Development of a nutrition screening tool for school age children with neurodisabilities

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Abstract

Children with neurodisabilities are noted to be smaller and lighter than their non-disabled peers. Many are chronically malnourished and few have had their nutritional status assessed by a dietitian.

The aim of this study was to design a screening tool as a method of screening children with neurodisabilities to ensure the early detection of malnutrition and referral to dietetic services.

The tool was designed using the clinical characteristics of malnutrition for this population. Content validity of the tool was undertaken using a nominal group approach involving 12 expert dietitians. Face validity of the tool was tested with a group of 5 school nurses.

The tool was piloted on 10 nurses and 22 children attending Chailey Heritage School. Levels of agreement were measured using Kappa coefficient scores. The scores highlighted the items on the tool that performed better in terms of having higher levels of agreement with the dietitian, thus identifying malnutrition risk. Inter-rater reliability was explored to determine whether the nurses were using the tool in the same way. Verbal feedback was also sought from the tool users at the end of the data collection period. These results led to several further refinements including the removal of items which did not discriminate between a malnutrition risk and no risk, and re-wording of other items to improve clarity of interpretation.

The refined tool now requires testing for its psychometric properties on a larger group of children.

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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

Dated

Chapter 1 Malnutrition in children with neurodisability

Chapter Overview

This literature review sets the scene for discussion of the nutritional needs of children with neurodisabilities. The concept of nutrition of the healthy child from infancy to the end of adolescence will be explored and how this may differ in children with neurodisability. Current literature (Andrew et al 2010) suggests that poor nutritional status in children with neurodisability is a perpetuating cycle with the effects of the disability leading to worsening nutritional status. Sullivan (2010) also identifies the need for early recognition of children at risk of malnutrition to prevent the perpetuation of the cycle which culminates in continuing deterioration. The literature review within this chapter attempts to identify areas where information is not known because research is not conclusive or has not yet been carried out, which may result in quandaries which dietitians face on a day to day basis when caring for these children. This lack of information could potentially lead to variability of dietetic practice which has been anecdotally noted in dietetic clinical supervision circles (Almond unpublished). The lack of knowledge about nutritional management of children with neurodisabilities may provide scope for future areas of research.

1.0 Neurodisability

Neurodisability, according to the Royal College of Paediatrics and Child Health (RCPCH 2003), is an umbrella term used to describe conditions affecting the brain and central nervous system and includes muscular, developmental, motor, sensory, learning and neuropsychiatric disorders. The most common neurodisability is cerebral palsy (CP), which describes a group of non-progressive permanent disorders of movement and posture which cause limitations to the activities of daily living, communication and self feeding (Rosenbaum et al 2007; Surman et al 2009). Damage to the central nervous system can be due to disease, genetics, oxygen deprivation or acquired brain injury amongst other causes, and can occur antenatally, neonatally or at any stage in a child's life.

1.1 Cerebral palsy definition

Cerebral palsy (CP) has been defined by many (Bax 1964, McCarthy 1992, Gangil et al 2001, Bax et al 2005, Rosenbaum et al 2007) but without consensus. This lack of worldwide agreement became the primary reason that a Surveillance of Cerebral Palsy in Europe group (SCPE) was formed (SCPE 2000). SCPE consisted of fourteen members, covering eight European countries. Cerebral palsy prevalence rates were documented for 3 consecutive years in order to collate data for producing a consensus agreement. Where possible, centers provided information on birth weight specific cerebral palsy rates, subtypes of cerebral palsy, proportion of cerebral palsy children with learning disabilities as well as their own definitions of cerebral palsy. Rules for the definition of cerebral palsy were agreed by all 14 members who then harmonized their databases using the new definitions.

The SCPE agreed definition of cerebral palsy encompasses the following 5 key elements. It

- is an umbrella term covering a range of disorders
- is permanent but not unchanging
- involves a disorder of movement and / or posture and / or motor functions
- is caused by a lesion / abnormality in the cerebral cortex
- is a lesion / abnormality occurred in the developing / immature brain.

Harmonising existing data into the new definitions of cerebral palsy has allowed for comparing of ‘true’ prevalence rates between counties and cities.
An algorithm for clinicians to use to help confirm a diagnosis of cerebral palsy rather than other movement, postural or motor disorders was developed and is included in Appendix 2 of this thesis.

Children with cerebral palsy may also have sensory and intellectual or learning difficulties (Bundy 1991; Bohmer et al. 1997). SCPE have not agreed an IQ score for defining intellectual difficulties however in 10 of the 14 participating centres the reported incidence of intellectual difficulty varied between 23 -56% of children.

1.2 Presentation

There are varying presentations of cerebral palsy depending on the degree of motor involvement.

Damage to the developing brain means that many children have both cognitive and physical difficulties in varying degrees. (Robinson 1973, Hare et al 1998, Sullivan 2008). This suggests that a child whose functional ability is poor can be intellectually able and vice versa. Those with severe motor impairment will be wheelchair bound, require assistance with communication and activities of daily living such as feeding, washing and toileting.

The definition for cerebral palsy suggests that the damage to the brain is permanent, however it effects can transform over time due to physical changes relating to maturation and growth (Hare et al 1998, Sullivan 2008). In reality it is not uncommon to see a relatively mobile young child who has the skills to feed himself independently develop into a severely incapacitated wheelchair bound adolescent who requires tube feeding.

1.3 Prevalence

The occurrence of cerebral palsy is frequently reported to be 2-3 in every 1000 live births (McCarthy 1992b, Pharoah et al 1998, Cronk et al 2001). However incidence cannot be measured at the time of birth as cerebral palsy cannot be diagnosed until the child is old enough for the motor disorder to become evident. The age at which a diagnosis can be made was defined by SCPE to be 4 years, as this is the agreed age at which it is possible to identify the characteristics of the disorder. However delaying diagnosis until this age will automatically exclude all children who died before then. Nevertheless it is a useful benchmark to define the incidence of the disorder within a population.

1.4 Aetiology

The cerebral palsy brain lesion can occur antenatally, neonatally or at a later stage in a child's life. The true proportion of children affected antenatally is not known however, indicators of causes such as genetic predisposition prior to conception or infections encountered during pregnancy amongst others (Stanley et al 2000) can be determined. For those infants who suffered their lesion or insult perinatally, only a fraction is associated with poor obstetric care during birth. The precise figure is unknown as diagnosis cannot be made till developmental milestones are missed, however by the age of 5 years, 0.2% of all births will have cerebral palsy. (Stanley et al. 2000). Obstetric medicine has improved over the years however; the rate of damage that results in cerebral palsy has remained constant at 0.2% by age 5. This may suggest that the actual cause of cerebral palsy occurs during labour and birth rather than during delivery, and that certain infants may be more susceptible to damage than others (Hagberg et al 1996).

Historically children born with brain damage often did not survive however, with the advances of neonatal medicine mortality rates have declined (Hagberg et al 1996) and the incidence of cerebral palsy has increased. This is particularly the case amongst preterm and low birth weight infants (Pharoah et al. 1998) and those infants born from multiple pregnancies (Stanley et al. 2000). Johnson et al (1998) report data from a study undertaken in Oxford in 1984 suggesting that 28.4% of low birth weight (weighing <1500g) premature infants did not walk by the age of 5. By 1992 this had increased to 45.7% (Johnson et al 1998). Cerebral palsy can also be acquired later in a child's life whilst the brain is still immature as a result of exposure to infections which affect the brain, infantile spasms or trauma. Incidence rates of cerebral palsy due to these causal factors differ between countries of the world, for example in Turkey half of postnatal acquired cerebral palsy was reported to be due to infection (Ozmen et al 1993) where as in India, infection was reported to be the causal factor in 74% of all cases (Laisram et al 1992).

1.5 Classification of cerebral palsy

There are many classifications of cerebral palsy. Classifications include being based on the distribution in the body such as monoplegia, diplegia and quadriplegia (Balf et al 1955), the severity of the condition - mild, moderate or severe (Ratanawongsa 2001), the functional ability of the person - spastic, ataxic, dystonic, choreo-athetotic, and mixed (Yokochi et al. 1993), the level of gross motor function (Palisano et al 1997), the level of manual ability (Eliasson et al 2006), the communication function (Hidecker 2011) or eating and drinking ability (Sellers, pending publication). These classification methods rely on the clinical judgment of the physician involved, and with the exception of gross motor function, have not been validated nor had their reliability investigated. However, the most common method for classifying cerebral palsy is provided by SCPE using a second algorithm. See appendix 3.

1.6 Classification by motor ability

A frequently referenced classification system in nutrition research is the gross motor classification system (Sleigh et al 2004, Stenberg et al 2009, Andrew et al 2010). This is a validated grading scale consisting of 5 levels of ability and is the standard method of assessment of children with cerebral palsy used by Allied Health Professionals (Stark 2010). It focuses on self initiated movement with the emphasis on sitting and walking. It has been applied to children with cerebral palsy and has been shown to have good inter-rater reliability and predictive validity when used by clinicians (Palisano et al 1997). The usability has also been tested on parents who have been asked to rate their own children on this scale and accurate results have been obtained (Russell et al. 2000). Thus the use of this classification system may be significant in future descriptions of CP.

1.7 Appearance of children with severe CP

Children with neurodisabilities such as cerebral palsy appear smaller and slimmer than their non disabled peers (Sullivan 2002; Sleigh et al 2004). Their energy intake is often lower than their energy expenditure which implies an element of malnutrition, thus they present as thin children with short statures (Thommessen et al 1991, Reilly et al 1996). Body composition in children with cerebral palsy is also adjusted and studies have shown that these children have decreased muscle mass and lower fat stores (Spender et al. 1989; Stallings et al. 1995). Thus compared to non disabled children they would be classified as chronically malnourished. Moreover energy is not the only nutrient in limited supply. Studies on vitamin and mineral intakes in children with neurodisability are not well documented, but clinical practice suggests that disabled children's intakes of vitamins and minerals are less than the current recommendations as set out by the Department of Health (DOH). This is commonly encountered because small quantities are eaten, only a limited variety of foods are tolerated, and vitamin losses can occur through liquidising foods or long cooking methods to soften foods (Sullivan 2000, Somerville et al 2008).

Until recently there was an acceptance that children with neurodisability were small and thin (Stevenson et al 1995, Andrew et al 2010) and that this resulted from their condition. There was also a belief that it is 'normal' for children with severe disabilities to have small stature and low weights has often been ascribed to their underlying cerebral deficit or physical inactivity rather than to chronic malnutrition (Sanders et al. 1990; Stallings et al. 1993; Samson-Fang et al 2000). Faltering growth or low weight for height has been extensively documented for children with neurodisability (Karle et al 1961, Tobis et al 1961, Krick et al 1984, Thommessen et al 1991). Stallings, in her summary states:

> 'Nutrition and growth status in children and adults with cerebral palsy and other severe types of developmental disabilities, is an essential component of care……. it is clear that many patients with moderate and severe cerebral palsy and other disabilities have malnutrition and growth failure as the result of inadequate caloric intake' (Stallings 1996)

1.8 Summary

Neurodisability including cerebral palsy is not uncommon in the UK population. Children have varying degrees of motor function affecting their ability to participate in activities of daily living including eating and drinking. These children are often noted to be smaller and lighter than their age matched peers which may be as a consequence of insufficient nutritional intake.

The nutritional needs of children with or without neurodisabilities are discussed in the next section of this chapter.

2.0. Nutrition for Children

It is important to establish what normal growth and nutrition is in non-disabled children prior to exploring these issues in children with neurodisability.

2.1 Nutritional needs of children (with or without neurodisability)

The nutritional requirements of all children are quite different to those of adults (Thomas et al 2007). Children grow from birth to 19 years during which there are periods of rapid growth and slower growth. The rate at which children grow has a direct impact upon their nutritional needs at each stage of their development. Infants, from birth to 12 months of age have very high nutritional requirements relative to their size as they triple their birth weight in the first year of life, while increasing their length by 50%.

The nutritional requirements of children can be divided into three groups encompassing the major growth spurts and thus changes in their needs. These groups are:

Preschool children (aged 1-4 years)
School aged children (aged 5-11 years)
Adolescents (12-19 years)

The focus of this thesis is school aged children, therefore the nutritional needs of infants will not be considered.

2.2 Nutritional Requirements

Nutritional requirements for children are based on Dietary Reference Values (DoH 1991). These were published over 20 years ago by the Committee on medical Aspects of Food Policy (COMA) and were based upon actual food intake of healthy active children and the incidence of deficiency. Other than the requirement for energy, they have not since been updated.

The Scientific Advisory Committee on Nutrition was set up in 2001 to replace COMA to advise government on nutritional issues relating to public health. In 2012, SACN published an updated guideline for energy intake for population groups based on more scientifically advanced methods of determining energy expenditure (Total Body Water). This was in context with the growing obese population, and other organisations who had updated their guidelines simultaneously (Food and Agriculture Organization of the United Nations, World

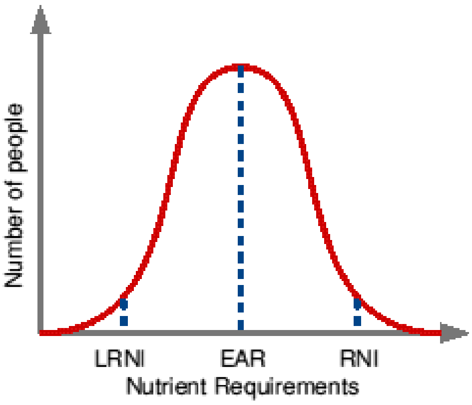
Health Organization, and United Nations University and Institute of Medicine). SACN calculate energy requirements for children by multiplying their Basal Metabolic Rate (BMR) for age by their Physical Activity Level (PAL) which can be one of three levels of intensity: ‘less active’, ‘typically active’ or ‘more active’ (SACN 2011). It is anticipated that in the near future other nutrient guidelines will be updated.

At a European level the European Food Safety Authority (EFSA) has been tasked by the European Commission to re-evaluate up to date scientific evidence and dietary recommendations to update the values for nutrients and energy. Some of these have been published for member states to adopt as necessary, however as yet SACN have not adopted these for the UK and so in practical terms the 1991 DRV’s still apply today (EFSA 2013).

2.3 Dietary Reference Values

DRV (1991) data was gathered by COMA from the average intakes of each nutrient amongst a large population and included children of varying sizes, with varying physical activity levels and also those with and without disabilities. Data forms a normal distribution curve where the mid point of the curve is the Estimated Average Requirement (EAR), two standard deviations above the EAR is considered the Reference Nutrient Intake (RNI) and two 2 standard deviations below the EAR is the Lower Reference Nutrient Intake (LRNI).
The LRNI is the point which signifies that the majority of the population are unlikely to encounter a dietary deficiency if they receive this amount of each nutrient, whereas the EAR is the average intake of the average population.

Children with neurodisabilities are likely be those who were smaller than average in the cohort, and so their nutritional requirements are likely to be closer to the LRNI.



Graph 1. Graph to show the normal distribution curve of nutrient intakes forming Dietary Reference Values. Cited in DoH (1991) Figure 1.1 Dietary reference values - definitions

2.4 The National Diet and Nutrition Survey

Commissioned by the government, the National Diet and Nutrition Survey (NDNS) is a continuous cross-sectional survey, designed to assess the diet, nutrient intake and nutritional status of the general population aged 18 months upwards living in private households in the UK. The first survey on children's dietary intakes was published in 1995 based on data collected in 1992 - 1993 of preschool age children (Gregory et al 1995). School age children's dietary intakes were published in 2000 for data collected in 1997. (Gregory et al. 2000). Headline results from 2008-09 and 2009-10 have been published on the Department of Health website (DoH July 2011). Key findings show that the overall picture of the British diet and nutritional intakes of the UK population is broadly similar to the previous survey.

2.5 Key Nutrients

2.5.1 Macronutrients

The key macronutrients linked to growth are carbohydrate, fat and protein which all provide the body with energy (kcal) for activity and growth. All nutrient requirements are expressed within age groups as age and weight predetermines their values.

Energy and protein requirements vary within each age group as this denotes the difference between males and females, where males tend to need more because they are larger and heavier and thus metabolically have higher requirements than females. For all age groups the requirement for carbohydrate should be 50% of

the total energy consumed with sugar accounting for no more than 11% of this. Similarly fat should constitute 35% of the total energy consumed.
See table below:

Age	**Energy (Kcal)**		**Protein (g)**	**Carbohydrate (g)**	**Fat (g)**
	COMA	**SACN**			
Preschool **1-3 years**	1165 -1230	1076-1386	14.5	145-153	45-48
School age **4-10 years**	1545 -1970	1362-2177	19.7 – 28.3	193-246	60-76
Adolescent **11-18 years**	1845 -2755	2103-3155	41.2 – 55.2	230-344	72-107

Table 1. Nutritional requirements for energy, protein, carbohydrate and fat for children (range denotes males to female variation) taken from DoH 1991, SACN 2011.

2.5.2 Micronutrients

There are several vital micronutrients which are required for adequate growth and development these are listed below:

- Fat soluble vitamins A,D,E & K
- Water soluble vitamins C, B complex
- Sodium
- Potassium
- Calcium
- Magnesium
- Phosphorus
- Iron
- Zinc
- Copper
- Chromium

- Flouride
- Molybdenum
- Manganese
- Chloride
- Selenium
- Iodine

The requirement for sodium and potassium increases within each age bracket with children needing larger amounts as they grow. Males require more calcium because of their size, but the opposite is true for iron where the female requirement is higher due to menstrual losses.

Age	Sodium mmol	Potassium mmol	Calcium Mg	Iron Mg
Preschool 1-3 years	22-30	20-28	352-452	6.1-6.7
School age 4-10 years	30-50	28-50	452-552	6.1-8.9
Adolescents 11-18 years	70	80-90	800-1000	11.2-14.5

Table 2. Nutritional requirements for sodium, potassium, calcium and iron in children. Cited in GOS 2000.

2.6 Preschool age children

The nutritional requirements of preschool children are considerably higher than adolescents and adults when calculated per kilogram of body weight. This is because their rate of growth is twice the rate school age children however it has slowed down when compared to the rate of growth in infancy. Energy requirement of this age group based on DRV data are 95-90kcal / kg (reducing with age) but recently SACN have recalculated this to be around 80 kcal / kg. Energy intake from food however is known to be chaotic where young children consume very little at one meal then make up for it at another (Thomas et al 2007). Despite this variable eating pattern an earlier study by Birch et al (1991) showed that total average energy intakes over a period of time were actually relatively constant indicating that young children are able to self regulate their energy / food intake dependent upon their requirement.

2.7 School aged children

From the age of 5 years energy requirements increase because of growth. The ‘mid growth spurt’ occurs between the ages of 6 and 8 years where energy requirements per Kg of body weight at this age are higher than they are for adults. Children at this age are good at self regulating their intake of food and will vary their food consumption appropriately. Excessive weight gain occurs when children have access to calorie dense foods as opposed to balanced meals. The National Diet and Nutrition Survey’s (Gregory et al 2000, DoH 2011) indicate that mean energy intakes were below the DRV estimated average requirement, yet children were taller and heavier than in 1983. However the SACN recalculation suggests energy requirements are up to 14% lower than the DRV. It is likely that current energy intakes are sufficient rather than low but at the same time children have a reduced level of physical activity than in previous years.

NDNS (2011) suggests that healthy eating guidelines are not being met in this age group. Only 70-190g of fruit and vegetables was consumed daily versus the recommended 400g/day. Less than 0.1portions of oily fish were consumed each week when the guideline is for more than 1 portion per week. Sugar intake is higher (at 19%) than the recommended maximum intake of 11% of food energy, and low biochemical levels of vitamin and mineral status were observed. This was paramount in low income families.

2.8 Adolescents

The pubertal growth spurt lasts approximately 3 years however the age at which it starts differs tremendously between children. The growth spurt is caused by a mixture of sex hormones and growth hormones, thus the nutritional requirements required to match this can only be pinpointed after early sexual characteristics of puberty begin to appear. There is a large increase in height during the adolescent growth spurt which happens in girls earlier than in boys with boys having their growth spurt an average of two years later. Boys may also continue to grow beyond adolescence and into early adulthood. During these periods of rapid growth, energy and nutrient requirements increase with parents often reporting a massive increase in their child's appetite. Energy requirements in adolescences are high with boys requiring approximately 3000kcal / day. SACN guidelines for energy for this age group are between 9 and 18% higher than previously calculated by COMA.

Adolescents who do not receive adequate nutrition during this time (such as those with neurodisability) can result with poor bone growth leading to a lower peak bone mass and height stunting. Severe under-nutrition can delay or stop puberty and halt menarche in girls (Couzinet et al 1999).

The NDNS identified that the nutritional quality of food intake of adolescents was very poor compared to the younger groups, in particular with the micronutrients (Gregory et al. 2000, DoH 2011). Iron deficiency in girls was common and salt intake in both boys and girls was high. There is less parental influence of food choices in adolescence, with teenagers choosing to snack or graze on high salt or sugary snack foods in preference to eating balanced meals (Gregory et al. 2000).

2.9 Summary

The nutritional needs for children are different to those of adults and there is variation through the age groups of childhood and adolescence. Their requirement for nutrients is sometimes mismatched by their nutritional intake and food choices. Additional considerations for children with neurodisabilities are discussed in the next section of this chapter.

3.0 Causes and consequences of malnutrition amongst children with neurodisabilities

In order to investigate fully what the causes and consequences of malnutrition are in children with neurodisabilities, a comprehensive review of the medical and healthcare literature was conducted.

3.1 Search strategy

The following databases were searched between the years 1980 and 2011: Medline, Bandolier, British Nursing Index, Cinahl, Cochrane Library, AMED and Embase. In addition manual searches were undertaken from the bibliographies of papers once they had been reviewed.

The following keywords were used in the searches:

Cause	Malnutrition	Child*	Neurodisability
Reason	Malnourished	Paediatric	Cerebral palsy
Rational	Poor nutrition	Pediatric	CP
Explan*	Undernutrition	Adolescen*	Retardation
Consequence	*nourish	Teen*	Special needs
Result	Food	Youth	Neurodevelopmental delay
Effect	Starvation		
Outcome	Failure to thrive		
	Faltering growth		

Figure 1 Search strategy - keywords to identify causes and consequences of malnutrition in children with neurodisabilities.

3.2 Inclusion criteria

Both qualitative and quantitative, intervention and non-intervention research papers were included in this literature review providing they met the following inclusion criteria:

- Human studies.
- Research papers describing a cause of malnutrition were only included providing the subject group were children with a neurodisability.

- Research papers describing the effects of starvation (i.e. the consequence of malnutrition) were included irrespective of the subject group's age or medical condition.

Papers were not restricted by geography and thus research throughout the whole world was included.

3.3 Evidence appraisal

The titles and abstracts obtained from the electronic searches were assessed for relevance according to the above inclusion criteria before full text articles were obtained and critically appraised. The discussion below describes the findings.

3.4 Causes of malnutrition

Studies have proposed that malnutrition and growth failure are caused by both nutritional and non-nutritional factors, either separately or in combination with each other. The non-nutritional factors effecting growth are hypothesis only and none have been backed up with hard evidence to date (Stevenson et al 1994, Krick et al 1996, Andrew et al 2012). The proposed non-nutritional factors are:

- The damage to the brain has a direct effect on growth/energy regulation (Azcue et al 1996)
- Decreased physical activity results in muscle atrophy (Sanders et al 1990)
- Lack of weight-bearing affects limb and muscle growth e.g. leg length is more compromised than arm length (Sanders et al 1990, Stallings et al 1995)

The nutritional cause is simply:

- Insufficient nutritional intake.

There are many reasons why children with disabilities are unable to obtain sufficient nutrition. Some of these are specific to this patient group where as others can affect any child. These will be explored fully:

3.5 Feeding difficulties

Feeding difficulties are commonly reported in children with cerebral palsy and can affect between 60-90% of children (Dahl et al. 1996; Reilly et al. 1996; Sullivan et al. 2000). Those children with CP who have gross motor, physical or sensory impairments in addition are more likely to struggle more (Sullivan et al 2000). Fung et al conducted a large multi-centre study of 230 children and young people with cerebral palsy, living in the community in USA and Canada. Their findings suggest the level of feeding dysfunction was directly related to degree of under nutrition, and even those who had mild feeding difficulties, had reduced growth and lesser fat stores. The more complex and severe the overall disability is, the more likely the child is to be at nutritional risk (Fung et al 2002). The data on feeding dysfunction was reported by parent by means of a questionnaire and under nutrition calculated by skilled anthropometrists. Similar findings have been produced within the UK via a validated questionnaire sent to 377 families of children with neurodisabilities including cerebral palsy. The intention was to establish the prevalence and severity of feeding dysfunction in this client group. A 72% questionnaire return rate was reported. The findings suggested that 89% of children with neurodisabilities need help with feeding as they are unable to manage to eat unaided and in addition 56% regularly choked at mealtimes. Furthermore 31% had suffered a chest infection within the previous 6 months, which could be related to aspiration of solids (Sullivan 2000). Faltering growth has been linked to a reduced energy intake in children with cerebral palsy (Thommessan et al 1991), and Arrowsmith et al (2010) noted a reduced body weight and body composition measurements in the majority of children with spastic quadriplegia when compared to non disabled children. Thus there is a body of evidence to suggest that feeding difficulties result in less food being eaten resulting in fewer nutrients being received which in turn will contribute to the development of malnutrition.

Feeding difficulties can be improved by adjustment to the posture, environment and manipulation of feeding utensils. However, despite these modifications feeding dysfunction is never completely resolved, and as a child grows these factors must be reviewed on a regular basis. The multidisciplinary feeding team involved in a feeding assessment will include an occupational therapist, physiotherapist, speech and language therapist and dietitian as they all need to be involved in considering the optimum environment for mealtimes.

Muscle tone can also affect the child’s ability to coordinate hand to mouth movement and thus their ability to self feed. Both Reilly et al (1996) and Thomas et al (1989) found that more than half of all children with cerebral palsy had significant difficulty with self feeding.

3.6 Dysphagia

Oral motor dysfunction resulting in dysphagia is prevalent in children with CP (Krick et al 1984, Reilly et al 1995, Reilly et al 1996, Southall et al 2011). According to a survey by Field et al (2003), children with cerebral palsy form the largest group of referrals into dysphagia clinics. Dysfunction may result from either structural abnormalities such as high roof of the mouth, enlarged tongue, abnormal dentition or fine motor difficulties. The more severely affected the child's oral motor skills are, the greater the likelihood of feeding difficulties and so the higher the risk is of malnutrition (Fung et al 2002).

There are five stages of swallowing or deglutition which is the process of food or fluid moving from table to stomach. These all need to be functioning correctly for the safe and efficient passage of fluid or solids to the stomach.
The five stages are:

Anticipatory stage

This includes all the activities taking place before feeding occurs and is extremely important as the entire swallowing process can be disrupted if the child is not prepared to receive the food or drink. The child with neurodisability needs as much information as possible about the mealtime in order to organise the movements of the jaw, lips, tongue etc and breathing.

Oral preparatory stage

This begins once the food has reached the lips and is prepared in the mouth before swallowing. The process consists of head and jaw movements including voluntary opening of the mouth, lip closure around the utensil or biting food, transferring the food around the mouth including chewing, sorting and mixing to form a bolus and holding on to this bolus ready for swallowing. Problems with altered muscle tone, which affect this stage, include an inability to open mouth voluntarily, inadequate lip closure and so loss of foods and fluids, tongue thrust due to low tone and possible aspiration. Oral hypersensitivity indicated by food refusal or hyposensitivity indicated by poor trigger of swallow is also seen in those with neurodisabilities.

Oral stage

This relates to the initiation of the swallow and involves elevation of the front of the tongue to seal the mouth, propulsion of the bolus by the tongue to the back of the mouth and raising the soft palate to provide a nasopharyngeal seal. Difficulties seen at this stage include lack of co-ordination of tongue movement, incomplete nasopharyngeal seal and risk of aspiration.

Pharyngeal stage

This is an involuntary stage triggered by the closure of the pharynx. The bolus of food is transported through the pharynx and into the oesophagus by peristalsis. Closure of the vocal fold prevents aspiration. Indications of problems at this stage include coughing, choking, gagging and aspiration and can be due to ineffective function of peristalsis or any part of the pharyngeal anatomy.

Oesophageal stage

This depends on the peristaltic action of oesophageal muscles to propel the bolus of food into the stomach and the contraction of the criopharyngeus muscle to prevent reflux. Common difficulties arising at this stage include oesophageal obstruction and gastro-oesophageal reflux.

3.7 Sensory and perceptual difficulties

Sensory impairments such as visual abnormalities and perceptual difficulties resulting in an altered interpretation of the senses can impact on eating and drinking skills (Barnes 2001, Jefferies 2001). The result can be a reduced desire to eat and subsequent malnutrition. The use of verbal prompts can be useful to clarify the child’s expectation of the mealtime. A running commentary of the meal can be helpful for the visually impaired child to help them prepare for the type or amount of food offered (Jefferies 2001).

3.8 Mobility

The disabled child will not be able to seek food independently like able bodied children are able to do, thus their nutritional intake is solely dependent upon what is given to the child (Straus et al 1998).

3.9 Posture

A small study of 6 children in which videofluroscopy using barium isotope identified that when children with cerebral palsy were reclined by 30 degrees for feeding, aspiration decreased (Lanert et al 1995). Logermann in 1998 noted head position influences swallow. Managing to get the optimal head position for successful swallowing is dependent on trunk control. The trunk and pelvis must be stabilised in order for the head to be stable enough for the fine oral motor movements (Langley et al 1991, Jones-Owens 1991, Herman et al 1999, Seikel et al 2000).

Positioning to achieve core stability and optimal head position is essential for a child with neurodisabilities to have the best opportunity for a successful mealtime experience (Bosma 1992, Stevenson et al 1996, Reilly et al 2010). This demonstrates the close relationship between oral motor ability and postural and seating needs, and further supports the multidisciplinary element necessary in a feeding team.

3.10 Communication

A child or young person with a severe neurodisability may not be able to verbalise or signal their wish for food. There are many reasons why difficulties in communication can effect feeding in children with neurodisabilities, as well as being unable to adequately make requests, a child may be unable to tell their carer if the food is too hot, cold, being fed to them to quickly or whether they like or dislike the food on offer. This inability to make their request heard also contributes to an increased risk of insufficient nutrition, as these children are unable to make the same demands that their non-disabled counterparts do (Latham et al 2000). Feeding children can be stressful for the parents and carers and as a result mealtimes are often not the enjoyable social occasions they are for others (Sullivan et al 2004, Venness et al 2008).

It is known that neurodisability can affect oral motor skills (Krick et al 1984, Reilly et al 1995, Reilly et al 1996, Southall et al 2011). As a child grows older or their condition progresses, their oral motor abilities may also change which can result in difficulties with managing food and drinks. Children with unrecognized feeding difficulties may be incorrectly interpreted at meal times. Often rejection of certain textures or consistencies can be mistaken for the child being fussy, disliking the food, lazy or being badly behaved (Jefferies 2001). They may even display self injurious behavior or pica as a sign of distress. Furthermore an inability to vocalize means that carers may not recognize when eating and drinking causes discomfort (Southall et al 2012). The child's way of displaying this may initially be food refusal or passive behavior at mealtimes or, if in extreme discomfort or pain, can result in confused non-verbal signals such as excessive movements and spasm (Jefferies 2001).

3.11 Dental Problems

Dental caries can be caused by a number of factors in children with disabilities including poor dental hygiene due to hypersensitivity to teeth cleaning, cariogenic medications, an inability to clear the mouth of food after eating, reduced saliva production, gastro oesophageal reflux disease (GORD) causing gastric acids to erode the teeth and frequent consumption of cariogenic foods. Poor dentition can result in pain which will in turn reduce food intake and contribute to malnutrition. Also a child in pain who can't communicate is likely to exhibit negative behaviors around what he feels is the cause i.e. food and drink, thus increasing feeding difficulties and reduced food intake (Jefferies 2001).

3.12 Gastrointestinal problems

Digestive problems can result in malnutrition in any human being, however in children with complex disabilities there are certain problems which are commonly seen over others. These are:

- Gastro oesophageal reflux disease
- Gastric dysrhythmias
- Delayed gastric emptying
- Constipation

3.13 Gastro oesophageal reflux disease (GORD)

GORD is commonly documented and can be as prevent as 70-90% in children with severe neurological impairment (Sondheimer et al 1979, Wesley et al 1981, Gustafsson et al 1994, Heine et al 1995, Del Giudice et al 1999). It is the passage of stomach contents into the oesophagus and mouth (vomit) which causes secondary complications such as faltering growth, oesophagitis and feeding difficulties. Its mechanism is attributed to the child's motility disorder being present in the upper gastrointestinal tract which leads to regurgitation of stomach contents (Rudolph et al. 2001).

3.14 Gastric dysrhythmias

This is a second most common gastrointestinal problem in neurologically impaired children. Its mechanism is a heightened emetic reflex secondary to vagal nerve dysfunction or an anatomical abnormality (Kawahara et al. 1997). The symptom is vomiting and the condition can be as common as GORD thus it is frequently mistaken for this and is often the reason why surgical treatment for GORD is considered ineffective (Ravelli et al 1998). GORD and gastric dysrythmias differ from vomiting, which is the emetic reflex following ingested toxins, which acts as a protective mechanism.

3.15 Delayed gastric emptying

Delayed gastric emptying times are also regularly seen which exacerbate both GORD and gastric dysrythmias as the contents of the stomach is present for longer than usual thus the frequency for vomits is higher.

3.16 Management of Gastrointestinal problems

All these conditions impact on nutritional status as they can contribute to faltering growth and malnutrition, because the child is unable to keep ingested food in their stomach long enough for digestion and absorption. They can also cause discomfort and pain as oesophagitis can result from frequent passage of the acidic stomach contents into the mouth and so children may refuse food or display 'fussy eating' behaviour because they associate eating with pain.

Treatment of mild GORD is managed by drug therapy and success can be attained using a combination of Prokinetic agents, H_2 receptor antagonists and

Proton Pump Inhibitors. In more severe cases when drug therapy fails, the child may be offered antireflux surgery (fundoplication).

Antireflux surgery involves wrapping the fundus of the stomach around the base of the oesophagus to prevent regurgitation of gastric contents. It relieves symptoms of vomiting in many patients, however morbidity and recurrence is especially high in neurologically impaired children (Stringel et al 1989, Spitz et al 1993, Kimber et al 1998, Sullivan 1999). Side effects from the surgery include gas bloating, disabling retching, dumping syndrome and altered gut motility resulting in diarrhoea all of which have nutritional significance (Spitz et al 1993, Sullivan 1999, Hussain et al 2002). Although the fundoplication provides an anti-reflux barrier, the underlying dysmotility remains and if retching or attempted vomiting are not controlled by continuing drug therapy, slippage or unwrapping of the fundoplication can occur (Hassall 2005). Hassall suggests that, in view of the potential misdiagnosis of gastric dysrythmias as GORD in neurologically impaired children and of the complications of anti-reflux surgery, it should only be performed when all alternative therapy has failed such as experimenting with postural management, drug therapy and post-pyloric feeding (Sullivan 1999).

3.17 Constipation

Constipation is a common problem for children with neurodisabilities (Sullivan et al 2000, Bohmer et al 2001, Sullivan 2008). Constipation can occur as a result of inadequate fluid intake, excessive fluid loss via spillage, poor lip closure, poor head control or dribbling which are all caused by poor oral motor skills (Park 2004). Other reasons include lack of mobility, incorrect positioning, abnormal gastric motility, side effects of medication and lack of the urge to defecate. Occasionally a lack of dietary fibre may be the reason (Parkman-Williams 1998, Chong 2001, Shaw et al 2002, Sullivan 2008).

The nutritional consequence is that constipation produces a feeling of fullness and so has a negative effect on appetite and therefore food intake, which can lead to malnutrition. Dietetic assessment is necessary in order to avoid significant nutritional compromise (Clayden 1996) and to define whether treatment needs to be supplementation with dietary fibre or simply to increase the child's fluid intake (Liebl et al 1990, Tolia et al 1997, Trier et al 1998, Staiano et al 2000, Tse et al 2000, Daly et al 2004).

Constipation has also been linked to increased seizure activity although this has not yet been studied in detail to be considered consistently true (Epilepsy Research UK 2008).

3.18 Social issues

Mealtimes should be enjoyable social occasions; however mealtimes can be stressful events for both the parents and children with feeding difficulties. The usual family mealtime routine may require modification to allow for additional time, adjusting posture and texture of food in order to eat a meal and successfully obtain adequate nutrition. There is little empirical evidence to support the impact on social inclusion at mealtimes; however one small study (Venness et al 2008) explored the characteristics of the communication at mealtimes between 20 mothers and their children with cerebral palsy. Findings were that mothers dominated communications and the child's role was more passive.

Financial difficulties are also known to be greater in a family where there is a disabled child (Quine et al 1985; Jefferies 2001). Social eating such as eating out, picnics and barbecues are limited unless careful arrangements are made prior to the event, thus the opportunity to learn normal mealtime behaviour is reduced.

Government documents have stated that children with disabilities and their families should live as 'ordinary' a life as possible (NSF Standard 8: 'Disabled children and young people and those with complex health needs' states that they should. '*receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives (DoH 2004).*

There is also significant pressure on the carer and expectations to provide a nutritionally balanced, correct consistency diet whilst ensuring the child is in the correct position. The practice required for development of oral motor skills can understandably be stressful. Time is also a major consideration, as it takes longer to prepare a modified diet and feed a child with feeding difficulties. One study of children with cerebral palsy and oral motor dysfunction showed that some required up to18 times longer than non disabled children for every mouthful of food (Gisel et al 1988).

3.19 Medication

Children on medication may experience side effects which directly or indirectly affect their nutrition. Anti-convulsant therapy, can cause taste changes, affect appetite, cause drowsiness induce nausea and gastro-intestinal irritation (Guo et al 2001, Harvey 2003). Moreover, changes in medication may negatively or positively impact on oral skills, e.g. the introduction of a muscle relaxant may improve the position of the child during feeding. Oral medications especially in liquid forms commonly have unpleasant flavours and cause reluctance in accepting food in which the child suspects it is hidden.

3.20 Summary

In summary, the reason why children with complex disabilities are malnourished is multifactorial. Whilst the simple explanation is that they do not receive adequate nutrition, the reasons underpinning this are as a consequence of one or a combination of the above factors. Thus these children present as being small and thin because they have not had enough nutrition to grow and gain weight. This claim was substantiated when, in the 1970's, enteral feeding was introduced. The evidence clearly demonstrated that children who experienced such feeding (and thus received adequate nutrition) began to grow. (Sanders et al 1990, Thommessen et al 1991, Stevenson 1996, Corwin et al 1996, Samson-Fang et al 1998).

4.0 Consequences of malnutrition

4.1 Physical / medical consequences of malnutrition

Malnutrition is defined by Elia in 2000 as:

“a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein and other nutrients causes measurable adverse effects on tissue body form (body shape, size, composition), body function and clinical outcome.” Malnutrition is common and is a major public health concern in the UK (Elia 2003). There more than 3 million people at any one time in the UK malnourished (Elia 2009).

In the1970’s the prevalence of malnutrition was identified in hospitals (Bistran et al 1974, Hill et al 1977) and it is still a common problem in hospitals today. Between 10% and 60% of patients being admitted to hospital are at risk of developing malnutrition during their stay as identified by the Malnutrition Universal Screening Tool (Stratton 2005). In children the prevalence of acute malnutrition varies between 6-14% in hospitalised children surveyed in Germany, France and the United Kingdom (Puntis 2009, McCarthy 2008, Moy 1990). The overall prevalence of malnutrition including chronically growth restricted children was 19% of hospital admissions in the Netherlands (Joosten et al 2010).

Malnutrition is most common in the very young and very old. Patients requiring critical care, undergoing surgery, with burns, malignancy, renal, respiratory and gastrointestinal problems are at greatest risk (Bistran et al 1974, Hill et al 1977, Elia 2003, Stratton 2005).

Malnutrition is dangerous and the consequences are positively linked to poorer health status and reduced ability to participate in normal activities of daily living (Samson-Fang et al 2002). Malnutrition affects every system in the body. As well as adverse effects on physical health, it also affects psychological wellbeing (Stratton et al 2003). If left undetected and untreated its consequences are wide ranging and include:

Effect	Consequence
Impaired immune response	Impaired ability to fight infection.
Reduced muscle strength and fatigue	Inactivity and reduced ability to self-care. Poor muscle function may result in falls, and in the case of poor respiratory muscle function result in poor cough pressure – delaying expectoration and recovery from chest infection.
Inactivity	In bed-bound patients, this may result in pressure ulcers and venous blood clots, which can break loose and embolise.
Loss of temperature regulation	Hypothermia with consequent further loss of muscle strength.
Impaired wound healing	Increased wound-related complications, such as infections and un-united fractures. Poor outcomes post surgery.
Impaired ability to regulate salt and fluid	Predisposes to over-hydration, or dehydration.
Impaired ability to regulate periods	Impaired reproductive function.
Impaired foetal and infant programming	Malnutrition during pregnancy predisposes to common chronic diseases such as cardiovascular disease, stroke and diabetes (in adulthood).

Effect	Consequence
Specific nutrient deficiencies	Anaemia and other consequences of iron, vitamin and trace element deficiency.
Impaired psycho-social function	Even when uncomplicated by disease, malnutrition causes apathy, depression, introversion, self-neglect, hypochondriasis, loss of libido and deterioration in social interactions (including mother-child bonding).
Additional effects specific to children and adolescents	Growth failure and stunting, delayed sexual development, reduced adolescents muscle mass and strength, impaired neuro-cognitive development, rickets and increased lifetime osteoporosis risk.

Table 3. Clinical effects of malnutrition (adapted from Combating Malnutrition: Recommendations for Action, BAPEN 2009)

Children and adults in the community, who are at risk of malnutrition or are already malnourished are more likely to be admitted to hospital for minor ailments (Martyn et al 1998). It is also known that they visit their GP more often than their well nourished counterparts (Stratton et al 2002). Once in hospital patients at risk of malnutrition stay in hospital significantly longer and are more likely to be discharged to other healthcare facilities rather than directly to home. Studies on nutrition support and intervention whilst in hospital have had positive outcomes on decreased length of hospital stay and improved nutritional status (Robinson et al 1987, Chima et al 1997) .

Malnutrition and its consequences require greater use of healthcare resources and thus the financial impact to the health economy is great. In 2005 the cost of malnutrition was estimated to be in excess of £7billion (Elia et al 2005) and this is increasing. The health and social care costs associated with malnutrition are estimated to amount to at least £13 billion annually (Elia 2009).

NICE Guidance published in 2009 identified nutrition as the fourth largest potential cost saving to the NHS and as a result nutrition has also been identified in the SHA Chief Nurses eight 'high impact actions' that could make huge cost savings for the whole health economy.

Over the last few years NHS Trusts nationally have started to make small investments in dietetic services in order to achieve savings (Guest et al 2011; Meijers et al 2012; NICE 2012, NICE 2013).

4.2 Dietetic services in paediatric neurodisability

Despite extensive knowledge of the causes, consequences and cost of malnutrition, in clinical practice paediatric multidisciplinary teams for children with neurodisability still do not routinely focus on nutrition (Parkes et al 2001). The impact of which is the late identification of children of children who are already malnourished or at risk of becoming so. Malnutrition is often noticed later rather than earlier in life, for example when the child had difficulty maintaining centile curves during growth spurts or did not enter puberty at the expected time (Sullivan et al 2000). A later study of 100 children, conducted by the same research team highlighted that 64% of children with neuro-developmental delay had never had their feeding and nutrition assessed. A recommendation from the study was that children with neurological impairments would benefit from individualized nutrition assessments to improve health outcomes (Sullivan et al 2002).

The importance of good nutrition is a relatively new concept in paediatric neurodisability, and therefore changes within the structure of child development centers and clinical services attending to special needs schools are yet to be established. Many medics and therapists are still unaware of the importance of nutrition and further malnutrition education would be beneficial.

Anecdotally colleagues have commented that dietetic provision remains limited, many special needs schools do not commission regular visits from the dietitian and child development centres do not have access to nutrition advice. Consequently disabled children often are only identified as needing dietetic intervention when malnutrition becomes marked, (Hartley et al 2003) and then are referred on to long waiting lists often in acute hospital dietetic departments, who may or may not have the specialist expertise required to successfully manage the nutritional state of neurodisabled children.

5.0 Nutritional assessment and dietetic management

The nutritional management of children involves firstly the assessment of nutritional status, growth, food intake and ability to eat prior to estimating nutritional requirements and determining the most appropriate nutritional management plan for each individual child. The next section of the literature review will discuss each of these steps.

5.1 Assessing nutritional status

There are several parameters which should be considered when carrying out a dietetic assessment. In terms of assessing the nutrition status of the child various factors should be considered and each one in turn is discussed below. Nutritional assessment is intended to be an in-depth examination of an individual's nutritional state and as such is a fundamental component of dietetic practice (Thomas et al 2007), and should only be carried out by suitable qualified individuals.

5.1.1 Physical examination

The physical appearance of a child can provide an indication of their nutritional status. An appearance of emaciation indicates that the child may not be receiving adequate nutrition in comparison to their requirements and this is a common feature in neurodisability as discussed earlier in this chapter. Often the liver is palpable as hepatomegaly can be a consequence of malnutrition including micronutrient deficiency (zinc), however this can also indicate other medical conditions and as such, this examination should be carried out by a physician. Changes in the condition of a child's hair (wiry) or hair loss can also indicate malnutrition in terms of micronutrient deficiency (Grover et al 2009). This is typically associated with low vitamin A status. Low iron can present in changes to the nails presenting with fissures or ridges and skin may appear dry, cracked and more susceptible to breakdown. Fluid retention (oedema) particularly around the ankles and wrists is also seen and in severe cases oedema can be widespread generalised across the body.

In chronic malnutrition children will have a decreased amount of subcutaneous fat and muscle wasting may also be seen. This is sometimes referred to as moon face, where the eyes appear sunken. This can also be apparent in the hands, buttocks and thighs. A useful table of physical signs of malnutrition is in a paper by Grover et al (2009).

