. The adoption of such a system by clinical and research communities would be enhanced by attention being paid to levels of consensus about its content and the 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>57</sup> and facilitate more robust clinical and population-based research.

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## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

**Table SI:** Example of search strategy used with MEDLINE.

**Table SII:** Identified key texts and number of papers from forward chasing and backward chasing of citations using Web of Knowledge and Scirus.

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