Site	**Sign**
Face	Moon face (kwashiorkor), simian facies (marasmus)
Eye	Dry eyes, pale conjunctiva, Bitot's spots (vitamin A), periorbital edema
Mouth	Angular stomatitis, cheilitis, glossitis, spongy bleeding gums (vitamin C), parotid enlargement
Teeth	Enamel mottling, delayed eruption
Hair	Dull, sparse, brittle hair, hypopigmentation, flag sign (alternating bands of light and normal color), broomstick eyelashes, alopecia
Skin	Loose and wrinkled (marasmus), shiny and edematous (kwashiorkor), dry, follicular hyperkeratosis, patchy hyper- and hypopigmentation, erosions, poor wound healing
Nail	Koilonychia, thin and soft nail plates, fissures or ridges
Musculature	Muscles wasting, particularly in the buttocks and thighs
Skeletal	Deformities usually a result of calcium, vitamin D, or vitamin C deficiencies
Abdomen	Distended - hepatomegaly with fatty liver, ascites may be present
Cardiovascular	Bradycardia, hypotension, reduced cardiac output, small vessel vasculopathy
Neurologic	Global development delay, loss of knee and ankle reflexes, poor memory
Hematological	Pallor, petechiae, bleeding diathesis
Behavior	Lethargic, apathetic

Table 4 Physical signs of malnutrition (Grover et al 2009).

5.2 Growth

Growth refers to a positive change in size over a period of time. In children growth is measured by changes in height and changes in weight. Stunted growth is defined when changes in height and / or weight do not happen or in the case of weight there is a negative change. Child development defines the achievement of developmental milestones which are not discussed here.

5.2.1 Weight

Weight is a sensitive indicator of changes in nutritional status. Changes in weight occur more rapidly than in any other parameter used to measure the effect of nutrition, so is often the primary measurement used. A survey of dietitians practice in children with neurodisability by Hartley at al (2003) reported that 98% of responders used weight to assess nutritional status (Hartley et al 2003). Weight is often the easiest measurement to take however, can be more troublesome in a disabled child, due to their inability to stand unsupported on scales (Hartley et al 2003). Alternative weighing machines such as wheelchair scales and hoist scales are available in most child development centres and some special schools, however obtaining a weight can be a lengthy process due to the need to take a child out of their wheelchair in order to weigh the equipment or position the child in a hoist sling.

In order to be useful weight should be measured routinely on the most appropriate weighing equipment for the individual child or situation (Stevenson 1996). There is no evidence comparing the accuracy of the various weighing methods, thus all have to be assumed to be equal to each other at this point in time, however the method chosen for the individual child should be used on consecutive occasions.

5.2.2 Height

Height is an extremely useful measurement to have in determining a child’s nutritional status as it is a measure of growth and thus a direct illustration of adequate nutrition. Height for age calculations can be made to determine whether the child’s growth has been retarded or stunted. Height age can be calculated and is a crude measure of bone age which is considered best practice to use to calculate a child’s nutritional requirements (Jefferies 2001), See chapter 1, section 5.4.2.

Accurate height measures are often difficult to obtain in disabled children and young people, due to scoliosis or kyphosis caused by a twisted posture or contractures of the spine (Sanders et al 1990). Where possible a standing height is preferable however a supine length is an acceptable second choice (Stewart et al 2006.). A supine length measures longer than a standing height thus serial measures using the same technique should be used.

Where accurate length or height is not possible then there are three suggested alternatives in the literature; upper arm length, lower leg length and knee height all of which have been found to correlate highly with actual height (Spender et al 1989, Stallings et al 1995, Stevenson 1995). These techniques are detailed in appendix 5 of this thesis however; competence to use them with minimal inter-observer error can only be achieved with frequent and regular practice.

When an alternative length measurement is chosen, consecutive measures should be made on the same limb to minimise variation. There are centiles specifically for each of the alternative measurements based on American data measured in the 1970's (Synder et al 1977) however these tables are presently not widely available within the UK. The exception being, centiles for tibial length but these are for ambulatory children with cerebral palsy only (Oeffinger et al 2010). Therefore converting the measure into a height and plotting on a standard growth chart is the suggested alternative (Stevenson 1995). Only 8.8% of Hartley et al's (2003) survey of dietitians used an alternative measure to ascertain height, which indicates that despite good evidence of its accuracy and the difficulties in obtaining standing height, alternative measurements are not commonly used amongst dietitians (Hartley et al 2003).

As with any segmental measure there are potential sources of error, in particular inter and intra-observer error is noted and therefore it is recommended that the same person carry out serial measurements.

5.2.3 Weight for height calculations

This calculation reflects the child's weight appropriateness to height without consideration of their age. It indicates whether the child's weight is within the normal limits for their height or length or if not the severity of malnutrition or degree of obesity. There is only one reference for this calculation with in the literature relating to children with neurodisabilities which states that weight for height centiles lack sensitivity for identifying depleted fat stores in children with cerebral palsy (Samson-Fang et al 2000).

5.2.4 Body Mass Index (BMI)

BMI uses weight, height and age combined to give a degree of fatness within the normal limits of age. There are only three references to BMI and children with cerebral palsy in the literature. Day et al (2007) published growth charts which included a BMI chart specifically for children with cerebral palsy which for the first time allows this measure to be interpreted within the norms of growth in the cerebral palsy population. Hurvitz et al (2008) used BMI to identify children with cerebral palsy who were overweight and underweight from his clinic population, and concluded that using this measure it appears that children with cerebral palsy have a high rate of being overweight. However, the BMI calculations were plotted on standard American growth charts and not those produced by Day (2007). These are produced from healthy non-disabled children with normal activity levels. Therefore the implication is that the children are being compared against an inappropriate control group and so results should be interpreted with caution. Samson-Fang (2000) reports that BMI was a poor indicator of low body fat in children with cerebral palsy, but again this was carried out prior to the publication of Day's cerebral palsy growth charts (Samson-Fang et al 2000). Further research using Day's BMI charts is anticipated.

5.2.5 Body composition

There is good evidence that body composition of disabled children can be ascertained by measuring skin fold thickness (Stallings et al 1993, Stallings et al 1995, Stevenson 1996, Samson-Fang et al 2000). Triceps and subscapular skin fold thickness in particular correlates highly with true fat and fat free mass when compared to reference standards (Frisancho 1981). However in routine practice, it can be difficult to take accurate skin fold thickness measurements for example a subscapular skin fold thickness measurement may be impractical due to the need to remove supportive clothing or spinal jackets (Stewart et al 2006). Calf anthropometrics are often easier to obtain however if the child has limited use of this muscle, such as those with diplegia or quadriplegia, skin fold thicknesses may overestimate the amount of fat as muscle wasting will be significant (Kong et al 2005). In practical terms annual serial measurements of mid arm circumference using a tape measure and triceps skin fold thickness with a caliper can be a useful monitoring tool when plotted on Tanner-Whitehouse skin fold charts (Tanner et al 1975).

5.2.6 Bioelectrical impedance (BEI)

This technique is used frequently with adults to measure body composition. It is a non invasive test which passes a low voltage electrical current through the body and measures resistance against this current. The resistance measured is total body water and from this an estimation of fat free mass and fat mass can be made using conversion calculations. Anecdotally there has been an assumption amongst dietitians that BEI would be very difficult to carry out on children as it involves the requirement for them to lay still for periods of time. In disabled children this has always been considered to be even more troublesome. However Liu et al (2005) validated this technique in children with neurodisability in a small study of 8 children with cerebral palsy. Excellent correlation coefficients (above 0.9) for determining fat free mass was reported but only moderate correlations (between 0.4-0.8) were observed for fat mass (Liu et al 2005). This was repeated by Veugelers in 2006 on a larger sample of 35 children with cerebral palsy (Veugelers et al. 2006). Although resistance was difficult to measure initially, the authors concluded that in a relaxing and non threatening environment a valid measure was obtainable and they were able to achieve this in 71% of their sample. This exciting finding prompted a further prospective study by Bell et al (2010a) which attempted to measure bioelectric impedance along with other parameters in terms of a longitudinal study looking in to the growth, nutrition and sedentary behaviour of children with cerebral palsy. Toumoum et al (2010) following this published a study describing a significantly altered body composition in children with cerebral palsy with lower fat mass, fat free mass, total body water and basal metabolic rate than children without cerebral palsy. There was no suggestion that there was any difficulty measuring resistance in cerebral palsied children. However this was contradicted by Sert et al (2009) who found that lean body mass and fat mass were the same as children without cerebral palsy who also claimed that bioelectrical impedance can easily be carried out on children with cerebral palsy. The potential for BEI to determine body composition in children with neurodisability is exciting but due to the controversial findings thus far, further research is required to determine whether this truly is a useful technique.

5.2.7 Critical periods of growth

In order for infants, children and adolescents to achieve their potential for growth and development, nutritional intervention must be provided at critical periods of time. In infancy Sanders's prospective study demonstrated the importance of early intervention during the first year of central nervous system (CNS) damage in order to prevent or reverse growth deficits comparing against older children (Sanders, Cox et al. 1990). This study showed that supplying adequate nutrition to this age group is crucial to prevent future growth problems.

Pre puberty it is known that children who do not receive adequate nutrition during these years often have delayed puberty (Marshall 1978; Frisch 1983) and this is seen routinely in clinical practice. Furthermore those who do not receive adequate nutrition during puberty appear to lose weight velocity and become thin as time progresses (Beattie 2010).

A study in 2007 by Day et al, showed that children with lower gross motor function tended to gain weight in a straight line pattern when plotting weight for age centiles as opposed to the logistic S shaped curved observed in the general population (Day et al. 2007). This phenomenon occurred irrespective of whether they were fed orally or via a tube. This shows that children with severe cerebral palsy do not display the same 'growth spurts' as the normal population and may further support the hypothesis that non-nutritional growth factors are also involved in the reasons why the appearance of children with neurodisability is different.

5.2.8 Interpretation of growth data

Day et al (2007) were the first to report growth patterns in a US population of children and adolescents with cerebral palsy. Prior to this, interpretation of growth data for children with cerebral palsy had been unclear as no large studies had been completed to establish normal growth profiles for these children, so it was uncertain whether typical parameters for identifying faltering growth in non disabled children was appropriate for this group. Growth charts for children with cerebral palsy had been suggested by Krick et al (1996) however they were never reproduced for clinical use and in fact were based on a small study sample size and poor method of data collection, thus had questionable use in routine practice (Krick et al 1996).

Day et al (2007) however presented growth charts for children aged 2 to 20 years with cerebral palsy. Data was based on serial measurements collected over a 15 year period from a large population of almost 25,000 children in California. The evidence Day provided during this lengthy study, was that children with more severe cerebral palsy weigh less and have a smaller stature. This was already known reported by other authors (Thommessen et al 1991, Reilly et al 1996, Sullivan 2002, Fung et al 2002, Sleigh et al 2004). However this led to the publication of individual growth charts for five groups of children stratified by their gross motor ability, and for each of these groups separate charts were produced for males and females, totalling 30 growth charts for children with cerebral palsy.

The data collected showed that female children with mild cerebral palsy i.e. those who could walk well alone, had a similar potential for weight gain as female children without cerebral palsy, however while males showed this pattern in the early years, as they got older weights fell consistently below weights for the general population. The trend for lower weight than the general population worsens across the declining motor function and also the gaps widen with age. What is interesting however, is that the earlier study by Krick et al (1996) showed very similar results, although their sample size was small and methodology questionable as discussed above, the data they collected was correct for the cerebral palsy population (Krick et al 1996). Prior to the publication of Day's growth charts in 2007, all studies compared the growth of children with cerebral palsy against healthy non disabled children using the standard UK Child Growth Foundation growth charts. Vik et al (2001) showed almost a third of children with cerebral palsy were found to have a height-for-age below the 25th centile on these charts and only 7% were classified as being obese with weight above the 97.5th centile (Vik et al 2001). This indicates that children with CP are smaller and lighter than their non disabled peers. Growth trajectories appear on lower centiles on the standard UK Child Growth Foundation charts which are created from a large population of normal healthy children and do not take into account the differences seen in height and weight of disabled children. Day's cerebral palsy charts may be useful for monitoring the growth of children but they cannot be presented as an ideal standard of growth for this group of children as this has yet to be determined.

5.3 Assessment of nutritional intake

The purpose of conducting a dietary assessment is to obtain a quantitative measure of the nutrients consumed on a daily basis. They are also useful to identify meal patterns, habits and compliance with dietary prescriptions. There are several methods for assessing or measuring usual food intake.

5.3.1 Dietary assessments

Dietary assessments can be measured by weighing food and fluids or more simply by recall, they require keeping a record or diary of everything consumed over a specified period of time. Weighed food intakes involve patients weighing each item before and after the meal and recording the actual amount consumed. A detailed diary describing the food needs to be kept. Recall methods can include actual intake where food is recorded in a diary at the time of consumption, or 24 hour recall with estimated portion sizes, or usual intake via historical interview with the patient. The current evidence to support the methods of assessing food intake in children with neurodisabilities is poor (Reilly et al 1996, Stallings 1996, Fung et al 2002). There are three common methods of dietary assessment detailed in the literature: food diaries, dietary recall and food frequency questionnaires. All available evidence emphasizes that no method gives truly accurate information on food intake and over-reporting is a problem (SACN 2008) and can be as high as 54% over the actual intake (Stallings 1996). Calis et al (2010) reported a study using food diaries to measure energy intake of children with severe cerebral palsy. The findings suggested that there was no correlation between the child’s reported energy intake and their nutritional status. However, this finding needs to be considered in the context of the problems associated with the use of food diaries such as under and over reporting (Bingham et al 1994, Day et al 2001). Thus the use of food diaries to determine nutritional intake is questionable. Despite this they are popular and are frequently used by dietitians. Hartley et al (2003) reported that 100% of the dietitians in their study used diaries to ascertain dietary intake. More recent research also indicates the use of food diaries and reports that they are a tool that is regularly employed to draw conclusions about the food intake of children with cerebral palsy (Kilpinen-Loisa et al 2009). Knowing that parents over report and that there appears to be no correlation between food intake and nutritional status, the data arising from the use of food diaries need to be interpreted with caution.

However all methods of dietary assessment can be useful for assessing meal patterns and the types of food offered and eaten, but simple observation of a child at a mealtime may be more useful and can highlight other factors that affect dietary intake such as the child's posture, their oral abilities, physical feeding skills and the mealtime environment (Stewart et al 2006). The benefits of observing a child's feeding at home has been emphasised by several researchers (Bax 1989, Reilly et al 1996). However, the numbers of dietitians actually participating in home visits has been shown to be low at 21% (Hartley et al 2003). Home visits are time consuming and often minimised with the dietitians time focussed on clinic appointments where there is a greater throughput of patients.

5.3.2 Feeding assessments

A Speech and Language Therapist's (SALT) feeding assessment provides vital information for identifying children at risk from poor nutritional status (Reilly et al 1996, Thomas et al 2000, Troughton et al 2001, Fung et al 2002) . Studies indicate that feeding dysfunction is related to nutritional risk and even those who had mild dysfunction were still lighter and shorter than their peers (Reilly et al 1996, Fung et al 2002). A SALT feeding assessment also may highlight any problems with drooling or excess salivation, which can be useful for the dietitian in estimating fluid requirements. Hartley et al (2003) suggest that, just over 50% of dietitians worked in a multidisciplinary team which included a SALT. This suggests that the remaining half of dietitians may not have access to a speech and language therapists feeding assessment (Hartley et al 2003).

5.4 Assessing nutritional requirements

5.4.1 Energy

Most disabled children have lower resting energy expenditure due to reduced mobility and low muscle tone thus often their total requirement for energy is lower. The exceptions are the small number of children with athetoid or mixed cerebral palsy who have many involuntary movements and thus may have energy requirements closer to the norm. The majority of prediction equations and Dietary Reference Values therefore overestimate their energy needs (Bandini et al 1991, Azcue et al 1996, Hogan 2004). This has been reflected in projects carried out by the Oxford Feeding Study research team, where disabled children tended to lay down stores of fat rather than muscle when tube fed beyond their requirement (Vernon-Roberts et al 2002, Bachlet et al 2003). However the amount is yet to be established. A more recent publication by the Oxford Feeding team has suggested that children with spastic quadriplegic cerebral palsy fed at 75% of the estimated average requirement for energy continued to grow (Vernon-Roberts et al 2010).

There are three key papers that explore estimating the energy requirements of children with neurodisabilities. However, a consensus on the most appropriate methodology to be used has yet to be agreed.

Krick et al (1992) advocated a prediction equation as a method of calculating nutritional requirements (Krick et al 1992). The study involved only 27 non ambulatory children aged 9 months to 18 years with cerebral palsy who were observed as inpatients in hospital for an average of 32 days. The prediction equation used muscle tone, activity and growth in its formula. The equation was based on a complex series of calculations including some clinical judgements and adjustments and making several assumptions informed by studies not relevant to this population (Culley et al 1969, Spady et al 1976). Thus it was not a robust tool. Furthermore the children involved in the study were unwell, requiring hospitalisation and therefore the results would not be transferable to children living in the community.

This complicated and flawed method was impractical to use routinely in everyday clinical practice. A modified simpler version was published in the previous edition of Clinical Paediatric Dietetics (Jefferies 2001) however, it was not recommended for use because it was based on the subjective opinion of the author and not validated for use (Almond et al 2007).

A later study published in 2002 by the Oxford Feeding team, suggested that energy requirements could be as low as 63% of the EAR for children with cerebral palsy (Vernon-Roberts et al 2002). It reported that despite receiving comparatively low energy diets these children appeared to lay down more fat stores than their non disabled peers. Since then, a small but well controlled study published in 2010, by the same team, measured body composition as well as energy requirements. This has shown that children fed with a median energy intake of 48.8% of the EAR grew well with no significant increase in fat mass (Vernon-Roberts et al 2010).

The most recent paper is a review paper by a Canadian dietitian Hogan, who evaluated a number of formulae for calculating energy requirements and attempts to apply these to a population of children with cerebral palsy (Hogan 2004). The formulae they evaluated include the Harris Benedict equation, the Schofield equation, the Mayo clinic normogram and the WHO equation all of which are routinely used in dietetics to predict energy requirement in normal healthy adult populations. All were found to overestimate the needs of individuals with cerebral palsy. The Schofield equation, determined from 114 studies on basal metabolic rate, and which used the weight and height of the subject, had the lowest prediction error; however this was just 40% (Hogan 2004). Hogan (2004), however, suggests that the best method of assessing energy requirements is by indirect calorimetry, but this is a research instrument and is not widely available in clinical settings, moreover it requires the subject to lay still which is not something a child with the involuntary movements of cerebral palsy could manage. Her summary concludes that the Krick equation is appropriate as it has been designed specifically for children with cerebral palsy however, she does not critically evaluate it nor acknowledge the clinical limitations.

However what is known is that children with neurodisability are smaller than their non-disabled counterparts, thus the consensus amongst practitioners is that height age may be more appropriate then chronological age when looking for a basis for estimating nutritional requirements (DISC unpublished).

5.4.2 Height age

Height age is the term referred to which describes the age the child would be if their height was on the 50th centile of their growth chart. For example a short 9 year old boy whose height is on the 0.4th centile for their actual age, would have a height age of 5.5 years. This is the age at which their height hits the 50th centile when traced back in time. See appendix 4.

Currently until further research becomes available, dietetic clinical consensus is to use height age as a basis to estimate energy needs, reflecting the child's actual size not necessarily their age. This preliminary figure should be adjusted depending on whether weight loss or weight gain is needed. In general a child entering their pubertal growth spurt will require more energy than one who is not. In practice the energy requirement is often no more than 75% of the EAR for height age and often considerably less.

The exceptions to this rule are those children with mixed cerebral palsy which includes an athetoid component. Excessive involuntary movements and high muscle tone will mean that their energy requirements may actually be higher and closer to the Estimated Average Requirement (EAR) for height age. In practice dietitians need to monitor the growth and weight gain of the child against their nutritional intake to determine what they actually need.

5.4.3 Protein and micronutrients

There are currently no studies that advise on suitable levels of these nutrients. However as disabled children tend to be smaller than non-disabled age matched peers, Dietary Reference Values for chronological age are likely to be surplus to their actual need (DoH 1991). Thus using the same rationale as energy, height age may be more appropriate than chronological age for nutrient estimations (Jefferies 2001).

Interestingly, inadequate sodium and potassium intakes versus the RNI are commonly reported by dietitians however there is no published data to support this, but the child always remains asymptomatic and blood and urine levels are maintained within the normal ranges. This further supports the theory that the nutritional requirements of children with neurodisability may be lower than their non disabled counterparts.

5.4.4 Fluid

Again, there are no studies available to advise how to calculate fluid requirements, however a professional consensus document was produced by Great Ormond Street Hospital in 2000 to be applied to all children (GOS 2000). The calculation given is based on body weight and is irrespective of the child's age. However what is interesting to note is that in clinical practice many disabled children appear well hydrated despite only managing to take a lower fluid intake than calculated. This is well documented within clinical meetings.

5.4.5 Fibre

Currently there are no UK recommendations for fibre intake in children. Williams et al (1995) in America suggest the following calculation predicts a child's fibre requirement.

Fibre requirement (g/ day) = Age (years) + 5g to 10g.

Thus a 10 year old child would have a requirement of 15 to 20g / day. This calculation is based on a survey of the intakes of dietary fibre of children in America between the years of 1976 and 1988 (Williams et al 1995). This was compared to recommendations made by the American Academy of Paediatrics Committee on Nutrition for levels of fibre for certain health benefits as well as levels leading to adverse effects. As a result the new recommendation above was produced based on the age of the child, heath benefits and safety concerns (Williams et al 1995).

5.5 Dietetic Management

5.5.1 Treatment of the malnourished child

The aim of the treatment of a malnourished child with neurodisability is the same as for any malnourished child; to maximise nutritional intake in order to meet nutritional requirements for normal growth and development.

5.5.2 Non Dietetic treatment

Consideration will need to be given to the causes of inadequate nutrition for interventions to be successful, for example if a child has visual impairment and is afraid to eat as he is unsure of what food will be coming, no amounts of additional nutrition will overcome this problem. This child may need sensory integration therapy to overcome his fear of mealtimes for an improvement in his nutritional status. Non nutritional strategies should be considered within the multidisciplinary team, such as asking the occupational therapist and physiotherapist to review the child's seating and posture for maximum benefit for oral feeding.

5.5.3 Dietetic treatment

5.5.3.1 Oral nutrition support

When dietary intervention is required the child can be placed on a high calorie, nutrient dense diet in order to encourage growth. Dietary advice given to the parent and carer using ordinary foods and fluids is the first step in nutrition support and frequent consumption of meals, snacks and nourishing drinks is encouraged. Nutrient dense foods such as full fat dairy products, meat, fish and eggs, all cooked using butter or oil would routinely be advised (Thomas et al 2007). Meals can be enriched further without increasing the volume by adding cream, cheese or butter to enhance energy density. Snacks using foods often considered being ‘unhealthy’ such as cake, chocolate, biscuits, pastries, crisps etc are often advised to be eaten in between meals, but should never replace meals.

Prescribed nutritional supplements are available in the form of sip feeds, milkshakes, fortified puddings, fat emulsions, glucose polymers, protein powders or a combination of these which can also be used to supplement the diet when food alone is insufficient. However they are sometimes considered to be unpalatable and can be filling and thus may inhibit appetite.

5.5.3.2 Enteral nutrition support

When oral nutrition support has failed to be sufficient to correct or prevent malnutrition, enteral nutrition support is the next step (NICE 2006). Enteral feeding directly into the stomach via a nasogastric or gastrostomy tube provides a means of delivering nutritionally complete enteral feeds to the child whilst bypassing the mouth. Feeds can also be delivered post pylorically into the duodenum or jejunum for those with gastric stasis or those who could be at risk of aspirating stomach contents.

Feeds can be delivered as the sole source of nutrition or as a top up to the amount that the child can manage orally. Various enteral feed formulae are commercially available in order to meet the varied requirements of individual children.

Disabled children form the largest group of children requiring long term home enteral tube feeding in the UK (Jones et al 2005). Furthermore data is collected annually by means of British Artificial Nutrition Survey (BANS) a voluntary system for gathering data related to home enteral tube feeding across the UK. BANS data details 30% of all new BANS registrations each year are from children with neuro related conditions and this figure has been stable for many years (BAPEN 2011).

5.5.3.2.1 Home enteral tube feeding

Gastrostomy feeding is more commonly used than nasogastric tube feeding in children with neurodisabilities as it is considered to be safer by minimising the risks of tube displacement and possible feeding into the lungs. Children with neurodisabilities often have unusual structural anatomy which makes placement of nasogastric feeding tubes more difficult. Moreover involuntary movements and spasms may cause the tube to be dislodged and more simply nasogastric tubes can be pulled out by hand. Due to the tube displacement risk of nasogastric tube feeding, prior to each feed the position of the tube needs to be ascertained which is checked by aspirating a small amount of gastric contents and testing its PH for acid using pH paper. This is absolutely necessary as feeding into the lungs can be fatal. Testing can be problematic as Gastro oesophageal reflux is a common problem for these children and is often managed by H_2 receptor antagonist medication which increases gastric PH thus making clarification of tube placement by PH impossible. Tube placement can be confirmed by x-ray but this is impractical in the community as its position needs to be tested prior to every feed.

For these reasons gastrostomy tube feeding is preferred. Initially parents are often against the idea of having a gastrostomy placed for feeding and require information, support and all the time they need to make their choice for or against placement (Craig et al 2003, Guerriere et al 2003). Feeding a child is one of the most basic means of nurture and parents (particularly mothers) struggle to come to terms with handing this responsibility over to clinicians. Familiarisation with feeding equipment, watching a video and supplying relevant literature as well as meeting other families who have a child with a gastrostomy are often helpful. Following gastrostomy placement the quality of life for caregivers has been found to improve dramatically (Tawfik et al 1997, Smith et al 1999, Sullivan et al 2004).

5.5.3.2.2 Delivery of enteral feeds

Continuous overnight pump feeding can be a useful addition to the child’s diet without interfering with appetite or mealtimes and thus is a preferred method.

However, children who are very restless at night or those with gastro oesophageal reflux disease and may be at risk of aspirating stomach contents, may be precluded from continuous overnight feeding for safety reasons. For those children who are unable to eat and drink due to inadequate oral motor skills, bolus feeds can be delivered at mealtimes to mimic the normal physiology of eating. The regimen should consider the family routine and allow the child to take part in daytime activities and should be flexible enough to be able to be adjusted as and when required to suit changes in living circumstances.

5.5.3.2.3 Benefits of enteral feeding

There is evidence that children begin to grow when adequate nutrition is provided via an enteral tube (Patrick et al 1986, Rempell et al 1988, Sanders et al 1990, Thommessen et al 1991, Corwin et al 1996, Stevenson 1998, Samson-Fang 2003, Rogers 2004) Increase in weight is very apparent however height is more sensitive but does occur more readily in younger children supporting the suggestion that there are critical periods for optimum growth. (Patrick et al 1986, Rempel et al 1988, Sanders et al 1990, Stevenson 1998, Thommessen et al 1991, Corwin et al 1996, Samson-Fang 2003, Rogers 2004). A prospective study published in 1999 by Brant et al explored weight and height changes in children with cerebral palsy receiving gastrostomy feeds, with the intention of identifying the optimal age range that would benefit most from enteral feeding (Brant et al 1999). The small study involved only twenty children who were reviewed monthly to assess nutritional status in order to evaluate nutritional improvement. All children showed improvement in weight, but changes in height and body composition did not reach statistical significance. Whilst the sample size was small, the main confounding factor was that not all the children received an adequate nutritional review in order to determine improvement in nutritional status. The range of time dedicated to follow up varied from only 2 months to 10 months, which may not be adequate to determine the effectiveness of the enteral tube feed. When the data was broken down into age groups the sample sizes were very small, some with only 3 children per sample. All age groups showed improvement in weight gain but none showed improvement in height. The 2-4 year olds, 5-7 year olds and 12-18 year olds all showed improvements in body composition methods but this must be interpreted with caution due to very small sample sizes.

In 2004 a Cochrane review was published entitled Gastrostomy Feeding versus oral feeding alone, for children with cerebral palsy (Sleigh et al 2004). It attempted to identify conclusive evidence to support enteral tube feeding but there were no good quality research studies available. The same author also conducted a systematic review of the literature on gastrostomy feeding in cerebral palsy (Sleigh et al. 2004). This revealed that benefits of the procedure are hard to assess from the available evidence because of the methodological weakness of most of the studies included. Subsequently Sullivan et al (2005a) published a prospective study on 57 children, from 3 UK centres, who were reviewed at 6 months and one year post gastrostomy insertion for nutritional improvement. Data capture was made as robust as possible with the same observer taking repeated measures on each child. Findings showed a statistically significant increase in weight, length, head circumference and several body composition measures. Other benefits included that children had fewer chest infections and hospital admissions. This is an important study as it provides the evidence that was identified as lacking in the Cochrane review (Sleigh et al 2004).

Day et al (2007) conducted a large study involving a sample of 141,961 children with cerebral palsy in the state of California USA to obtain anthropometric data to study growth patterns of children with cerebral palsy with view to producing growth charts (Day et al 2007). As well as the development of growth charts (discussed earlier in this thesis) the research team identified that children who were enterally tube fed tended to weigh heavier and measure taller than those who were fed orally. This further supports the notion that nutrition plays a significant role in growth.

A more recent study (2008) of 45 young children up to the age of 9.1 years with spastic quadriplegic cerebral palsy was carried out. The children received nutrition support for 6 months but there is no description of the route that this was administered ie orally, enterally or parenterally. Data was obtained for 31 children due to drop outs who did not attend follow up appointments. However, the study noted improvements in constipation, anthropometrics and a decreased number of infections. It is not evident however, if is the improvement was directly related to enteral feeding or nutrition support in general. (Soylu et al 2008).

5.5.3.2.4 Complications of enteral feeding

Gastrostomy tube feeding is not without its complications. It is a surgical procedure and so has associated risks which are not uncommon in clinical practice, however there is only one paper published on this matter (Sullivan et al. 2005a). In this observational study there was only one report of a serious post gastrostomy surgical complication. Other minor complications within one year of tube placement included minor gastrostomy site infections around the wound and over granulation tissue in approximately half of the patients. A further third of the cohort had leakage from the gastrostomy site. Despite the good evidence that gastrostomy feeding improves nutritional status and growth, it is not without its complications. This must be fully understood by parents and carers before making such a decision.

5.5.4 Additional Considerations

There are two sets of anomalies which occur in relation to enteral feeding in children with neurodisability which need separate consideration. These are:

- Children with very low energy requirements
- Children with altered body composition

5.5.4.1 Children with very low energy requirements

Some children with neurodisabilities have very low energy requirements. Feeding with standard enteral formulae can result in them becoming overweight easily (Bandini et al 1995). However, in order to reduce their energy intake to prevent excessive weight gain, protein and micronutrient intake will be reduced to drastically low levels. Careful calculating of feeding regimens must be undertaken by dietitian to ensure that when feeding these children that at least the LRNI is met for protein and micronutrients and children are not at risk of developing nutritional deficiencies. Special low energy formulae, is now available for this group of children however in some circumstances supplementation of micronutrients may also be necessary.

Conversely those children who have been overfed in order to provide adequate micronutrients have become overweight as expected. However, they have also been found to have altered body composition with an increased fat mass (Andrew et al 2010).

5.5.4.2 Children with altered body composition

Enterally fed children with neurodisabilities have been found to have higher mean percentage body fat than orally fed children with neurodisablility or able bodied children (Sullivan et al 2004, Sullivan et al 2006). It has been suggested that in the face of minimal physical activity, energy from any macronutrient which is being supplied in excess of requirements, is being converted in the body and stored as fat. It is likely that either energy requirements are being over estimated by dietitians when preparing feeding regimens or macronutrient requirements are being over prescribed in an attempt to meet micronutrient requirements. Therefore to encourage a small thin child to gain weight and grow via enteral tube feeding may result in the promotion of fat stores rather than lean body mass. In clinical practice therefore it is advisable to ‘underfeed’ initially and monitor the child closely so that adjustments can be made to the volume given if the anticipated weight gain or growth is not achieved.

Similarly, there are extraordinary variations in both bone and muscle tissue in neurodisabled children when compared to the non-disabled population (Smith et al 1999), which is thought to be secondary to the effects of altered muscle tone, involuntary movement, immobility and posture. This unusual body composition could theoretically impact on the basal metabolic rate and thus skew the nutritional requirements and growth rate of children with neurodisability. This could be an important area for future research.

5.5.5 Dietetic monitoring

Dietetic monitoring of children with neurodisability is actually the re-assessment of their nutritional needs. Since their last dietetic review, the child may or may not have grown taller and weight may or may not have changed. This is because of the difficulty in predicting their nutritional requirements. Despite which of these has occurred, re-calculation and re-assessment is necessary. Monitoring children therefore can be as lengthy as the initial assessment. There are no guidelines to suggest how often children with neurodisabilities receiving nutritional intervention should be re-assessed and so this currently is left to the discretion of the individual dietitian.

6.0 Conclusions

This literature review has highlighted that children with neurodisabilities are smaller and lighter than their peers and the cause of this is likely to be linked to insufficient nutrition. Malnutrition is multifactorial in cause and is a common feature in children with neurodisabilities. The consequences of malnutrition can lead to poor health outcomes for the child as well as an escalated financial cost to the health economy. Dietary interventions have clearly proven to be successful in managing these problems but can be complicated and time consuming and so the focus must now shift on to how children at risk of becoming malnourished can be identified before they present in an undernourished state.

Chapter 2 Critical Review of Nutrition Screening

Chapter Overview

This chapter explains the purpose of nutrition screening tools, how they are used and why they are needed. It will also justify their use in various healthcare settings, examining their place in the modern NHS and reference within the healthcare agenda as part of the increasing focus to improve the quality of care for its service users. Within this chapter a thorough review of the literature is conduced to explore the nutrition screening tools currently available and determine whether any would be suitable for applying to children with neurodisabilities.

1.0 Nutrition Screening Tools

1.1 Justification for nutrition screening tools

Assessment of nutritional status is notoriously difficult to measure as there is currently no single objective indicator of malnutrition available. Therefore nutritional assessment can only be carried out by a fully qualified Registered Dietitian (Reilly et al 1995).

However, a method of screening children for malnutrition risk that could be undertaken by health care workers, that are not qualified dietitians, would be helpful to identify those who do need an assessment of nutritional status. This is because it is not physically possible, nor would it be an efficient use of dietetic time, for dietitians to assess the nutritional status of all of the patients living in the community within their geographical area or hospital ward. This is particularly the case when dietetic resources in paediatric neurodisability are limited. Nutrition screening therefore, should rationalise dietetic resource by identifying those patients who are malnourished and those who have the potential to become malnourished. Both of whom will require a full dietetic assessment of nutritional status and subsequent nutritional intervention.

1.2 History of Nutrition Screening Tools

Historically the proposal for nutrition screening tools occurred following the Kings fund report published in 1992 (Lennard-Jones 1992). This report highlighted that 50% of surgical patients and 44% of medical patients in hospital were malnourished and many more became that way during their stay. A subsequent study confirmed the high incidence of malnutrition in hospitals and highlighted the need for education of medical and nursing staff in clinical nutrition (McWhirter et al

1994). As a consequence it became apparent that the nutritional knowledge of these professionals was so poor that this was one of the reasons that patients were not able to meet their nutritional requirements. Further to these hospital based studies, research was carried out in the community and it was recognized that 10% of the population were also malnourished (Edington et al 1996).

In 2008 a UK wide nutrition screening survey was carried out by British Association of Parenteral and Enteral Nutrition (BAPEN) in order to determine the current prevalence of malnutrition risk on admission to different care settings. This uncovered that there remained almost a third of patients on hospital wards who needed dietetic support. The figure was even higher in care homes, and unexpectedly there was even 20% of patients requiring dietetic intervention in mental health units where typically these patients do not have medical or surgical problems (Russell et al 2008).

Healthcare setting	**No of patients screened**	**Percentage at risk of malnutrition**
Hospital	5089	28%
Care Home	614	42%
Mental Health Unit	185	20%

Table 5. Table to show the prevalence of malnutrition in different healthcare settings taken from Russell et al 2008.

1.3 Definition and purpose

Nutrition screening is intended to be a simple, reliable, and rapid process of identifying the clinical characteristics known to be associated with malnutrition (British Dietetic Association 1999). The purpose of a nutrition screening tool is for it to be simple enough to be used by front line nursing and care staff after initial user training. It should be short and quick to complete and the available answers to each question should have weighted scores dependent upon the severity of nutritional risk. The scores should be added up to provide a total figure which indicates whether an individual is at risk of becoming malnourished or is already malnourished and needs a referral to a Registered Dietitian. Nutrition screening tools are designed to highlight those patients who need nutrition support, and define which patients are severely at risk and needing dietetic intervention as well as those at mild or moderate risk who simply need extra help from front line nursing staff. Thus a nutrition screening tool's outcomes should be linked to a set of specific actions for nursing staff to follow.

As well as their primary role, nutrition screening tools also empower nurses to take initial nutrition focused action, such as offering snacks in between meals or monitoring the patient's food intake prior to their dietetic assessment. Tools are also an excellent method of raising the awareness of the importance of nutrition amongst other health professionals and also to increase the profile of dietetics within the healthcare setting.

Malnutrition is not uncommon and attributes a preventable cost to NHS budgets; as a result, identifying and treating malnutrition has become topical in organisations providing health and social care. Consequently the British Dietetic Association has produced a guidance document for dietitians called 'A framework for screening for malnutrition'.
It aims to:

- Highlight the importance of nutritional screening
- Identify key drivers with supporting rationale
- Signpost suitable nutritional screening tools
- Give guidance on the role of the dietitian in the screening process
- Recognise training needs of the multidisciplinary team
- Support care planning at both a strategic and local/individual level.

The guidelines quote "Dietitians should use this resource to increase awareness amongst service users of the importance of nutrition and the expectation that nutrition screening should be carried out appropriately in all care settings (BDA 1999)."

Although primarily aimed at the adult population the document also has a section on applying nutrition screening to children. It states "Current best practice for establishing nutrition risk in children includes a combination of anthropometry, dietary and medical information. This is the responsibility of the multidisciplinary team but in practice, falls to the nursing staff that are at the front line of patient care". (BDA 1999)

2. Existing nutrition screening tools

2.1 Quality of existing nutrition screening tools

Currently there are many nutrition screening tools for adults in existence but only a few have been designed for use with children (Attard-Montalto et al 1994, Reilly et al 1995, Sermet-Gaudelus et al 2000, Secker et al 2007, Hulst et al 2009, McCarthy et al 2012). However almost all have not been adequately validated (Jones 2002). Few have actually been published in scientific journals and of those which have, only one has been published in sufficient detail regarding its intended use, method of derivation, and with an inadequate assessment of its effectiveness. In 2002 an appraisal of these features was conducted by a statistician who judged that no single tool out of the 44 in existence at that time satisfied a set of criteria regarding scientific merit (Jones 2002). This author concluded that there is a need to ensure that nutritional screening tools are developed using procedures based on good design and sound statistical practice and that a unified approach using multivariate techniques could make a significant contribution to this process (Jones 2002).

Since Jones' (2002) appraisal of nutrition screening tools there have been new tools launched including MUST (Elia 2003) which is widely used. MUST is the Malnutrition Universal Screening Tool for adults which is used in acute hospitals and in community locations such as nursing homes, GP clinics and by district nurses.

2.2 Applying the adult tools to paediatrics

Screening tools are commonly used within the adult population, but none of these could be adapted to be used in a paediatric population as adult nutrition screening tools rely on weight loss as a key factor for determining nutritional risk. The greater the percentage weight loss the greater the nutritional risk. As most adults will have a stable weight for a number of years, any weight loss will be both noticeable and measurable. Children however are continuously growing and thus gaining weight. Unless regular serial weights are taken in advance of screening it would not be possible to determine if weight has been lost. Static weight (or no weight gain) in children also has nutritional significance, which it does not in adults.

Appetite is a second key factor used on adult nutrition screening tools. Once again as adults are not growing, their appetite and thus portion sizes of foods consumed will remain stable for many years and so any change will be obvious. Children's appetites vary widely and on a day to day basis irrespective of their health status.

2.3 Specific indicators of malnutrition in paediatric neurodisability

Malnutrition is prevalent in this group (Stallings 1996, Fung et al 2002) and dietetic resource is limited, at present there is no means of identifying which children need nutritional intervention. An early study by Amundson (1994) noted that a gradual changes in a chronic condition (such as worsening nutritional state in cerebral palsy) often go un-noticed by care givers (Amundson et al 1994). Acute changes are easier to see, such as frequent viruses and infections which may occur as a result of ineffective immune function caused by chronic malnutrition. At this point malnutrition may have already affected the child's health and quality of life as well as contributing a financial cost to the National Health Service.

In an attempt to identify factors associated with nutritional risk, various authors (Amundson et al 1994, Fung 2002, Samsumg-Fang 2002) have studied this group of children and have noted associations linking stunted growth and malnutrition.

- Amundson et al (1994) explored monitoring serial weight and height measurements and intervening when these deviated from the norm. Height however is notoriously difficult to measure if the child has contractures of the spine, scoliosis or kyphosis as they are unable to lie flat or stand straight and so serial measures are often not reproducible. Serial weight measurements however appear to be reliable, but they will only highlight a growth concern after the event when the weight has been lost. Weight monitoring also requires frequent and regular measurements to be taken however there is no agreed protocol how this could be carried out in practical terms with children who often cannot mobilise. This highlights an area for future research to see whether a simple feeding assessment (traditionally carried out by a SALT) could be designed and incorporated into a screening procedure.

- Fung et al (2002) noted that the severity of feeding dysfunction was strongly correlated with the degree of malnutrition. Their recommendation was for a Speech and Language Therapy feeding assessment to be part of the dietetic assessment. However the implications of this would be immense in that Speech and Language Therapists would need to assess every child in advance of the dietitian to highlight those who needed nutrition intervention. Often Speech and Language Therapy resource is as limited as dietetic resource thus this suggestion is not practical.

- Samson-Fang (2002) explored whether normal weight for height centile charts could highlight children with neurodisability who he knew to be malnourished. The results however proved to the contrary as many fell below the 0.4th centile and so were significantly ‘off the chart’. Secondary to the main outcome of this study, the author did note that a triceps skin fold thickness measurement of less than 10th centile was a good indicator or malnutrition. This therefore may be worth investigating further to determine whether it really is a valid and reliable technique for routine use in clinical practice as intra and inter observer variation is known to be high for all anthropometric measurements unless they are being taken by a trained and competent anthropometrist, which is a rare skill within dietitians.

3.0 Malnutrition the national and local context

Routine nutrition screening for malnutrition is recommended across all healthcare settings by government, national and professional organisations. These include amongst others, the Department of Health, Care Quality Commission (CQC), NHS Quality Improvement Scotland, the Welsh Assembly Government, BAPEN, the British Dietetic Association, the Royal College of Nursing, the Royal College of Physicians, the National Patient Safety Agency (NPSA) and National Institute for Clinical Excellence (NICE).

3.1 Liberating the NHS

In July 2010 the coalition government set the NHS QIPP agenda (Quality Innovation Productivity and Prevention). The NHS White Paper, Equity and excellence: Liberating the NHS sets out the Government's long-term vision for the future of the NHS. The White Paper recognises the financial challenges the NHS faces and the role QIPP will play in supporting the NHS in identifying efficiencies whilst driving up quality (DoH 2010). QIPP plans are intended to support the NHS to make efficiency savings, which can be reinvested back into the service to continually improve quality of care.

Following the White paper in August 2010, eight High Impact Actions (HIAs) for Nursing and Midwifery were published by the NHS Institute for Innovation and Improvement, one of which is entitled ‘Keeping Nourished, Getting Better’(NHS and Improvement 2010). These HIA’s were developed following a ‘call for action’ which asked frontline staff to submit examples of high quality and cost effective care that, if adopted widely across the NHS, would make a transformational difference. This is tremendously important for the nutrition agenda as it acknowledges firstly that prevention of malnutrition is cost effective and secondly that it is part of good quality care, both of which fall within the QIPP agenda.

3.2 Care Quality Commission

Organisations that provide care to patients are required by law to meet the nutritional needs of their patients as a compulsory part of their registration. This is inspected by the Care Quality Commission (CQC) who is the independent regulator of health and social care in England. Outcome 5 (of 16) states that providers must:

- Reduce the risk of poor nutrition and dehydration by encouraging and supporting people to receive adequate nutrition and hydration.
- Provide choices of food and drink for people to meet their diverse needs, making sure the food and drink they provide is nutritionally balanced and supports their health.

Their inspection entitled the Dignity and Nutrition Inspection (DANI) of 100 organisations was published in October 2011 and highlighted that 49% of organisations needed to make improvements (CQC 2011). This compulsory regulation has prompted healthcare providers to highlight the nutrition agenda within their organisations.

3.3 BAPEN

The British Association for Parenteral and Enteral Nutrition (BAPEN) conducts an annual audit on nutrition screening and the most recently published results show that 1 in 4 patients being admitted to hospital were malnourished or at risk of becoming malnourished. The figure was higher at 1 in 3 in care home residents and 1 in 5 in patients in mental health units. For the first time the prevalence of malnutrition in young adults was found to be increasing with the problem effecting 26% of 20-29 year olds being admitted to hospital. BAPEN concluded that if a quarter of all adults in healthcare were malnourished “there is a very real need for consistent and integrated strategies to detect, prevent and treat malnutrition to exist within all care settings”. (BAPEN 2011)

3.4 Essence of Care

Nutrition screening is also a key part of the clinical governance agenda for all NHS Trusts. As early as 2001 the Essence of Care document produced by the Department of Health listed nutrition as one of the key aspects of nursing care (DoH 2001). The first benchmark in the nutrition section is on nutrition screening and the target is for every nursing department to routinely use a nutrition screening tool.

3.5 National Patient Safety Association

All of these guidelines, strategies and policies have raised the awareness of nutrition screening but compliance among nursing and medical staff is known to be problematic. The National Patient Safety Association (NPSA) acknowledges that the failure to detect malnutrition or the risk of becoming malnourished has the potential to cause harm to patients (NPSA 2008). They advise that: ‘all health and social care staff need to be accountable for their practice in all aspects of the provision of food, fluid and nutritional care and need to be able to demonstrate that service and care are delivered to the highest standard possible. Staff need to be fully aware of their local screening policy and understand their roles and responsibilities within it, and dietitians have a key role in the training of staff in nutrition screening’. The NPSA hold annual ‘Nutrition and Hydration’ campaign weeks in January each year to raise awareness of malnutrition and the responsibilities of frontline staff in all health provider organisations (NPSA 2012).

3.6 Health Overview Scrutinising Committee (HOSC)

HOSC was established by East Sussex County Council as a result of a central government initiative to involve the public in improving local care. Locally East Sussex Healthcare (ESHT) has been subject to inspection by HOSC for the provision of nutrition in its hospitals. Nutrition screening on admission and during the patients stay is one of its primary benchmarks (HOSC 2010).

3.7 National Service Framework for children

The 2004 DoH National Service Framework for Children, Young People and Maternity Services has highlighted the importance of ‘improving the lives’ of disabled children. Although there are no specific references to nutrition or nutrition screening within this document, it could be argued that by improving a child’s nutritional well being, their health will improve impacting on their quality of life (DoH 2004).

3.8 NHS Operating Framework

NHS Operating Framework sets out the annual business and planning arrangements that commissioners of healthcare must plan for in order to make future improvements, one of which is improving the experience of services for children with a disability and their families (DoH 2009). Children with disabilities, is on the commissioning agenda, and it would be timely for healthcare providers to attempt to influence local commissioning intentions with regards to nutrition and dietetic service provision.

3.9 Summary

Malnutrition is high on the healthcare agenda with many organisations supporting the need to identify and treat it in a timely manner. Screening for malnutrition is a necessity to optimise dietetic resource which is insufficient in order to assess every patient individually. Most of the research into malnutrition and screening for malnutrition has been carried out in adult populations, which does not fit with children, as there are very specific indicators of malnutrition amongst children that are not apparent in adults. A critical review of the evidence is indicated to determine whether there are nutrition screening tools designed and validated for use in the paediatric population and if so can they be applied to children with neurodisabilities.

4.0 A review of the literature on paediatric nutrition screening tools

4.1 Introduction

The intention of the next part of this chapter is to identify and critically appraise the nutrition screening tools currently in existence for children. Secondly it is to assess whether any of these screening tools would be applicable to children with neurodisabilities.

4.2 Methods

In order to thoroughly review the literature available on paediatric nutrition screening tools a literature search was carried out using the following online databases: Bandolier, British Nursing Index, AMED, Embase, Medline from Pubmed, Cochrane Library, Cinahl and Web of Knowledge.

The following keywords were searched for in titles and abstracts:

Nutrition	Screening	Child*
Food	Risk	Paediatric
	Assessment	Pediatric
		Adolescen*
		Teen*

Table 6. Search terms used in database searches (* indicates truncation)

References of interest that were cited in the research papers found were also obtained. Finally dietetic and research colleagues were contacted to ask if they had or knew of any further material or grey literature of interest.

4.3 Inclusion and exclusion criteria

The inclusion criteria are:

- All papers needed to describe a process or tool designed to identify malnutrition or those at risk of developing malnutrition.

- All tools or processes needed to be able to be administered by person who was not a registered dietitian.

- All tools also needed to have been intended for use on a paediatric population, i.e. individuals under 19 years of age.

Papers were excluded if they were not evidenced based, clinical opinions or individual letters to journal editors.

The types of research papers included in the search were randomised controlled trials, cohort studies, observational studies and case control studies. The search dates were from the years 1960 to 2012.

4.4 Search methodology & critical appraisal

All research papers and reviews underwent critical appraisal using the Scottish Intercollegiate Guideline Network (SIGN) criteria as described by Harbour et al in 2001 (Harbour et al 2001). This was to determine the quality of evidence.

This is a system for grading research evidence with a view to forming evidence based guidelines and recommendations for clinical practice. It is also the methodology used to conduct a systematic review of the literature, using an explicit search strategy and critical appraisal of all the research papers found.

There are a number of SIGN checklists for critically appraising the various types of research. The criteria required to critically appraise each type of research paper differs, hence the need for several checklists. The criteria on each checklist ask questions to ensure that all aspects of the study design are robust, there is minimal risk of bias and that the results reported and conclusions drawn are truly accurate. The range of checklists are externally validated and bring uniformity to the critical appraisal process (Liddle et al 1996, SIGN 1999, Shea et al 2007, Whiting et al 2011).

The SIGN methodology was chosen for this literature review following guidance in the ‘SIGN 50 - A Guideline Developers handbook’ with particular reference to chapter 6 Systematic Literature Review (SIGN 2004) as there is evidence to show that the SIGN approach is robust (Woolf 1992).

4.5 Evidence appraisal

Firstly each paper was characterised according to the SIGN Hierarchy of Evidence (Harbour et al 2001) where 1 indicates a systematic review, meta analysis or randomised controlled trial; 2 is an observational, cohort or case control study; 3 indicates a survey or non experimental study and 4 is merely expert opinion. This grading of evidence was carried out using SIGN pre-defined checklists based on a number of key questions that focus on those aspects of the study design that research has shown to have a significant influence on the validity of the results reported and conclusions drawn.

To assign a rank of quality each study was given a score by the researcher of ++, + or – which are codes associated with the level of evidence it contained using the criteria set out below:

- Is there a clear study question?
- Has the question been answered?
- Were treatment and control groups similar at the start of treatment?
- Were relevant outcomes measured in a valid and reliable manner?
- Were confounding factors discussed?
- Were tests compared against gold standards?
- What is the likely direction of bias?

++ Indicates that all or most of the above criteria are met
+ Indicates that some of the above criteria have been met
– Indicates few or none of the above criteria have been met.

All papers were then assessed for their appropriateness of use in a neurodisability population and are discussed individually later in this chapter.

4.6 Results and discussion

The literature review yielded 90 research papers of which 43 were nutrition screening tools or assessment processes. Only 6 of these were intended for paediatric patients. A 7th paper was identified by a dietetic colleague from the grey literature after attending a conference prior to its publication, and was obtained shortly afterwards.

	Date	Author	Country	Population
1	1995	Reily et al	UK	General
2	1998	Attard-Montalto et al	UK	Oncology
3	2000	Sermet-Gaudelus et al	France	General
4	2007	Secker et al	Canada	Pre-surgery
5	2009	Hulst et al	Netherlands	Hospital
6	2010	Gerasimidis et al	UK	Hospital
7	2012	McCarthy et al	UK	Hospital

Table 7. Research papers identified for critical appraisal

The 7 papers resulting from the literature review were firstly assessed for quality then critically reviewed individually below (Reilly et al 1995, Attard-Montalto et al 1998, Sermet-Gaudelus et al 2000, Secker et al 2007, Hulst et al 2009, Gerasimidis et al 2010, McCarthy et al 2012). Validation was established if the tool had been tested on a sample population for its intended use, i.e. identifying children at risk of malnutrition or being malnourished.

4.7 Quality of research

None of the 7 studies identified were meta-analysis, systematic reviews or randomised controlled trials thus none were able to receive the highest quality grade of 1 that SIGN allocates. All of the studies were graded at a level 2 which is the grade given to cohort or case-control studies. They were however, difficult to classify into the SIGN cohort or case control study categories as the SIGN pre-defined checklists are based on a number of aspects of study design which seemed not to apply to population based interventions such as screening. SIGN do acknowledge this in their Guideline Developers Handbook and suggest the case control methodology checklist should be used.

Scores of ++, + or – were given to each study. None of the papers achieved a score of ++ which indicates that none were published in enough detail to ensure that the conclusions of the study were robust and unlikely to alter. The papers by

Reilly et al, Secker et al, Sermet-Gaudelus et al, McCarthy et al and Gerasimidis et al all achieved a score of +, which indicated that the papers were adequately written and that some of the SIGN criteria were met. This indicates that the conclusions of the study were also unlikely to change (Reilly et al 1995, Sermet-Gaudelus et al 2000, Secker et al 2007, Gerasimidis et al 2010, McCarthy et al 2012). The papers by Attard-Montalto et al and Hulst et al were assigned a – negative score which indicates that the studies were not published in sufficient depth to ensure their quality and thus it is assumed that the conclusions drawn were not sufficiently robust (Attard-Montalto et al 1998, Hulst et al 2009).

Author	Quality grade	Score
Reily et al	2	+
Attard-Montalto et al	2	-
Sermet-Gaudelus et al	2	+
Secker et al	2	+
McCarthy et al	2	+
Hulst et al	2	-
Gerasimidis et al	2	+

Table 8: Quality grade based on SIGN Criteria

4.8 Critical review

The earliest nutrition screening tool which was considered suitable for use on children was published in 1995 by a dietitian at Birmingham Hartlands Hospital (Reilly et al 1995). The tool intends to identify both adult and paediatric inpatients at risk of becoming undernourished as well as identifying those who are already malnourished. It encompasses multi-choice weighted options for the following parameters: weight loss, body mass index or centile charts in children, food intake and ‘stress factors’ which are the effects of the medical condition on the nutritional requirements of the patient. Validation was against the ‘gold standard’ dietitians own nutrition assessment and 20 patients were assessed by two dietitians. Additional cross checking by an already validated assessment method called Nutritional Risk Index was carried out to further validate the tool (Wolinsky et al 1990). Ease of use was measured amongst nurses on 19 different patients. 100% correlation was observed between the tool and the two different dietitian’s assessments, indicating that different dietitians using the tool are able to produce the same results. There was a lower correlation at 93% between the result from the dietitian's tool and the full nutritional assessment suggesting that the screening tool is not as accurate as a full nutritional assessment. The correlation against the already validated tool (Nutrition Risk Index) was lower again at 85%.

Ease of use testing was reported to show that 14 of the 19 patients were identified correctly.

Whilst the design of this study appears to be robust, the numbers used to validate the tool and assess its effectiveness are small. Moreover there is no indication of how many of the 20 patients were children and therefore it cannot be applied to the paediatric population. Further validation studies using this tool are required in order for it to be considered for widespread paediatric use.

Furthermore the first question in the paediatric section of the screening tool asks what the present weight of the child is and the answer options are:

- 90 – 99% of expected weight for length
- 80 - 89% of expected weight for length
- < 79% of expected weight for length

It is unlikely that a question of this complexity could be answered by nursing staff because complex calculations to ascertain weight for height involve skill and experience of highly qualified clinicians. More simply however it is not an appropriate question to be included on a nutrition screening tool as it does not fulfil the basic criteria of being quick and easy to use (Reilly et al 1995).

This tool would not be useful in either a paediatric neurodisability population or any paediatric population because of its complexity (Reilly et al. 1995). It requires complex calculations regarding growth velocity which is not a routine skill of a school nurse. Moreover it requires the assessment of 'stress factors' which are the effects of the medical condition on the nutritional requirements of the patient, most children with neurodisabilities are in a clinically stable state and only acute illnesses that they acquire on top of their stable state will have associated stress factors, thus to trigger this criterion the child would need to be in an acute phase.

A second nutrition screening tool was published in 1998, by Attard-Montalto et al, from the department of paediatric oncology at St Bartholomews Hospital, London (Attard-Montalto et al 1998). This tool was developed because traditional methods of assessing nutritional status are often meaningless in children undergoing chemotherapy. The tool was created from clinical symptoms known to alter food intake and absorption in cancer patients such as neutropaenia, white cell count, oral mucositis etc. and each criterion was assigned a score. It was tested on 30 patients, ages ranging from 0.7 – 17.5 years, on a daily basis over a 5 year period, producing a total of 511 daily nutrition risk scores. Higher scores correlated with neutropenia, a fall in neutrophil count and fever. Scores improved with first remission, and haematological recovery. However, the tool is not transferable outside oncology and because the score appears to change with recovery and relapse.

This tool cannot be applied to children with cerebral palsy and other neurodisabilities as the clinical characteristics associated with malnutrition in children with cancer are not the same characteristics as for children with neurodisabilities. For example children with neurodisabilities may have a completely normal white cell count which is one of the indicators of nutritional risk in the oncology population (Attard-Montalto et al 1998).

In 2000 Sermet-Gaudelus et al (2000) reported their development of a simple nutritional risk scoring tool. It was designed to be used on hospital admission to identify children at risk of acute malnutrition during their hospital stay (Sermet-Gaudelus et al 2000). The study consisted of 296 consecutive paediatric admissions to an acute hospital in France. However, age and sex data were missing, thus the heterogenicity of the sample is unclear. A full nutritional assessment to ascertain their level of nutritional risk was carried out within 24 hours of admission. The children were then monitored during their stay and those with more than 2% calculated weight loss, were considered to have become malnourished. The factors used in the full nutritional assessment were then used as predictors of nutritional risk and a nutrition screening tool was produced. The authors found that the items to be the biggest predictors of nutritional risk (and thus to be included in their nutrition screening tool) were poor food intake, severity of disease and pain. Children with neurodisabilities may not be able to rate their level of pain because many have communication problems and most are unable to verbalise. Severity of disease is described as an indicator of nutritional risk. This may encompass cerebral palsy, but this is unknown because the tool has not been published.

In 2007 a Canadian team, Secker et al published data on a type of nutritional screening, based on subjective global assessment (SGA). SGA is a physical examination looking for areas of fat and muscle wasting and functional weakness and is a method of diagnosing malnutrition. The study also included the use of a questionnaire investigating weight and height history, feeding patterns, appetite and gastrointestinal symptoms (Secker et al 2007).

The results reported that 175 children aged 8.1 years +/- 6.1 years were consecutively admitted to a large children's hospital for major surgery. Of the sample 99 of the 175 were male. The SGA measures identified that 51% of children were malnourished.

Whilst this is not a screening tool per se; it did however demonstrate that subjective global assessment is capable of identifying malnutrition. It does however require a dietitian to carry out the assessment defeating the main purpose of a screening tool. SGA does not identify those at risk of becoming malnourished, just those who already are. The authors concluded that the major problem they encountered was concordance between the 5 dietitians carrying out the SGA measures which were low at only 56%. They report that training of the assessors was vitally important. SGA is also a lengthy and time consuming method of identifying malnutrition and so would not suit the basic principle of nutrition screening which needs to be quick and easy to use.

This tool was only included in this literature review as it matched the search terms.

More recently STRONGkids has been produced which is a hospital based screening tool that has been tested in the Netherlands. (Hulst et al 2009). The tool consists of 4 key items: risk of disease, food intake, weight loss and subjective global assessment. Each item was allocated a score of 1-2 points and a maximum score of 5 could be achieved. The tool was tested only for feasibility in 44 hospitals across the Netherlands and data was collected over a 3 day period on 424 children on the day of admission to hospital. At the same time children were weighed and measured and malnutrition was defined by weight for height and height for age calculations. Scores of 4 and above defined high risk of malnutrition, and 8% of the 424 children fell into this category. However weight and height calculations identified that 19% of children were already malnourished on admission to hospital. As this was a feasibility study, sensitivity and specificity were not assessed nor discussed but nevertheless this mismatch is of concern.

The authors noted that those identified as ‘at risk’ of malnutrition were also those who had lower weight for height scores, and thus already acutely malnourished. Children already malnourished clearly do need dietetic treatment, but the intention of a nutrition screening tool is also to identify those who may be at risk of becoming malnourished in order to prevent it from happening in the first place. The first two items on the STRONGKids tool were subjective global assessment and presence of high risk disease. Both of which required the skills of a paediatrician to assess. Nutrition screening tools are intended to be a simple and rapid process which is carried out on admission. If a paediatrician is required the tool is no longer simple, nor is it likely to be carried out immediately upon admission as there would be a time lag waiting for the paediatrician’s first visit. The high risk disease category includes ‘mental handicap / retardation’ which is reassuring as children with neurodisability would be picked up by this tool. However the author’s note that 97% of the children identified as at ‘high risk’ of malnutrition had an underlying disease. This item appears not to have the ability to discriminate, and so almost all children with ‘mental handicap / retardation’ would be referred. Conversely if this is accurate, there is no need for the rest of the tool as it would be simpler just to state that all children with an underlying high risk disease required nutritional intervention.
Furthermore the standard to which the tool is compared is simply the weight for height and height for age calculation scores rather than a full dietetic assessment, which is considered to be the gold standard. Calculations alone are too crude to identify malnutrition risk, and can only be used to diagnose the malnourished state. With regards to face validity, there is one reference made to ‘testing’ involving checking for ease of use but there are no further details of what this process involved. There is no evidence that the tool has been validated nor tested for reliability.

The more recent paper by Gerasimidis et al (2010) entitled the Paediatric Yorkhill Malnutrition Score or PYMS, was intended for use in acute paediatric hospital wards. The tool assessed four recognised predictors or symptoms of malnutrition: body mass index, history of recent weight loss, changes in nutritional intake and effect of current medical condition. Each item has a possible score of 2 and the total score defines the degree of nutrition risk where 2 or more is considered high risk.

The validation study included 247 children aged 1-16 years admitted to 5 acute paediatric wards over a 4 month period. There was also 160 nursing staff included as the tool users. Children were screened by the nurses on admission and a research dietitian blindly carried out a full dietetic assessment to define true nutritional status.

This tool was also assessed for inter rater reliability. However instead of looking to see if different nurses used the tool in the same way, the nurse's tools were compared with the dietitian's tools. This concurred a moderate agreement with a kappa score of k=0.53, however as nurses are intended to be the tool users, it was unclear why they were compared against dietitians.

There was moderate agreement between the nurse's classification of malnutrition and the dietitian's assessment of true nutritional status, yielding a sensitivity of 59% and specificity of 92%. This meant that just over half of children truly at risk of malnutrition were identified by the tool. The authors state that this is acceptable by nutrition screening standards, however this also indicates that just under half of 'at risk' children are missed. Thus this lack of sensitivity and specificity would indicate that it is an inappropriate tool for use in clinical practice. This tool was designed for acutely ill patients admitted to paediatric hospital wards. There is no indication within the paper of how this tool might work in a community setting for children with neurodisabilities.

The STAMP (Screening Tool for the Assessment of Malnutrition in Paediatrics) was developed between 2004 and 2008 by McCarthy et al a Paediatric Dietitian at Manchester Children's Hospital. It was initially published as an abstract in 2008 and as a full paper four years later in 2012 (McCarthy et al 2008, McCarthy et al 2012).

STAMP is intended to be used in hospitals while children are inpatients. The tool has 3 criteria making it quick and easy to use and thus fulfils the BDA's basic requirement for a nutrition screening tool (BDA 1999). The first criterion is the child's diagnosis, where those with direct nutritional implications such as bowel failure and inborn errors of metabolism are given the highest score of 3. Interestingly children with neurodisabilities such as cerebral palsy are given only a moderate score of 2 when it is known that neurodisabilities can have a profound impact on their ability to maintain an adequately nourished state. Those diagnoses with no nutritional implications such as investigations or day-surgery are given the lowest score of 0.

The second criterion considers the child's current nutritional intake and is scored as 3 for no nutritional intake, 2 for recently decreased nutritional intake or 0 for no change in eating pattern and a good nutritional intake.

The final criterion looks at weight and height and the number of centiles apart that they are, scoring 3 for more than 3 centiles apart, 2 for more than 2 centiles apart and 0 for 0-1 centile apart. A quick reference chart has also been developed for nurses unfamiliar with children's growth centile charts. 3 centiles apart equates to 2 standard deviations on the UK90 child growth charts which is a known indicator of faltering growth.

Scores from each of the three criteria are summated to determine the category of nutritional risk. A care plan is given for each category of nutritional risk to inform the nurses of the required action to be taken.

The STAMP tool was validated on 238 children aged 2-17 years admitted to medical and surgical wards, 51% and 49% respectively at Manchester Children's Hospital. 56% were male. The average age of the children was 8.4years +/- 4.6years. All 238 children had the STAMP tool completed by nursing staff; they were also fully assessed by a registered dietitian to determine their true nutritional status. 82% of the time the tool agreed with the dietitian's assessment. A small percentage (7%) were incorrectly identified as being at nutritional risk when they were not but 4% of children were at nutritional risk and were not identified by the tool. This demonstrated a sensitivity of 70% and a specificity of 91% with a kappa value of 0.56 indicating fair to substantial agreement.

		STAMP tool	
		At risk	Not at risk
Dietitian	At risk	23	10
	Not at risk	19	186

Table 9. To show the STAMP tools level of agreement with the dietitian in identifying those 'At risk' and 'Not at Risk' of malnutrition. (McCarthy 2012)

Although the STAMP tool shows promising statistical validation, the author advises that the indicators of nutritional risk used on the tool were obtained from questionnaires completed by parents as well as information that would be sought from a dietetic assessment. Themes that were common to both were chosen to be ‘significant predictors of nutritional risk’ and a scoring system of 1, 2 or 3 was arbitrarily applied, where 3 is the most severe. A more scientific method would have been to seek this information from the evidence base found in published literature or the clinical practice of other professionals working in paediatric nutrition. This proffers some doubt around the design quality from which it was derived.

The STAMP tool has not yet been peer reviewed, however despite this, it is being widely advertised in dietetic forums across the UK by a commercial sponsor. Since its launch, some children’s hospitals have started to implement the tool on their inpatient wards. However a study by Ling et al in 2011 suggested that the STAMP tool was too sensitive and identified more children to be high risk who in fact did not actually need nutritional intervention. Anecdotally over-reporting of STAMP is also a common discussion within dietetic clinical supervision forums.

The STAMP tool is published with a comprehensive instruction booklet for nurses and a frequently asked questions page for dietitians implementing the STAMP tool in their hospitals. There is also promotional material such as leaflets and posters to highlight STAMP to ward staff which have been financially supported by a commercial medical nutrition company.

5.0 Conclusion

This literature review has critically reviewed and evaluated the literature and studies pertaining to nutritional screening tools. The evidence suggests that current provision is limited and thus there is a clear rationale for developing a nutrition screening tool intended for use for the paediatric neurodisability population. There are currently very few screening tools in existence for children and none are suitable for children living in the community with neurodisabilities such as cerebral palsy. It appears that it is not possible to have one generic nutrition screening tool for all patient groups and care settings as the clinical characteristics associated with malnutrition differ depending upon the associated clinical condition and age or developmental stage.

Moreover of the 7 paediatric screening methods identified, none apply to children outside of hospital. The STAMP tool is likely to be the simplest and most user friendly of all of them but at present is only intended for use in hospitalised patients and its sensitivity is questionable.

There is clearly a need for a simple method for nursing staff to identify children at risk of malnutrition and as there is currently no tool suitable it is likely that some children who are at nutritional risk will be missed and left to suffer the consequences of being malnourished. The inspiration behind this piece of research was the lack of any means of identifying children with neurodisabilities at risk of malnutrition other than a full dietetic assessment. As dietetic resource is limited and NHS finances are stretched a nutrition screening tool for this group of children living in the community is warranted.

Chapter 3 Development of the Nutrition Screening Tool

Chapter overview

The evidence presented thus far in Chapter 1 has identified the nutrition and growth concerns for children with neurodisabilities and discussed the importance of identifying malnutrition risk. Chapter 2 highlighted the clinical need for an instrument or tool to be able to identify children at risk of malnutrition specifically from the population of children with neurodisabilities. It also identified that currently, there is not a tool that is reliable, valid or clinically suitable for such use.

The aim of this chapter is to detail the stages and the methods that were used to develop a suitable clinical nutritional screening tool for children with neurodisability aged 5 – 19 years. Each stage will be reported and explained. The satisfactory completion of each stage was necessary before moving on to the next.
The initial stage involved identification of the clinical characteristics associated with malnutrition in children with neurodisability, from the literature and from clinical expertise, and to put this into the tool format.
The second stage involved exploring the concept of questionnaire design with regards to how questions should be presented and order or sequencing to ensure the accuracy of the information obtained.
The third stage addressed content validity, defined as the degree in which the tools content represents what its intending to measure (Sireci 2007). This was in the form of a Nominal group process where expert dietitians collectively agreed the tools content.
The final stage assessed face validity and practicability or ease of use of the tool, amongst the intended group of tool users.

1.0 Background to the Nutrition Screening Tool Design

The British Dietetic Association produced guidelines on the development of nutrition screening tools in 1999, which state that “any tool should be simple and be a rapid process to complete, thus any questions which require the user to seek out information needs to be kept to a minimum” (BDA 1999). These were superseded in 2009 with the BDA publication entitled ‘A Framework for Screening for Malnutrition’ (BDA 2009). This document states that ‘Nutrition screening tools should be simple to use, non-invasive, concise, acceptable to the client group and linked to an agreed policy on further action’.

The 1999 document gives overarching themes with regards to a tools layout and format are given in terms of how to produce a tool which is acceptable to the users for which it is designed. They advised that presentation is important and the format must be concise, clear and simple to follow, with unambiguous language. They also suggested that the tool should comprise of one side of an A4 sheet of instructions, supported by a flow chart on the reverse with sufficient instructions to allow the tool user to complete the score correctly and independently (BDA 1999). The 2009 document emphasised how important it was that the tool should be evidence based, reproducible, validated and practical. The document also states that a screening tool needed to include three broad factors: to be able to determine the current status; to define recent change and to identify probably direction of change. The focus of the guidelines however were directed to screening adults for malnutrition. In the paediatric neurodisability population defining only recent change may not reflect a slow paced chronically evolving problem. The guidance document did have a subsection for screening paediatric patients which stated that:
"Current best practice for establishing nutrition risk in children includes a combination of anthropometry, dietary and medical information". It also goes on to note that of the few paediatric screening tools in existence, both objective and subjective questions have been shown to be necessary for determining nutrition risk (BDA 2009).

There is no guidance within either of these documents on how the questions should be sequenced, nor is there guidance advising on the actual content or questions to use, thus these are explored further and outlined later in this chapter

1.1 Psychometric Validation

Questionnaires requiring the user to choose from a range of answer have normally been psychometrically validated. Psychometrics is the field of psychology concerned with the construction and validation of measurement instruments such as questionnaires (Bowling 2009). The term *psychometrics* is derived from the greek *psyche* meaning mind and *metron* meaning measure.
Psychometric theory suggests that when a concept cannot be measured directly (e.g. assessing a child's nutritional status), a series of questions explore different aspects of the concept (factors effecting the child's nutritional status). However,

these must be tested for validity and reliability before they can be accepted (Bowling 2009).

Validity measures whether the tool does what it is supposed to do and reliability measures the extent to which it produces consistent and dependable results (Gomm et al. 2000; Babbie 2003; Bowling 2009).

1.1.1 Rationale for Psychometric Assessment in the development of the Nutrition Screening Tool

There are four types of validity which should be considered in the development the nutrition screening tool and include content validity, face validity, construct validity and criterion validity. Content validity is required to ensure that the content of the tool is complete and that there are no clinical areas missing. Face validity is required to make sure that the intended tool users, in this case school nurses, understand what the tool requires of them. Construct validity is required to measure the extent to which each question on the nutrition screening tool agreed with the ‘gold standard’ which in this case is the child’s true nutritional status as defined by the dietitians nutritional assessment of the child. Construct validity will enable identification of the items that are better predictors of nutritional risk. Finally criterion validity is required in order to measure how well the questions or items on the tool predict the outcome. Items which are found to be poor indicators of identifying malnutrition risk could then be omitted.

Reliability assessments are also required. An inter-rater reliability study examines how well different tool users or nurses agree with one another when assessing the same child. Internal consistency reliability studies are useful when there is more than one way of examining a particular clinical area such as items A and D which were both assessing body weight, to determine whether both questions equally produced the same outcome or whether one is a better predictor of malnutrition risk than the other.

2.0 Methods

The methods used to determine the content of the nutrition screening tool included collection of clinical characteristics associated with malnutrition from the literature, exploring the concepts of questionnaire design, determining content validity via the nominal group process and testing the tool for face validity with the intended tool users.

2.1 Clinical content of the nutrition screening tool

Ideas for the content of the nutrition screening tool were developed from clinical observation and expertise which were developed by the researcher reading around the area and having reviewed the literature as discussed in Chapter 1. The researcher was specifically looking for clinical characteristics associated with malnutrition in children with neurodisability. The identified risk factors were:

- Growth
- Bowel habits
- Activity levels
- Ability to eat and drink
- Quantity of food consumed
- Quantity of fluid consumed
- Oral motor skills

However, the relative contribution of each of the risk factors was unknown. Similarly the order in which they were presented in a questionnaire needed to be determined.

2.2 Questionnaire Design

Two important features to consider in questionnaire design are content and format (Sommer et al 2001). The content is listed above and discussed in detail later in this chapter. The format refers to the structure of the questions: how they were worded, how they were organised on the page and how they should be answered. Closed questions allow for easier interpretation and analysis as opposed to open questions which can be difficult to draw conclusions from (Oppenheim 1992). Closed questions also tend to be quicker and easier to answer for the respondents (Oppenheim 1992). Leung (2001) advises on the way questions should be worded:

- Use short and simple sentences
- Only ask for one piece of information in each question
- Avoid negatives if possible

- Ask precise questions to reduce ambiguity
- Only ask for information that the tool users are able to provide

The length of a questionnaire is also an important point. Sommer et al (2001) suggests 'the shorter the better' to avoid questionnaire fatigue. Both the 1999 and 2009 British Dietetic Association briefing papers on Nutrition Screening tools concur with this stating that the tools should be quick and easy to use. (BDA 1999, BDA 2009)

Terwee et al (1997) advises that the way questions are worded is also important and that questions should be clear, without the use of jargon or abbreviations. Sommer et al (2001) also states not to overestimate the vocabulary level of the respondents and to keep wording simple. Sapsford further suggests that the phrasing of the questions needs to be precise and unambiguous to retrieve accurate information (Sapsford 2007). Sommer concurs and suggests the use of synonyms to aid understanding (Sommer et al 2001).

Furthermore the order or sequence of the questions should be logical for the user (Oppenheim 1992). Commonly the first questions are general, and non controversial questions which help to engage the respondent and establish a good relationship with the topic (Sommer et al 2001).

In terms of how questions should be answered, check boxes such as ☐ are reported to the most acceptable method as it involves less effort for the responder (Sommer et al 2001; Major et al 1976).

2.2.1 The design of the nutrition screening tool

The guidance on questionnaire design was applied to the structure and format of the nutrition screening tool.

As the primary objective of the nutrition screening tool was to obtain accurate information about a child in order to form a judgment of their malnutrition risk, the use of closed questions were selected to enable the user to be guided into choosing predefined answer options. This method allows for the answers to be numerically categorised for analysis. The flow of questions was based around the order of a nutritional assessment and the check box answer format adopted to encourage ease of use.

2.3 Nominal Group Process

The nominal group process or NGP was employed as a means of structuring face to face group meetings with an expert panel of clinicians in order to determine a common understanding of the concept of the nutrition screening tool and its contents. The nominal group process was defined by Van de Ven et al (1972) and Delbecq et al (1975) as a series of steps in order to generate ideas and opinion. The initial stage involves a period of quiet contemplation of the topic under consideration. The subsequent stages encourage verbal interaction.

2.3.1 Formulation and presentation of the 'problem' at hand

The process requires the group leader welcome the members and describe the objectives for the meeting. Emphasis is placed upon the importance of each and every individual group member's participation.

2.3.2 Silent generation of ideas

The group leader presents the question or problem in both a verbal and written form. Each member is asked to work independently and in silence to jot down ideas on paper. The group leader needs to ensure that silent working is maintained and that the members focus on the task in hand.

2.3.3 Feedback from group members without discussion

Each member of the group is approached one at a time to ask for feedback. One idea or comment only from each member is recorded before moving on the next member of the group. The process continues till each group member exhausts his / her list. This process may help stimulate ideas from other group members or encourage someone to state something previously not disclosed. Duplicate items are not recorded and the ideas generated formulate a list.

2.3.4 Group discussion of each idea

Each idea or comment is discussed in turn to obtain clarification and a fuller understanding of the point in hand. Differences of opinion and debate are accepted. New items that may emerge through discussion are recorded.

2.3.5 Voting on priority ideas

Group members are invited to rank the ideas in order of importance. They must do this independently and in writing. It is not unusual for this part of the process to be part of a ‘coffee break’ to allow participants freedom to move about the room.

2.3.6 Feedback, further discussion and final vote

The results of the individual votes are aggregated and fed back to the group with the opportunity for further discussion. Group members are invited to make final clarification of their positions before a final vote is requested, following the same independent process above.

2.4 Critical appraisal of the nominal group process

The NGP was developed from research which showed that when groups of people brainstormed silently in the presence of each other, more ideas were generated than when brainstorming occurred individually or in traditional discussion groups (Delbecq et al 1975). In discussion group situations members tended to place more emphasis on social interactions or critiquing each others ideas, but when they worked alone the focus shifted on to the task in hand.

The NGP also separated the exploration of a problem from the search for the solution. Delbecq et al (1975) recognised that there was a tendency for answers to be sought before the problem itself was fully investigated in traditional discussion groups. Allowing participants to focus on the problem at hand without the other group members commenting, prevented this tendency to rush ahead to find a solution. Avoiding group discussion at this stage also allowed for uninhibited creative thinking and avoided unhelpful group behaviours such as dominant personalities influencing others and critical judgements from others. Delbecq et al (1975) also identified limitations of the NGP. They take time to set up and organise and not all people will feel comfortable with the rigidity of a structured group meeting. However since publication, several other authors have promoted the usefulness of the process (Fink et al 1984, Gallagher et al 1993, Carney et al 1996).

2.5 Determining content validity of the Nutrition Screening Tool

The NGP was employed as a means of testing the content validity of the nutrition screening tool, where the problem at hand was the draft tool. The draft tool was revised in response to the voting as described above until no new ideas for changes were made.

The NGP procedure:

- There were 12 participants in the nominal group.
- Recruitment was by means of an email invitation circulated around the 'Dietitians Interested in Special Children' DISC group
- The group was made up of dietitians with expertise in paediatric neurodisability.
- The NGP meeting took half a day and was located at Chailey Heritage Clinical Services in the Boardroom where there was ample space for silent working, a flipchart and laptop computer with projector.
- Lunch and refreshments were provided.
- Prior to the arrival of participants, the Boardroom was set up so each person had a sticky name label, a copy of the nutrition screening tool, a copy of the questions, a pencil, some blank paper and 'Post-It' notes labelled 1 to 5.
- After arrival the participants were required to introduce themselves and their backgrounds.
- All participants were required to sign a confidentiality disclaimer and were advised not to take any paperwork away from the meeting
- The researcher led the NGP meeting but facilitated only, refraining from giving her own thoughts or opinions.
- Participants were asked to examine the first draft of the nutrition screening tool looking at both the items and answer options.
- Participants were asked to consider the following questions when evaluating each item:
    - Is this item a good indicator of nutritional status in children with neurodisability?
    - Is the wording of the questions on the tool ambiguous?
    - Are there any points on the answer options rating scale unnecessary?
- In addition the group was asked to consider if there was anything missing that you feel would be useful?
- The researcher's assistant (a volunteer) took formal minutes.

- The researcher wrote up each participant's comments on the flip chart for all to see.
- Each participant was given 5 'Post-it' notes numbered 1 to 5. They were asked to rank each comment for importance where 5 was most important and 1 was least important. As there were only 4 comments provided Post-It' number 5 was omitted.
- The NGP meeting was then closed.

2.6 Face Validity

Face validity is a measure of the tool user's subjective opinion of the nutrition screening tool. A separate focus group to determine face validity was organised. The intention of the focus group was to establish whether the tool was practical in terms of clarity and ease of use.

The focus group procedure:

- There were 5 participants in the focus group.
- Recruitment was by means of an email invitation to all nurses working at Chailey Heritage.
- Participation was voluntary.
- The meeting was scheduled for 1 hour and was held in the Boardroom at Chailey Heritage Clinical Services
- The meeting was organised over a lunchtime period and lunch and refreshments were provided.
- All members of the focus group were asked to sign a confidentiality disclaimer and were advised not to take any paperwork away from the meeting.
- The researcher facilitated the group giving a brief overview of the nutrition screening tool and the background to the project.
- Each participant was provided with a copy of the nutrition screening tool that had been agreed for content validity via the NGP.
- The researcher explained how the tool should be used and gave a case study of a child to demonstrate.
- Then each nurse was asked to complete the tool on a test case using case study paperwork provided by the researcher based on real patient data from the researcher's current caseload.

- Following this exercise the nurses were asked to provide feedback as a group which consisted of an open discussion based on the following questions:
    - How easy was the tool to use?
    - Is the wording of the questions on the tool ambiguous at all?
    - Is there anything missing from the tool that you feel would be useful?
    - Would you have any concerns using the tool in clinical practice?
- During the focus group the researcher acted as minute taker, documenting all comments made by the nurses.
- The group agreed that if during the meeting a suggestion was made to change the tool, it would only be agreed by consensus opinion.

3.0 Results

3.1 Nominal Group Process - Content Validity

The NGP consisted of 12 dietitians who were members of the DISC group (Dietitians Interested in Special Children). All dietitians were aware of the nutrition screening tool project and felt that the production of a nutrition screening tool for this population of children was a necessary and important piece of work and were enthusiastic about helping to progress the project. The clinical characteristics associated with malnutrition that the researcher had identified were formulated into questions for inclusion into the nutrition screening tool and each had a suggested series of answer options. The dietetic pro-forma to determine true nutritional status in conjunction with the intended process for data collection was also discussed. These were presented to the nominal group as the problems at hand. The following conclusions were drawn:

3.1.1 Growth

Weight and height data are known to be indicative of adequate nutrition. Inadequate nutrition will result in a child being underweight and lacking height (see chapter 1 section 5.2). Thus growth is an obvious first choice indicator to be included into the nutrition screening tool.
Questions on growth were asked in a variety of ways in items A – D.

<u>Item A:</u> required the tool user to make a subjective assessment of the child's physical appearance. This was one of three questions to explore whether something as simple as a visual assessment of the child could be as reliable as a more objective measure. The Likert scale provides a range of 5 answer options.

A	**In your opinion is the child:** **Tick one box**	Very Overweight ☐	Overweight ☐	Normal ☐	Thin ☐	Very Thin ☐

Figure 2 Item A of the nutrition screening tool.

Item B: This item was intended to assess the child's weight over the past year according to the trajectory followed on their centile chart. It is a more objective measure than item A, intended to quantify weight change

B	**Over the past year how does the weight relate to the centiles?**	Increasing across 2 or more centiles	Increasing across 1 centile	Follows centile line	No Weight gain	Weight loss
		☐	☐	☐	☐	☐
	Tick one box					

Figure 3 Item B of the nutrition screening tool

Item C asks the tool user a similar question to item B but for the child's height

C	**Over the past year how does the height relate to centiles?**		Increasing across one centile	Follows centile line	Dropping one centile	No growth
			☐	☐	☐	☐
	Tick one box					

Figure 4 Item C of the nutrition screening tool

Item D: is used to determine whether the child's weight is appropriate for their height.

D	**In your opinion is the child's weight appropriate for height?**		Yes	No
			☐	☐
	Tick one box			

Figure 5 Item D of the nutrition screening tool

In order to accurately provide an answer to items B, C and D the tool user would be required to interpret the child's growth chart. It is usual practice for a child to have to have been weighed and measured at regular intervals over the previous year. School children with special needs are routinely weighed and measured each school term.

In item B the five answer options were specifically chosen according to the pattern of weight gain or weight loss portrayed on a growth chart. A child can gain weight across one or two centiles upwards if the are receiving too much nutrition. Optimal nutrition ensures that the centile curve is followed. The effect of too little nutrition could result in either the child's weight remaining static or if the nutrition received was very inadequate weight loss and a downward shift in the centile would be observed. See appendix 6 for growth chart displaying this information. The participants of the nominal group discussed this pattern of growth in detail and concurred with the researcher's proposal.

Similarly in item C the answer options were chosen as a result of the pattern of growth that can be seen on a growth chart. Height is less sensitive to nutrition intervention than weight. Therefore a child is highly unlikely to increase over more than one centile for height as the result of nutrition intervention (Vernon-Roberts et al. 2002; Bachlet et al. 2003; Sullivan et al. unpublished). However if growth had been stunted due to chronic under nutrition and then optimum nutrition given, it is possible that there would be an increase across one centile (Prader 1963). Tracking the centile curve for height and weight together indicates that the child is receiving optimal nutrition for growth. However the weight centile would be affected first if inadequate nutrition occurred. This is because height growth is preserved in the short term if nutrition is limited (Vernon-Roberts 2002). The nominal group participants agreed with the recommended question and answer options and reflected having seen similar growth patterns in their own clinical practice.

Item D is a subjective question which does not require the use of growth charts to be able to answer it, however because the tool user will have accessed the growth charts to answer items B and C it is anticipated that the user will provide a more objectively considered answer. The nominal group participants discussed whether the words 'using the growth charts' should be added to this question, but others felt that subjectively assessing the child's weight for height was just as useful and perhaps more often done. Voting resulted in favour of the latter and so this item remained unchanged.

There was concern expressed by some participants of the group that school nurses may struggle to answer items B and C because some of the paediatric nurses with whom the dietitians had worked with were unfamiliar with interpreting growth charts. This resulted in discussion regarding who was responsible for interpreting growth charts. The consensus was that it was the nurse's responsibility. Some members therefore expressed concern that if nurses were struggling to answer items B and C, it would highlight a competence issue requiring that staff members education and training needs. However no changes to the nutrition screening tool questions were made as a result of these discussions as they were considered to be only subjective opinion.

3.1.2 Bowel habits

Item E: Bowel habits are an important factor in monitoring nutritional status see chapter 1 section 4.16.

E	**How are the child's bowel habits?**		Constipated with or without medication	Normal	Diarrhoea
	Tick one box		☐	☐	☐

Figure 6 Item E of the nutrition screening tool

Both constipation and diarrhoea can impact on the nutritional status of a child (Roma et al 1999). Del Giudice et al (1999) found 74% of children with cerebral palsy had chronic constipation. Constipation is frequently described as a 'feeling of fullness' and therefore appetite is suppressed and food intake is reduced (Elawad et al 2001). If this is an ongoing problem, inadequate nutrition could result. The participants of the nominal group agreed that it was important to know whether the child was constipated, had diarrhoea or normal bowel movements. The Bristol Stool Chart was discussed as a possible tool to classify stool type however, the 7 stool type choices was felt to be too detailed when just 3 would give the dietitian the information they needed to inform them on whether bowel habits were impacting on nutritional status.

3.1.3 Activity

Item F attempted to measure the impact of activity on the child's nutritional status including their level of mobility (see chapter 1 section 3.8). Activity levels are positively correlated with nutritional status; the more active the child is the more energy they will expend (Bell et al 2010).

This required the tool user to choose from a range of levels on a decreasingly active scale. These descriptions were selected from clinical observations as the typical levels of activity commonly seen amongst children with neurodisabilities.

Item F

F In your opinion how active is the child?	Excessive activity i.e. continuously 'on the go'	Jerky involuntary movements	Fully mobile	Limited mobility	Wheelchair bound	Sleeps a lot
Tick one box	☐	☐	☐	☐	☐	☐

Figure 7 Item F of the nutrition screening tool

3.1.4 Food and fluid intake

The quantity and type of food and drink directly effects nutritional status (see chapter 1 section 5.3). A lack of food will result in undernourishment and too much will result in weight gain. A varied diet is necessary otherwise micronutrient deficiency could occur. These effects are more pronounced in children who have smaller appetites, reduced capacity for food and disproportionate nutritional needs. Moreover children with neurodisability are at a higher risk as the skills required to consume adequate amounts of food and drinks, whether that be chewing and swallowing or foraging for food, may be compromised as a result of their disability.

Items G, H and I rate the child's food and fluid intake.

G	**Does the child eat & drink?** **Tick one box**	Yes ☐	No ☐ **If No proceed to K**

Figure 8 Item G of the nutrition screening tool

If the answer is no (for example if the child is nil by mouth and tube fed), the tool user is directed to item K at the end of the tool. If they answer yes, the user is asked to proceed to the following questions regarding quantity of food eaten and fluid intake:

H	**If Yes in your opinion how much do they eat?** **Tick one box**	Eats large meals and Snacks ☐	Eats average sized meals and snacks ☐	Eats average sized meals No snacks ☐	Frequently leaves food ☐	Eats very little ☐

Figure 9 Item H of the nutrition screening tool

Answer options were subjective assessments on a reducing scale. The nominal group felt that the tool user needed to be familiar with a child's usual eating pattern in order to be able to assess a response. This question initiated a discussion about whether this would be the case in practice as the child's usual nurse may not be the one completing the tool. One member of the group suggested that the tool could be used by parents, however whilst this was a good idea the majority felt that the tool should be validated within health care professionals initially. The answer options were chosen to be in reducing quantities of food so that the tool user could compare one option with the next and chose what they felt best fit the child's food intake.

Item I rated the child's fluid intake. It was a subjective evaluation.

I.	**In your opinion does the child have:** **Tick one box**	A good fluid intake ☐	Average fluid intake ☐	A poor fluid intake ☐

Figure 10 Item I of the nutrition screening tool

Fluid intake can impact not only on nutritional status but also on bowel function where insufficient fluid can cause constipation and so may be linked to item E.

The subjectivity of the answer options for items G, H and I on food and fluid intake prompted some group discussion. Several participants suggested that there should be more objective measures to quantify food and fluid intake, for example, by weighing plates of food before and after a meal and measuring the fluid consumed from the children's cups. One participant suggested weighing the child's bib before and after each drink to try and account for fluid loss from the mouth. The researcher facilitated a discussion on the difference between nutrition screening and nutrition assessment. The group acknowledged that nutrition screening tools need to be quick and easy to use by non-dietetic heath care professionals; where as detailed assessments of food and fluid intake should be undertaken by a qualified dietitian.

3.1.5 Oral motor skills - Speech and Language Therapist Review

The nominal Group felt assured by the fact that the researcher had organised a meeting with a speech and language therapist to validate item J, about eating and drinking skills, as they concurred that dietitians do not have the appropriate expertise.

Item J rated the child's physical ability to eat and drink (see chapter 1 section 3.6). The items listed below are either directly related to compromise of oral skills such as tongue thrust or indirectly such as snoozing at mealtimes, which may be a child's way of communicating that they do not wish to participate in this activity.

J. Does the child have any of the following?	Gagging or grimacing when eating / drinking	Difficulty opening and / or closing the mouth	Food loss from the mouth	Snoozing around mealtimes	Coughing or choking at mealtimes
Tick all appropriate Boxes	☐	☐	☐	☐	☐
	Changes in breathing rate, eye watering or colour change at mealtimes	Tongue thrust or chewing problems	Reflux or vomiting	Problems with vision	Known breathing difficulties or frequent chest infections
	☐	☐	☐	☐	☐

Figure 11 Item J of the nutrition screening tool

Item J asked the tool user to indicate if the child experienced any of the following:

- Gagging or grimacing when eating or drinking
- Difficulty opening and / or closing the mouth

- Food loss from the mouth
- Snoozing around mealtimes
- Coughing or choking at mealtimes
- Changes in breathing rate, eye watering or colour change at mealtimes
- Tongue thrust or chewing problems
- Reflux or vomiting
- Problems with vision
- Known breathing difficulties or frequent chest infections

All of these are symptoms are indicative of inadequate functioning of the stages of swallow (as described in section 3.6). This would indicate that a child with any one of these symptoms would be at risk of developing malnutrition because they are not managing to eat and drink effectively.

The Speech and Language Therapist consulted was a clinical expert at Chailey Heritage Clinical Services who agreed that the answer options for item J were all symptoms that would be considered when assessing a child's eating and drinking skills. There were no symptoms missing and thus no further changes suggested at this time.

3.1.6 Criteria for automatic referral

The nominal group was made up of dietitians who all felt uneasy that the tool did not have a 'safety net' item. This was described by the group as a question which could default into referring the child to the dietitian if necessary. It was agreed therefore that an additional item would be included at the end of the tool for this purpose. The safety net item was:

Does the child have any other medical problems?

- Food related problems e.g. behavioural, food allergy or intolerance, limited variety of food.
- Other chronic metabolic conditions e.g. diabetes, renal, liver, coeliac, Prader Willi syndrome (PWS) or Phynylketonurea (PKU).
- Nasogastric tube, Gastrostomy, jejunostomy, or I.V. feeding

Item K was incorporated to make sure that the nutrition screening tool did not exclude children who have other problems which directly affect their nutritional status.

K Does the child have any other Medical Problems? **Tick all appropriate Boxes**	Food related problems e.g. a) Behavioural b) Food allergy / intolerance c) limited variety of food ☐	Other chronic medical / metabolic conditions E.g. Diabetes, Renal, Liver, Coeliac, PWS, PKU. ☐	Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding ☐

Figure 12 Item K of the nutrition screening tool

Whilst the purpose of the nutrition screening tool was to identify those children with neurodisabilities who are at risk of malnutrition as a result of their condition, it does not mean than this group of children are not at the same risk of developing other medical problems such as diabetes, coeliac disease etc. Nor does neurodisability exclude behavioural feeding problems such as food refusal or fussy eating, that non disabled children commonly present with. Item K provided that assurance to make sure that these children are made known to the dietitian as they may need nutritional intervention of a different nature. Item K also aimed to highlight any children who receive artificial nutrition support including feeding via the enteral route (nasogastric, gastrostomy, jejunostomy) or intravenous route. It is very unlikely that a child receiving artificial nutrition support would not be under the supervision of a dietitian but this item ensures that they will not be missed.

3.1.7 Nurses' opinion

Item L was included as a means of testing the reliability of the nutrition screening tool.

L. Which category do you feel the child should the child be assigned to? **Tick one box**	Does not need to be referred to a dietitian ☐	Should be monitored and may need to be referred to a dietitian ☐	Needs to be referred to dietitian ☐

Figure 13 Item L of the nutrition screening tool

This was intended to be the last item on the nutrition screening tool to ensure that the nurse could use all the information obtained on the child to formulate their decision. Ultimately this item was not included when the tool was being used in clinical practice because the results from the combination of other items would direct the nurse or tool user to the correct category.

3.2. Test Population

The target group for the tool was also discussed. There was a unanimous agreement by the nominal group that the tool should be used within schools by school nurses on school aged children aged 5 to 19 years. This age range was chosen because it fits with the age range of children attending special needs schools where children are start in the school year they turn 5 years of age and stay at the school until the term after their 19th birthday.

3.3 Dietetic pro-forma

The pro-forma that had been designed to capture all aspects of dietetic assessment in order to ensure that each child received a uniform dietetic assessment was presented to the group. The group did not make any comments on the pro-forma except to acknowledge that it appeared to be very thorough. One participant asked if the pro-forma could be shared amongst the DISC (Dietitians Interested in Special Children) Group as a standardised dietetic assessment tool, however the researcher advised that until the research was published it needed to remain confidential.

3.4 Timing of assessment

The nominal group participants were asked to comment on the timing of the tool and the length of time between the nurses completing the screening tool and the dietitian's assessment of the child. It was important that the child must be in the same nutritional state for both screening and assessment. The group were asked to consider how long a time lag there could be between them. There is no research in this area as serial assessments to determine the rate of decline in nutritional status have not been done. However a consensus was agreed by the group that 4 weeks should be the maximum length of time between nutrition screening and dietetic assessment as any acute changes such as a loss of swallowing ability could impact on a child's nutritional state rapidly.

3.5 Nurses focus group results – Face Validity

Five school nurses, employed by Chailey Heritage School, and experienced in looking after children with severe neurodisabilities volunteered to attend the focus group after a meeting with the researcher who was also the school dietitian. None of the nurses were ‘Specialist Nurses in Nutrition’ but they all considered nutrition to be one of their key responsibilities when looking after the children in their care. Their advice was sought on the questions listed on the tool and each nurse agreed that the topics covered were appropriate. There was some concern that they may have to rely on the child’s carers or parents to supply some of the information required rather than them knowing this first hand. An example of this was assessing the child’s bowel habits, as often it’s the carers who are involved in the toileting of the children rather than the nurses; however the nurses felt that accurate written records were kept by the care staff in order for them to obtain this information.

3.6 Additional feedback

The nurses were concerned that completing a nutrition screening tool could be an additional responsibility to their already stretched workload and could become a burden. The researcher acknowledged the importance that the nutrition screening tool would need to be concise to minimise the burden.

Some of the nurses informed the researcher that they felt that they would need to have training on how to use the nutrition screening tool before it could be launched. They also requested that the nutrition screening tool came with instructions or guidelines for them to follow. The development and delivery of a training session and instruction sheet was therefore included in the validation part of the study.

4.0 Conclusions

A pilot nutrition screening tool for identifying children with, or at risk of developing malnutrition was carefully constructed using questionnaire design criteria obtained from the literature and guidance from the British Dietetic Association.

The questions and answer options that were included were chosen following a literature review and refined based on the clinical expertise within the nominal group process. The nominal group process was undertaken to establish content validity. Face validity was assessed via a focus group of tool users. This process also identified the need for a training package and written literature to support the use of the tool.

The results from the pilot nutrition screening tool suggested that it was ready to be tested on a small sample of children. It was further assessed for ease of use and practicality and also validated in terms of its psychometric properties.

PILOT NUTRITION SCREENING TOOL

CHILD'S NAME : ……………………………………………………………….
HEIGHT : ………………………………☐Actual ☐ Estimate
WEIGHT : ……………………………..

D.O.B : …………………………………
SCHOOL : ……………………………..
DATE COMPLETED : ………………..

For office Use only
code………………………..

NAME OF PERSON FILLING IN FORM : ……………………………………..........

A.	**In your opinion is the child:** **Tick one box**	Very Overweight ☐	Overweight ☐	Normal ☐	Thin ☐	Very Thin ☐
B.	**Over the past year how does the weight relate to the centiles?** **Tick one box**	Increasing across 2 or more centiles ☐	Increasing across 1 centile ☐	Follows centile line ☐	No Weight gain ☐	Weight loss ☐
C.	**Over the past year how does the height relate to centiles?** **Tick one box**		Increasing across one centile ☐	Follows centile line ☐	Dropping one centile ☐	No growth ☐
D.	**In your opinion is the child's weight appropriate for height?** **Tick one box**				Yes ☐	No ☐
E.	**How are the child's bowel habits?** **Tick one box**			Constipated with or without medication ☐	Normal ☐	Diarrhoea ☐
F.	**In your opinion how active is the child?** **Tick one box**	Excessive activity i.e. continuously 'on the go' ☐	Jerky involuntary movements ☐	Fully mobile ☐	Limited mobility ☐	Wheelchair bound ☐ Sleeps a lot ☐

G.	**Does the child eat & drink?** **Tick one box**			Yes ☐	No ☐ **If No proceed to K**

H.	**If Yes in your opinion how much do they eat?** **Tick one box**	Eats large meals and Snacks ☐	Eats average sized meals and snacks ☐	Eats average sized meals No snacks ☐	Frequently leaves food ☐	Eats very little ☐

I.	**In your opinion does the child have:** **Tick one box**			A good fluid intake ☐	Average fluid intake ☐	A poor fluid intake ☐

J.	**Does the child have any Of the following?** **Tick all appropriate Boxes**	Gagging or grimacing when eating / drinking ☐	Difficulty opening and / or closing the mouth ☐	Food loss from the mouth ☐	Snoozing around mealtimes ☐	Coughing or choking at mealtimes ☐
		Changes in breathing rate, eye watering or colour change at mealtimes ☐	Tongue thrust or chewing problems ☐	Reflux or vomiting ☐	Problems with vision ☐	Known breathing difficulties or frequent chest infections ☐
K.	**Does the child have any other Medical Problems?** **Tick all appropriate Boxes**	Food related problems e.g. - Behavioural - Food allergy/intolerance - limited variety of food ☐	Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWS, PKU. ☐		Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding ☐	
L.	**Which category do you feel the child should the child be assigned to?** **Tick one box**			Does not need to be referred to a dietitian ☐	Should be monitored and may need to be referred to a dietitian ☐	Needs to be referred to dietitian ☐

Figure 1. Pilot Nutrition Screening tool – Version 1

Chapter 4 Pilot study - testing the Nutrition Screening Tool

Chapter overview

Chapter 3 described how the nutrition screening tool for children with neurodisabilities was developed. This chapter will explain the process that was undertaken to pilot the nutrition screening tool and test it for usability, validity and reliability. Statistical analysis allowed for sensitivity and specificity of the tool to be defined in order to understand how well the tool would function in a larger group.

1.0 Introduction

The nutrition screening tool is a structured questionnaire with fixed questions or items which are presented to respondents in the same way using closed questions with predefined multiple choice answer options.

This strength of such a design is that it less likely to report ambiguous responses and therefore theoretically is more robust (Bowling 2009). A potential weakness of using a structured questionnaire is that it does not allow respondents to answer in their preferred way thereby forcing the selection of a predefined answer. In this case however, this was not perceived as a disadvantage because the answer options given were the only possible options. These types of structured questionnaires require validation before more widespread use.

1.1 Psychometric validation

Face and content validity of the nutrition screening tool have already been established and are detailed in the previous chapter. The tool has been ratified and approved by the tool users to determine face validity and specialist dietitians and a speech and language therapist to determine content validity. Further measures of validity and reliability are required for full psychometric validation.

1.2 Sensitivity and Specificity

In addition to psychometric validation, the nutrition screening tool was also tested for sensitivity and specificity which is a measure of the tools ability to be precise (Bowling 2009). Sensitivity in this case describes the number of children the tool identifies who are truly at risk of malnutrition, and specificity is the measure of the probability of the tool correctly identifying children who are not at risk of malnutrition. It refers to the tools ability to discriminate.

1.3 Practicality and usability

Finally the nutrition screening tool was tested for practicality and usability. Practicality describes the tools test length and scoring time (i.e. whether it can be used simultaneously or retrospectively after the nurse has finished caring for the child) whether the tool contains simple, trainable criteria and definitions for the user. Usability refers to the layout of the tool, its clarity and user-friendliness.

2.0 Aims

The aims of this pilot study were:

1. To test the nutrition screening tool's psychometric properties i.e. its validity and reliability.
2. To determine its practicality and usability.
3. To produce training materials for the tool users to aid accuracy.

In order to achieve these aims, this part of the research was divided into several objectives as follows:

3.0 Objectives

- To enable nurses to complete a nutrition screening tool appropriately for their assigned children, including provision of a training pack.
- To carry out a full nutritional assessment to determine to true nutritional risk of each child.
- To analyse nurse data versus the data of the true nutritional status of the child, for each item on the nutrition screening tool in order to assess criterion validity and determine whether some items are better indicators of malnutrition risk than others.
- To assess inter rater reliability between pairs of nurses who assessed the same child to see if they use the tool in the same way.
- To gain feedback from the nurses and reflections from the researcher in order to assess the tools usability and practicality.

4.0 Procedure for data collection

The following order of events in order to collect the data required is described below:

4.1 Ethical approval

Prior to the commencement of the data collection, ethical approval was applied for via the Brighton, Hove and East Sussex Ethics Committee. Chairman’s actions were instructed and resubmission granted full ethical approval. The letter granting ethical approval, the consent forms and child & parent information sheets which were also submitted as part of this process can be found in Appendix 7.

4.2 Recruitment of participants - nursing staff

All 20 school nurses at Chailey Heritage School were approached by the researcher at a routine staff meeting and asked if they wished to participate in the study. The study was explained and participants were advised of the time commitment. The Chailey Heritage Clinical Services research committee granted ethical approval of participants being offered a complementary lunch and £10 cash incentive for attending the training sessions and agreeing to complete the nutrition screening tools.

Funding for the incentives was sourced from the Research & Development budget at Chailey Heritage Clinical Services.

4.3 Training programme for school nurses

In order to assist the school nurses prior to completing the nutrition screening tool, training on the tool was provided. The British Dietetic Association guidance on producing nutrition screening tools highlights the importance of this in ensuring accurate assessment and timely responses (BDA 1999). It also allows for further emphasis of nutritional issues in order to keep it in the forefront of the raters’ thoughts.

Nurses participating in the study were mandated to attend two training sessions with the researcher prior to commencing the study. A supporting instruction sheet was also provided for reference information at both sessions and is included in appendix 8.

4.3.1 Session 1

Ten nurses agreed to participate. Session 1 was an hour long training session focusing on clinical characteristics associated with malnutrition in children with neurodisability with particular reference to those that are itemised on nutrition screening tool. The session also outlined details of the research project and their role as participants. It was delivered in a lecture style session. The attendance rate was 100% of school nurses who had volunteered to participate in the study.

4.3.2 Session 2

This session was held one week later and intended to follow the first session's content, but in a more experiential manner where theory was put into practice. Nurses were asked to work in pairs and each pair was given a case study of a child and asked to complete a nutrition screening tool, based on the case study information provided. The instruction sheet was explained in detail to help them complete the tool. There were two case studies and each case study was discussed by the group as a whole to ensure that all possible queries were addressed. 100% attendance at the training session was again achieved.

4.3.3 Guidance notes

An instruction sheet of guidance notes was given out along with a sample nutrition screening tool at the end of both session 1 and session 2. It was also used for teaching the nurses during session two. The instruction sheet gave clear instructions to the nurses on how to complete the nutrition screening tool, for example it gave the nurses information on how best to measure height or length and when weighing the child what they needed to consider. It also included instructions on what they needed to do with the nutrition screening tool once complete. A copy of the instruction sheet is included in appendix 8.

4.4 Recruitment of participants - Children

A purposive sample of school age children with neurodisabilities was required for the pilot study. The study sample needed to be a subsection of the accessible population, which in this case was those children attending Chailey Heritage School where the researcher was employed. The intention was that the sample would have adequate external validity in order for results to be generalised to the

accessible population (school). Further work would be required to generalise outcomes to the theoretical population i.e. all children with neurodisabilities.
All 102 children attending Chailey Heritage School were invited to take part in the study by means of a letter, written to the parents and sent to their home address, Forty Six returned the signed consent form agreeing for their child to take part. A sample size of 20 was chosen as it was considered by the researcher to be a purposive sample for testing the tool, representing a fifth of the school population and the number of children on a typical busy dietetic caseload. A sample size calculation was not made. A subset of 20 children were randomly chosen to participate which was carried out by a volunteer who had no affiliation with the school or children. The volunteer was sourced from the NHS Trusts Voluntary Services Department.

The parents / guardians of each school-child fitting the inclusion criteria were written to by the researcher to ask if they would be willing to participate in the study. Consent forms and information sheets for both the parent and child were supplied. Parents were asked to sign consent forms in triplicate and return two copies to the researcher, keeping one for their own records. Each child entering the study was allocated a random number by the volunteer upon return of the completed consent form.

4.4.1 Inclusion criteria

- School aged children (5 – 19 years old)
- Any condition considered a neurodisability such as cerebral palsy, including undiagnosed conditions
- Attending Chailey Heritage special needs school

There were no exclusion criteria.

4.5 Allocation of children to nurses

Once the nurses and children were recruited, the volunteer made the allocations. This ensured allocation concealment from the researcher to eliminate selection bias as the researcher had worked with the participants of the study for many years and knew them well. Moreover knowledge of the participants may have affected the researcher’s response, resulting in a less thorough nutritional

assessment particularly if she knew and trusted the nutritional judgement of the participating nurse (Karanicolas et al 2010). The volunteer also ensured that all nurses had equal numbers of children to screen so that one would not become more practiced at using the nutrition screening tool than the others. Each nurse had 10 children to screen which were assigned over a 3 month period so that each nurse received 2-3 children to screen each month, this was in order to ensure the nurses did not feel over burdened with work. The random allocation also meant that a nurse may or may not have been allocated a child they knew well.
Each of the 20 children had a nutrition screening tool completed by 3 different nurses. Thus the expected number of completed tools was 60.

4.6 Data collection

The nutrition screening tools were sent out by the volunteer to the participating nurses. Each screening tool had a copy of the instruction sheet attached as a reminder on how to complete the tool. A covering letter also indicated which child they had been asked to assess, and gave a return date of 3 weeks from the date of issue. Each tool was provided with a self addressed envelope addressed to the researcher. The screening tool and envelope were coded with the child's number (randomly generated by the volunteer) and a nurse code to enable data tracking. The nurse was also asked to note the child's height (in cm) and weight (in kg) and the date they were measured on the front of the envelope in the space provided.

The completed screening tools were posted to the volunteer who checked that the coded tool correctly matched the envelope in order to ensure that all the expected screening tools were received. She followed up those that had not been returned (with the nurse directly) so that all nutrition screening tools were returned within a 4 week period.

At the same time a 3 day food diary, pre-coded with the child's random number, a prepaid envelope, a return date and instructions for use were sent to the parent or carer at the child's permanent address (see Appendix 9). The food diary was included for use by the researcher at the time of the full dietetic assessment to inform her about the child's food intake, diet, meal patterns and fluids consumed.

An appointment date within a 4 week period was set for the child's full dietetic assessment to ascertain true nutritional status of the child. The parent or carer and primary nurse were also invited to attend. It was made clear that it was essential for the parent or carer to attend to facilitate lifting and moving the child however the primary nurses' attendance was voluntary.

All completed paperwork was stored by the volunteer until data analysis was required.

4.7 Procedure to define true nutritional status

The researcher carried out a full dietetic assessment to determine the true nutritional status of the child. At the same time the researcher completed a nutrition screening tool. This was to provide a gold standard to which to compare the nurse nutrition screening tool data.

4.7.1 Design of a dietetic assessment pro-forma

To ensure that each child received a uniform dietetic assessment by the researcher a pro-forma was designed, firstly to be used as a prompt to make sure aspects of a nutritional assessment were covered and secondly as somewhere to record all the information gathered in order to make the assessment of nutritional status. The content of the pro-forma (Appendix 10) was validated by the nominal group as described in chapter 3.

The dietetic assessment incorporated the following:

4.7.1.1 Physical examination

The child and carer attended a clinic with the dietitian, with or without the school nurse and parent / guardian present. The physical examination consisted of:

- Measuring height or length. A standing height was preferable but as many children with neurodisability cannot stand, a supine length was taken as an alternative.
- Knee height or tibial length using a Harpenden anthropometer, if a true height or length was unobtainable.

- Weight measured preferably on wheelchair scales with the weight of the child's wheelchair, clothing and any equipment weighed separately and subtracted.
- Mid arm circumference using a steel tape measure.
- Triceps skinfold thickness using Holtain skin callipers.
- Clinical observations of any physical signs of malnutrition including wiry hair, dermatitis or loss of skin quality and pigment, moon face, hepatomegaly and oedema.

Chapter 1 describes the clinical justification of the physical examination. If the child was unable to attend a clinic, a home visit was made to carry out this examination. Portable equipment, consisting of the Marsden MPWS 300 portable wheelchair weighbeams and Harpenden anthropometer were purchased in order to ensure that the same equipment was used and so measurement error was minimised. The researcher carried out all measurements herself to eliminate inter-observer error.

4.7.1.2 Examination of Medical Notes

The child's medical notes were obtained to ascertain other factors influencing the child's nutritional status. Past medical history, gastrointestinal disturbances, medications and abnormal blood biochemistry results were all noted. The child was not sent for venepuncture specifically for this assessment but access to recent blood results was available if needed.

4.7.1.3 Speech and Language Therapy

If the child had a Speech and Language Therapist, their assessment report was also consulted. The Redway Communication Scale was used as a method of categorising communication ability and was readily available in the child's assessment (Latham and Miles 2000). The Speech and Language Therapists report also documented the child's oral motor ability if the child was known to have eating and drinking difficulties. This information was also used as part of dietetic assessment.

4.7.1.4 Physiotherapy

The child's physiotherapy report was also obtained for information regarding mobility. The Gross Motor Classification System was used to identify degrees of immobility (Palisano et al. 1997).

4.7.1.5 Dietary Assessment

A dietary assessment will provide information about an individual's food intake, meal pattern and behaviours. Human beings vary the amounts and types of foods consumed each day and so any assessment of diet needs to span a length of time. There are various methods of dietary assessment available to dietitians as detailed in section 6.3.1. The method chosen for this project was a 3 day written food diary, kept by the parent / carer. Three days were chosen in order to obtain optimum accuracy and compliance. It is known from clinical practice that the longer food intake has to be recorded the less accurate it becomes due to waning compliance and this has been further researched in weight management situations (Wing 2001, Burke 2011). It is documented in the Manual of Dietetic Practice, that when a recording period of less than 7 days is chosen, a weekend day should be incorporated as peoples eating habits often differ at weekends compared to weekdays (Thomas, Bishop 2007). Many of the children at Chailey Heritage School are residential between Monday – Friday, and their eating patterns and habits could be very different at home at the weekend. Similarly some children had food provided from home (packed lunches) whilst others had food provided by the school or residential bungalows.

A 3 day food diary was chosen because it provided an insight to the parents / carers perception of what their child ate. Parents were also requested to keep packaging of uncommon food products or supplements given, and details within the food diary were clarified at the clinical appointment where necessary. At the start of the food diary a short questionnaire was included which asked questions such as what type of milk, spread, bread, drinks etc were used. This was to clarify likely omissions in advance, such as the parent documenting 'milk' rather than 'whole milk' 'semi skimmed' or 'skimmed'. The decision of what to use here was based on previous experience of working with children and families in dietetic practice.

The 3 day food diary was supplemented with a second type of dietary assessment, a meal observation by the dietitian, where this was possible, for example where the child stayed at school for lunch. The intention here was to provide more information and improve accuracy of usual intake.

4.7.1.5.1 Meal Observation

For all children who received nutrition orally, a meal observation was carried out in the child’s usual lunchtime environment at school. This was sometimes in the schools dining room or for residential school children in their accommodation. Observations were made of the type of food offered, quantity consumed, quantity lost from the child’s mouth, texture of food, mealtime environment, any specialist equipment used, method of feeding and interaction with the child and carer. If a ‘Mealtime Guidance Sheet’ was available this was also consulted for information.

The ‘Mealtime Guidance Sheet’ is a laminated table mat produced by the Speech and Language Therapist. It contains information on strategies and techniques for the person feeding the child, in order to make feeding a more successful and enjoyable experience. It also documents the child’s food likes and dislikes, any allergies or special diet as reported by the parents / guardians.

4.7.1.5.2 Nutritional intake analysis

For children who received nutrition orally a completed 3 day food diary was analysed for nutritional adequacy using the dietary analysis computer software package CompEat PRO. For those children who were enterally fed (gastrostomy, jejunostomy or nasogastric tube), a full nutritional breakdown of their enteral feed was calculated.

4.7.2 Completion of nutrition screening tool & assignment of nutritional risk

Once the dietetic assessment was complete, the researcher used her clinical expertise as an experienced dietitian to evaluate all of the information obtained in order to make an informed clinical judgement to determine true nutritional status. In addition the dietitian completed a nutrition screening tool for each child including item L which assigns the child into one of three categories. The categories are:

1. The child is not at risk of malnutrition and does not need to be referred to the dietitian.
2. The child may be at risk of malnutrition and should be monitored, and may need to be referred to the dietitian.
3. The child is at risk of malnutrition and needs to be referred to the dietitian.

4.8 Debriefing with nurses

Following the data collection period, the nurses were all asked to attend a debriefing session facilitated by the researcher. The aim of this session was to allow the nurses an opportunity to give feedback on their experiences of using the nutrition screening tool and for the researcher to assess for practicality and usability of the tool. The session was held at Chailey Heritage Clinical Services over the nurses' lunch break. A light lunch and refreshments were provided to encourage attendance. The items on the tool were addressed in turn and participation in the discussion was encouraged. The researcher took notes.

4.9 Researcher's reflections on ease of use

Throughout the data collection phase, the researcher detailed notes on the usability and practicality of the nutrition screening tool. The aim of this was to facilitate further refining of the tool if necessary.

PILOT NUTRITION SCREENING TOOL

CHILD'S NAME : …………………………………………………………………… **D.O.B : …………………………………** **For office Use only**

HEIGHT : ………………………………☐Actual ☐ Estimate **SCHOOL : ……………………………..** code………………………..

WEIGHT : …………………………….. **DATE COMPLETED : ………………..**

NAME OF PERSON FILLING IN FORM : …………………………………..........

A.	**In your opinion is the child:** **Tick one box**	Very Overweight ☐	Overweight ☐	Normal ☐	Thin ☐	Very Thin ☐
B.	**Over the past year how does the weight relate to the centiles?** **Tick one box**	Increasing across 2 or more centiles ☐	Increasing across 1 centile ☐	Follows centile line ☐	No Weight gain ☐	Weight loss ☐
C.	**Over the past year how does the height relate to centiles?** **Tick one box**		Increasing across one centile ☐	Follows centile line ☐	Dropping one centile ☐	No growth ☐
D.	**In your opinion is the child's weight appropriate for height?** **Tick one box**				Yes ☐	No ☐
E.	**How are the child's bowel habits?** **Tick one box**			Constipated with or without medication ☐	Normal ☐	Diarrhoea ☐
F.	**In your opinion how active is the child?** **Tick one box**	Excessive activity i.e. continuously 'on the go' ☐	Jerky involuntary movements ☐	Fully mobile ☐	Limited mobility ☐	Wheelchair bound ☐ Sleeps a lot ☐

G. **Does the child eat & drink?** **Tick one box**				Yes ☐	No ☐ If No proceed to K
H. **If Yes in your opinion how much do they eat?** **Tick one box**	Eats large meals and Snacks ☐	Eats average sized meals and snacks ☐	Eats average sized meals No snacks ☐	Frequently leaves food ☐	Eats very little ☐
I. **In your opinion does the child have:** **Tick one box**			A good fluid intake ☐	Average fluid intake ☐	A poor fluid intake ☐
J. **Does the child have any Of the following?** **Tick all appropriate Boxes**	Gagging or grimacing when eating / drinking ☐	Difficulty opening and / or closing the mouth ☐	Food loss from the mouth ☐	Snoozing around mealtimes ☐	Coughing or choking at mealtimes ☐
	Changes in breathing rate, eye watering or colour change at mealtimes ☐	Tongue thrust or chewing problems ☐	Reflux or vomiting ☐	Problems with vision ☐	Known breathing difficulties or frequent chest infections ☐
K. **Does the child have any other Medical Problems?** **Tick all appropriate Boxes**	Food related problems e.g. - Behavioural - Food allergy/intolerance - limited variety of food ☐	Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWS, PKU. ☐		Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding ☐	
L. **Which category do you feel the child should the child be assigned to?** **Tick one box**			Does not need to be referred to a dietitian ☐	Should be monitored and may need to be referred to a dietitian ☐	Needs to be referred to dietitian ☐

Figure 15 Nutrition Screening tool – Version 1

5.0 Results

5.1 Quantitative analysis

66 nutrition screening tools were returned despite only 60 tools being sent out. This anomaly was explained by means of notes from the nurses who described the need to share out the workload due to staff absences. Of the 20 children allocated all 20 had nutrition screening tools completed, an additional 2 children were also unexpectedly screened, totalling 22 children participating in the study. All of the 10 nurses who volunteered, participated fully in the study.

Despite this unexpected irregularity, 21 of the 22 children had all 3 nurses complete the nutrition screening tool thus only 1 child had just two nurses assess them. The dietitian managed to obtain a full dietetic assessment and complete a nutrition screening tool to produce a 'gold standard' for the additional two children within the 4 week deadline and so they were able to be included in data analysis. Fortunately consent for these two children had been obtained prior to the start of the study.

5.1.1 Statistical analysis

Data was input into Microsoft Excel initially then transferred across to SPSS for statistical analysis.

5.1.1.1 Demographic data

Decimal age	Sex	Ethnic Origin
Youngest 5.48 years	9 Female	95.5% white British
Median 13.9 years	13 Male	4.5% Black other
Oldest 18.7 years		

Table 10. Demographic data of the sample

Table 9 shows the ethnic group, sex and age of the 22 children in the sample. 21 of the 22 children were classified as white in terms of ethnic, 13 were male which equates to 59% of the sample. The youngest child was 5.48 years, oldest 18.7 years and median 13.9 years.

5.1.1.2 Diagnosis

The inclusion criteria stated 'any neurodisability'. The children's actual diagnosis's were:

- 19 Cerebral palsy children (caused by prematurity, cerebral abscess, severe epilepsy, Foetal stroke, head injury)
- 1 H-ABC Syndrome child
- 1 Undiagnosed progressive dystonia child
- 1 child with Salla disease

5.1.1.3 Construct Validity - measures of agreement

Frequency tables and Kappa coefficient were used within SPSS to measure the agreement between the gold standard dietetic assessment and the nurse's assessment of each child screened. Kappa is a statistical measure of inter-rater agreement and was chosen in this instance as it adjusts its values accounting for agreement by chance alone. A value of 1 implies perfect agreement and a value of <1 is less than perfect agreement.

There are no universally accepted guidelines for the magnitude of Kappa values, however for the purpose of offering a degree of explanation as to how well the nurses and dietitian agree, the following assumptions are made. These assumptions were first described by Landis et al in 1977 and are not scientifically derived, but are based purely on their personal opinions (Landis et al 1977).

0.2	Slight agreement
0.2-0.4	Fair agreement
0.4-0.6	Moderate agreement
0.6-0.8	Substantial agreement
0.8-1.0	Almost perfect agreement

For the purpose of analysis the median score of all 3 nurses' assessments was compared against the dietetic standard. This was because 10 different nurses were involved and so nurse 1, 2 and 3 were not always the same person and the purpose of the statistical analysis was to investigate how well nurses in general scored compared to the dietetic gold standard, rather than as individuals.

5.1.1.4 Case Summaries

Listed below are the case summaries for all of the items on the nutrition screening tool.

Item A

A.	**In your opinion is the child Tick one box**	**Very Overweight** ☐		**Overweight** ☐		**Normal** ☐		**Thin** ☐		**Very Thin** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Normal	Thin	Normal	Normal	Normal	Y
2	Normal	Normal	Normal	Normal	Normal	Y
3	Normal	Normal	Normal	Normal	Normal	Y
4	Thin	Thin	Thin	Thin	Thin	Y
5	Thin	Very thin	Thin	Thin	Very thin	N
6	Normal	Thin	Thin	Thin	Thin	Y
7	Normal	Thin	Normal	Normal	Normal	Y
8	Thin	Thin	Normal	Thin	Thin	Y
9	Very thin	Thin	Very thin	Very thin	Very thin	Y
10	Normal	Normal	Normal	Normal	Normal	Y
11	Normal	Thin	Normal	Normal	Normal	Y
12	Thin	Thin	Normal	Thin	Normal	N
13	Thin	Normal	Very thin	Thin	Thin	Y
14	Thin	Normal	Thin	Thin	Thin	Y
15	Thin	Normal	Normal	Normal	Normal	Y
16	Normal	Thin	Normal	Normal	Normal	Y
17	Normal	Thin	Normal	Normal	Thin	N
18	Thin	Very thin	Thin	Thin	Thin	Y
19	Thin	Thin	Thin	Thin	Thin	Y
20	Normal	Normal	*.	Normal	Normal	Y
21	Thin	Normal	*.	Normal	Normal	Y
22	Normal	Normal	Normal	Normal	Normal	Y
					% agreement	86.4
					Kappa	0.75

* missing date from incomplete nutrition screening tools

Table 11. Ratings and agreement for Item A for nurses and dietitian

Table shows subjective judgement of size by three different nurses and their true size as advised by the dietitian. Agreement between the median of the nurses judgement and the dietitians assessment was 86.4% with a kappa value of 0.75 indicating a good correlation.

Note there were no overweight or very overweight children in the sample.

Item B

B	**Over the past year how does the weight relate to the centiles?** **Tick one box**	**Increasing across 2 or more centiles** ☐		**Increasing across 1 centile** ☐		**Follows centile line** ☐		**No Weight gain** ☐		**Weight loss** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	>1 centile	>2 centiles	Follows centile	>1 centile	>1 centile	Y
2	>1 centile	Weight loss	>2 centiles	>1 centile	Follows centile	N
3	Follows centile	Follows centile	Follows centile	Follows centile	Follows centile	Y
4	No weight gain	Follows centile	Follows centile	Follows centile	Follows centile	Y
5	Weight loss	Follows centile	Follows centile	Follows centile	Follows centile	Y
6	Weight loss	No weight gain	Weight loss	Weight loss	Weight loss	Y
7	>1 centile	*	>1 centile	>1 centile	Follows centile	N
8	Follows centile	Follows centile	Follows centile	Follows centile	Follows centile	Y
9	Follows centile	Follows centile	Follows centile	Follows centile	No weight gain	N
10	Weight loss	Follows centile	Weight loss	Weight loss	Follows centile	N
11	Follows centile	>1 centile	Follows centile	Follows centile	Follows centile	Y
12	Follows centile	Follows centile	>1 centile	Follows centile	Follows centile	Y
13	Follows centile	Follows centile	Weight loss	Follows centile	Follows centile	Y
14	No weight gain	Weight loss	Weight loss	Weight loss	No weight gain	N
15	Follows centile	No weight gain	No weight gain	No weight gain	Follows centile	N
16	Follows centile	Follows centile	*	Follows centile	No weight gain	N
17	*	Follows centile	Follows centile	Follows centile	Follows centile	Y
18	No weight gain	Weight loss	Weight loss	Weight loss	Follows centile	N
19	No weight gain	Weight loss	Weight loss	Weight loss	Weight loss	Y
20	*	Weight loss	Weight loss	Weight loss	Weight loss	Y
21	Follows centile	*	*	Follows centile	>1 centile	N
22	Follows centile	Follows centile	No weight gain	Follows centile	Follows centile	Y
Total	20	20	20	22	22	
					Percentage agreement	59%
					Kappa	0.31
* missing date from incomplete nutrition screening tools						

Table 12. Ratings and agreement for item B for nurses and dietitian

Table 11 shows assessment of weight changes over the last year by 3 different nurses. The median is compared to the true weight change as defined by the dietitian. The Kappa value of 0.31 indicates a fair agreement.

Item C

C.	**Over the past year how does the height relate to centiles? Tick one box**		**Increasing across one centile** ☐		**Follows centile line** ☐		**Dropping one centile** ☐		**No growth** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Follows centile	increasing across 1 centile	Follows centile	Follows centile	increasing across 1 centile	N
2	Follows centile	Dropping one centile	Follows centile	Follows centile	Follows centile	Y
3	Follows centile	Follows centile	Follows centile	Follows centile	Follows centile	Y
4	Follows centile	increasing across 1 centile	Follows centile	Follows centile	Follows centile	Y
5	increasing across 1 centile	Follows centile	Follows centile	Follows centile	Follows centile	Y
6	No growth	Dropping one centile	No growth	No growth	No growth	Y
7	increasing across 1 centile	No growth	No growth	No growth	increasing across 1 centile	N
8	Follows centile	No growth	No growth	No growth	No growth	Y
9	Follows centile	Follows centile	Follows centile	Follows centile	No growth	N
10	increasing across 1 centile	increasing across 1 centile	increasing across 1 centile	increasing across 1 centile	Dropping one centile	N
11	Dropping one centile	increasing across 1 centile	increasing across 1 centile	increasing across 1 centile	Follows centile	N
12	increasing across 1 centile	Follows centile	increasing across 1 centile	increasing across 1 centile	Follows centile	N

		Nurse 1	**Nurse 2**	**Nurse 3**	**Median**	**Dietitian**
13	increasing across 1 centile	increasing across 1 centile	No growth	increasing across 1 centile	Follows centile	N
14	No growth	No growth	No growth	No growth	Follows centile	N
15	Follows centile	No growth	No growth	No growth	No growth	Y
16	Follows centile	Dropping one centile	*	Dropping one centile	Dropping one centile	Y
17	Follows centile	Dropping one centile	increasing across 1 centile	Follows centile	Follows centile	Y
18	No growth	Dropping one centile	No growth	No growth	No growth	Y
19	*	*	*	.	Follows centile	N
20	*	No growth	No growth	No growth	No growth	Y
21	Follows centile	*	*	Follows centile	Dropping one centile	N
22	increasing across 1 centile	Dropping one centile	Dropping one centile	Dropping one centile	Follows centile	N
Total	20	20	19	21	22	
					Percentage agreement	50%
					Kappa	0.31
* missing date from incomplete nutrition screening tools						

Table 13. Ratings and agreement for item C for nurses and dietitian

Table 12 shows assessment of height / length changes over the last year by 3 different nurses. The median is compared to the true weight change as defined by the dietitian. The Kappa value of 0.31 indicates a fair agreement.

Item D

D.	**In your opinion is the child's weight appropriate for height?** **Tick one box**		**Yes** ☐		**No** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Yes	Yes	Yes	Yes	Yes	Y
2	Yes	Yes	No	Yes	Yes	Y
3	Yes	Yes	Yes	Yes	Yes	Y
4	No	No	No	No	No	Y
5	No	No	No	No	No	Y
6	No	No	No	No	No	Y
7	Yes	No	No	No	Yes	N
8	Yes	No	Yes	Yes	No	N
9	No	No	No	No	No	Y
10	Yes	Yes	Yes	Yes	Yes	Y
11	Yes	No	Yes	Yes	Yes	Y
12	Yes	Yes	Yes	Yes	Yes	Y
13	No	No	Yes	No	Yes	N
14	Yes	Yes	Yes	Yes	No	N
15	No	No	Yes	No	Yes	N
16	Yes	Yes	No	Yes	Yes	Y
17	Yes	No	Yes	Yes	No	N
18	No	No	Yes	No	Yes	N
19	No	No	No	No	No	Y
20	Yes	No	Yes	Yes	Yes	Y
21	Yes	*	*	Yes	Yes	Y
22	Yes	No	Yes	Yes	Yes	Y
Total	N	21	21	22	22	
					Percentage agreement	68.1%
					Kappa	0.33
* missing date from incomplete nutrition screening tools						

Table 14. Ratings and agreement for item D for nurses and dietitian

Table 13 shows opinion of weight for height of 3 different nurses. The median is compared with the true weight for height of the child as defined by the dietitian. The Kappa value of 0.33 indicates a fair agreement.

Item E

E.	**How are the child's bowel habits?** **Tick one box**		**Constipated with or without medication** ☐		**Normal** ☐		**Diarrhoea** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Constipated	Constipated	Constipated	Constipated	Constipated	Y
2	Normal	Constipated	Constipated	Constipated	Constipated	Y
3	Constipated	Constipated	Constipated	Constipated	Constipated	Y
4	Normal	Constipated	Constipated	Constipated	Constipated	Y
5	Constipated	Constipated	Constipated	Constipated	Constipated	Y
6	Normal	Normal	Constipated	Normal	Normal	Y
7	Normal	Normal	Constipated	Normal	Constipated	N
8	Constipated	Constipated	Constipated	Constipated	Constipated	Y
9	Normal	Normal	Constipated	Normal	Normal	Y
10	Constipated	Normal	Constipated	Constipated	Constipated	Y
11	Normal	Normal	Normal	Normal	Constipated	N
12	Normal	Normal	Normal	Normal	Normal	Y
13	Constipated	Constipated	Constipated	Constipated	Constipated	Y
14	Normal	Constipated	Normal	Normal	Constipated	N
15	Normal	Constipated	Constipated	Constipated	Constipated	Y
16	Constipated	Constipated	Constipated	Constipated	Constipated	Y
17	Constipated	Constipated	Constipated	Constipated	Constipated	Y
18	Constipated	Constipated	Constipated	Constipated	Constipated	Y
19	Normal	Normal	Normal	Normal	Normal	Y
20	Constipated	Constipated	Constipated	Constipated	Constipated	Y
21	Normal	Normal	*	Normal	Constipated	N
22	Constipated	Constipated	Normal	Constipated	Constipated	Y
Total	22	22	21	22	22	
					Percentage Agreement	81%
					Kappa	0.56
* missing date from incomplete nutrition screening tools						

Table 15. Ratings and agreement for item E for nurses and dietitian

Table 14 shows assessment of bowel habits by 3 different nurses. The median is compared to the child's true bowel habits as defined by the dietitian. The Kappa value of 0.56 indicates moderate agreement.

Item F

F.	In your opinion how active is the child? Tick one box	Excessive activity i.e. continuously 'on the go'	Jerky involuntary movements	Fully mobile	Limited mobility	Wheelchair bound	Sleeps a lot
		☐	☐	☐	☐	☐	☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Excessive Activity	Jerky involuntary movements	Wheelchair bound	Jerky involuntary movements	Wheelchair bound	N
2	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
3	Wheelchair bound	Wheelchair bound	Limited Mobility	Wheelchair bound	Wheelchair bound	Y
4	Wheelchair bound	Wheelchair bound	Jerky involuntary movements	Wheelchair bound	Jerky involuntary movements	N
5	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
6	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
7	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
8	Limited Mobility	Limited Mobility	Wheelchair bound	Limited Mobility	Limited Mobility	Y
9	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
10	Wheelchair bound	Limited Mobility	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
11	Limited Mobility	Limited Mobility	Limited Mobility	Limited Mobility	Limited Mobility	Y
12	Wheelchair bound	Limited Mobility	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
13	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
14	Limited Mobility	Wheelchair bound	Limited Mobility	Limited Mobility	Wheelchair bound	N

	Nurse 1	**Nurse 2**	**Nurse 3**	**Median**	**Dietitian**	**Agreement**
15	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
16	Limited Mobility	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
17	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
18	Limited Mobility	Limited Mobility	Limited Mobility	Limited Mobility	Limited Mobility	Y
19	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
20	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Wheelchair bound	Y
21	Excessive Activity	Wheelchair bound		Wheelchair bound	Wheelchair bound	Y
22	Excessive Activity	Excessive Activity	Excessive Activity	Excessive Activity	Wheelchair bound	N
Total	22	22	21	22	22	
					Percentage agreement	81%
					Kappa	0.51
* missing date from incomplete nutrition screening tools						

Table 16. Ratings and agreement for item F for nurses and dietitian

Table 15 shows assessment of activity by 3 different nurses. The median is compared to the child's true activity level as defined by the dietitian. The Kappa value of 0.51 indicates moderate agreement.

Item G

G.	**Does the child eat & drink?** **Tick one box**		**Yes** ☐	**No** ☐ **If No proceed to K**

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	Yes	Yes	Yes	Yes	Yes	Y
3	Yes	Yes	Yes	Yes	Yes	Y
4	Yes	Yes	Yes	Yes	Yes	Y
5	Yes	Yes	Yes	Yes	Yes	Y
6	Yes	Yes	Yes	Yes	Yes	Y
7	Yes	Yes	Yes	Yes	Yes	Y
8	Yes	Yes	Yes	Yes	Yes	Y
9	Yes	Yes	Yes	Yes	Yes	Y
10	Yes	Yes	Yes	Yes	Yes	Y
11	Yes	Yes	Yes	Yes	Yes	Y
12	Yes	Yes	Yes	Yes	Yes	Y
13	Yes	Yes	Yes	Yes	Yes	Y
14	Yes	Yes	Yes	Yes	Yes	Y
15	Yes	Yes	Yes	Yes	Yes	Y
16	Yes	Yes	Yes	Yes	Yes	Y
17	Yes	Yes	Yes	Yes	Yes	Y
18	Yes	Yes	Yes	Yes	Yes	Y
19	Yes	Yes	Yes	Yes	Yes	Y
20	Yes	Yes	Yes	Yes	Yes	Y
21	Yes	Yes	No	Yes	No	N
22	Yes	Yes	Yes	Yes	Yes	Y
Total	22	22	21	22	22	
					Percentage Agreement	95.4%
					Kappa	0.65

Table 17. Ratings and agreement for item G for nurses and dietitian

Table 16 shows eating and drinking ability defined by 3 different nurses. The median is compared to the child’s true ability as defined by the dietitian. Note only

2 children were unable to eat or drink. The Kappa value of 0.65 indicates substantial agreement.

Item H

H.	**If Yes in your opinion how much do they eat?** **Tick one box**	**Eats large meals and Snacks** ☐		**Eats average sized meals and snacks** ☐		**Eats average sized meals No snacks** ☐		**Frequently leaves food** ☐		**Eats very little** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Nil by Mouth	Nil by Mouth	Nil by Mouth	Nil by Mouth	Nil by Mouth	Y
2	Eats very little	Average meals and snacks	Average meals only	Average meals only	Average meals only	Y
3	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Y
4	Eats very little	Eats very little	Eats very little	Eats very little	Eats very little	Y
5	Average meals only	Eats very little	Eats very little	Eats very little	Eats very little	Y
6	Average meals and snacks	Average meals only	Average meals and snacks	Average meals and snacks	Average meals and snacks	Y
7	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals only	N
8	leaves food	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Y
9	Average meals and snacks	Eats very little	Average meals only	Average meals only	Eats very little	N
10	Average meals only	Average meals and snacks	Average meals only	Average meals only	Average meals and snacks	N
11	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Y

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
12	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Y
13	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals only	N
14	Average meals and snacks	Average meals only	Average meals and snacks	Average meals and snacks	Average meals only	N
15	Average meals only	Average meals and snacks	Average meals only	Average meals only	Average meals only	Y
16	Average meals and snacks	leaves food	Average meals and snacks	Average meals and snacks	Average meals only	N
17	Average meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	leaves food	N
18	leaves food	leaves food	leaves food	leaves food	leaves food	Y
19	Average meals and snacks	Average meals only	Large meals and snacks	Average meals and snacks	leaves food	N
20	Average meals and snacks	Average meals only	Average meals only	Average meals only	Average meals only	Y
21	Eats very little	Eats very little	Nil by Mouth	Eats very little	Nil by Mouth	N
22	Average meals and snacks	Large meals and snacks	Average meals and snacks	Average meals and snacks	Average meals and snacks	Y
Total	22	22	22	22	22	
					Percentage agreement	59.0%
					Kappa	0.44

Table 18. Ratings and agreement for item H for nurses and dietitian

Table 17 shows quantity of food eaten defined by 3 different nurses. The median is compared to the child's true ability as defined by the dietitian. The Kappa value of 0.44 indicates moderate agreement.

Item I

I.	**In your opinion does the child have:**		**A good fluid intake**		**Average fluid intake**		**A poor fluid intake**
	Tick one box		☐		☐		☐

	Nurse 1	**Nurse 2**	**Nurse 3**	**Median**	**Dietitian**	**Agreement**
1	Nil by Mouth	Nil by Mouth	Nil by Mouth	Nil by Mouth	Nil by Mouth	Y
2	Poor	Good	Poor	Poor	Poor	Y
3	Average	Average	Average	Average	Average	Y
4	Average	Average	Average	Average	Average	Y
5	Average	Poor	Poor	Poor	Average	N
6	Average	Average	Average	Average	Average	Y
7	Average	Poor	Average	Average	Poor	N
8	Average	Average	Poor	Average	Poor	N
9	Average	Poor	Average	Average	Poor	N
10	Good	Average	Average	Average	Average	Y
11	Average	Average	Average	Average	Average	Y
12	Average	Average	Average	Average	Poor	N
13	Good	Poor	Poor	Poor	Poor	Y
14	Average	Average	Average	Average	Good	N
15	Average	Average	Poor	Average	Average	Y
16	Poor	Poor	Poor	Poor	Poor	Y
17	Poor	Poor	Average	Poor	Average	N
18	Average	Poor	Poor	Poor	Average	N
19	Average	Good	Good	Good	Good	Y
20	Average	Average	Poor	Average	Poor	N
21	Poor	Good	Nil	Average	Good	N
22	Good	Average	Average	Average	Good	N
Total	22	22	22	22	22	
					Percentage agreement	50%
					Kappa	0.21

Table 19. Ratings and agreement for item I for nurses and dietitian

Table 18 shows fluid intake defined by 3 different nurses. The median is compared to the child's true fluid intake as defined by the dietitian. The Kappa value of 0.21 indicates fair agreement.

Item J

J.	**Does the child have any of the following?** **Tick all appropriate Boxes**	**1** **Gagging or grimacing when eating / drinking** ☐		**2** **Difficulty opening and / or closing the mouth** ☐		**3** **Food loss from the mouth** ☐		**4** **Snoozing around mealtimes** ☐		**5** **Coughing or choking at mealtimes** ☐
		6 **Changes in breathing rate, eye watering or colour change at mealtimes** ☐		**7** **Tongue thrust or chewing problems** ☐		**8** **Reflux or vomiting** ☐		**9** **Problems with vision** ☐		**10** **Known breathing difficulties or frequent chest infections** ☐

Item J consists of 10 parts and so is referred to as J1 to J10.

Item J1

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	No	No	No	Y
3	No	No	No	No	No	Y
4	No	No	Yes	No	No	Y
5	No	Yes	Yes	Yes	Yes	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	Yes	Yes	Yes	Yes	No	N
10	No	No	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	Yes	No	No	No	No	Y
17	No	No	No	No	No	Y
18	No	Yes	No	No	No	Y
19	No	No	Yes	No	No	Y
20	No	No	Yes	No	Yes	N
21	No	Yes	Yes	Yes	Yes	Y
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	91.%
					Kappa	0.61

Table 20. Ratings and agreement for item J1 for nurses and dietitian

Table 19 shows whether the child gags or grimaces when eating / drinking as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.61 indicates substantial agreement.

Item J2

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	No	No	No	Y
3	No	No	No	No	Yes	N
4	No	Yes	Yes	Yes	Yes	Y
5	No	Yes	No	No	Yes	N
6	No	No	No	No	No	Y
7	Yes	Yes	Yes	Yes	Yes	Y
8	No	No	No	No	No	Y
9	No	No	No	No	Yes	N
10	No	No	No	No	Yes	N
11	No	No	No	No	No	Y
12	Yes	No	No	No	Yes	N
13	No	Yes	No	No	Yes	N
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	No	No	No	No	Yes	N
17	No	No	Yes	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	Yes	N
20	Yes	Yes	Yes	Yes	Yes	Y
21	No	No	No	No	Yes	N
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	0.59%
					Kappa	0.23

Table 21. Ratings and agreement for item J2 for nurses and dietitian

Table 20 shows whether the child has difficulty opening and or closing the mouth as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.23 indicates fair agreement.

Item J3

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	Yes	Yes	Yes	Yes	Yes	Y
3	No	No	Yes	No	No	Y
4	Yes	Yes	No	Yes	Yes	Y
5	No	Yes	No	No	Yes	Y
6	No	No	No	No	No	Y
7	Yes	Yes	Yes	Yes	Yes	Y
8	No	No	No	No	No	Y
9	No	Yes	Yes	Yes	No	N
10	No	Yes	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	Yes	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	No	No	Yes	No	No	Y
17	No	Yes	No	No	No	Y
18	No	No	No	No	No	Y
19	No	No	Yes	No	No	Y
20	No	Yes	Yes	Yes	Yes	Y
21	No	No	No	No	Yes	N
22	No	No	Yes	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	86.4%
					Kappa	0.64

Table 22. Ratings and agreement for item J3 for nurses and dietitian

Table 21 shows whether the child looses food from the mouth as defined by 3 different nurses. The median is compared to the child’s status as defined by the dietitian. The Kappa value of 0.64 indicates substantial agreement.

Item J4

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	Yes	Yes	Yes	Yes	Y
3	No	No	No	No	No	Y
4	No	No	No	No	No	Y
5	No	No	No	No	No	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	No	No	No	No	Yes	N
10	No	No	No	No	Yes	N
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	No	No	No	No	No	Y
17	No	No	No	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	No	No	No	No	Yes	N
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	86.4%
					Kappa	0.35

Table 23. Ratings and agreement for item J4 for nurses and dietitian

Table 22 shows whether the child snoozes around mealtimes as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.35 indicates fair agreement.

Item J5

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	Yes	No	Yes	Yes	Yes	Y
3	No	No	No	No	No	Y
4	No	Yes	No	No	Yes	N
5	Yes	Yes	No	Yes	Yes	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	Yes	Yes	Yes	Yes	Yes	Y
10	Yes	No	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	Yes	No	No	No	No	Y
17	No	No	Yes	No	No	Y
18	No	Yes	No	No	No	Y
19	Yes	No	Yes	Yes	No	N
20	No	Yes	Yes	Yes	Yes	Y
21	No	Yes	No	Yes	Yes	Y
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	90%
					Kappa	0.77

Table 24. Ratings and agreement for item J5 for nurses and dietitian

Table 23 shows whether the coughs or chokes at mealtimes as defined by 3 different nurses. The median is compared to the child’s status as defined by the dietitian. The Kappa value of 0.77 indicates substantial agreement.

Item J6

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	Yes	No	No	Y
3	No	No	No	No	No	Y
4	No	No	No	No	No	Y
5	Yes	Yes	No	Yes	No	N
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	Yes	No	Yes	Yes	Yes	Y
10	No	No	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	No	No	No	No	No	Y
17	No	No	No	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	No	No	No	No	Yes	N
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	90%
					Kappa	0.45

Table 25. Ratings and agreement for item J6 for nurses and dietitian

Table 24 shows whether there are changes in breathing, colour or eye watering at mealtimes as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.45 indicates moderate agreement.

Item J7

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	No	No	No	Y
3	Yes	Yes	No	Yes	No	N
4	No	No	No	No	No	Y
5	No	No	No	No	Yes	N
6	No	No	No	No	No	Y
7	Yes	Yes	No	Yes	Yes	Y
8	No	No	No	No	No	Y
9	Yes	Yes	No	Yes	Yes	Y
10	No	No	Yes	No	No	Y
11	No	No	No	No	No	Y
12	No	Yes	Yes	Yes	No	N
13	No	Yes	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	Yes	No	Yes	N
16	No	No	No	No	No	Y
17	No	No	Yes	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	No	Y
20	Yes	Yes	Yes	Yes	Yes	Y
21	Yes	Yes	No	Yes	Yes	Y
22	No	No	No	No	Yes	N
Total	22	22	22	22	22	
					Percentage agreement	77.2%
					Kappa	0.45

Table 26. Ratings and agreement for item J7 for nurses and dietitian

Table 25 shows whether the child has tongue thrust or chewing problems at mealtimes as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.45 indicates moderate agreement.

Item J8

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	No	No	No	Y
3	No	No	No	No	No	Y
4	Yes	Yes	Yes	Yes	Yes	Y
5	Yes	Yes	No	Yes	Yes	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	No	No	No	No	No	Y
10	No	No	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	Yes	No	No	Y
14	No	Yes	No	No	No	Y
15	No	No	No	No	No	Y
16	Yes	Yes	Yes	Yes	No	N
17	No	No	No	No	No	Y
18	No	No	Yes	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	No	Yes	No	No	Yes	Y
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	95.4%
					Kappa	0.61

Table 27. Ratings and agreement for item J8 for nurses and dietitian

Table 26 shows whether the child has reflux or vomiting as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.61 indicates substantial agreement.

Item J9

	Nurse 1	Nurse 2	Nurse 3	median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	Yes	Yes	Yes	Yes	Yes	Y
3	No	No	No	No	No	Y
4	No	Yes	No	No	Yes	N
5	Yes	Yes	No	Yes	Yes	Y
6	Yes	No	No	No	Yes	N
7	No	Yes	No	No	Yes	N
8	No	No	No	No	Yes	N
9	No	Yes	Yes	Yes	Yes	Y
10	Yes	Yes	Yes	Yes	Yes	Y
11	No	No	No	No	No	Y
12	Yes	No	Yes	Yes	Yes	Y
13	No	No	No	No	No	Y
14	No	No	No	No	Yes	N
15	No	No	No	No	Yes	N
16	No	Yes	No	No	Yes	N
17	No	No	Yes	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	Yes	N
20	No	No	No	No	Yes	N
21	No	No	No	No	Yes	N
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	54.5%
					Kappa	0.24

Table 28. Ratings and agreement for item J9 for nurses and dietitian

Table 27 shows whether the child has visual problems as defined by 3 different nurses. The median is compared to the child’s status as defined by the dietitian. The Kappa value of 0.24 indicates fair agreement.

Item J10

	Nurse 1	Nurse 2	Nurse 3	median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	No	No	No	Y
3	No	No	No	No	No	Y
4	No	No	No	No	No	Y
5	No	No	No	No	No	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	No	Yes	Yes	Yes	Yes	Y
10	No	No	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	No	No	No	No	No	Y
17	No	No	No	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	No	No	No	No	Yes	N
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	95.4%
					Kappa	0.65

Table 29. Ratings and agreement for item J10 for nurses and dietitian

Table 28 shows whether the child has breathing difficulties or frequent chest infections as defined by 3 different nurses. The median is compared to the child's status as defined by the dietitian. The Kappa value of 0.65 indicates substantial agreement.

Item K1

K	Does the child have any other Medical Problems?		1 Food related problems e.g. d) Behavioural e) Food allergy/intolerance f) limited variety of food		2 Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWD, PKU.		3 Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding
	Tick all appropriate boxes		☐		☐		☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	No	No	No	No	No	Y
3	No	No	Yes	No	No	Y
4	Yes	No	No	No	No	Y
5	Yes	No	No	No	No	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	No	Yes	No	No	No	Y
10	No	No	Yes	No	No	Y
11	No	No	No	No	No	Y
12	No	Yes	Yes	Yes	No	N
13	No	Yes	Yes	Yes	Yes	Y
14	No	Yes	No	No	Yes	N
15	No	No	Yes	No	No	Y
16	No	No	No	No	No	Y
17	No	No	No	No	No	Y
18	No	No	Yes	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	No	No	No	No	No	Y
22	No	No	Yes	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	90.9%
					Kappa	0.45

Table 30. Ratings and agreement for item K1 for nurses and dietitian

Table 29 shows whether the child has any food related medical problems according to 3 different nurses. The median is compared to the child’s true status as defined by the dietitian. The Kappa value of 0.45 indicates moderate agreement.

Item K2

K	Does the child have any other Medical Problems?		1 Food related problems e.g. g) Behavioural h) Food allergy/intolerance i) limited variety of food		2 Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWS, PKU.		3 Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding
	Tick all appropriate boxes		☐		☐		☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	No	No	No	No	No	Y
2	Yes	No	No	No	No	Y
3	Yes	Yes	Yes	Yes	Yes	Y
4	No	No	No	No	No	Y
5	Yes	No	No	No	No	Y
6	No	No	No	No	No	Y
7	No	No	Yes	No	No	Y
8	No	No	No	No	No	Y
9	No	No	No	No	No	Y
10	No	No	Yes	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	Yes	No	No	Y
16	No	No	No	No	No	Y
17	No	No	Yes	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	Yes	Yes	No	Yes	No	N
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	95.4%
					Kappa	0.65

Table 31. Ratings and agreement for item K2 for nurses and dietitian

Table 30 shows whether the child has any other chronic medical / metabolic conditions according to 3 different nurses. The median is compared to the child's true status as defined by the dietitian. The Kappa value of 0.65 indicates substantial agreement.

Item K3

K	**Does the child have any other Medical Problems?**		**1** **Food related problems e.g.** **j) Behavioural** **k) Food allergy/intolerance** **l) limited variety of food**		**2** **Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWD, PKU.**		**3** **Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding**
	Tick all appropriate boxes		☐		☐		☐

	Nurse 1	Nurse 2	Nurse3	Median	Dietitian	Agreement
1	Yes	Yes	Yes	Yes	Yes	Y
2	Yes	Yes	Yes	Yes	Yes	Y
3	No	No	No	No	No	Y
4	Yes	Yes	Yes	Yes	Yes	Y
5	No	No	No	No	No	Y
6	No	No	No	No	No	Y
7	No	No	No	No	No	Y
8	No	No	No	No	No	Y
9	No	No	No	No	No	Y
10	No	No	No	No	No	Y
11	No	No	No	No	No	Y
12	No	No	No	No	No	Y
13	No	No	No	No	No	Y
14	No	No	No	No	No	Y
15	No	No	No	No	No	Y
16	No	No	No	No	No	Y
17	No	No	No	No	No	Y
18	No	No	No	No	No	Y
19	No	No	No	No	No	Y
20	No	No	No	No	No	Y
21	Yes	Yes	Yes	Yes	Yes	Y
22	No	No	No	No	No	Y
Total	22	22	22	22	22	
					Percentage agreement	100%
					Kappa	1.0

Table 32. Ratings and agreement for item K3 for nurses and dietitian

Table 31 shows children on enteral or parenteral feeds according to 3 different nurses. The median is compared to the child’s true status as defined by the dietitian. The Kappa value of 1.00 indicating perfect agreement.

Item L

L.	**Which category do you feel the child should the child be assigned to?** **Tick one box**		**Does not need to be referred to a dietitian** ☐		**Should be monitored and may need to be referred to a dietitian** ☐		**Needs to be referred to dietitian** ☐

	Nurse 1	Nurse 2	Nurse 3	Median	Dietitian	Agreement
1	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	N
2	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	N
3	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor and may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
4	Monitor & may need dietitian referral	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Y
5	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Y
6	Does not need dietitian referral	Does not need dietitian referral	Needs dietitian referral	Does not need dietitian referral	Needs dietitian referral	N
7	Does not need dietitian referral	Monitor & may need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Y
8	Monitor & may need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Y
9	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Needs dietitian referral	Y
10	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Y
11	Monitor & may need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Y
12	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Does not need dietitian referral	Monitor & may need dietitian referral	N

	Nurse 1	Nurse 2	Nurse3	Median	Dietitian	Agreement
13	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	N
14	Monitor & may need dietitian referral	Needs dietitian referral	Does not need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
15	Needs dietitian referral	Monitor & may need dietitian referral	Does not need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
16	Needs dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
17	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Does not need dietitian referral	Monitor & may need dietitian referral	Does not need dietitian referral	N
18	Does not need dietitian referral	Needs dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Does not need dietitian referral	N
19	Monitor & may need dietitian referral	Needs dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
20	Monitor & may need dietitian referral	Does not need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Needs dietitian referral	N
21	Needs dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
22	Does not need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Monitor & may need dietitian referral	Y
Total	22	22	22	22	22	
					Percentage agreement	63.3%
					Kappa	0.45

Table 33. Ratings and agreement for item L for nurses and dietitian

Table 32 shows nurses decision on whether to refer to the dietitian or not. The median is compared with the child's true need to be referred to the dietitian as defined by the dietitian. The Kappa value of 0.45 indicates moderate agreement.

6.1.1.5 Summary table

Item	Correlation	% agreement	Kappa value	Non agreement	Agreement
A	19/22	86.4%	0.75	3	Substantial
B	13/22	59%	0.31	9	Fair
C	11/21	50%	0.31	10	Fair
D	15/22	68.1%	0.33	7	Fair
E	18/22	81%	0.56	4	Moderate
F	18/22	81%	0.51	4	Moderate
G	21/22	95.4%	0.65	1	Substantial
H	12/21	59%	0.44	9	Moderate
I	10/21	50%	0.21	11	Fair
J1	20/22	91%	0.61	2	Substantial
J2	13/22	59%	0.23	9	Fair
J3	19/22	86.4%	0.64	3	Substantial
J4	19/22	86.4%	0.35	3	Fair
J5	20/22	90%	0.77	2	Substantial
J6	20/22	90%	0.45	2	Moderate
J7	17/22	77.2%	0.45	5	Moderate
J8	20/22	95.4%	0.61	2	Substantial
J9	12/22	54.5%	0.24	10	Fair
J10	21/22	95.4%	0.65	1	Substantial
K1	20/22	90.9%	0.45	2	Moderate
K2	21/22	95.4%	0.65	1	Substantial
K3	22/22	100%	1.00	0	Perfect
L	14/22	63.3%	0.45	8	Moderate

Table 34. Agreement between dietitian’s assessment and nurses’ judgement

5.1.2 High and low levels of agreement

There were varying levels of agreement between the nurse's assessment and the dietitian's assessment for all of the items on the nutrition screening tool. Based on the interpretation of Kappa values (Landis et al 1977) as described below it can be determined that:

0.2	Slight agreement
0.2-0.4	Fair agreement
0.4-0.6	Moderate agreement
0.6-0.8	Substantial agreement
0.8-1.0	Almost perfect agreement

Only one item had 100% agreement between the nurses and dietitians answers. This was item K, point 3 which is the 'safety net' question to ensure no children are missed, thus it was expected that the correlation between nurses and dietitian's assessment should be good.

K	**Does the child have any other Medical Problems?** **Tick all appropriate boxes**		1 Food related problems e.g. m) Behavioural n) Food allergy / intolerance o) limited variety of food ☐		2 Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWD, PKU. ☐		**3** Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding ☐

Figure 16 Item K3 of the nutrition screening tool

Item J5 (coughs or chokes at mealtimes) had the second highest Kappa value of 0.77

J	**Does the child have any Of the following?** **Tick all appropriate boxes**	1 Gagging or grimacing when eating / drinking ☐		2 Difficulty opening and / or closing the mouth ☐		3 Food loss from the mouth ☐		4 Snoozing around mealtimes ☐		**5** Coughing or choking at mealtimes ☐
		6 Changes in breathing rate, eye watering or colour change at mealtimes ☐		7 Tongue thrust or chewing problems ☐		8 Reflux or vomiting ☐		9 Problems with vision ☐		10 Known breathing difficulties or frequent chest infections ☐

Figure 17 Item J5 of the nutrition screening tool

Item A (weight assessment) had the third highest kappa value of 0.75.

A	**In your opinion is the child:** **Tick one box**	**Very Overweight** ☐	**Overweight** ☐	**Normal** ☐	**Thin** ☐	**Very Thin** ☐

Figure 18 Item A of the nutrition screening tool

Item I (fluid assessment) had the lowest Kappa value of 0.21.

I	**In your opinion does the child have:** **Tick one box**		**A good fluid intake** ☐	**Average fluid intake** ☐	**A poor fluid intake** ☐

Figure 19 Item I of the nutrition screening tool

5.1.3 Items showing substantial agreement

There were several items which showed substantial agreement (Kappa of 0.6 – 0.8) between the nurses and the dietitian's tools. These were items G, J1, J3, J5, J8, J10, K2, and are listed below:

Item G Does the child eat and drink had a substantial kappa value of 0.65.

G	**Does the child eat & drink?** **Tick one box**			Yes ☐				No ☐		

Figure 20 Item G of the nutrition screening tool

Item J1,3,5,8 and 10 describing oral motor abilities had the following substantial kappa values:

J1 kappa 0.61

J3 kappa 0.64

J5 kappa 0.77

J8 kappa 0.61

J10 kappa 0.65

J	**Does the child have any Of the following?** **Tick all appropriate**	1 Gagging or grimacing when eating / drinking		3 Food loss from the mouth		5 Coughing or choking at mealtimes		8 Reflux or vomiting		10 Known breathing difficulties or frequent chest infections

	Boxes	☐		☐		☐		☐		☐

Figure 21 Item J1,3,5,8 and10 of the nutrition screening tool

Item K2 describing other chronic conditions had a substantial kappa value of 0.65

K	**Does the child have any other Medical Problems?** **Tick all appropriate boxes**			2 Other chronic medical / metabolic conditions e.g. Diabetes, Renal, Liver, Coeliac, PWS, PKU. ☐						

Figure 22 Item K2 of the nutrition screening tool

5.1.4 Inter-rater reliability

Inter-rater reliability measures the degree in which nurses assessing the same child agree with one another by choosing the same outcomes on the nutrition screening tool. There were six pairs of nurses who assessed the same group of 4 children. Their nutrition screening tools were examined to see if they used the tool in the same way.

The outcome variables were cross tabulated to look at levels of agreement. Table 34 shows that out of the levels of agreement for the 22 items on the nutrition screening tool, 13 items showed good inter-rater reliability where nurses chose the same answer as one another 75% of the time. Only 3 items had poor inter rater reliability agreeing 50% or less of the time and these were items A, I and L.
Item A asked about the child's weight. There were 5 answer options for this item of which 3 were chosen – normal, thin and very thin. This was a subjective judgement and one which appeared to cause confusion. The nurses were unable to discriminate between the thin and very thin options.
Item I which assessed the child's fluid intake as good, average or poor also had inconsistency between nurses assessing the same child.
Item L determined whether or not the child should be referred to the dietitian. In a fully validated nutrition screening tool the answers to the previous questions would direct this decision by means of adding up the points achieved for each question. Thus item L has no significance in terms of assessing inter-rater reliability. However the poor inter-rater reliability for item L shows uncertainty amongst

nurses of whether or not to refer a child to the dietitian. This further endorses the need for an objective tool to help them make this decision as at present children are referred to the dietitian purely upon nurses’ opinion.

However, the other good inter-rater reliability results for the majority of the items on the tool indicate that the nurses understood how to use the tool appropriately and so it provided reassurance that the training sessions and instruction sheet provided were adequate for the purpose.

	Pair 1		Pair 2		Pair 3		Pair 4		Pair 5		Pair 6		Average	
	agree	%	agree	%	Agree	%	Agree	%	Agree	%	Agree	%	Agree	%
A	2/4	50	3/4	75	4/4	33	2/4	50	2/4	50	1/4	25	14/24	58
B	3/4	75	0/4	0	1/3*	33	3/4	75	2/3*	66	3/4	75	12/22	55
C	3/4	75	2/3*	66	2/2*	100	2/4	50	0/3*	0	2/4	50	11/20	55
D	2/4	50	4/4	100	3/4	75	4/4	100	1/4	25	1/4	25	15/24	63
E	3/4	75	3/4	75	3/4	75	4/4	100	3/4	75	3/4	75	19/24	79
F	3/4	75	2/4	50	2/4	50	3/4	75	3/4	75	4/4	100	17/24	71
G	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	24/24	100
H	2/4	50	2/4	50	1/4	25	3/4	75	2/4	50	3/4	75	13/24	54
I	2/4	50	2/4	50	1/4	25	2/4	50	3/4	75	2/4	50	12/24	50
J1	3/4	75	4/4	100	2/4	50	4/4	100	3/4	75	4/4	100	20/24	83
J2	3/4	75	4/4	100	4/4	100	2/4	50	4/4	100	3/4	75	20/24	83
J3	3/4	75	3/4	75	2/4	50	4/4	100	2/4	50	2/4	50	16/24	67
J4	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	24/24	100
J5	4/4	100	2/4	50	3/4	75	3/4	75	3/4	75	3/4	75	18/24	75
J6	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	24/24	100
J7	3/4	75	4/4	100	4/4	100	1/4	25	4/4	100	1/4	25	17/24	71
J8	4/4	100	4/4	100	3/4	75	4/4	100	4/4	100	3/4	75	22/24	92
J9	3/4	75	3/4	75	4/4	100	2/4	50	4/4	100	2/4	50	18/24	75
J10	3/4	75	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	23/24	96
K1	4/4	100	4/4	100	3/4	75	1/4	25	4/4	100	3/4	75	19/24	79
K2	4/4	100	4/4	100	4/4	100	3/4	75	4/4	100	2/4	50	21/24	88
K3	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	4/4	100	24/24	100
L	2/4	50	2/4	50	3/4	75	4/4	100	1/4	25	0/4	0	12/24	50

Table 35. To Show inter-rater reliability between pairs of nurses assessing the same child. There were six pairs of nurses who assessed the same group of 4 children.

* denoted missing data where some nurses omitted this question form their completed screening tool

5.1.5 Item analysis

There were two items on the nutrition screening tool which assessed body weight. One involved the subjective opinion of the nurses (item A) and the other was a more objective measure that allowed the nurses to use the child's weight and height centile charts (item D). The nurses were required to interpret centile charts for items B and C which gives them the information in order to be able to answer item D.

A	**In your opinion is the child:** **Tick one box**	Very Overweight ☐	Overweight ☐	Normal ☐	Thin ☐	Very Thin ☐
D	**In your opinion is the child's weight appropriate for height?** **Tick one box**			Yes ☐		No ☐

Figure 23. Items A and D assessing body weight

Item A achieved the highest Kappa value of 0.75 indicating a substantial agreement between the nurse's assessment and the dietetic assessment of the child. 19 out of the 22 nurses' assessments agreed with the dietetic gold standard, indicating that this question was relatively easy for the nurses to answer with a degree of accuracy.

Item D however can be answered objectively using the growth charts or subjectively by looking at the child. However whichever method was used the correlation between the nurses and dietetic assessments was only fair with a Kappa score of 0.33. There were 7 out of 22 nurses who did not agree with the dietitian.

Therefore it can be surmised that item A was a more accurate item than item D for nurses assessing body weight.

5.1.6 Sensitivity

Sensitivity was a measure of how well the nutrition screening tool correctly identified which children were really at risk of malnutrition and who need to be referred to the dietitian. Sensitivity was assessed by using the answers to item L on the nutrition screening tool from both the nurse and dietitian. The sensitivity value was 0.375 (0.085,0.755). This shows that the nutrition screening tool in its current form correctly identifies 37.5% of children at risk of malnutrition. This indicates that the tool was not sensitive enough. A weighted score system in order to enhance the sensitivity was required.

5.1.7 Specificity

The specificity was a measure of how accurately the tool identified children that did and did not need to be referred to the dietitian. The data from the dietitians and nurses response to item L was again used to calculate specificity. The value for specificity is 1.0 which is the ultimate figure, indicating that none of the well-nourished children will be inappropriately referred to the dietitian using the nutrition screening tool.

5.1.8 Positive predictive value

The positive predictive value is a measure of the proportion of children who were correctly identified as malnourished by the nutrition screening tool who were actually malnourished. This was calculated using data collected from item L. The positive predictive value is 1.0 which means that all children identified as malnourished were in-fact truly malnourished.

5.1.9 Primary nurse influence on results

As an adjunct to the main study, data was available on those children who had nutrition screening tools completed on them by their Primary Nurse, i.e. the nurse who knew them best. The design of the original study was to randomly allocate nurses to children so that there would be a mixture of nurses involved, thereby ensuring that some nurses would know some of the children well and some less well.

Analysis of the data suggested that the majority of the children had nutrition screening tools completed on them by nurses who were not their Primary Nurse and did not know them well. However there were 6 children who were assessed by their Primary Nurse.

Primary Nurse data was cross-tabulated against the true nutritional status data collected by the dietitian to see if there was a higher correlation with the child's true nutritional status amongst nurses who knew the children well. 10 out of the

22 questions on the nutrition screening tool were answered with 100% agreement with the dietitian. There were only two items which had poor correlation with the true answers and they were items I and J7. Item I asked subjectively about a child's fluid intake and responses to this have been poor throughout the study. Item J7 asked the nurse to identify tongue thrust or chewing problems, something which is within the Speech and Language Therapists remit rather than the nurses.

Thus it could be determined that those people who know the children best are in the best position to answer questions about them. There may be some scope in the future for testing the nutrition screening tool for use with parents and carers and not just nurses.

Item	**Agreement between Primary nurse & dietitian**	**Percentage**
A	6/6	100%
B	4/6	66.7%
C	3/6	50%
D	5/6	83.4%
E	6/6	100%
F	4/6	66%
G	6/6	100%
H	5/6	83.4%
I	2/6	33%
J1	6/6	100%
J2	4/6	100%
J3	6/6	100%
J4	6/6	100%
J5	6/6	100%
J6	5/6	83.4%
J7	2/6	33%
J8	5/6	84%
J9	6/6	100%
J10	6/6	100%
K1	4/6	66%
K2	6/6	100%
K3	6/6	100%
L	3/6	50%

Table 36. Percentage agreement between Primary Nurse and Dietitian

Table 35 shows the levels of agreement between the true nutritional assessment of the child and the assessment made by the primary nurse. There are high levels of correlation for most items on the nutrition screening tool.

5.2 Qualitative analysis

Following data collection, information was gathered from the nurses involved in the study and the researcher concerning the ease of use and practicalities of the nutrition screening tool.

5.2.1 De-briefing with nurses

After the nurses had completed the nutrition screening tools, a debriefing session was held. Common themes that were identified included:

- Ease of use of the screening tool which was quick and easy for those items which did not require further investigation.
- Difficulty in obtaining centile data. Many of the nurses felt they were unsure what the centiles actually meant in terms of growth. Centile charts were kept with the medical notes not with the child or parent and were often unavailable.
- Difficulty in measuring profoundly disabled children who were. Some children could not lie straight due to scoliosis or kyphosis.
- The value and relevance of measuring height. Some children who were measurable appeared to have shrunk from previous measures. This may have been due to the development of contractures of the spine.
- Difficulties in obtaining specifics about a child’s oral motor ability due to these notes being held by the Speech and Language Therapist’s (SALT) and not with the child.

Because of these issues limiting the successful completion of the tool, the nurses reported that it took too long to seek out this information and potentially could become a burden if they were required to complete nutrition screening tools routinely.

5.2.2 Researcher’s reflections on ease of use

During the data collection period the researcher made reflective notes on the ease of use of the nutrition screening tool and any issues encountered. The notes included the following:

- Whether there was a need for 5 answer options for item A? Particularly as the tool was intending to identify children at risk of malnutrition. Thus does it matter if the child is very overweight, overweight or normal?

- The answer options for item F were ambiguous as the child maybe wheelchair bound but have lots of jerky movements, if for example he or she had high muscle tone, frequent spasms or fits.
- Item H about the size of meals and snacks eaten is too subjective to quantify accurately.
- Item I about the volume of fluid consumed is too subjective to accurately measure.
- Item J about the child’s oral motor skills is very difficult to answer without having a speech and language therapist to assist, as Speech Therapy notes are not readily available.
- Item K asking about the child’s other medical problems or nutritional alludes to other reasons for dietetic referral, but not to risk of malnutrition and so is irrelevant in terms of the context of defining malnutrition risk severity.

6.0 Discussion

6.1 Sample demography

The sample selected was intended to reflect the population for whom the nutrition screening tool had been designed i.e. children aged 5 to 19 years with neurodisabilities, attending a special needs school in the UK. The age range of the 22 children who voluntarily entered the study was from 5 years and 8 months to 18 years and 9 months, with the average age at 13 years and 6 months. This would suggest that the sample were an accurate and adequate representation of school aged children. All the children who participated within the study had severe neurodisabilities and all but one had an ethnic background of white British, the exception being one male child who's parents classified him as 'Black – other'. This is perhaps not representative of the UK population as a whole as the 2011 census estimated the white British population to be 81.9% (Office for National Statistics 2011) and the sample in this study is higher that the UK estimate at 95.5%.

The sample consisted on 9 female and 13 male children. The 2011 census estimated a roughly equal split of males to females in the younger age groups (0-5 and 6-65 years) therefore the sample used in this study is weighted towards male children. This is a consequence of random allocation and perhaps a more representative sample could have been chosen if the study design was not blind.

6.2 Interpretation of data

Sensitivity and specificity are valid statistical tests to measure how well questionnaires are designed. For the tool to be clinically useful and comparable to the gold standard dietetic assessment, the nutrition screening tool needs to demonstrate good sensitivity and specificity.

Sensitivity and specificity have been calculated in this study however must be acknowledged that the sample size of just 22 children in this pilot study is very small and so the sensitivity and specificity data should be interpreted with caution.

In order to understand how the tool measured against the gold standard dietetic assessment, a kappa coefficient score to determine measures of agreement accounting for chance alone, was calculated for each of the items.

Kappa scores indicating substantial or almost perfect agreement highlighted the items which the nurse could report with confidence when compared to the dietitian. It was these items that would therefore be more useful for inclusion in the screening tool.

Item A (subjectively assessing a child’s shape) achieved the highest Kappa value of 0.752 demonstrating good agreement between the nurse’s assessment and the dietetic assessment of the child. 19 out of the 22 nurses agreed with the dietetic gold standard, indicating that this question was relatively easy for the nurses to answer with a degree of accuracy.

However, it should be noted that there were no ‘overweight’ or ‘very overweight’ children in the sample. Thus the discriminant ability of the tool was not tested within this range. It is not unusual that there were no overweight or very overweight children in the sample as it is well documented that children with neurodisability tend to be smaller and thinner than their peers (Sullivan et al 2002; Sleigh et al 2004). On reflection both of these answer options were probably not needed and were included for completeness.

The relevance of including all 5 options in the answer is therefore debatable in the context of malnutrition, the item could be simplified to having just 2 answer options ‘overweight or normal’ and ‘thin’. A child being thin is a significant indicator of malnutrition or malnutrition risk and so holds a weighting greater than a child being normal weight or overweight as there is a much lower malnutrition risk.

Thus streamlining the answer options would improve usability and potentially improve the levels of agreement. In this case the kappa value may change as a result of such alterations and so this item would require re-testing.

6.2.2 Items B, C and D - Analysing growth charts

The level of agreement between nurse and dietitian for items B, C and D on the nutrition screening tool was fair with Kappa values for B and C at 0.31 and D at 0.33. The range of answers the nurses gave for these three items was very diverse suggesting that the nurses were not using the tool in the same way as the dietitian. This was identified during the nominal group session who anticipated that the nurses may not be able to interpret growth charts accurately.

In the debriefing session the nurses acknowledged that they often did not have access to growth charts and because they used them so infrequently they did not feel confident that they had the skills to interpret them correctly all of the time.

If a child is not growing or gaining weight at an appropriate velocity, the nurses had no way of assessing this without growth charts. Noting whether the weight or length has increased or decreased since the last time they were measured will not tell them if the rate or velocity of growth is normal and thus they are unlikely to note concern. This further highlights the need for a method of identifying children at risk of malnutrition more easily.

Item D is the only item of the three which could be answered subjectively by looking at the child or objectively by using growth charts. However irrespective of which method the nurses adopted, the correlation between the nurses and gold standard dietetic assessment remained only fair with a Kappa score of 0.33.

However, there needs to be some method of acknowledging a change (or no change) in a child’s weight as this is crucial measure of nutritional status. Thus it was felt that item B concerning weight must remain on the tool. However it could be rephrased to avoid the necessary use of growth charts. The amount of answer options could be reduced and may reduce variability:

- ‘weight increasing’
- ‘weight decreasing’
- ‘weight staying the same’

Malnutrition risk is clinically significant when weight velocity falls across a centile and this could be observed if a child’s weight is decreasing or weight is staying the same, therefore both of these answer options hold a weighting greater than the ‘weight increasing’ answer option. Again this item would require re-testing as it has been significantly altered to determine the new measure of agreement and Kappa value.

In addition to the statistical evidence, item C regarding height requires reconsidering as there is evidence that measuring standing height or supine length is difficult to do in children with motor disorders and therefore can be inaccurate (Sanders, Cox et al 1990). Moreover some disabled children appear to shrink over time due to spinal contractures, scoliosis or kyphosis; however this has no significance on their nutritional needs, and so could lead to confusion. This was also fed back to the researcher by the nurses in their debriefing session. There are alternative growth measures which can be carried out by the dietitian and are listed in Chapter 1 and shown in Appendix 5 however these require specialist skill and training and so would not be an appropriate expectation of the school nurse.

6.2.3 Item E – Bowel habits

The statements to assess the child's bowel habits also lacked agreement amongst each of the nurses. As bowel problems are prevalent in this group of children (Sullivan et al 2005b) records are kept by the nursing team detailing the child's frequency of bowel movement, texture of stool and medication required. Confusion appeared to lie with the answer option 'constipated with or without medication' as a constipated child once on medication should have normal bowel movements. Thus some nurses reported that the child was constipated and others reported that their bowel movements were normal. The nutritional significance is related to whether the child is constipated, has diarrhoea or normal bowel habits irrespective of whether they are on medication or not.

A suggestion for revision of the tool would be to omit the word 'medication' leaving just 'constipated', 'normal' or 'diarrhoea' as answer choices.

Secondly it may seem logical to combine this question about bowels with the other common gastrointestinal (GI) problem - reflux and / or vomiting, which currently sits within the 'oral motor skills' question - item J. All gastrointestinal problems have a clinical significance in terms of detecting malnutrition and in practice the GI system of the body would be clinically assessed as a whole.

Finally in relation to GI problems, excessive wind or flatulence has not been addressed within the screening tool however and on reflection this omission is an error as evidence suggests it can have a significant impact on the child's appetite and thus food intake (Spitz et al 1993; Sullivan 1999; Hussain et al 2002). A modified tool should include this important topic.

Again this item on GI problems will require re-testing to determine the new measure of agreement and Kappa value.

6.2.4 Item F - Activity and mobility

This item was intended to gauge energy expenditure and covers both mobility and activity. This was confusing for the tool users as these variables refer to two different parameters. This in turn resulted in the question being answered differently by different nurses and therefore poor agreement. For example a child can be wheelchair bound, but also have high muscle tone resulting in lots of involuntary movements. The child may also be prone to muscle spasms and even uncontrolled seizures, which would result in being labelled as ‘excessive activity’. The nutritional significance of this is paramount as a child who may be wheelchair bound yet have excessive activity will have very high nutritional requirements as they will have a great energy expenditure, thus their calorie needs will be significantly higher. However, a wheelchair bound child who does not exhibit such behaviours and is more static will have much lower energy requirements which in some studies has been estimated to be as little as 10% above the basal metabolic rate (Sullivan et al. 2002). Both these extremes are reflected in clinical practice.

Secondly, the difference between a wheelchair bound child and one who sleeps a lot has little significance in terms of the child’s malnutrition risk as both reflect a low physical activity level and thus lower energy need.

Finally, in the debriefing session there was confusion over the term ‘limited mobility’ where some nurses felt a child who walked with aids and a physiotherapist fitted in to this category. Other more independent children who could walk without supervision but still required mechanical aids were also assigned to this category. Again this causes a significant nutritional discrepancy in terms of the child’s energy expenditure and thus nutritional requirements, and so this item warranted further clarification.

Mobility and activity require separation into two individual items for a modified nutrition screening tool. Mobility can be graded from 1 – 5 based on the gross motor classification system (Palisano et al 1997) which is a validated scale which classifies a child’s mobility level. However in terms of being a probable cause of malnutrition, mobility is not clinically significant and so could in fact be discarded in its entirety from a revised nutrition screening tool.

However activity still needs to be assessed as this has nutritional significance. In the absence of any classification system to describe activity, the answers are presented in a declining Likert scale based on the nurses' experience of working with the child. Activity, however, has great significance on malnutrition risk and so all options weigh greater than 'normal'.

6.2.5 Item G - Does the child eat & drink?

This item again returned poor levels of agreement, both between nurses and with the gold standard. Of the 22 children used in the reliability study, 2 received tube feeding, one who ate food orally but in insufficient amounts for growth and development and one was classed as nil by mouth due to significant risk of respiratory aspiration of food and fluids. There was only one child where there was disagreement with the gold standard dietetic assessment, however, this lack of agreement could potentially put the life of that child at risk, particularly if the child was to be orally fed when supposed to be nil by mouth. Further investigation into this particular case was carried out, and it was discovered that communication between carers and health professionals was not clear.
The Kappa score was 0.645 indicating a good level of agreement between the nurses and the dietitian. This indicates that the item should therefore remain on future versions of the nutrition screening tool.

Children with neurodisabilities who eat and drink and who are not known to the dietitian may be more at risk of malnutrition than those who are nil by mouth (who will be under a dietitian for artificial feeds). This is because the muscle tone problems that this group of children have, also occurs in their oral motor muscles. Parents and carers may need help and advice in terms of modified textures, food fortification, specialist utensils and nutrition support in order to maximise nutrients in small quantities. Therefore, if the answer to the question 'Does the child eat and drink? is 'Yes' the related weighting needs to be greater than if the answer is 'No'.

6.2.6 Item H & I – Quantifying food and fluid intake

Item H was concerned with the quantity of food eaten. It had a moderate level of agreement between the nurses and the dietitians answers with a Kappa value of 0.44. This meant that only 12 out of the 21 nurse tools agreed with the dietetic assessment and that the nurse's response to this item was not a good predictor of the child's true food intake. The same is true of item I which was concerned with fluid intake. For this item only 10 out of 21 nurses agreed with the dietitian which resulted in a poor level of agreement with a Kappa value of 0.21. This was the lowest computed kappa score. There was also poor inter-rater reliability for this item indicating that individual nurses were also answering the question differently.

Children who eat and drink small amounts are more likely to become malnourished but asking the nurses to quantify how much relies on subjectivity which has been shown to have poor agreement, and therefore cannot be included on the nutrition screening tool.

6.2.7 Item J – Oral motor skills

Item J explored the child's oral motor skills. The agreement between each of the nurses was again was variable. The nurses may not be aware of the child's specific oral motor abilities concerning each of the characteristics of the 5 phases of swallowing, as this is more specialist knowledge of the speech and language therapist. Nurses were more likely to simply know whether the child does or does not have difficulties with eating and drinking at mealtimes.

The debriefing session revealed that this information was actually very difficult to gather by the school nurses and there was no clear documentation of oral motor abilities in the child's medical or nursing notes. The speech and language therapists are responsible for diagnosing the degree of oral motor ability, however they keep their own records which are not cross referenced or summarised for the other members of the multidisciplinary team. This has highlighted an important issue for sharing information and has been discussed with the relevant teams at Chailey Heritage.

There were three items in which the nurses had good levels of agreement with the dietitian. They were items J5, J8, J10.

- J5 explored whether the child coughs or chokes at mealtimes. 20 out of 22 nurses answered this correctly with a high Kappa score of 0.77.
- J8 explored whether the child has reflux of vomiting. With a kappa score of 0.61 this is considered substantial agreement with the dietitian. There were only 2 discrepancies and 20 out of 22 nurses agreed with the dietitian.
- J10 explored whether the child had known breathing difficulties or frequent chest infections. The Kappa score was 0.65 and indicated

substantial agreement. In this case there was only 1 nurse who disagreed with the dietitian.

Despite substantial agreement, these items were among the ones which the nurses reported that they struggled to answer. During the debriefing session this was explored further and it became apparent that the nurses ‘guessed’ the answers. This was probably because they form part of the speech and language therapists’ assessment. The nurses reported that in order to obtain this information, they needed to liaise with the speech and language therapist, which is time consuming and lengthens the screening process.
The researcher experienced some difficulty with these statements and had to obtain information on oral motor ability by observing the child at mealtimes. Following this, clarification of eating behaviours occurred with the speech and language therapist at a later date. This was very time consuming and does not fulfil the basic criteria which requires a nutrition screening tool to be quick and easy to use. Furthermore nurses are not normally around at mealtimes as carers (rather than nurses) help feed the children at school. At home children would be fed by their parents. This could explain why the nurses had difficulty in completing this section of the nutrition screening tool.

There is a strong link between degree of oral motor ability and risk of malnutrition (Fung et al 2002). Fung recommends that speech and language therapists should classify a child’s oral motor abilities on a grading scale which would be helpful in identifying those more at malnutrition risk, not only for dietitians but also for front line workers such as the child’s nurse and carer (Fung et al. 2002). Such scales have been published by Reilly et al (1995) but these are highly complex and require the skills of a qualified speech and language therapist for interpretation (Reilly et al. 1995). They are however validated and ready for use in the clinical setting. A numeric outcome measure from such a scale could be incorporated into a future nutrition screening tool and is likely to be an excellent contributor to predicting nutritional risk. This however is beyond the scope of this project and is a suggestion for further research.

Reflux and vomiting was an answer option included in item J. Whilst the cause of this may be due to impairment in the oesophageal phase of swallowing, it is also a motor disorder presenting in the oesophagus and oesophageal sphincter. In children with neurodisability reflux is often associated with forgut dysmotility secondary to vagal nerve dysfunction or an anatomical abnormality. Thus in terms of the multidisciplinary assessment it would be the medical member of the team rather than the speech and language therapist who looks after this aspect of the child. In practice the nurse would monitor reflux and vomiting alongside other GI functions such as bowel habits. Therefore any future version of the nutrition screening tool reflux and vomiting should be regrouped to promote ease of use of the tool.

All other aspects of oral motor ability should be considered for exclusion as the information is not quick easy enough for nurses to obtain and therefore does not full fill the basic criteria of a nutrition screening tool.

6.2.8 Item K - Automatic referral

This was the safety net question which ensures that a child who needs dietetic referral will not be missed even if none of the other questions suggest a likelihood of malnutrition. However the first two answer options ‘food related problems’ and ‘other chronic medical / metabolic conditions’ do not relate to malnutrition risk and are indicators for referral to other dietetic services. As this tool is looking at malnutrition risk only, they should therefore be removed from future versions of the tool.

6.2.9 Item L - Decision making

The item which had the highest degree of variation was whether or not the nurse’s should refer the child to the dietitian. This decision is based purely on what the nurse felt was ‘right’ for the child. Only 14 out of 22 nurses agreed with the dietitian about whether the child needed a dietetic referral producing only a moderate kappa score of 0.45. This variability reflects the difficult decision the nurses are faced with when deciding if a referral is appropriate in the light of there being no evidence based guidance on how to do this. This further substantiates the need for a nutrition screening tool to help guide nurses. Clinical practice has shown that clinicians are sympathetic of their dietetic colleague’s already overstretched caseloads, and that this is a factor in deciding whether to make the referral. More of a concern is that the nurse’s or clinician’s ‘opinion’ is the current method used across the UK for referral to the dietitian.

This item should not be left to the nurses judgement and a modified nutrition screening tool should incorporate a score system to guide the nurse into choosing the correct option, where a high score would indicate referral to dietetics and a low score would not indicate referral.

6.2.10 Summary of suggested amendments to the tool

	Item	Changed?	Justification for change
A.	In your opinion is the child: very overweight, overweight, normal, thin, very thin?	Yes	Reduce number of answer variables
B.	Over the past year what has the child's weight done?	Yes	Reduce number of answer variables, remove need for centile charts.
C.	Over the past year how does the height relate to centiles?	Yes	Delete as inaccurately measured
D.	In your opinion is the child's weight appropriate for height?	Yes	Delete as duplicate of item A
E.	How are the child's bowel habits?	Yes	Remove reference to medication Add excessive wind and flatulence Add reflux and vomiting from item J
F.	In your opinion how active is the child?	Yes	Split into two separate items: mobility and activity. Delete mobility and keep activity
G.	Does the child eat & drink?	No	-
H.	If Yes in your opinion how much do they eat?	Yes	Delete as inaccurate answers obtained
I.	In your opinion does the child have a good / average / poor fluid intake?	Yes	Delete as inaccurate answers obtained
J.	Does the child have any Of the following oral motor issues?	Yes	Delete except for reflux question which is now with item E
K.	Does the child have any other Medical Problems?	Yes	Keep nasogastric tube, gastrostomy, jejunostomy or IV feeding answer option only as others don't indicate malnutrition
L.	Which category do you feel the child should the child be assigned to?	Yes	Apply a scoring system to direct nurses to a decision.

Table 37. Table to show a summary of the changes proposed for the Nutrition Screening Tool following its pilot study.

6.3 Version 2 of the nutrition screening tool

Following the suggested changes outlined above, the second version of the nutrition screening tool was constructed.

However, because many of the items had significantly changed as a result of feedback from version 1, the tool required re-testing. The same process needed to be undertaken including testing on a population of children to determine the measures of agreement, and inter-rater reliability between pairs of nurses in the same way as the original tool.

It is also proposed that the tool should also have a scoring system applied where answer options are weighted in line with their malnutrition risk. The score obtained at the end of the tool should direct the nurse into making the correct decision about whether to refer the child to the dietitian or not and so an appropriate cut off marker needs to be determined and assigned.

NUTRITION SCREENING TOOL VERSION 2

In your opinion is the child: **Tick one box**	Overweight ☐	Normal ☐		Thin ☐
Over the past year what has the child's weight done? **Tick one box**	Increased ☐	Stayed same ☐		Decreased ☐
Does the child have any gastrointestinal problems? **Tick all that apply**	Reflux, retching or vomiting ☐	Excessive wind or flatulence ☐	Constipation ☐	Diarrhoea ☐
Does the child eat and drink? **Tick one box**		Yes ☐		No ☐
How active is the child? **Tick one box**	Excessive activity i.e. continuously 'on the go' ☐	Sometimes has jerky involuntary movements ☐	Normal ☐	Limited activity ☐
Does the child have any artificial feeds? **Tick if appropriate**		Nasogastric tube, Gastrostomy, Jejunostomy, or I.V. feeding ☐		
Add up your scores to determine which category the child should the child be assigned to? **Tick one box**	NOT AT RISK OF MALNUTRITION Does not need to be referred to a dietitian ☐	POSSIBLY AT RISK OF MALNUTRITION Should be monitored and may need to be referred to a dietitian ☐	AT RISK OF MALNUTRITION Needs to be referred to dietitian ☐	

Figure 24. Version 2 of the nutrition screening tool

7.0 Summary

This chapter described the process undertaken to pilot the nutrition screening tool on a small sample of children with special needs.
Face and content validity were obtained via the nominal group process and nurses focus group.

The original version of the nutrition screening tool did not have sufficiently good psychometric properties and did not perform in the way that was required for use in clinical practice.
Kappa coefficients were used to explore the levels of agreement between the nurses using the tool and the gold standard dietetic assessment. This was to determine whether the tool was being used in the way it was intended to be used. It also identified which items had better agreement than others. Inter-rater reliability between pairs of nurses assessing the same child allowed for further exploration to see whether nurses were using the tool in the same way. Sensitivity and specificity calculations were made to measure the tools performance.

The small sample size was noted as being a weakness in the methodological design. However, the qualitative data obtained in terms of verbal feedback from the tool users on how they found the tool to use was considered to be a strength and contributed to the development of the tool. Similarly the researchers' reflections herself on ease of use were also a valuable adjunct to the study.

In light of the findings and feedback second version of the nutrition screening tool has been developed and it is ready to be tested on the same population as a future piece of research.

Chapter 5 Discussion & Conclusions

Chapter overview

The following chapter includes a discussion about the findings of the research study, which aimed to develop a nutrition screening tool for school aged children with neurodisabilities. Limitations are discussed as are suggestions for the future direction for research connected both to the tool and in other areas of nutritional management of children with these conditions.

1.0 Overview of findings

The need to create a nutrition screening tool was identified in response to the high volume of queries received from fellow dietetic colleagues asking for advice on children with neurodisabilities (including cerebral palsy) in their care. The researcher worked in a well known specialist centre for children with severe neurodisabilities as the Advanced Specialist Dietitian and was assumed, by other dietitians in the UK, that the researcher had the expertise to explain many of their unanswered clinical questions. Whilst the researcher had a depth of clinical experience and expertise, in reality the researcher did not have the answers to their queries without undertaking research.

A literature review confirmed that the issues being raised in clinical practice were worthy of investigation. There was a dearth of literature and understanding about the nutritional status of children with severe disabilities. Moreover, it was also evident that children with severe neurodisabilities such as cerebral palsy were smaller and lighter than their non-disabled peers (Thommessen et al 1991, Stallings 1996, Reilly et al 1996, Sullivan et al 2000, Sullivan et al 2002, Sleigh et al 2004, Somerville et al 2008). Clinically it was speculated that the reasons for being under nourished were caused by a variety of factors.

Malnutrition contributes to high levels of morbidity and mortality (Martyn et al 1998, Samson-Fang et al 2002, Stratton et al 2003, BAPEN 2009, Heismayr et al 2009) and a high financial cost to the health economy.

A systematic review of the literature to explore paediatric nutrition screening tools or processes confirmed that the ones that were in current use were not suitable because non applied to children living in the community with neurodisabilities such as cerebral palsy and that there was a need for a new nutrition screening tool for this group.

The tool was developed in the context of the clinical characteristics associated with malnutrition observed in clinical practice and backed up by the literature. This was validated by a nominal group process using the expertise of other specialist dietitians from throughout the UK, a specialist Speech & Language Therapist and tested for face validity by school nurses.

The tool described the nutritional status of children with neurodisability. Key features include the signs and symptoms of malnutrition frequently observed within this group. The tool was designed as a questionnaire with pre determined answer options that were assigned to each item on the tool and require the tool user to select only one answer.

Results from the pilot study identified that some items had high levels of agreement, but also some that needed reviewing. In total there were 12 items that required changes. Levels of agreement, as defined by Kappa Coefficient, between the school nurse and the dietitian identified those items which had good levels of agreement as well as those where agreement was poor. Qualitative feedback on the ease of use of the tool also identified other changes to improve the tools usability. Inter-rater reliability was examined between 6 pairs of nurses which showed consistency between nurses offering assurance that the training package was adequate.

A second version of the tool was produced taking all of the above factors into consideration. The revised pilot tool is now ready to be trialled in the same population of children.

2.0 Limitations

The major limitation of this study was the small sample size of children who participated. There were only 22 children in this study which meant that the sample was not big to reflect the population under investigation.

The limitation of the sample size was evident in the first item on the tool which required the nurses to classify the child as very overweight, overweight, normal, thin or very thin. The children in the sample did not include any that were very overweight or overweight. Whilst it is known that it is unusual for children with neurodisabilities to be overweight, it is not impossible. A larger sample size may have included such children.

However the small sample did highlight where there was good agreement and where modifications were required which have been included into the revised tool. This second version will require further testing to explore the levels of agreement and inter-rater reliability.

A second unexpected finding occurred with the study design. This tool was intended to be used by school nurses and was tested by randomly allocating children to nurses in this way. However, by chance, data concerning how well the child's primary nurse completed the nutrition screening tool was also analysed and it was clear that a nurse who knew the child well provided more accurate results than a nurse who did not, when compared with the dietetic assessment. However there were only 6 primary nurses in this additional data set. A suggestion for future research would be to re-test this tool on a larger sample of children who are assessed by their primary nurse which would provide more robust evidence and clinically reflect practice.

Sensitivity, specificity and positive predictive value calculations were computed. Whilst these are valid statistics used to evidence how well the tool works, caution needs to be taken in interpreting them due to the small sample size of just 22 children. Moreover, drawing conclusions from these data requires caution. The specificity and positive predictive value of the tool was shown to be 100% indicating that the tool did not inappropriately refer well nourished children to the dietitian. However the high specificity value may exclude malnourished children by classifying them as well nourished because a high specificity value is not useful for ruling out malnutrition unless it is coupled with high a sensitivity, which in this case it was not.

Whilst calculating these statistics was interesting and gave an understanding of how the tool was performing it is important to understand them in the context of the study being small and not totally representative.

3.0 Next steps

Following the pilot of the nutrition screening tool and the identification of several changes, a refined draft has been developed. This will need to be tested on a larger sample of children to determine its true validity. The methodological approach to assess the new tool should be undertaken in the context of the other nutrition screening tools in existence. The two most widely reported are the MUST (Elia et al 2003, Stratton et al 2003b) and STAMP (McCarthy 2008, McCarthy et al 2008, McCarthy 2012).

It is reassuring to discover that the methodology employed to validate these two tools was similar to that used in the pilot study of this project. Different observers tested the MUST tool on the same patients to determine internal consistency and reliability (Elia 2003). It was also compared against other malnutrition screening tools to determine concurrent validity. The sample size tested was 346 patients (Stratton et al 2003b). The reliability of STAMP was measured by comparing the results of the STAMP tool carried out by nurses, to the dietitian's full nutritional assessment as the gold standard. The sample size tested was 238 children. This methodology was the same as that employed in the pilot study for this project, with the exception of comparing the tool developed in this project with another to determine concurrent validity. There are no other nutrition screening tools suitable for children living in the community to use for this purpose.

As previously discussed, neither tool is suitable for use with children with neurodisabilities. The MUST tool is a malnutrition screening tool for adult patients and cannot be used with children. The STAMP tool is a paediatric nutrition screening tool for use with acute inpatients and not suitable for children outside of hospital.

The tool in its current form was presented to the British Dietetic Association's DISC Forum in October 2013 and several dietitians from special needs schools throughout the UK have expressed an interest in collaborating to provide a large enough data set for further validation studies. A sample size calculation will be required however if the MUST and STAMP studies are used as research exemplars then it will be necessary to recruit in the region of 250-350 children. In order to achieve such a sample size a UK wide collaboration will enable a large enough sample to be recruited to fully test the tool.

4.0 Ideas for future work

During this research journey and particularly when conducting the literature review, there have been a number of ideas for future research which have been brought to attention. A summary of these are as follows:

4.1 Eating and drinking skills score

The literature review highlighted that the degree of oral motor ability was highly correlated with the child's risk of malnutrition. A simple eating and drinking skills score could be a useful addition to a nutrition screening tool in children with neurodisabilities. An area for future research could be for dietetics and speech and language therapy to work collaboratively to produce a useful simple feeding assessment.

4.2 Parents as tool users?

The nutrition screening tool was intended to be used by school nurses and as discussed earlier it had good results when used by a nurse that knew a child well. Could the tool be used by a non clinical person or even the child's parents? The Gross Motor Classification scale originally designed for clinicians to use to classify a child's motor function is a similar screening tool. This has been validated as being equally reliable for parents to carry out at home. This could be a further development to consider for the nutrition screening tool.

4.3 Serial measurements

Children with neurodisabilities are weighed and measured routinely but the optimal frequency of taking these serial measures has never been advised. A prospective study taking measurement of a weekly basis without nutritional intervention could identify how regularly weighing and measuring needs to happen in order to identify changes at the critical time.

4.4 Method of weighing

It is not always possible to weigh children with neurodisabilities on standing scales and certainly those children with complex disabilities are often weighed via hoist or wheelchair scales. Many of these children wear spinal jackets and orthosis, which are often weighed separately and subtracted from the total weight to obtain the child's actual weight. No studies have been carried out to look at the differences between different methods of weighing. This would be a relatively simple study to carry out and recommend the best method of weighing children with neurodisabilities.

4.5 Energy requirements

Calculating energy requirements for children with neurodisabilities is complicated and is discussed in detail in chapter 1. One method of attempting to do this could be to assess the volume of enteral feeds received by a cohort of children who are entirely fed via tube. Often prescribed volumes are different to those volumes actually administered, so regular monitoring to audit this would be necessary. From this information the daily energy intake could be calculated, and if looked at against the child's growth pattern a sense for whether they're meeting their nutritional requirements could be obtained, and by default their energy requirement would be defined. This potentially would need to be a large study conducted over several years from birth till the child is fully grown.

4.6 Bioelectrical impedance (BEI)

Within the literature on using BEI as a method of assessing body composition, there is controversy between whether it is in-fact possible or accurate on children with neurodisabilities. In order to obtain a reading, the child must lie down and keep still, which may be difficult to ensure. Studies have also shown conflicting results with one stating the children with neurodisabilities had altered body composition and another stating that body composition is normal. Further research needs to be carried out but this could be a potentially useful tool if it is possible and accurate. Theoretically unusual body composition could impact on the child's basal metabolic rate and effect their requirement for energy.

5.0 Implications on clinical practice

Having a fully validated nutrition screening tool for children with neurodisabilities will provide assurance that children are not being left underfed and malnourished as a result of their disability. Good nutrition will improve their health and quality of life. Growth and puberty will also be promoted. However this is likely to have an impact on the referral rate to dietetic teams, as more children will be appropriately identified as being at malnutrition risk, rather than referrals being based on the opinion of the doctor or nurse looking after the child. This pattern has in fact that has been seen locally within East Sussex since the adult MUST (Malnutrition Universal Screening Tool) was introduced in 2010, where an annual audit has shown year on year increase in the number of patients screened and a resulting impact on referral into dietetic services (Bushell, Campion. unpublished). Thus initially dietitians may be inundated with referrals as demand exceeds capacity, so managers must ensure that this is mitigated.

6.0 Conclusion

A nutrition screening tool for children with neurodisabilities is essential to prevent malnutrition, however at the outset of this research there was no method available for identifying those who might be at risk. As a result children were thinner and lighter than their aged match peers, with frequently periods of being unwell and all at a great cost to the NHS.

This thesis has drawn on the existing literature and expertise of dietitians working with children with neurodisabilities to identify the clinical characteristics associated with malnutrition in this particular group, to design a nutrition screening tool. The measure of agreement between the tool users (nurses) and the gold standard (dietitian) has been explored and the tool further refined to produce a version of the nutrition screening tool which is hoped to have satisfactory psychometric properties to be used in clinical practice. Supporting information has been produced to accompany the tool and facilitate its use. The tool is ready to be validated in terms of its psychometric properties.

7.0. Contribution to knowledge

The nutrition screening tool is very much wanted by dietitians working in the field of paediatric neurodisability. Frequent requests for updates on the tool have been made of the researcher over the years since the project commenced. The DISC Dietitians are aware of the current stage of development of the tool and demand remains high.

Widespread dissemination of a validated nutrition screening tool will ultimately raise the profile of nutrition within medical and nursing teams looking after children with neurodisabilities, further enhancing the nutritional knowledge of these staff. Such a tool would, for the first time, allow for prevalence data to be collected to determine the scale of malnutrition in neurodisability. It is the hope that annual screening surveys similar to those conducted by BAPEN will be conducted.

Ultimately such information could influence public health policy which sets the scene for post doctoral work.

8.0 Publications

As a result of the work that went into the literature review of this thesis the following publications have been produced: the researchers' involvement in these was the writer, co-writer or editor:

- British Dietetic Association, Professional Consensus Statement on Dietetic Assessment of Children with Special Needs with Faltering Growth. (Stewart, Mckaig et al 2006)
- Assessment and Monitoring of children with neurodisability on home enteral tube feeding. Clinical Nutrition Update 2005. (Stewart, Mckaig et al 2005)
- Challenges in feeding children with Neurodisabilities. Complete Nutrition 2005 (Almond 2005)
- Enteral feeding in Children with Severe cerebral palsy. Great Ormond Street Hospital. Nutricia Clinical Care. 2006 (Carter 2006)
- Clinical Paediatric Dietetics, 3rd Edition, Chapter 30 Feeding children with Neurodisabilities. Blackwell Publishing. 2007 (Almond, Allott, Hall 2007)

The researcher also presented the development of the nutrition screening tool at the following conferences:

- British Society of Paediatric Gastroenterology, Hepatology and Nutrition, Watford, 2005
- European Academy of Childhood Disability. London. 2005
- Nutritional Care of Children's with Disabilities, Birmingham, 2005
- Paediatric Group of the British Dietetic Association AGM, Luton, 2006
- British Dietetic Association DISC Forum, East Sussex, 2006
- British Dietetic Association DISC Forum, Surrey, 2013
- South East Coast Regional Dietitians Innovations Forum, 2013
- Surrey Regional Dietitians Innovations Forum, 2013

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Appendix 1

References

2011 Census: Population Estimates for the United Kingdom". Office for National Statistics. 27 March 2011

Almond, S. Estimating Nutritional Requirements in paediatric Neurodisability – A national survey of current dietetic practice. Unpublished.

Almond, S. (2005). Challenges in Feeding Children with Neurodisabilities. Complete Nutrition. 5(2), pp. 37-39.

Almond, S., Allott, E., Hall, K. (2007) Feeding children with Neurodisability. *Clinical Paediatric Dietetics*. 3rd Edition. Shaw & Lawson, Blackwell Publishing. Chapter 38.

Amundson, J., Sherbondy, A. et al. (1994). Early identification and treatment necessary to prevent malnutrition in children and adolescents with severe disabilities. *Journal of the American Dietetic Association*. 94 (8), pp. 880-883.

Andrew, M., Sullivan, P. (2010). Growth in cerebral palsy. *Nutrition in Clinical Practice*. 25(4), pp.357-361.

Andrew, M., Parr, J., Sullivan, P. (2012). Feeding Difficulties in children with cerebral palsy. *Archives of Diseases of Childhood Educational Practice.* 97(6), pp. 222-229.

Arrowsmith, Fiona E., et al. (2006). Reduced body protein in children with spastic quadriplegic cerebral palsy. *The American journal of clinical nutrition.* 83(3), pp. 613-618.

Arrowsmith, F., Allen, J. et al. (2010). The effect of gastrostomy tube feeding on body protein and bone mineralization in children with quadriplegic cerebral palsy. *Developmental Medicine & Child Neurology*. 52 (11), pp.1043–1047.

Attard-Montalto, S.P., Hadley, J. et al. (1998). Ongoing assessment of nutritional status in children with malignant disease. *Paediatric Haematology and Oncology*. 15 (5), pp.393-403.

Azcue, M.P., Zello, G.A. et al. (1996). Energy expenditure and body composition in children with spastic quadriplegic cerebral palsy. *The Journal of Paediatrics*. 129 (6), pp.870-876.

Babbie, E. (2003). *The Practice of Social Research.* Wadsworth Publishing.

Bachlet, A., Vernon-Roberts, A. et al. (2003). Body composition in severely disabled children fed either orally or via gastrostomy. *Journal of Paedatric Gastroenterology and Nutrition*.36, p. 525.

Balf, C. L. and Ingram, T.T.S. (1955). Problems in the classification of cerebral palsy in childhood. *BMJ*. 2, pp. 163–166.

Bandini, L.G., Schoeller, D.A. et al. (1991). Body composition and energy expenditure in adolescents with cerebral palsy or myelodysplasia. *Paediatric Research*. 29, pp.70-77.

Bandini, L.G., Puelzl-Quinn, H. et al. (1995). Estimation of energy requirements in persons with severe central nervous system impairments. *Journal of Paediatrics*. 126, pp.828-832.

BANS (2011). Artificial Nutrition Support in the UK. *Annual BANS Report*, published on BAPEN.org.uk ISBN: 978-1-899467-76-1 http://www.bapen.org.uk/pdfs/bans_reports/bans_report_11.pdf accessed 5.1.2012

BAPEN (2009). Improving nutritional care and treatment. Perspectives and Recommendations from Population Groups, Patients and Carers. M Elia and R M Smith on behalf of BAPEN and its collaborators.First published January 2009 by BAPEN www.bapen.org.uk.

BAPEN (2011). Malnutrition in the Community – One Quarter of Young Adults are at risk. *BAPEN report.* http://www.bapen.org.uk/res_press_rel_nsw_report_2011.html accessed 25.1.2012

Barnes, S. (2001). Sense and sensitivity: part 1. *Speech and Language Therapy in Practice spring*. pp. 4-7.

Bax, M. (1964). Terminology and classification of cerebral palsy. *Developmental Medicine and Child Neurology*. 6, pp 295-307.

Bax, M. (1989). Eating is Important. *Developmental Medicine and Child Neurology*. 31, pp. 285-286.

Bax, M., Goldstein, M., Rosenbaum, P. (2005). Proposed definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*. 47, pp. 571-576.

B. D. A. (1999). Nutrition Screening Tool. Briefing Paper No 9. P. D. Comittee. *British Dietetic Association*, Birmingham.

B. D. A. (2009). A framework for screening for malnutrition. *British Dietetic Association,* Birmingham.

Beattie, R. (2010). Young people, artificial nutrition and transitional care. Nutrition, growth and puberty in children and adolescents with Crohn's disease. *Proceedingsof the Nutrition Society*. 69(1), pp.174-177.

Bell, K.L., Davies, P.S.W. (2010a). Energy expenditure and physical activity of ambulatory children with cerebral palsy and of typically developing children. *The American Journal of Clinical Nutrition*. 92 (2), pp. 313-319.

Bell, K. L., Boyd, R.N., et al. (2010b) A prospective, longitudinal study of growth, nutrition and sedentary behaviour in young children with cerebral palsy. *BMC Public Health 2010*. 10, p.179.

Bingham, S.A. Gill, C. Welch, A. Day, K. Cassidy, A. Khaw, K.T. Sneyd, M.J. Key, T.J.A. Roe, L. Day, N.E. (1994) Comparison of dietary assessment methods in nutritional epidemiology: weighed records *v.* 24 h recalls, food-frequency questionnaires and estimated-diet records*. British Journal of Nutrition.* Vol 72(4): 619-643

Birch, L., Johnson, S. et al. 1991. The variability of young children's energy intake. *New England Journal of Medicine*. 324(4), pp. 232-235.

Bistran, B.R., Blackburn, G.L. et al. (1974). Protein status of general surgical patients. *Journal of the American Medical Association.* 230, pp. 858-860.

Bohmer, C. J., Niezen-de-Boer, M. C. et al. (1997). Gastro-oesophageal reflux disease in institutionalised intellectually disabled individuals. *The netherlands journal or medicine*. 51(4), pp. 134-139.

Bohmer, C. J. M., Taminiau, J. A. J. M. et al. (2001). The prevalence of constipation in institutionalised people with intellectual disability. *Journal of Intellectual Disability Research*. 45, pp. 212-218.

Bosma, J.F. (1992). Development and impairments of feeding in infancy and childhood. *Dysphagia: Diagnosis & management M.E. Groher.* Boston: Butterworth. *(2nd edition).* pp. 107-U1.

Bowling, A. (2009). Research Methods in Health: Investigation, Measurement and Analysis. *Open University press.*

Brant, C.Q. Stanich, P. Ferrari, A.P. (1999). Improvement of children’s nutritional status after enteral feeding by PEG: an interim report. *Gastrointestinal Endoscopy*. 50(2), pp183-188.

Bundy, A. and Fisher, A. G. (1991). Sensory integration theory and practice. *Philadelphia, Davies and Co.*

Burke, L.E. Wang, J. Sevick,M.A. (2011). Self-Monitoring in Weight Loss: A Systematic Review of the Literature. *Journal of the American Dietetic Association.* 111(1), pp 92-102.

Bushell, S., Campion, B. (pending publication). Improving Patient Care: The Nutrition Screening Audit Cycle in East Sussex Healthcare NHS Trust 2010 to 2013. Poster submitted for presentation at *Clinical Audit for Improvement Conference 2014* London.

Calis, Elsbeth A.C., Veugelers, R. et al (2010). Energy intake does not correlate with nutritional state in children with severe generalized cerebral palsy and intellectual disability. *Clinical Nutrition - October 2010.* 29(5) pp. 617-621.

Carney, O. McIntosh, J. Worth, A. (1996) The use of the nominal group technique in research with community nurses. *Journal of Advanced Nursing.* 23(5), pp1024-9

Carter, C. (2006). Enteral feeding in children with severe cerebral palsy. Great Ormond Street Hospital. *Nutricia Clinical Care.*

Chima, C.S., Barco, K. et al. (1997). Relationship of Nutritional status to length of stay, hospital costs and discharge status of patients hospitilised in the medicine service. *Ailmentary Pharmocology Therapeutics.* 11, pp. 975-978.

Chong, S. K. F. (2001). Gastrointestinal problems in the handicapped child. *Current Opinion in Paediatrics*. 13(5), pp. 441-446.

Clayden, G. (1996). Constipation in disabled children. *Feeding the Disabled Child*. P. B. Sullivan and L. Rosenbloom. Cambridge, Mackeith Press. pp. 106-16.

Corwin, D.S., Issacs, J.S et al. (1996). Weight and length increases in children after gastrostomy placement. *Journal of the American Dietetic Association.* 96(9), pp. 874-879.

Couzinet, B., Young, J., et al (1999). Functional hypothalamic amenorrhoea: a partial and reversible gonadotrophin deficiency of nutritional origin. *Clinical Endocrinology*. 50(2), pp. 229-35.

CQC (2011). Dignity and Nutrition Inspection report. http://www.cqc.org.uk/sites/default/files/media/documents/20111007_dignity_and_nutrition_inspection_report.pdf accessed 30.1.2012

Craig, G., Scambler, G. et al. (2003). Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support. *Developmental Medicine and Child Neurology*. 45, pp. 183-188.

Cronk, C. E., Fung, E. B. et al. (2001). Body composition in children with special health needs. Nutrition in the infant. Problems and practical procedures. *P. V.R, G. G and R.* Watson. London, GMM, pp. 31-38.

Culley, W., Middleton, T. (1969). Caloric requirements of mentally retarded children with and without motor dysfunction. *The Journal of Paediatrics*. 75(3), pp. 380-384.

Dahl, M.,Thommessen, M. et al. (1996). Feeding and nutritional chariceristics in children with moderate or severe cerebral plasy. *Acta Paediatrics.* 85, pp. 697-701.

Daly, A., Johnson, T. et al. (2004). Is fibre supplementation in paediatric sip feeds beneficial? *Journal of Human Nutrition and Dietetics*. 17, pp. 365-370.

Day, S., Straus, D.J et al. (2007). Growth patterns in a population of children and adolescents with cerebral palsy. *Developmental Medicine and Child Neurology*. 49, pp.167-171.

Day, N. McKeown, N. Wong, M. Welch, A. Bingham, S. (2001) Epidemiological assessment of diet: a comparison of a 7-day diary with a food frequency questionnaire using urinary markers of nitrogen, potassium and sodium. *International Journal of Epidemiology.* Vol 30(2):309-17.

Del Giudice,E., Staiano, A., Capano, et al. (1999). Gastrointestinal manifestations in children with cerebral palsy. *Brain Dev.* 21(5), pp.307-11.

Delbecq, A., Van de Ven, A. and Gustafson (1975) Group techniques for programme planning - a guide to nominal group and Delphi processes. Publisher Scott, Foresman and co.

DISC (Dietitians Interested in Special Children). Specialist interest group of the British Dietetic Association. Minutes of meetings 2002-2007 Unpublished

D. o. H. (1991). Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. No 41. R. o. H. a. S. Subjects. DoH, London., HSMO.

D. o. H. (2001). Essence of Care - Patient focused benchmarking for healthcare practitioners. DoH, London. Stationary Office.

D. o. H. (2004). National Service Framework for Children, Young People and Maternity Services. DoH.

D.o.H. (2009-10.) NHS Operating Framework 2009/10 Crown Copyright.

D.o.H (2010). The Care Quality Comission (Registration) Amendment Regulations.

D. o. H. (2010). Equity and excellence: Liberating the NHS. DoH, London. P002377484.

D.o.H. (2011). National Diet and Nutrition Survey. Headline results from Years 1 and 2 (combined) of the Rolling Programme (2008/2009 – 2009/10). https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216484/dh_128550.pdf

D.o.H. The operating Framework for the NHS in England 2012/13. Crown Copyright.

Edington, J., Kon, P et al. (1996). Prevalence of malnutrition in patients in general practice. *Clinical Nutrition* 15(2), pp. 60-63.

EFSA (2013) EFSA sets average requirements for energy intake. http://www.efsa.europa.eu/en/topics/topic/drv.htm

Elawad, M.A., Sullivan, P.B (2001). Management of constipation in children with disabilities. *Developmental Medicine & Child Neurology.* 43(12), pp. 829–832.

Elia, M. (2000). Guideline for detection and management of malnutrition. *Malnutrition Advisory Group (MAG), Standing Committee of BAPEN*. BAPEN, Maidenhead.

Elia, M. (2003). Screening for Malnutrition: a multidisciplinary responsibility. Development and use of the Malnutrition Universal Screening Tool (MUST) for adults. BAPEN, Redditch.

Elia M., Stratton R.J., et al. (2005.) The cost of malnutritrion in the UK and the economic case for oral nutrition supplementation in adults. BAPEN, Redditch.

Elia, M, Russell, C.A (eds). (2009). Combating malnutrition; Recommendations for Action. *A report from the advisory group on Malnutrition, led by BAPEN.* BAPEN, Redditch.

Eliasson, A.C., Krumlinde-Sundholm, L., et al. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurology.* 48(7), pp.549-54

Epilepsy Research UK 14. (2008). Frequently asked questions on anti-epileptic drugs.

Field, D., Garland, M., Williams, K. (2003). Correlates of specific childhood feeding problems *Journal of Paediatrics and Child Health*. 39 (4), pp. 299–304.

Fink, A, Kosecoff, J. Chassin, M. Brook, R. (1984) Consensus Methods: Characteristics and guidelines for use. *American Journal of Public Health*. 74 (9), pp979-983

Frisancho, R.A. (1981). New norms of upper limb fat and muscle areas for assessment of nutritional status. *American Journal of Clinical Nutrition.* 34, pp. 2540-5.

Frisch, R.E. (1983). Girls at Puberty. Chapter 2: Fatness, puberty and fertility. The effects of nutrition and physical training on menarche and ovulation. Plenum.

Fung, E.B., Samson-Fang, L. et al. (2002). Feeding dysfunction is associated with poor growth and health status in children with cerebreal plasy. *Journal of the American Dietetic Association.* 102(3), pp. 361-373.

Gallagher, M. Hares, T. Spencer, J. Bradshaw, C. Webb, I. (1993) The nominal group technique: a research tool for general practice? *Family Practice.* 10(1), pp 76-81

Gangil, A., Patwari, A.K. et al (2001). Gastroesophageal reflux disease in children with cerebral palsy. *Indian paediatrics.* 38. pp766-780.

Gerasimidis, K., Keane, O., Macleod, I., Flynn, D.M., Wright, C.M. (2010) A four stage evaluation of the Paediatric Yorkhill Malnutrition Score in a tertiary paediatric hospital and district general hospital. *British Journal of Nutrition.* 104, pp.751-56. http://dx.doi.org/10.1017/S0007114510001121 accessed 30.6.2011

Gisel, E. G. and Patrick, J. (1988). Identification of children with cerebral palsy unable to maintain a normal nutritional state. *The Lancet February*. 6, pp. 283-285.

Gomm, R., Needham, G. et al. (2000). Evaluating research in health and social care. Sage.

G. O. S. H. f. C. N. T. (2000). Nutritional Requirements for Children in health and Disease. GOSH, London.

Gregory, J.R., Collins, D. L. et al. (1995). National Diet and Nutrition Survey children ages 1 ½ years to 4 ½ years. *HMSO*, London.

Gregory, J., Lowe, S. et al. (2000). National Diet and Nutrition Survey Young people aged 4 to 18 years. *HMSO*, London.

Guerriere, D.N., McKeever, P. et al. (2003). Mothers' decisions about gastrostomy tube insertion in children: factors contributing to uncertainty. D*evelopmental Medicine and Child Neurology*. 45, pp. 470-476.

Grover, Zubin. Ee, Looi C. (2009). Protein Energy Malnutrition. *Pediatric Clinics of North America* 56, 5: 1055–1068

Guest, J.F. et al. (2011). Health economic impact of managing patients following a community based diagnosis of malnutrition in the UK. *Clinical Nutrition*. 30, pp. 422–429.

Guo, C.Y., Ronen, G.M. et al. (2001). Long-term valproate and lamotrigine treatment may be a marker for reduced growth and bone mass in children with epilepsy. *Epilepsia*. 42, pp. 1141-1147.

Gustafsson, P. and Tibbling, L. (1994). Gastro-oesophageal reflux and oesophageal dysfunction in children and adolescents with brain damage. *Acta Paediatrica.* 83, pp.1081–1085.

Hagberg, B. and Hagberg, G. (1996). The Changing Panorama of Cerebral Palsy-bilateral and spastic forms in particular. *Acta Paediatrica Suppl*. 416, pp. 48-52.

Harbour, R.M., (2001). A new system for grading recommendations in evidence based guidelines. *British Medical Journal*. 323(7308), pp. 334-336.

Hare, N. S., Durham, S. et al. (1998). The cerebral palsies and motor learning disorders. *Neurological Physiotherapy.* M. Stokes. London, Mosby.

Hartley, H. and Thomas, J. E. (2003). Current practice in the management of children with cerebral palsy: a national survey of paediatric dietitians. *Journal of Human Nutrition and Dietetics*. 16, pp. 219-224.

Harvey, A. S. (2003). Topiramate: Potential trade-offs between efficacy and tolerability in the treatment of epilepsy. *Journal of Paediatrics and Child Health*. 39(6), p. 414.

Hassall, E. (2005). Outcomes of fundopliation: causes for concern, newer options. *Archives of diseases in childhood*. 90, pp. 1047-1052.

Heine, R.G., Reddihough, D.S. and Catto-Smith, A.G. (1995). Gastro-Oesophageal reflux and feeding problems after gastrostomy i children with severe neurological impairment. *Developmental Medicine & Child Neurology.* 37, pp. 320–329.

Heismayr, M. et al. (2009). Decreased food intake is a risk factor for mortality in hospitalised patients: The Nutrition Day survey 2006. *Clinical Nutrition*. 28.

Herman, J.H., & Lange, M.L. (1999). Seating and positioning to manage spasticity after brain injury. *NeuroRehabilitation.* 12, pp. 105-117.

Hidecker, M.J., Paneth, N. et al. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Dev Med Child Neurol.* Aug. 53(8), pp. 704-10. Epub 2011 Jun 27.

Hill, G.L., Blackett, R.L. et al. (1977). Malnuitrition in surgical patients: an unrecognised problem. *The Lancett 1977*. pp. 689-692.

Hogan, S.E. (2004). Energy requirements of children with cerebral palsy. *Canadian Journal of Dietetic Practice and Research*. 65(3), pp. 124-130.

HOSC (2010). East Sussex HOSC Annual Report. East Sussex County Council. HOSC, Lewes.

Hulst, J.M., Zwart, H., Hop, W.C., Joosten, K.F.M. (2010). Dutch national survey to test the STRONGkids nutritional risk screening tool in hospitalized children. *Clinical Nutrition.* pp.106-11. http://dx.doi.org/10.1016/j.clnu.2009.07.006 accessed 30.6.2011

Hurvitz, E.A., Green, L.B. et al. (2008). Body Mass Index Measures in Children with cerebral palsy Related to Gross Motor Function Classification: A Clinic-Based Study. *American Journal of Physical Medicine & Rehabilitation*. 87(5), pp. 395-403.

Hussain, S. Z. and Di-Lorenzo, C. (2002). Motility disorders. Diagnosis and treatment for the paediatric patient. *Paediatric Clinics of North America*. 49(1), pp. 27-51.

Jefferies, K. (2001). Nutrition for children with feeding difficulties. *Clinical Paediatric Dietetics*. V. Shaw and M. Lawson. Blackwell Science Ltd. Oxford. 26, pp. 403-422.

Johnson, A. King, R. Sayer, J. Ashurst, H. Macfarlane, A. Berridge, G. (1998) Oxford Register of Early Childhood Impairments: a regional register (ORECI)' in Pilcher, L. kumiega, L. National Perinatal Epidemiology Unit Annual Report 1997. Oxford. National Perinatal Epidemiology Unit

Jones, J.M. (2002). The methodology of nutrition screening and assessment tools. *Journal of Human Nutrition and Dietetics*. 15, pp. 59-71.

Jones, B., Stratton, R. et al. (2005). Trends in home artificial nutrition support in the UK during 2000 - 2003. *Report by the British Artificial Nutrition Survey (BANS), a committee of BAPEN.* BAPEN.

Jones-Owens, J.L. (1991). Prespeech assessment and treatment strategies.

In M.B. Langley & L.J. Lombardino (Eds.), Neurodevelopmental strategies for managing communication disorders in children with severe motor dysfunction. Austin, Texas. pp. 49-80.

Joosten, K., Meyer, R. (2010). Nutritional screening and guidelines for managing the child with faltering growth. *European Journal of Clinical Nutrition*. 64, pp. S22-24.

Joosten, K.F., Zwart, H. et al. (2010). National malnutrition screening days in hospitalised children in The Netherlands. *Arch Dis Child 2010.*
95, pp.141-145.

Karanicolas, P.J. Farrokhyar, F. Bhandari, M. (2010) Blinding: Who, what, when, why, how? *Canadian Journal of Surgery*. 53(5): 345–348.

Karle, I.P., Bleiler, R.E. et al. (1961). Nutritional status of cerebral palsied children. *Journal of the American Dietetic Association*. 38, pp. 22-26.

Kawahara, H., Dent, J. et al. (1997). Mechanisms responsible for Gastroesophageal reflux in children. *Gastroenterology*. 113, pp. 339-408.

Kimber, C., Kiely, E. M.et al. (1998). The failure rate of surgery for gastro-oesophageal reflux. *Journal of Paediatric Surgery*. 33, pp. 64-66.

Kondrup, J., Allison, S. et al. (2002). ESPEN Guidelines for Nutrition Screening. *ESPEN.*

Kong, C., Wong, H. S (2005). Weight for height values and limb anthropometric composition of tube fed children with quadriplegic cerebral palsy. *Paediatrics*. 116, pp. 839-845.

Krick, J. and Van-Duyn, M. S. (1984). The relationship between oral motor involvement and growth: A pilot study in a paediatric population with cerebral palsy. *Journal of the American Dietetic Association*. 84, pp. 555-559.

Krick, J., Murphy, P. E. et al. (1992). A proposed formula for calculating energy needs of children with cerebral palsy. *Developmental Medicine and Child Neurology*. 34, pp. 481-487.

Krick, J., Murphey-Miller, P. et al. (1996). Pattern of growth in children with cerebral palsy. *Journal of the American Dietetic Association*.
96(7), pp. 680-685.

Laistram, N. Srivastava, V. Srivastava, R. (1992) Cerebral palsy – an etiological study. *Indian Journal of Paediatrics.* 59:723-728

Lancet. (1971, July 24). Relative energy requirements for maintenance, growth, and physical activity. 2 (7717), pp. 210-1.

Landis, J.R., Koch, G.G. (1977). The measurement of observer agreement for categorical data. *Biometrics.* 33(1), pp. 159–174.

Larnert, G. and Ekberg, O.(1995). Positioning improves the oral pharyngeal swallowing function in children with cerebral palsy. *Acta Paediatrica.* 84, pp. 689- 92.

Langley, M.B., Thomas, C. (1991). Introduction to the neurodevelop mental approach. Neurodevelopmental strategies for managing communication disorders in children with severe motor dysfunction. *In M.B. Langley & L.J. Lombardino (Eds.)*, Austin, Texas. pp. 1-28.

Latham, C., Miles, A. (2000). Making the curriculum work for VOCA's: The Redway School model. *Communication Matters*. 14, pp. 10-12.

Lennard-Jones, J. (1992). A positive approach to nutrition as treatment. *Kings Fund,* London.

Leung, Q.C. (2001) How to design a questionnaire. *Student BMJ, 9, pp 187-189*

Lewis SJ, Heaton KW (1997). Stool form scale as a useful guide to intestinal transit time. *Scandinavian Journal of Gastroenterology.* 32 (9): 920–4

Liddle J. Williamson M. Irwig L. (1996) Method for evaluating research and guideline evidence. Sydney: New South Wales *Department of Health*.

Liebl, B. H., Fischer, M. H. et al. (1990). Dietary fiber and long-term large bowel response in enterally nourished nonambulatory profoundly retarded youth. J*ournal of Enteral and Parenteral Nutrition*. 14, pp. 371-375.

Ling, R.E., Hedges, V., Sullivan, P.B. (2011).Nutritional risk in hospitalised children: An assessment of two instruments. *e-ESPEN.* 6, pp. 153-7.

Liu, L. Roberts, R. Moyer-Mileur, L. Samson-Fang, L. (2005). Determination of body composition in children with cerebral palsy: bioelectrical impedance analysis and anthropometry vs dual-energy x-ray absorptiometry. *Journal of the American Dietetic Association*. 105(5), pp. 794-7.

Logemann, J.A. (1998). Evaluation and treatment of swallowing disorders (2nd ed.). Austin, Texas.

Major, B.N. Jacoby, J. Sheluga, D.A. (1976) Questionnaire research on questionnaire construction. *Purdue Papers in Consumer Psychology*. No 166 Purdue University accessed via http://psychology.ucdavis.edu/faculty_sites/sommerb/sommerdemo/quests/format.htm accessed 31.3.2014

Marshall, W.A. (1978). The relationship of puberty to other maturity indicators and body composition in man. *Journal of Reproduction and Fertility*. 52(2), pp. 437-443.

Martyn, C. N., Winter, P. D. et al. (1998). Effect of nutritional status on use of health care resources by patients with chronic disease living in the community. *Clinical Nutrition*. 17(3), pp. 119-123.

McCarthy, G.T. (1992a). Cerebral Palsy: The clinical problem. In Squier W (ed) Acquiring damage to the developing brain: Timing and causation. London. Arnold. p.14.

McCarthy, G.T. (1992b). Cerebral palsy: definition, epidemiology, development and neurological aspects. Physical disability in childhood - an interdisciplinary approach. London, Churchill Livingstone.

McCarthy, H. (2008). Identification of nutrition risk in children. The development and validation of a children's nutrition risk screening tool. *Phd Thesis.* University of Ulster.

McCarthy, H., McNulty, H. et al. (2008). Nutrition screening in children - the validation of a new tool. Abbott Nutrition, Ulster.

McCarthy, H., Dixon, M. et al. (2012). The development and evaluation of the Screening Tool for the Assessment of Malnutrition in Paediatrics (STAMP©) for use by healthcare staff. *Journal of Human Nutrition and Dietetics*. 25, pp. 311–318.

McWhirter, J.P., Pennington, C. R. (1994). Incidence and recognition of malnutrition in hospital. *BMJ*. 308, pp. 945-948.

Meijers, J.M.M. et al. (2012). Estimating the costs associated with malnutrition in Dutch nursing homes. *Clinical Nutrition.* 31(1).

Moy, R., Smallman, S., Booth, I. (1990). Malnutrition in a UK children's hospital. *Hum Nutr Diet*. 3, pp. 93-100.

NICE. (2006). Nutrition Support in Adults (CG32). Benefits of Implementation: Cost saving guidance. *NICE*. (updated) 2013.

NICE. (2006). National cost impact report to accompany CG32.

NICE. (2009). Cost saving guidance. (Accessed January 30, 2010, at http://www.*nice.org.uk*/usingguidance/benefitsofimplementation/costsavingguidance.jsp.)

NICE. (2012). NICE support for commissioners and others using the quality standard on nutrition support in adults.

NHS Institute for Innovation and Improvement. (2009). High Impact Actions for Nursing and Midwifery. Accessed January 30, 2010, at http://*www.institute.nhs.uk/*images//stories/Building_Capability/HIA/NHSI%20High%20Impact%20Actions.Pdf)

NHS and I. f. I. a. Improvement (2010). High Impact Actions. London.

NPSA (2008) New guidance issued to improve nutrition and hydration standards in all healthcare settings. http://www.npsa.nhs.uk/corporate/news/new-guidance-issued-to-improve-nutrition-and-hydration-standards-in-all-healthcare-settings/

NPSA. (2012) http://*www.patientsafetyfirst.nhs.uk*/Content.aspx?Path=/Campaign-news/nutrition-and-hydration-week/.

Oeffinger, D., Conaway, M. et al. (2010). Tibial length growth curves for ambulatory children and adolescents with cerebral palsy. *Developmental Medicine & Child Neurology*. 52 (9), pp. e195–e201.

Ozmen, M. Caltskan, M. Apak, S. Gokcay, G. (1993) 8 year clinical experience in cerebral palsy. *Journal of Tropical Medicine*. 39:52-54

Palisano, R., Rosenbaum, P. et al. (1997). Development & reliability of a system to classify Gross Motor Function in children with cerebral palsy. *Developmental Medicine & Child Neurology*. 39, pp. 214-223.

Park, E.S., Park, C. et al. (2004). Colonic transit time and constipation in children with spastic cerebral palsy. *Archives of Physical Medicine and Rehabilitation*. 85 (3), pp. 453-456.

Parkes, J., Donnelly, M., Hill, N. (2001). Focusing on cerebral palsy Reviewing and communicating needs for services. *Scope.*

Parkman-Williams, C. (1998). *Paediatric Manual of Clinical Dietetics.* Developed by the Paediatric Nutrition Practice Group. Chicago, The American Dietetic Association.

Patrick, J., Boland, M. et al. (1986). Rapid correction of wasting in children with cerebral palsy. *Developmental Medicine and Child Neurology*. 28, pp. 734-739.

Pharoah, P.O.D., Cooke, T. et al. (1998). Epidemiology of CP in England and Scotland 1984-89. *Archives of Diseases in Childhood, Fetal and Neonatal edition.* 79, pp. 21-25.

Prader, A.,Tanner, J.M and Von Harnack,G. A. (1963). Catch-up growth following illness or starvation: an example of developmental canalization in man. *The Journal of pediatrics* . 62(5), pp. 646-659.

Puntis, J. (2009). Malnutrition in Developed Countries. *Annales Nestlé*. 67, pp. 65-72.

Ratanawongsa, B. (2001). Cerebral Palsy: *Encyclopaedia of CP - For lay persons / students.*

Quine, L. and Pahl, J. (1985). Examining the causes of stress in families with severe mentally handicapped children. *British Journal of Social Work*. 15, pp. 501-517.

Ravelli, A. M. and Milla, P.J. (1998). Vomiting and gastroesophageal motor activity in children with disorders of the central nervous system. *Journal of Paediatric Gastroenterology and Nutrition*. 26, pp. 56-63.

Reiken, R., Calis, E.A. et al. (2010). Validation of skinfold measurements and bioelectrical impedence in children with severe cerebral palsy. *Clinical Nutrition*. 29 (2), pp. 217-221.

Reilly, H.M., Martineau, J. K. et al. (1995). Nutritional screening - Evaluation and implementation of a simple nutrition risk score. *Clinical Nutrition*.
14, pp. 269-273.

Reilly, J.J., Hassan, T. M. et al. (1996). Growth retardation and undernutrition in children with spastic cerebral palsy. J*ournal of human nutrition and dietetics*. 9, pp. 429-435.

Reilly, S., Skuse, D. et al. (1995). The objective rating of oral motor functions during feeding. *Dysphagia*. 10, pp. 177-191.

Reilly, S., Skuse, D. et al. (1996). Prevelence of feeding problems and oral motor dysfunction in children with cerebral palsy: A community survey. *The journal of paediatrics*. 129(6), pp. 877-882.

Reilly, S., Morgan, A ., Wisbeach, A. (2010). The management of feeding in children with neurological problems. *Feeding Problems in Children: A Practical Guide p.* 188.

Rempel, G.R., Colwell, S. O et al. (1988). Growth in children with cerebral palsy fed via gastrostomy. *Paediatrics*. 82(6), pp. 857-862.

Robinson, G., Goldstein, M. et al. (1987). Impact of nutritional status on DRG length of stay. J*ournal of parenteral and enteral nutrition*. 11, pp. 49-51.

Rogers, B. (2004). Feeding method and health outcomes of children with cerebral palsy. *Journal of Paediatrics*. 145(2), pp. s28-32.

Roma, E., Adamidis, D. et al. (1999). Diet and Chronic Constipation in Children: The Role of Fibre. *Journal of Paediatric Gastroenterology & Nutrition*. 28(2), pp. 169-174.

Rosenbaum, P., Paneth, N., Leviton, A. (2007). A report: the definition and classification of cerebral palsy. *Dev Med Child Neuro Suplement*.
109, pp. 8-14.

Rudolph, C.D., Mazur, L.J. et al. (2001). Guidelines for evaluation and treatment of gastro oesophageal reflux in infants and children: Recommendations of the North American Society for Paediatric Gastroenterology and Nutrition. *Journal of Paedatric Gastroenterology and Nutrition*. 32, pp. S1-31.

Russell, D., Avery, L. M. et al. (2000). Improved Scaling of the Gross Motor Function Measure for Children with cerebral palsy: Evidence of Reliability and Validity. *Physical Therapy*. 80(9), pp. 873-885.

Russell, C., Elia, M. (2008). Nutrition Screening Survey in the UK in 2008. *BAPEN*. Redditch.

SACN (2008). The Nutritional Wellbeing of the British Population. *The Stationary Office.*

SACN (2011). Dietary Reference Values for Energy. *The Stationary Office.*

Samson-Fang, L., Stevenson, R.D. (1998). Linear growth velocity in children with cerebral palsy. *Developmental Medicine and Child Neurology.*
40, pp. 689-692
.

Samson-Fang, L., Stevenson, R. D (2000). Identification of malnutrition in children with cerebral palsy: poor performance of weight-for-height centiles. *Developmental Medicine & Child Neurology*. 42, pp. 162-168.

Samson-Fang, L., Fung, E., Stallings,V.A. et al (2002). Relationship of nutritional status to health and societal participation in children with cerebral palsy. *Paediatrics.*141, pp. 637-643.

Sanders, K.D., Cox, K. et al. (1990). Growth response to enteral feeding by children with cerebral palsy. *Journal of parenteral and enteral nutrition*.
14(1), pp. 23-26.

Sapsford, R. (2007). Survey Research. 2nd Edition, Sage Publishing

Scottish Intercollegiate Guidelines Network. (1999) Methodology Review Group. Report on the review of the method of grading guideline recommendations. Edinburgh: *SIGN.*

Secker, D.J., Jeejeebhoy, K. N. (2007). Subjective Global Nutritional Assessment for children. *American Journal of Clinical Nutrition*.
85, pp. 1083-1089.

Seikel, J.A., King, D.W., Drumwright, D.G. (2000). Anatomy and physiology for speech, language, and hearing (2nd ed.). San Diego.

Sellers, D., (pending publication). A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy. *Developmental Medicine & Child Neurology*.

Sert, C., Altindağ, O., Sirmatel, F. (2009). Determination of Basal Metabolic Rate and body composition with bioelectrical impedance method in children with cerebral palsy. *Journal of Child Neurology*. 24(2), pp.237-240.

Sermet-Gaudelus, I., Poisson-Salomon, A. et al. (2000). Simple paediatric nutritional risk score to identify children at risk of malnutrition. *American Journal of Clinical Nutrition*. 72(1), pp. 64-70.

Shaw, V. and M. Lawson (2002). *Clinical Paediatric Dietetics*. London, Blackwell Science Ltd.

Shea B. Bouter L. Peterson J. Boers M. Andersson N. Ortiz Z. (2007) External validation of a measurement tool to assess systematic reviews (AMSTAR). *PloS One*. 2(12). e1350.

Sireci, S. (2007). Content Validity. In Neil J. Salkind, & K. Rasmussen (Eds.), Encyclopedia of Measurement and Statistics. pp. 182-184. Thousand Oaks, CA: Sage Publications

Sleigh, G., Brocklehurst, P. (2004). Gastrostomy feeding in cerebral palsy: a systematic review. *Archives of Disease in Childhood*. 89, pp. 534-539.

Sleigh, G., Sullivan, P.B., Thomas, A.G. (2004). Gastrostomy Feeding versus oral feeding alone for children with cerebral palsy. *Cocherane Database Systematic Review*. CD 003943.pub2

Smith, S.W., Camfield, C. et al. (1999). Living with cerebral palsy and tube feeding: A population-based follow-up study. *Journal of Paediatrics*. 135(3).pp. 307-310.

Soylu, Ozlem Bekem, et al.(2008). Effect of nutritional support in children with spastic quadriplegia. *Pediatric neurology.* 39(5), pp. 330-334.

Sommer. R, et al (2001). A Practical Guide to Behavioral Research Tools and Techniques. 5th Edition. Clarendon Press

Somerville, H., Tzannes, G., Wood, J. et al. (2008). Gastrointestinal and nutritional problems in severe developmental disability. *Dev med child neurol*. 50, pp. 712-716.

Sondheimer, J. M. and Morris, B. A. (1979). Gastroesophageal reflux among retarded children. *Journal of Paediatrics*. 94, pp. 710-714.

Southall, A., Martin, C. (2011). Feeding Problems in children: *A guide for health professionals*. Southall & Martin Eds . Radcliffe Medical Press.

Spady, D., Payne, P. et al. (1976). Energy balance during recovery from malnutrition. *The American Journal of Clinical Nutrition*. 29, pp.1073-1088.

Spender, Q., Cronk, C. et al. (1989). Assessment of linear growth of children with cerebral palsy: use of alternative measures to height or length. *Developmental Medicine and Child Neurology*. 31, pp. 206-214.

Spitz, L., Roth, K. et al. (1993). Operation for gastro-oesophageal reflux associated with severe mental retardation. *Archives of Diseases of Childhood*. 68, pp. 347-351.

Staiano, A., Simeone, D. et al. (2000). Effect of the dietary fiber glucomannan on chronic constipation in neurologically impaired children. *Journal of Paediatrics*. 136, pp. 41-45.

Stallings, V.A., Charney, E.B. et al. (1993). Nutritional status and growth of children with diplegic or hemiplegic cerebral palsy. *Developmental Medicine and Child Neurology*. 35, pp. 997-1006.

Stallings, V.A., Cronk, C.E. et al. (1995). Body composition in children with spastic quadriplegic cerebral palsy. *The Journal of Paediatrics*.
126(5 part 1), pp. 833-839.

Stallings, V.E. (1996). Nutritional assessment of the disabled child. *Feeding the Disabled Child*. P. B. Sullivan and L. Rosenbloom. Mackeith Press, Cambridge. pp. 62-76.

Stanley, F., Blair, E. et al. (2000). Cerebral Palsies: Epidemiology and Causal Pathways. London, Mac Keith Press.

Stark, C., Nikopoulou-Smyrni, P. et al (2010). Effect of a new physiotherapy concept on bone mineral density, muscle force and gross motor function in children with bilateral cerebral palsy. *Musculoskelet Neuronal Interact*. 10(2), pp. 151-158.

Stenberg, R., Dahle, C. et al (2009). Increased Prevalence of Anti-gliadin Antibodies and Anti-tissue Transglutaminase Antibodies in Children with cerebral palsy. *Journal of Paediatric Gastroenterology & Nutrition*. 49 (4), pp. 424-429.

Stevenson, R.D., Hayes, L.P. et al. (1994). Clinical correlates of linear growth in children with cerebral palsy. *Developmental Medicine and child Neurology*. 36. pp. 135 - 142.

Stevenson, R.D. (1995). Use of segmental measures to estimate stature in children with cerebral palsy. *Archives of paediatric and adolescent medicine.* 149, pp. 658-331.

Stevenson, R.D. (1996). Measurement of growth in children with development disabilities. *Developmental Medicine and Child Neurology*. 38, pp. 855-860.

Stevenson, R.D., Allaire, J.H. (1996). The development of eating skills in infants and young children. In PB. Sullivan & L. Rosenbloom (Eds.), *Feeding the disabled child.* MacKeith Press, London. pp. 11-22.

Stewart, L., McKaig, N., Dunlop, C., Daly, H., Almond, S.(2005). Assessment and monitoring of children with neurodisability on home enteral tube feeding. Clinical Nutrition Update. 10(1), pp. 6-8.

Stewart, L., Mckaig, N. et al. (2006). Guidelines on Dietetic Assessment and Monitoring of Children with Special Needs with Faltering Growth. British Dietetic Association, Birmingham.

Stratton, R.J. (2005). Elucidating effective ways to identify and treat malnutrition. *Proceedings of the Nutrition Society*. 64, pp. 305-311.

Stratton, R., Thompson, R. L. et al. (2002). Healthcare utilisation according to malnutrition risk in the elderly; an analysis of data from the National Diet and Nutrition Survey. *Proceedings of the Nutrition Society*. 61, (20A).

Stratton, R.J., Green, C.J., Elia, M. (2003a). Disease related malnutrition: An evidenced based approach to treatment. Wallingford. Oxon. CABI Publishing.

Stratton, R.J. Longmore, D. Elia, M. (2003b) Concurrent validity of a newly developed malnutrition universal screening tool (MUST) *European Society of Parenteral and Enteral Nutrition.* Suppl 10. 034-P

Stratton, R.J. Hackston, A. Longmore, D. Dixon, R. Price, S. Stroud, M. King, C. Elia, M. (2004) Malnutrition in hospital outpatients and inpatients: prevalence, concurrent validity and ease of use of the 'malnutrition universal screening tool' ('MUST') for adults. *British Journal of Nutrition*. 92 05 pp 799-808

Stringel, G., Delgado, M. et al. (1989). Gastrostomy and Nissen fundoplication in neurologically impaired children. Journal of Paediatric Surgery. 24, pp.1044-1048.

Sullivan, P.B., Bachlet, A. M. E. et al. (unpublished). Body composition in children with cerebral palsy fed via gastrostomy tube - too much of a good thing?

Sullivan, P. B. (1999). Annotation - Gastrostomy feeding in the disabled child: when is an antireflux procedure required? *Archives of Diseases of Childhood*. 81, pp. 463-464.

Sullivan, P., Lambert, B., et al. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment. *Oxford Feeding Study. Developmental Medicine & Child Neurology*. 42, pp. 674-680.

Sullivan, P.B., Juszczak, E. et al. (2002). Impact of feeding problems on nutritional intake and growth:Oxford feeding study II. D*evelopmental Medicine and Child Neurology.* 44, pp. 461-467.

Sullivan, P.B., Juszczak, E. et al. (2004). Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Developmental Medicine and Child Neurology*. 46(12), pp. 796-800.

Sullivan, P.B., Juszczak, E. et al. (2005a). Gastrostomy tube feeding in children with cerebral palsy:a prospective longitudinal study. *Developmental Medicine and Child Neurology*. 47, pp. 77-85.

Sullivan, P.B., McIntyre, E. (2005b). Gastrointestinal problems in disabled children. *Current Paediatrics*. 15, pp. 347-353.

Sullivan, P.B., Alder, N., et al. (2006). Gastrostomy feeding in cerebral palsy: too much of a good thing? *Dev Med Child Neurol.* 48(11), pp. 877-82.

Sullivan. (2008). Gastrointestinal disorders in children with neurodevelopmental disabilities. *Developmental Disabilities Research Reviews: Special Issue Feeding and Swallowing.* 14(2), pp. 128–136.

Sullivan, P. (2010). Malnutrition in hospitalised children. *Archives of Diseases of Childhood*. 95(7).

Surman, G., Hemming, K., Platt, M.J. (2009). Children with Cerebral Palsy: severity and trends over time. *Paediatric Perinatal Epidemiology.* 23, pp. 513-521.

Synder, R.G., Golomb, D.H. et al. (1977). Anthropometry of Infants, Children and Youths to Age 18 for product Safety Design.UM-HSRI-77-17. *Consumer Product Safety Commission.* Bethesda,MD.

Tanner, J.M., Whitehouse, R.H. (1975). Revised standards for triceps and subscapular skinfolds in British children. *Archives of Diseases of Childhood.* 50, pp. 142-145.

Tawfik, R., Dickson, A. et al. (1997). Caregivers' perceptions following gastrostomy in severely disabled children with feeding problems. *Developmental Medicine and Child Neurology.* 39, pp. 746-751.

Terwee, C.B. Bot, S.D.M. De Boer, M.R. Van der Windt, D. Knol, D.L. Dekker, J. Bouter, L.M. Vet, H.C.W. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology.* 60, (1), pp34-42.

Thomas, A. P. et al. (1989). The Health and Social Needs of Young Adults with Physical Disabilities. *Clinics in Developmental Medicine No. 106*. London: MacKeith Press.

Thomas, A. G., Akobeng, A.K (2000). Technical aspects of feeding the disabled child. *Current Opinion in Clinical Nutrition & Metabolic Care*.
3(3), pp. 221-225.

Thomas, B., Bishop, J. (2007). *The Manual of Dietetic Practice*.
Wiley-Blackwell.

Thommessen, M., Heiberg, A. et al. (1991). Feeding problems, height and weight in different groups of diabled children. *Acta Paediatrics of Scandanavia*. 80, pp. 527-533.

Thommessen, M., Kase, B.F. et al. (1991). The impact of feeding problems on growth and energy intake in children with cerebral palsy. *European Journal of Clinical Nutrition*. 45, pp. 470-487.

Thommessen, M., Riis, G. et al. (1991). Energy and nutrreient intake of diabled children: Do feeding problems make a difference? *Journal of the American Dietetic Association*. 91(12), pp. 1522-1526.

Tobis, J., Saturen, P. et al. (1961). A study of growth patterns in cerebral palsy. *Archives of physical medicine and rehabilitation*. 42, pp. 475-81.

Tolia, V., Ventimiglia, J. et al. (1997). Gastrointestinal tolerance of a pediatric fiber formula in developmentally disabled children. *Journal of American College Nutrition.* 16, pp. 224-228.

Toumoum, H.Y., Badawy, N.B. et al. (2010). Anthropometry and body composition analysis in children with cerebral palsy. *Clinical Nutrition.*
29(4), pp. 477-481.

Trier, E. and Thomas, A.G. (1998). Feeding the disabled child. *Nutrition*. 14(10), pp. 801-805.

Troughton, K.E.V., Hill, A. E. (2001). Relation between objectively measured feeding competence and nutrition in children with cerebral palsy. *Developmental Medicine and Child Neurology*. 43, pp. 187-190.

Tse, P.W.T., Leung, S.S.F. et al. (2000). Dietary fibre intake and constipation in children with severe developmental disabilities. *Journal of Paediatrics and Child Health*. 36, pp.236-239.

Van de Ven, A.H. Delbecq, A.L. (1972) The nominal group as a research instrument for exploratory health studies. *American Journal of Public Health*; 62(3): 337–342

Venness, C., Reilly, S. (2008). Mealtime interaction patterns between young children with cerebral palsy and their mothers: characteristics and relationship to feeding impairment. *Child: Care, Health & Development*. 34(6), pp. 815–824.

Vernon-Roberts, A., Bachlet, A. et al. (2002). Energy balance and body composition in children with cerebral palsy*. Journal of Paediatric Gastroenterology and Nutrition*. 34(4), p. 478.

Vernon-Roberts, A., Wells, J. et al. (2010). Gastrostomy feeding in cerebral palsy: enough and no more. *Developmental Medicine and Child Neurology*. 52(12), pp. 1099-1105.

Veugelers, R., Penning, C. et al. (2006) Feasibility of bioelectrical impedance analysis in children with a severe generalised cerebral palsy. *Nutrition*.
22, pp. 16-22.

Vik, T., Skrove, M. S. et al. (2001). Feeding problems and growth disorders among children with cerebral palsy in south and north Trondelag. *Tidsskr Nor Laegeforen*. 121, pp. 1570-1574.

Wesley, J.R., Coran, A.G. et al. (1981). The need for evaluation of gastroesophageal reflux in brain-damaged children referred for feeding gastrostomy. *Journal of Paediatric* Surg. 16, pp. 866–71.

Williams, C.L., Bollella, M. et al. (1995). A new recommendation for dietary fibre in children. *Paediatrics*. 96, pp. 985-988.

Wing, R. Hill, J. (2001). Successful weight loss maintenance. *Annual Review of Nutrition.* 21: pp 323-341

Whiting P. Rutjes A. Westwood M.E. Mallett S. Deeks J.J. Reitsma J.B. (2011) QUADAS-2: A Revised Tool for the Quality Assessment of Diagnostic Accuracy Studies. *Ann Intern Med* .155(8) pp529-36.

Woolf S.H. (1992). Practice Guidelines, a New Reality in Medicine: II. Methods of Developing Guidelines. *Arch Intern Med.* 152(5), pp946-952.

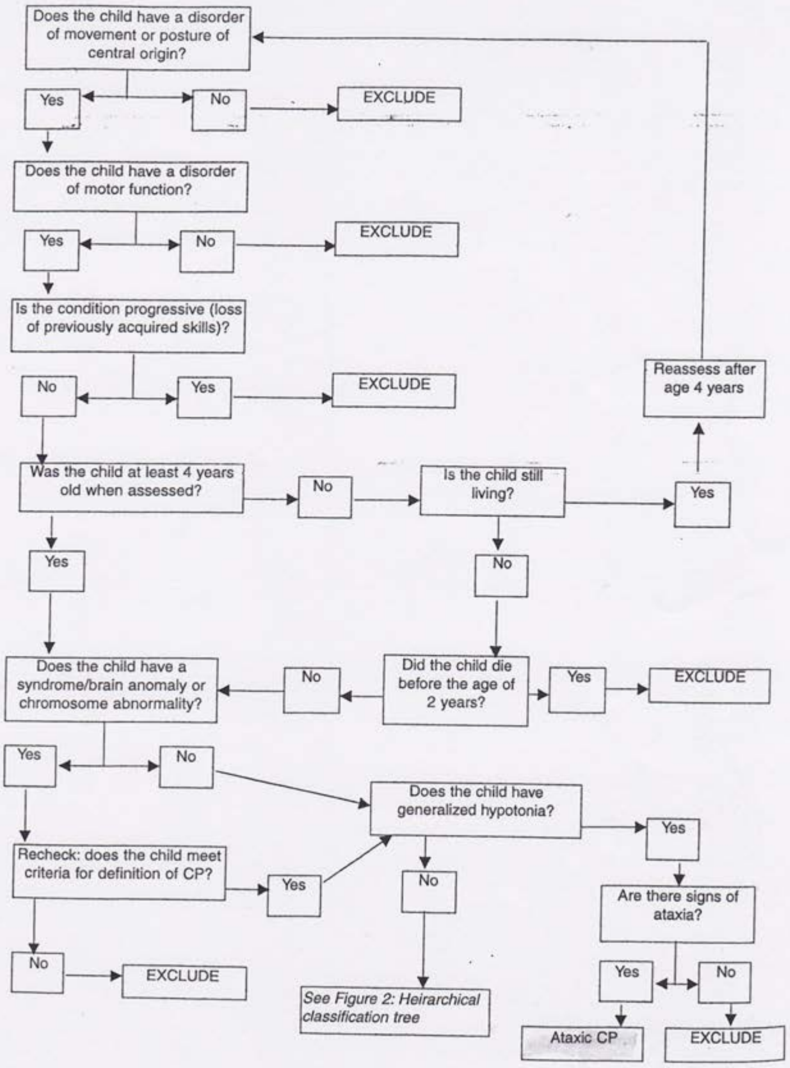
Wolinsky FD , Coe RM , McIntosh WA , Kubena KS , Prendergast JM , Chavez MN , Miller DK , Romeis JC , Landmann WA. (1990). Progress in the development of a nutritional risk index. *The Journal of Nutrition.* 120, Supplement 11. pp. 1549-1553

Yokochi, K., Shimabukuro, S. et al. (1993). Motor function of infants with athetoid cerebral palsy. *Developmental Medicine and Child Neurology*. 35(10), pp. 909-16.

Appendix 2

Algorithm to confirm diagnosis of Cerebral Palsy

Figure 1: *Decision tree for inclusion/ exclusion of cases of cerebral palsy on SCPE register.*



820 *Developmental Medicine & Child Neurology* 2000, 42: 816–824

Appendix 3

Algorithm to classify Cerebral Palsy

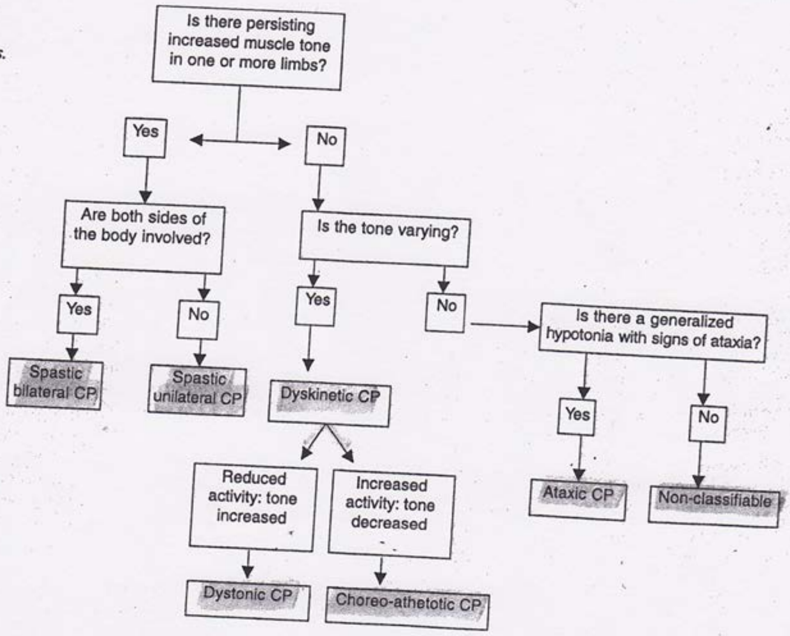
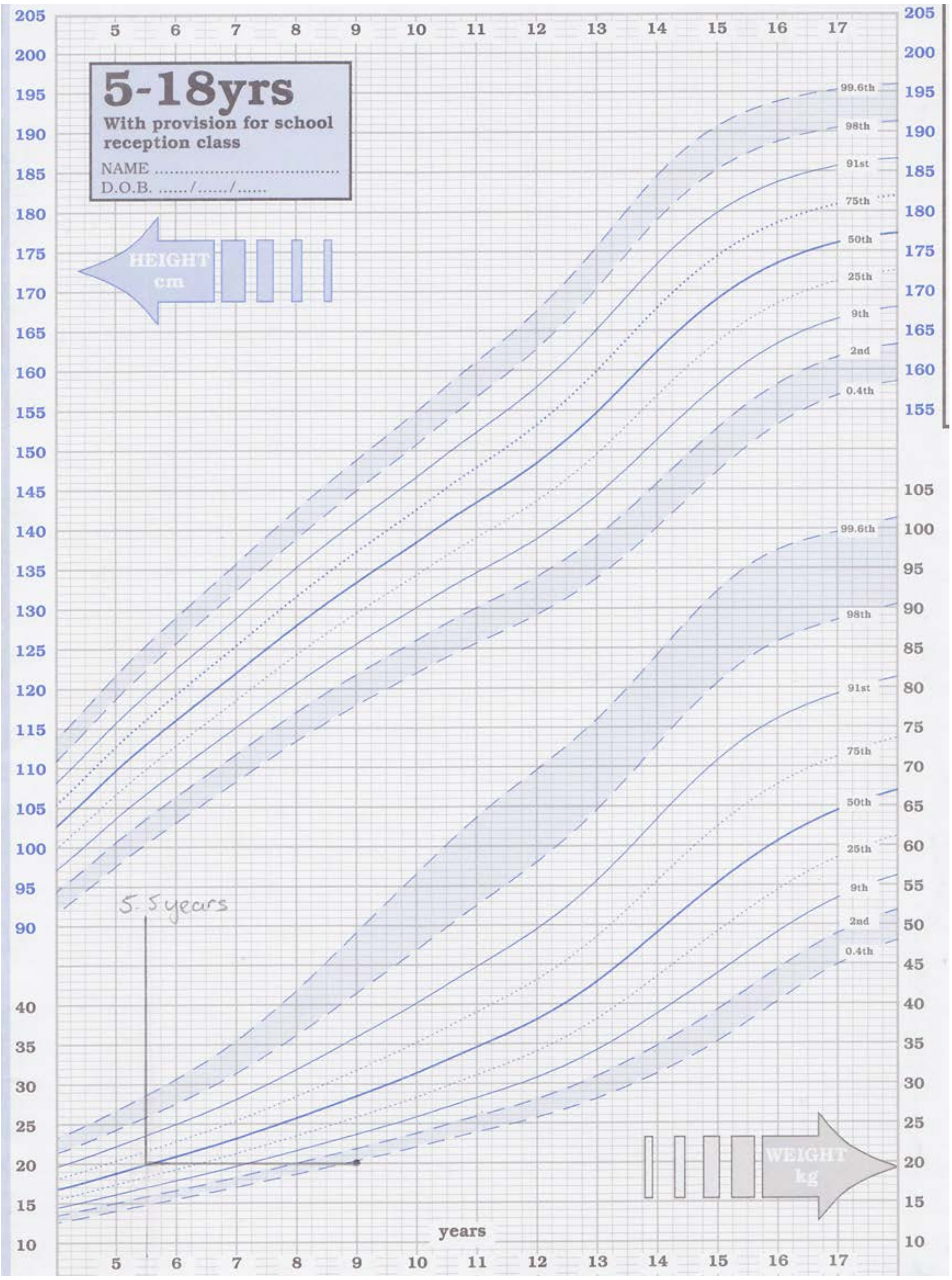


Figure 2: *Hierarchical classification tree of cerebral palsy sub-types.*

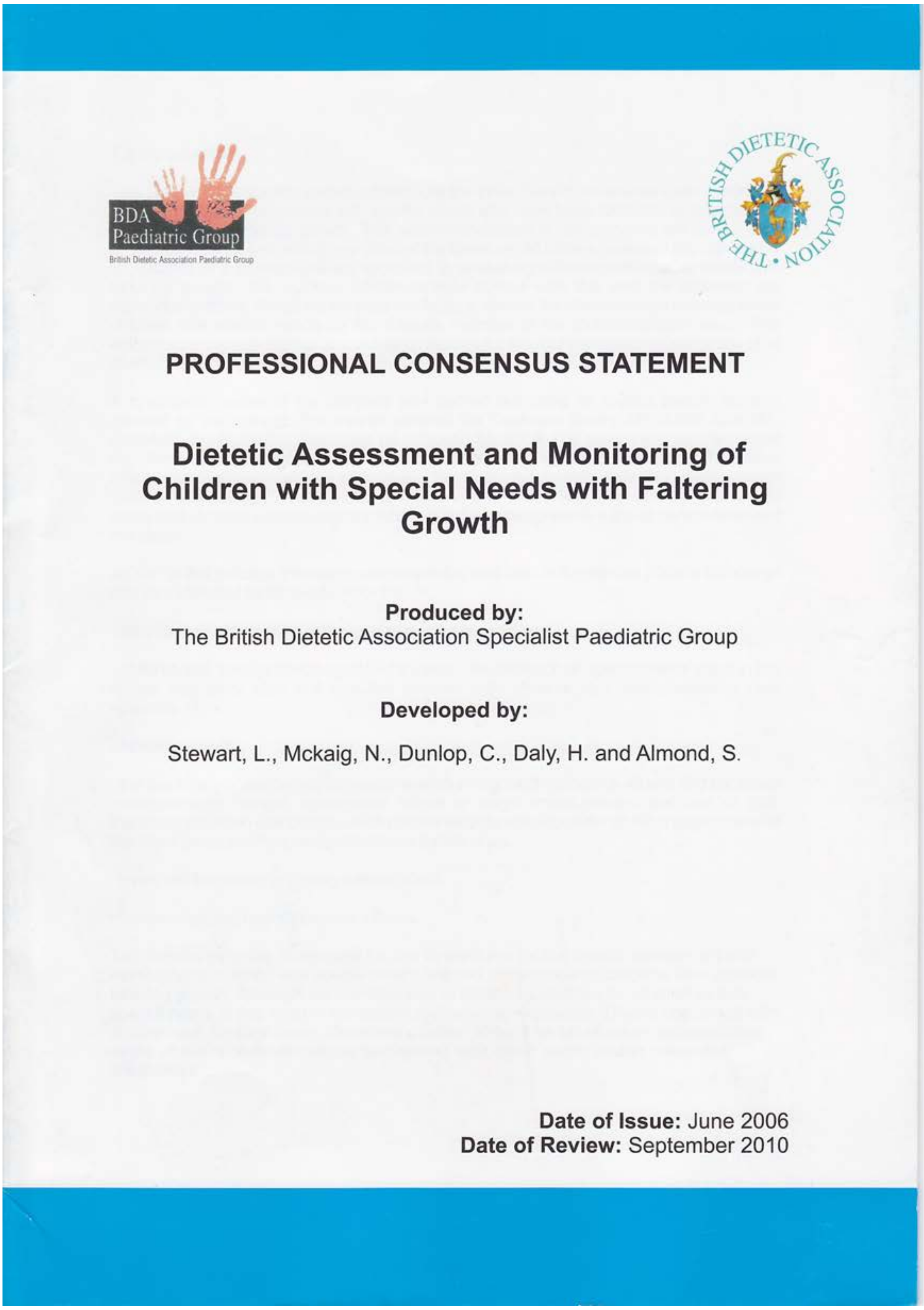
Appendix 4

Growth chart to show how height age is calculated.



Appendix 5

Alternative techniques to measure stature in Dietetic Assessment and Monitoring of Children with Special Needs with Faltering Growth.



PROFESSIONAL CONSENSUS STATEMENT

Dietetic Assessment and Monitoring of Children with Special Needs with Faltering Growth

Produced by:
The British Dietetic Association Specialist Paediatric Group

Developed by:

Stewart, L., Mckaig, N., Dunlop, C., Daly, H. and Almond, S.

Date of Issue: June 2006
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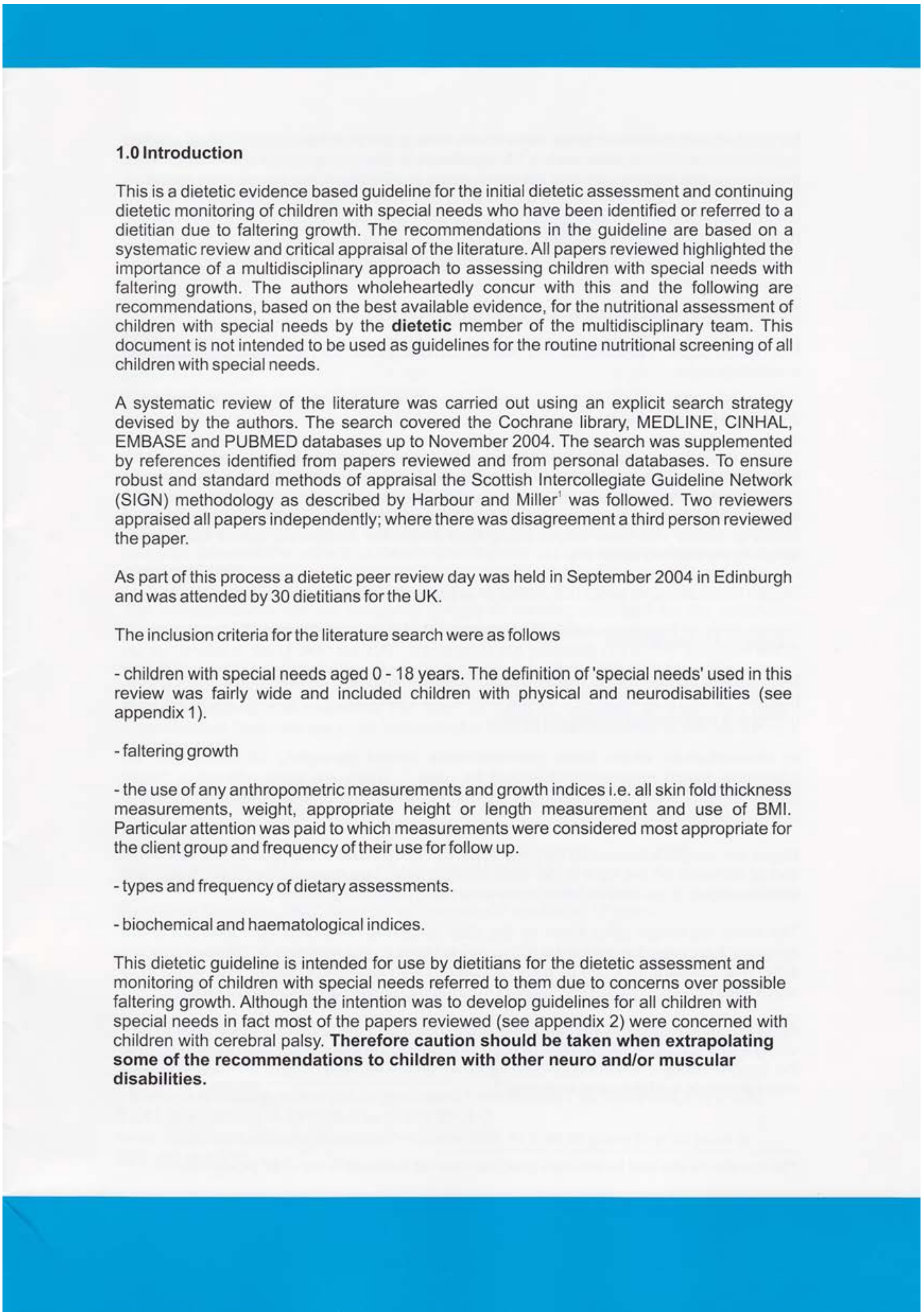


1.0 Introduction

This is a dietetic evidence based guideline for the initial dietetic assessment and continuing dietetic monitoring of children with special needs who have been identified or referred to a dietitian due to faltering growth. The recommendations in the guideline are based on a systematic review and critical appraisal of the literature. All papers reviewed highlighted the importance of a multidisciplinary approach to assessing children with special needs with faltering growth. The authors wholeheartedly concur with this and the following are recommendations, based on the best available evidence, for the nutritional assessment of children with special needs by the **dietetic** member of the multidisciplinary team. This document is not intended to be used as guidelines for the routine nutritional screening of all children with special needs.

A systematic review of the literature was carried out using an explicit search strategy devised by the authors. The search covered the Cochrane library, MEDLINE, CINHAL, EMBASE and PUBMED databases up to November 2004. The search was supplemented by references identified from papers reviewed and from personal databases. To ensure robust and standard methods of appraisal the Scottish Intercollegiate Guideline Network (SIGN) methodology as described by Harbour and Miller[1] was followed. Two reviewers appraised all papers independently; where there was disagreement a third person reviewed the paper.

As part of this process a dietetic peer review day was held in September 2004 in Edinburgh and was attended by 30 dietitians for the UK.

The inclusion criteria for the literature search were as follows

- children with special needs aged 0 - 18 years. The definition of 'special needs' used in this review was fairly wide and included children with physical and neurodisabilities (see appendix 1).

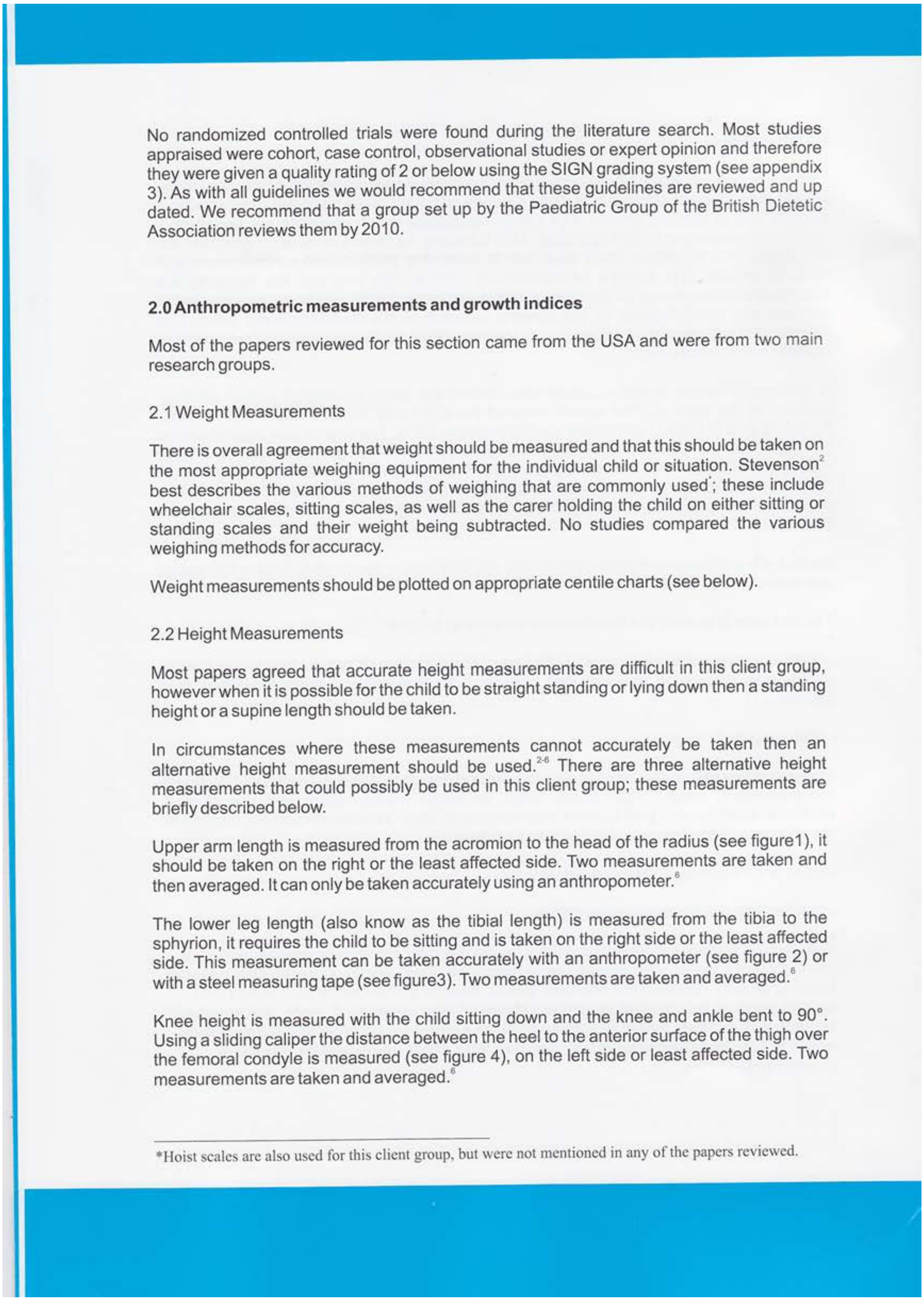
- faltering growth

- the use of any anthropometric measurements and growth indices i.e. all skin fold thickness measurements, weight, appropriate height or length measurement and use of BMI. Particular attention was paid to which measurements were considered most appropriate for the client group and frequency of their use for follow up.

- types and frequency of dietary assessments.

- biochemical and haematological indices.

This dietetic guideline is intended for use by dietitians for the dietetic assessment and monitoring of children with special needs referred to them due to concerns over possible faltering growth. Although the intention was to develop guidelines for all children with special needs in fact most of the papers reviewed (see appendix 2) were concerned with children with cerebral palsy. **Therefore caution should be taken when extrapolating some of the recommendations to children with other neuro and/or muscular disabilities.**



No randomized controlled trials were found during the literature search. Most studies appraised were cohort, case control, observational studies or expert opinion and therefore they were given a quality rating of 2 or below using the SIGN grading system (see appendix 3). As with all guidelines we would recommend that these guidelines are reviewed and up dated. We recommend that a group set up by the Paediatric Group of the British Dietetic Association reviews them by 2010.

2.0 Anthropometric measurements and growth indices

Most of the papers reviewed for this section came from the USA and were from two main research groups.

2.1 Weight Measurements

There is overall agreement that weight should be measured and that this should be taken on the most appropriate weighing equipment for the individual child or situation. Stevenson[2] best describes the various methods of weighing that are commonly used*; these include wheelchair scales, sitting scales, as well as the carer holding the child on either sitting or standing scales and their weight being subtracted. No studies compared the various weighing methods for accuracy.

Weight measurements should be plotted on appropriate centile charts (see below).

2.2 Height Measurements

Most papers agreed that accurate height measurements are difficult in this client group, however when it is possible for the child to be straight standing or lying down then a standing height or a supine length should be taken.

In circumstances where these measurements cannot accurately be taken then an alternative height measurement should be used.[2-6] There are three alternative height measurements that could possibly be used in this client group; these measurements are briefly described below.

Upper arm length is measured from the acromion to the head of the radius (see figure1), it should be taken on the right or the least affected side. Two measurements are taken and then averaged. It can only be taken accurately using an anthropometer.[6]

The lower leg length (also know as the tibial length) is measured from the tibia to the sphyrion, it requires the child to be sitting and is taken on the right side or the least affected side. This measurement can be taken accurately with an anthropometer (see figure 2) or with a steel measuring tape (see figure3). Two measurements are taken and averaged.[6]

Knee height is measured with the child sitting down and the knee and ankle bent to 90°. Using a sliding caliper the distance between the heel to the anterior surface of the thigh over the femoral condyle is measured (see figure 4), on the left side or least affected side. Two measurements are taken and averaged.[6]

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*Hoist scales are also used for this client group, but were not mentioned in any of the papers reviewed.

Various studies that have used these alternative height measurements have found good correlation with a standing height or supine length,[3,4,6] the correlation coefficients are knee height and stature $r^2 = .97$; tibial length and stature $r^2 = .94$ and upper arm length and stature $r^2 = .94$.[6] (in a perfect correlation r^2 is 1).

Inter- and intra- observer technical errors (TE) have also been reported and shown to compare well with those expected from standing heights or recumbent lengths taken in mainstream children.[3,6]

	Inter TE (cm)	Intra TE (cm)
Knee height[6]	0.34	0.16
Tibial length[3]	0.49	0.20
Upper arm length[3]	0.60	0.30
Standing height[3,6]	0.68	0.49
Recumbent length[3,6]	0.68	0.27

Stevenson 1995[6] concluded that the knee height measurement was the most reliable alternative, with lowest technical error and that it can be taken using the sliding caliper which has a relatively low cost of around £100. After this he believed the tibial length to be next as the use of the steel tape made it practical in most clinical areas. Least reliable and most difficult to take was the upper arm measurement which requires an anthropometer at a cost of around £1000.

The measurements can be compared directly to centiles produced for the alternative measurement.[2] The centiles as used by Spender and Stallings are based on work carried out by Snyder in the USA in the 70's;[7] these table are presently not widely available within the UK.

These alternative measurements can also be used to calculate an estimated height measurement (formulas are given below) that is then directly compared to standard height growth charts.

Segmental measurement	Estimate of stature (cm)	SE of estimate (cm)
Knee height (KH)	$S = (2.69xKH)+24.2$	±1.1
Tibial length (TL)	$S = (3.26xTL)+30.8$	±1.4
Upper arm length (UAL)	$S = (4.35xUAL)+21.8$	±1.7

Taken from Stevenson 1995[6]. Study on children with CP aged up to 12 years.

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[1] Harpenden anthropometer can be purchased from Holtain Ltd, Crosswell, Crymych, SA41 3UF. Tel 01239 891656. Fax 01239 891453. www.fullbore.co.uk/holtain/medical/welcome.html At time of going to print price is £822.00 excl VAT

Figure 1

Figure 2

Figure 3

Figure 4

From the evidence, it is not possible to indicate which alternative height measurement is the most appropriate and should be adopted. Each has its complexity dependent on the level of disabilities of the child and on the skills of the dietitian.*

We believe that it is important that weight and height measurements are taken in an appropriate manner as described in this section to ensure consistency and that serial measurements can be reliably compared. Clinical decisions are often taken on the basis of these measurements, such as the placement of a gastrostomy tube, change in type of feed or referral to Social Work. Therefore their accuracy is of immense importance

2.3 Body Mass Index

There was no evidence found supporting the use of BMI in this client group. The Samson-Fang 2000 paper found the BMI to be a poor indicator of low body fat in children with cerebral palsy.[9]

2.4 Anthropometric Arm Measurements

There is good evidence for the use of triceps skinfold thickness measurements and Stevenson recommends this for use with children with spina bifida and cerebral palsy.[2;4;9] The Samson-Fang 2000 paper showed that a tricep skinfold thickness measurement < 10th centile (compared to norms from Frisancho 1981[10]) was a good indicator of low body fat stores in children with cerebral palsy and that this cut off had both a high sensitivity and specificity.[9]

Stallings 1995[4] found that estimated fat free mass (FFM) and in turn fat mass (FM) calculated from using both the tricep and subscapular skinfold thickness measurements correlated best with FFM and FM derived from using total body water estimation. This conclusion was drawn from comparing the estimated values of 39 children without a disability and 28 children with quadriplegic cerebral palsy. This paper and Stallings 1993[5] recommend the use of mid arm circumference (MAC) with skinfold measurements to calculate mid arm muscle circumference (MAMC) then to estimate FM and FFM.

All papers compared the skinfold thickness measurements to the norm values from Frisancho.[10;11]

Note
In routine practice, it can be difficult to take accurate skinfold thickness measurements in some children with special needs. A subscapular skinfold thickness measurement may be impractical due to the need to remove clothing or spinal jackets.

2.5 Charts

There is support for the use of the Child Growth Foundation charts in main stream children.[12] There are some disease specific charts presently in use in the UK.

Krick et al carried out a study with the intention to produce growth charts for use with children with cerebral palsy.[13] However, these charts have not been reproduced for

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* A fourth possible alternative measure, the ulnar length, was reported in 2004[8]. Until further research has been carried out with this particular client group it's appropriate use is uncertain.

clinical use and caution should be taken for use of the charts in this paper due to the small study sample size and the method of data collection.

Reference charts can be purchased for anthropometric arm measurements from Castlemead Publications, Swains Mill, 4A Crane Mead, Ware, Herts, SG12 9PY

2.6 Frequency of measurements

Only Stallings et al made any recommendation for the frequency of measurements to be taken, they suggested that all measurements should be taken at 6 monthly intervals.[4] It should be noted that this statement was based on expert opinion. For children under 2 years of age see 2.8 recommendations.

2.7 Training

At peer review, a need for anthropometric training specifically on taking alternative height measurements and skinfold thickness measurements in children with special needs was identified.

2.8 Recommendations

- Those who have been identified, as 'at risk' of faltering growth should be weighed and the measurement plotted on growth charts. The frequency of measurements will be dependant on local practice and individual circumstances, however this should be a minimum of every 6 months.

  Group consensus opinion is that children under 2 years of age should probably be measured more frequently, by whom and how often will be determined by local circumstances.

- Those who have been identified as 'at risk' of faltering growth should have their standing height or supine length measured and plotted on growth charts a minimum of every 6 months. Where these measurements are not suggestive of true height, alternative segmental measurements such as upper arm length, tibial length, knee height may be taken. These measurements can be used to calculate an estimated height, which should then be plotted on standard UK growth charts or plotted on specific segmental growth charts (an appendix of the centile tables may be added at a later date). If an alternative length measurement is taken, note of which limb should be made and should be consistently used for each individual child.

- The UK Child Growth Foundation charts should be used for monitoring weight and height centiles; until well developed, disease specific charts are published.

- Those who have been identified as 'at risk' of faltering growth should have their tricep skinfold thickness and mid-arm circumference measurements taken as a minimum every 12 months. Where possible other anthropometric measurements such as subscapular skinfold thickness could be taken.

2.9 Good practice points

- ✓ Persons undertaking any anthropometric measurements should have appropriate training.
- ✓ Scales used for weighing should be calibrated and serviced annually.

2.10 Possible research

A UK multi-centre study collecting data on weight, height/length and anthropometric measurements of children with special needs. This would provide information on the appropriateness of using alternative segmental measurements in place of height measurements as well as data for the development of UK centile charts for children with special needs based on a large population sample.

A study comparing the accuracy between various common weighing methods e.g. carer holding the child compared with using wheel chair weighing scales.

3.0 Dietary Assessment

There is not good evidence for the various methods of assessing current and past food intake. The appraised papers highlighted the limitations of the dietary assessment methods used for current and previous food intake. There are three methods for assessing diet. These are food records, recall and food frequency questionnaires. Each paper emphasized that none of the methods give accurate information on food intake in this population group.[14-16]

Stallings et al (1996)[14] found that the reported energy intakes of 61 children with spastic quadriplegic cerebral palsy were greater by 44-54% than their actual energy intake. This was not the case for the control group of 37 mainstream school children. They concluded that dietary intake as measured by a weighed 3 day dietary record was markedly over reported in children with spastic quadriplegic cerebral palsy and that carefully collected energy intake data was so inaccurate as to be useless for clinical or research purposes.

Fung et al (2002)[16] carried out a multicentre cohort study to look at feeding dysfunction and its relation to food intake in 230 children (aged 2-18 years), with moderate to severe cerebral palsy. This suggested that dietary recall or prospective food records used to assess dietary intake are also inaccurate in this population. However, they did suggest that feeding dysfunction is the most relevant factor in limiting food intake in children with severe cerebral palsy which could form the basis of further assessment (see section 4).

Sullivan et al (2002)[17] concluded that 80 out of the 100 children with cerebral palsy consumed a diet that was lower in energy than that of non-disabled children. It also suggests that reference ranges for mainstream healthy children may be inappropriate for this client group. The following recommendations were made:

1. Children with neurological impairment would benefit from an individual nutritional assessment in which a dietitian should be actively involved.

2. Further research is required to determine appropriate energy requirements to maintain energy balance in this group of children.

Thomas and Akobeng (2000)[18] recommended that disabled children should have a detailed assessment of nutritional status but did not provide details of how this should be carried out. However, they did state that an experienced Paediatric Dietitian should be the person to assess nutritional intake. They also highlighted that even when energy intake is adequate, micronutrient intake may not be, resulting in multiple nutritional deficiencies. A multidisciplinary team is suggested as the best way to manage children with feeding difficulties.

3.1 Recommendations

- The 3 methods of dietary assessment; food records, recall and food frequency questionnaires do not reflect accurate food intakes in this population group.
- Calculating food intakes is usually inaccurate in this group and not routinely required.

3.2 Good Practice Points

- ✓ Food diaries / 24 hour recalls are useful for assessing meal patterns, types of food offered and eaten, in relation to the food groups.
- ✓ Observation of a child at a mealtime is useful when considering all factors that affect dietary intake (e.g. posture, environment etc.).

4.0 Feeding assessment

We had not originally considered feeding assessment as part of this systematic review as we considered it the remit of the Speech and Language Therapist (SALT) member of the multidisciplinary team. However so many of the papers highlighted the importance of a simple feeding assessment in recognizing children 'at risk' of under nutrition [15;16;19] that we felt it important to add it to this review. These studies indicate that an assessment of feeding competence provides vital information for identifying children at risk from poor nutritional status and suggest that a basic scoring system could be used. We propose that a SALT carries this out and that the results (e.g. a score) are incorporated into the dietetic assessment.

A simple 4 point feeding assessment tool was described by Reilly et al[15], who noted that feeding dysfunction correlated well with risk of poor nutritional status. Their simple feeding scale used in conjunction with a validated tool to assess the severity of motor impairment was useful in identifying greatest nutritional and health risk.

Fung 2002[16] used a basic tool to score feeding competence, based on Reilly et al.[15] This score correlated with growth, the need for tube feeding and number of days children had intercurrent infection requiring time in bed.

A Multidisciplinary Feeding Profile was used to score feeding competence in 90 children studied by Troughton.[19] This tool evaluated oro-motor skills during specific feeding tasks. Each behaviour was given a numeric value ranging from 1 to 5 where 5 indicated normal function and 1 indicated poor function. Children categorized as undernourished had a lower feeding competence compared to their adequately nourished peers.

4.1 Recommendations

- A SALT feeding assessment is part of all dietetic assessments of children with special needs referred as 'at risk' of faltering growth.
- Feeding assessment of children with special needs should be multidisciplinary.
- That the BDA should liaise with the Royal College of Speech and Language Therapists to develop a national simple feeding assessment score for children with special needs which can be used as part of a dietetic/nutritional assessment process.

4.2 Good Practice Points

✓ Be aware of the recommended consistency of the child's diet. An inability to manage textures may indicate poor feeding competence and therefore risk of nutritional inadequacy.

5.0 Biochemical and haematological indices

Only two papers were found and both of these were concerned with calcium, vitamin D and risk of fractures.[20],[21]

We acknowledge that the monitoring of biochemical and hematological indices in this group is an important area but due to lack of evidence feel unable to make any comment.

5.1 Possible research

To investigate the most appropriate indices to be monitored at initial assessment and follow up including minimum frequency of monitoring.

6.0 Summary of recommendations

- Those who have been identified, as 'at risk' of faltering growth should be weighed and the measurement plotted on growth charts. The frequency of measurements will be dependant on local practice and individual circumstances, however this should be a minimum of every 6 months.

  Group consensus opinion is that children under 2 years of age should probably be measured more frequently, by whom and how often will be determined by local circumstances.

- Those who have been identified as 'at risk' of faltering growth should have their standing height or supine length measured and plotted on growth charts a minimum of every 6 months. Where these measurements are not suggestive of alternative segmental measurements such as upper arm length, tibial length, knee height may be taken. These measurements can be used to calculate an estimated height, which should then be plotted on standard UK growth charts or plotted on specific segmental growth charts (an appendix of the centile tables may be added at a later date). If an alternative length measurement is taken, note of which limb should be made and should be consistently used for each individual child.

- The UK Child Growth Foundation charts should be used for monitoring weight and height centiles; until well developed, disease specific charts are published.
- Those who have been identified as 'at risk' of faltering growth should have their tricep skinfold thickness and mid-arm circumference measurements taken as a minimum every 12 months. Where possible other anthropometric measurements such as subscapular skinfold thickness could be taken.
- The 3 methods of dietary assessment; food records, recall and food frequency questionnaires do not reflect accurate food intakes in this population group.
- Calculating food intakes is usually inaccurate in this group and not routinely required.
- A SALT feeding assessment is part of all dietetic assessments of children with special needs referred as 'at risk' of faltering growth.
- Feeding assessment of children with special needs should be multidisciplinary.
- That the BDA should liaise with the Royal College of Speech and Language Therapists to develop a national simple feeding assessment score for children with special needs which can be used as part of a dietetic/nutritional assessment process.

7.0 Summary of good practice points

- ✓ Persons undertaking any anthropometric measurements should have appropriate training.
- ✓ Scales used for weighing should be calibrated and serviced annually.
- ✓ Food diaries / 24 hour recalls are useful for assessing meal patterns, types of food offered and eaten, in relation to the food groups.
- ✓ Observation of a child at a mealtime is useful when considering all factors that affect dietary intake (e.g. posture, environment etc.).
- ✓ Be aware of the recommended consistency of the child's diet. An inability to manage textures may indicate poor feeding competence and therefore risk of nutritional inadequacy.

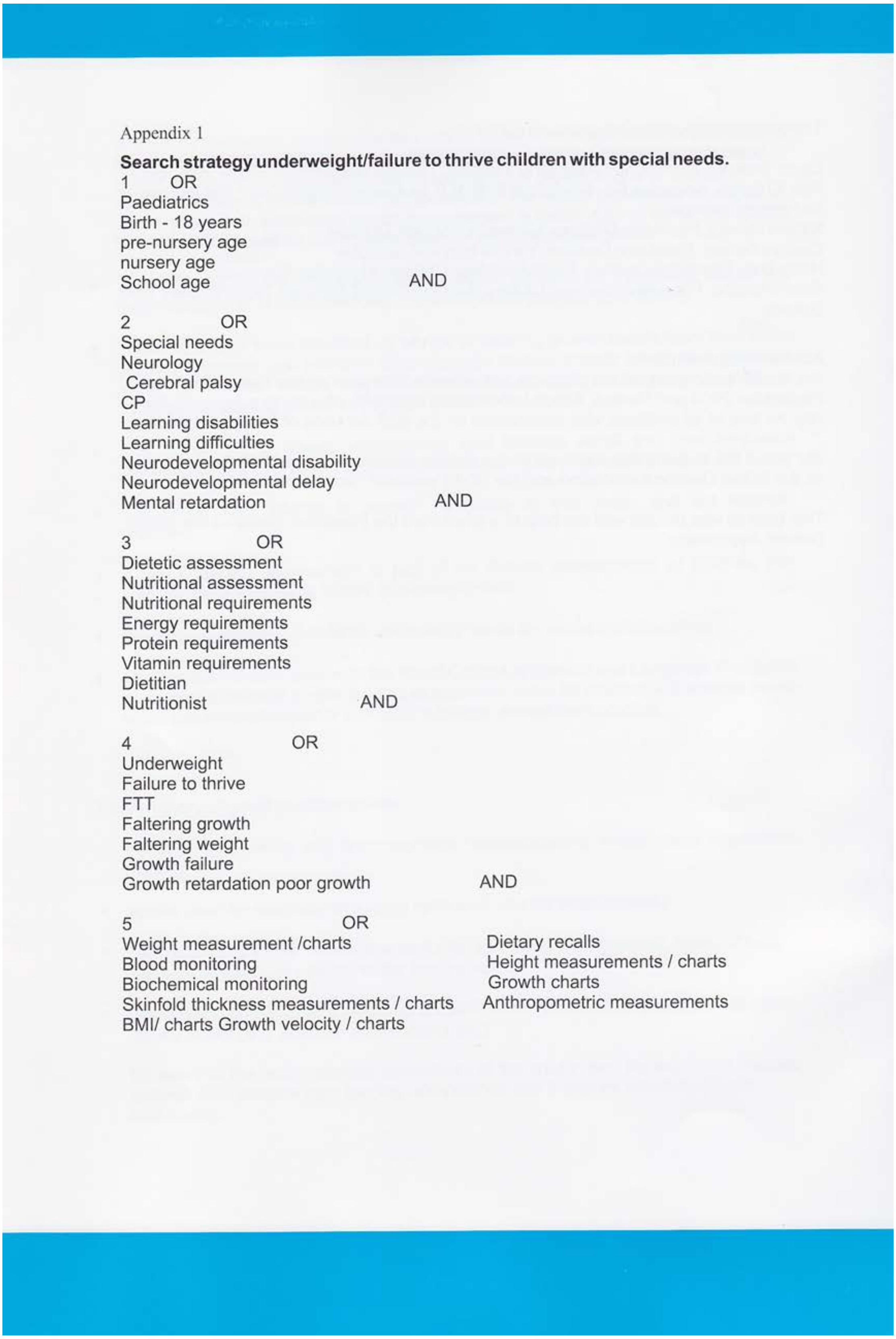
The guidelines development group consisted of -

Laura Stewart, Community Paediatric Dietitian, Dietetic Department, Royal Hospital for Sick Children, Sciennes Rd, Edinburgh EH9 1LF. laura.stewart@luht.scot.nhs.uk (author for correspondence)
Natalie Mckaig, Paediatric Dietitian, Ninewells Hospital, Dundee
Carolyn Dunlop, Paediatric Dietitian, Yorkhill Hospital, Glasgow
Hilary Daly, Paediatric Dietitian, Royal Aberdeen Children's Hospital, Aberdeen
Sarah Almond, Paediatric Dietitian, Chailey Heritage Clinical Services, North Chailey, East Sussex

Acknowledgements
We would like to thank all the dietitians who attended the peer review day in Edinburgh, September 2004 and Nutrica, Abbott Laboratories and SHS who kindly sponsored this day. As well as all dietitians who commented on the draft versions of these guidelines.

We would like to thank the members of our dietetic departments and NHS Trusts as well as the British Dietetic Association and the BDA Paediatric Group for their support.

This booklet was printed with the help of a grant from the Paediatric Group of the British Dietetic Association.



Appendix 1

Search strategy underweight/failure to thrive children with special needs.

1 OR
Paediatrics
Birth - 18 years
pre-nursery age
nursery age
School age AND

2 OR
Special needs
Neurology
Cerebral palsy
CP
Learning disabilities
Learning difficulties
Neurodevelopmental disability
Neurodevelopmental delay
Mental retardation AND

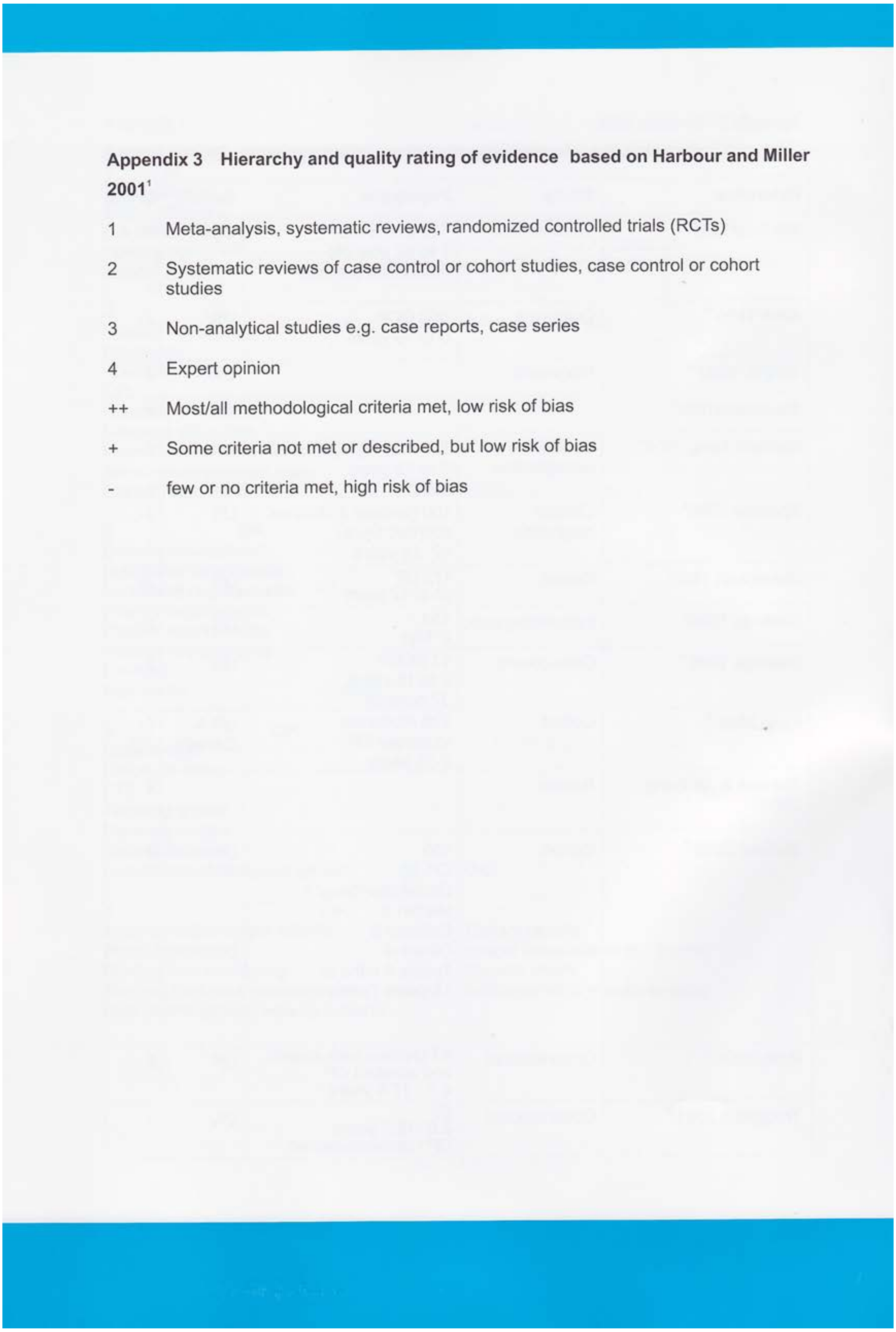
3 OR
Dietetic assessment
Nutritional assessment
Nutritional requirements
Energy requirements
Protein requirements
Vitamin requirements
Dietitian
Nutritionist AND

4 OR
Underweight
Failure to thrive
FTT
Faltering growth
Faltering weight
Growth failure
Growth retardation poor growth AND

5 OR
Weight measurement /charts
Blood monitoring
Biochemical monitoring
Skinfold thickness measurements / charts
BMI/ charts Growth velocity / charts
Dietary recalls
Height measurements / charts
Growth charts
Anthropometric measurements

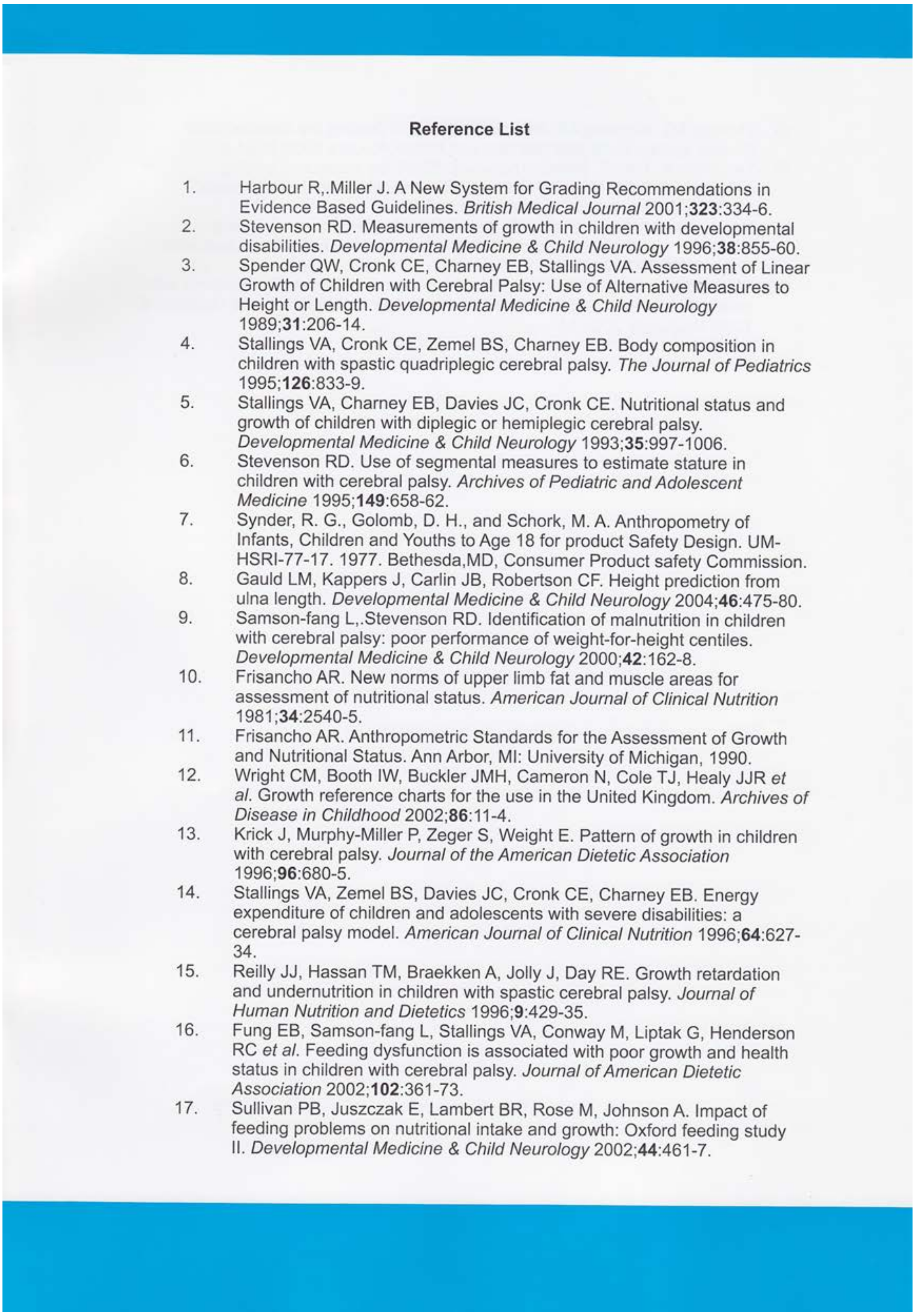
Appendix 2 Evidence table

Reference	**Study**	**Population**	**Setting**	**Grade**
Stallings1995[4]	Case control	136 with SQCP 2 to 12 year old 39 healthy controls	US	2-
Krick 1996[13]	Diagnosis	360 QCP 0 to 10 years	US	2-
Wright 2002[12]	Diagnostic		UK	4
Stevenson1996[2]			US	4
Samson Fang 2000[9]	Cohort/ retrospective	276 varying levels of CP 3 to 12 years	US	2+
Spender 1989[3]	Cohort/ diagnostic	100 (unclear if children counted twice) <2 18 years	US	2-
Stevenson 1995[6]	Cohort	172 CP up to 12 years	US	2+
Stallings 1993[5]	Cohort/diagnostic	154 2-18yr	US	2+
Stallings 1996[14]	Case control	61 SQCP 2 to 18 years 37 controls	US	2-
Fung 2002[16]	Cohort	230 moderate to severe CP 2-18 years	US & Canada	2+
Thomas & Akobeng 2000[18]	Review			4
Sullivan 2002[17]	Cohort	100 CP 90 Global dev delay 3 Marfan 1 Epilepsy 2 Others 4 4years 6 mths to 13 years 7 mths	UK	2+
Reilly 1996[15]	Observational	43 children with spastic and athetoid CP 4.3 - 17.9 years	UK	3
Troughton 2001[19]	Observational	90 2.6 -18.7 years CP / undernourished	UK	3



Appendix 3 Hierarchy and quality rating of evidence based on Harbour and Miller 2001[1]

1	Meta-analysis, systematic reviews, randomized controlled trials (RCTs)
2	Systematic reviews of case control or cohort studies, case control or cohort studies
3	Non-analytical studies e.g. case reports, case series
4	Expert opinion
++	Most/all methodological criteria met, low risk of bias
+	Some criteria not met or described, but low risk of bias
-	few or no criteria met, high risk of bias



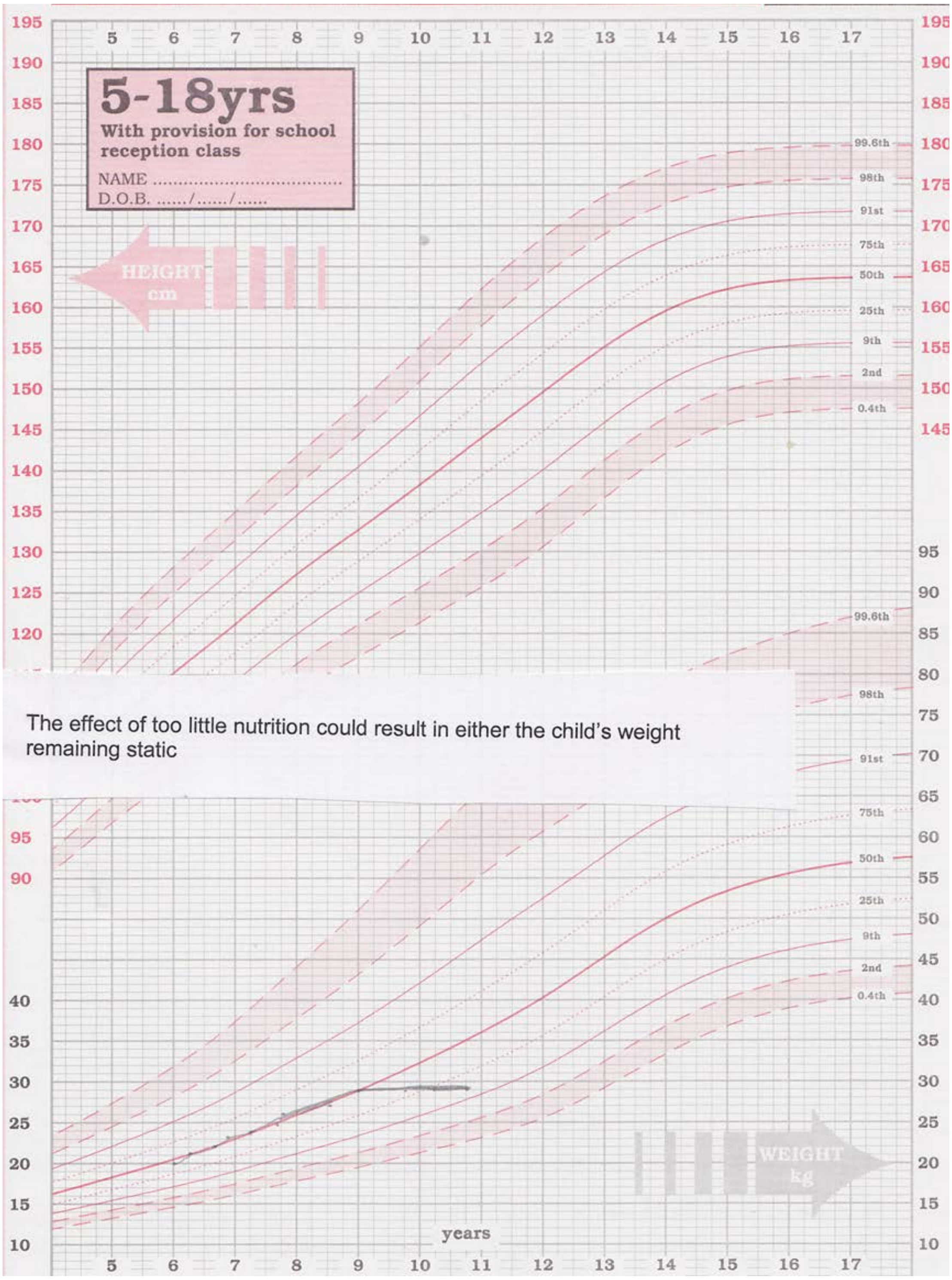
Reference List

1. Harbour R,.Miller J. A New System for Grading Recommendations in Evidence Based Guidelines. *British Medical Journal* 2001;**323**:334-6.
2. Stevenson RD. Measurements of growth in children with developmental disabilities. *Developmental Medicine & Child Neurology* 1996;**38**:855-60.
3. Spender QW, Cronk CE, Charney EB, Stallings VA. Assessment of Linear Growth of Children with Cerebral Palsy: Use of Alternative Measures to Height or Length. *Developmental Medicine & Child Neurology* 1989;**31**:206-14.
4. Stallings VA, Cronk CE, Zemel BS, Charney EB. Body composition in children with spastic quadriplegic cerebral palsy. *The Journal of Pediatrics* 1995;**126**:833-9.
5. Stallings VA, Charney EB, Davies JC, Cronk CE. Nutritional status and growth of children with diplegic or hemiplegic cerebral palsy. *Developmental Medicine & Child Neurology* 1993;**35**:997-1006.
6. Stevenson RD. Use of segmental measures to estimate stature in children with cerebral palsy. *Archives of Pediatric and Adolescent Medicine* 1995;**149**:658-62.
7. Synder, R. G., Golomb, D. H., and Schork, M. A. Anthropometry of Infants, Children and Youths to Age 18 for product Safety Design. UM-HSRI-77-17. 1977. Bethesda,MD, Consumer Product safety Commission.
8. Gauld LM, Kappers J, Carlin JB, Robertson CF. Height prediction from ulna length. *Developmental Medicine & Child Neurology* 2004;**46**:475-80.
9. Samson-fang L,.Stevenson RD. Identification of malnutrition in children with cerebral palsy: poor performance of weight-for-height centiles. *Developmental Medicine & Child Neurology* 2000;**42**:162-8.
10. Frisancho AR. New norms of upper limb fat and muscle areas for assessment of nutritional status. *American Journal of Clinical Nutrition* 1981;**34**:2540-5.
11. Frisancho AR. Anthropometric Standards for the Assessment of Growth and Nutritional Status. Ann Arbor, MI: University of Michigan, 1990.
12. Wright CM, Booth IW, Buckler JMH, Cameron N, Cole TJ, Healy JJR *et al.* Growth reference charts for the use in the United Kingdom. *Archives of Disease in Childhood* 2002;**86**:11-4.
13. Krick J, Murphy-Miller P, Zeger S, Weight E. Pattern of growth in children with cerebral palsy. *Journal of the American Dietetic Association* 1996;**96**:680-5.
14. Stallings VA, Zemel BS, Davies JC, Cronk CE, Charney EB. Energy expenditure of children and adolescents with severe disabilities: a cerebral palsy model. *American Journal of Clinical Nutrition* 1996;**64**:627-34.
15. Reilly JJ, Hassan TM, Braekken A, Jolly J, Day RE. Growth retardation and undernutrition in children with spastic cerebral palsy. *Journal of Human Nutrition and Dietetics* 1996;**9**:429-35.
16. Fung EB, Samson-fang L, Stallings VA, Conway M, Liptak G, Henderson RC *et al.* Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of American Dietetic Association* 2002;**102**:361-73.
17. Sullivan PB, Juszczak E, Lambert BR, Rose M, Johnson A. Impact of feeding problems on nutritional intake and growth: Oxford feeding study II. *Developmental Medicine & Child Neurology* 2002;**44**:461-7.

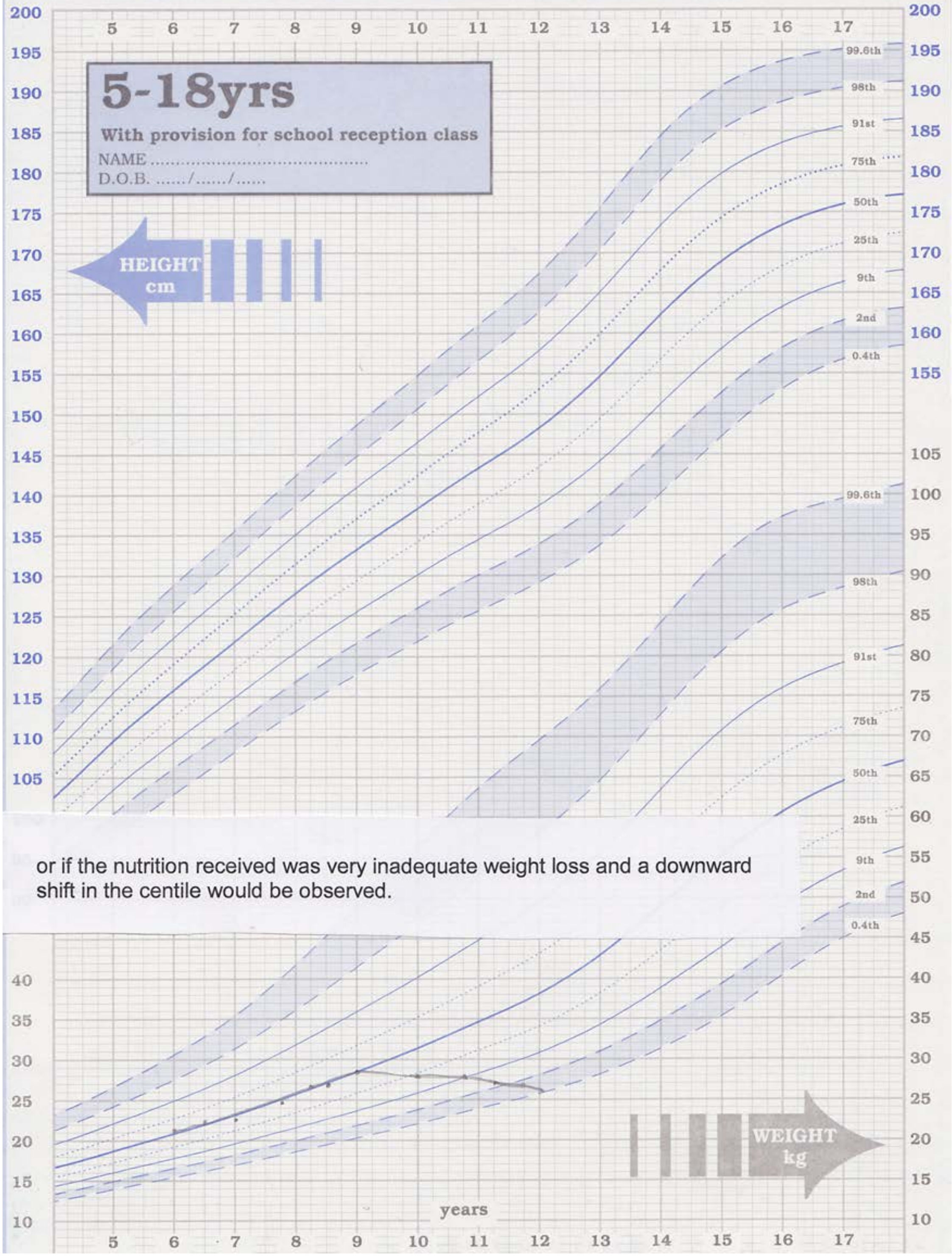
18. Thomas AG,.Akobeng AK. Technical aspects of feeding the disabled child. *Current opinion in Clinical Nutrition and Metabolic Care* 2000;**3**:221-5.
19. Troughton K,.Hill AE. Relation between objectively measured feeding competence and nutrition in children with cerebral palsy. *Developmental Medicine & Child Neurology* 20001;**43**:187-90.
20. Henderson RC, Lin P, Greene B. Bone-mineral density in children and adolescents who have spastic cerebral palsy. *The Journal of Bone and Joint Surgery* 1995;**77-A**:1671-81.
21. Bischol F, Basu D, Pettifor JM. Pathology long-bone fractures in residents with cerebral palsy in a long-term facility in South Africa. *Developmental Medicine & Child Neurology* 2002;**44**.

Appendix 6

Growth charts to show the effect of too little nutrition.



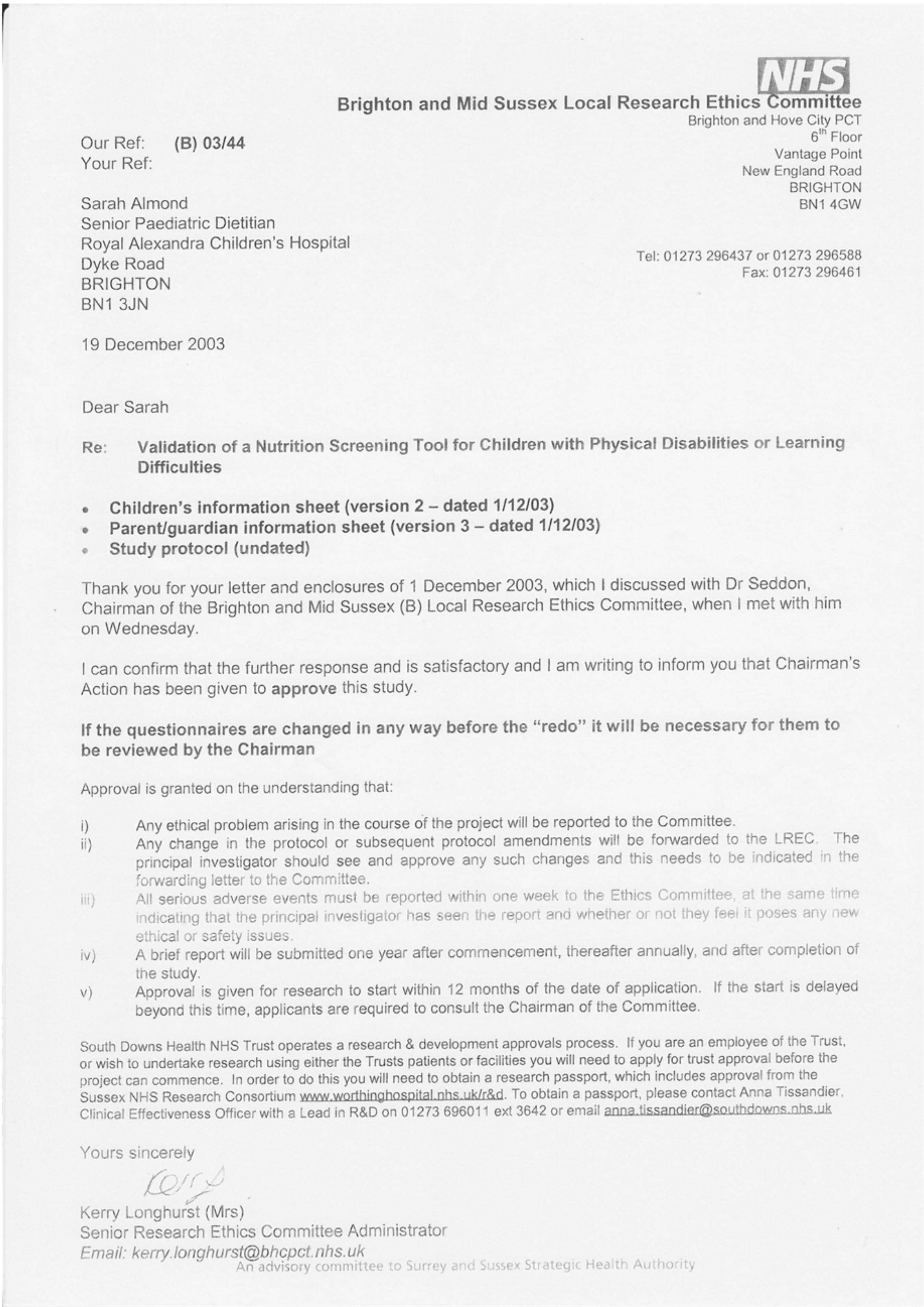
The effect of too little nutrition could result in either the child's weight remaining static



or if the nutrition received was very inadequate weight loss and a downward shift in the centile would be observed.

Appendix 7

Ethical approval letter, consent letter, consent form, parents information sheet and children's information sheet.



NHS
Brighton and Mid Sussex Local Research Ethics Committee
Brighton and Hove City PCT
6th Floor
Vantage Point
New England Road
BRIGHTON
BN1 4GW

Tel: 01273 296437 or 01273 296588
Fax: 01273 296461

Our Ref: **(B) 03/44**
Your Ref:

Sarah Almond
Senior Paediatric Dietitian
Royal Alexandra Children's Hospital
Dyke Road
BRIGHTON
BN1 3JN

19 December 2003

Dear Sarah

Re: **Validation of a Nutrition Screening Tool for Children with Physical Disabilities or Learning Difficulties**

- **Children's information sheet (version 2 – dated 1/12/03)**
- **Parent/guardian information sheet (version 3 – dated 1/12/03)**
- **Study protocol (undated)**

Thank you for your letter and enclosures of 1 December 2003, which I discussed with Dr Seddon, Chairman of the Brighton and Mid Sussex (B) Local Research Ethics Committee, when I met with him on Wednesday.

I can confirm that the further response and is satisfactory and I am writing to inform you that Chairman's Action has been given to **approve** this study.

If the questionnaires are changed in any way before the "redo" it will be necessary for them to be reviewed by the Chairman

Approval is granted on the understanding that:

i) Any ethical problem arising in the course of the project will be reported to the Committee.
ii) Any change in the protocol or subsequent protocol amendments will be forwarded to the LREC. The principal investigator should see and approve any such changes and this needs to be indicated in the forwarding letter to the Committee.
iii) All serious adverse events must be reported within one week to the Ethics Committee, at the same time indicating that the principal investigator has seen the report and whether or not they feel it poses any new ethical or safety issues.
iv) A brief report will be submitted one year after commencement, thereafter annually, and after completion of the study.
v) Approval is given for research to start within 12 months of the date of application. If the start is delayed beyond this time, applicants are required to consult the Chairman of the Committee.

South Downs Health NHS Trust operates a research & development approvals process. If you are an employee of the Trust, or wish to undertake research using either the Trusts patients or facilities you will need to apply for trust approval before the project can commence. In order to do this you will need to obtain a research passport, which includes approval from the Sussex NHS Research Consortium www.worthinghospital.nhs.uk/r&d. To obtain a passport, please contact Anna Tissandier, Clinical Effectiveness Officer with a Lead in R&D on 01273 696011 ext 3642 or email anna.tissandier@southdowns.nhs.uk

Yours sincerely

Kerry

Kerry Longhurst (Mrs)
Senior Research Ethics Committee Administrator
Email: kerry.longhurst@bhcpct.nhs.uk

31st October 2005

Dear Parent / Guardian

My name is Sarah Almond; I am your Childs dietitian at Chailey Heritage. Alongside my job I am designing a questionnaire which will enable school nurses to identify when your child would benefit best from seeing a dietitian. Currently I see your child as required which is roughly once a year at school.

I am writing to ask whether you will allow the information I collect about your child to be used as part of my study. Please read through the attached information sheet which will explain in more detail what my study is about and how I am hoping to achieve it. I have also enclosed a children's information sheet which explains my study in more simplistic terms that can be read to your child for their understanding. Incidentally I may not need to meet with you to collect information as the Nursing Team at Chailey already have most of the information I require.

If you agree for your child to take part I would be grateful if you would sign the 3 copies of the attached consent form and return two copies to me in the prepaid envelope.

If you have any questions about my study please do not hesitate to contact me on the above telephone number on Mondays, Tuesdays or Thursdays.

Yours sincerely

Sarah Almond
Senior Paediatric Dietitian

Consent Form

Title of Project: Validation of a nutrition screening tool for children with physical disabilities or learning difficulties

Name of Researcher: Sarah Almond, Senior Paediatric Dietitian
Royal Alexandra Children's Hospital

Please initial box

1. I confirm that I have read and understand the information sheet dated 1st December 2003 (version 3) for the above study and I have had the opportunity to ask questions. ☐
2. I understand that my child's participation is voluntary and that he/she is free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected. ☐
3. I understand that sections of any medical notes may be looked at by the dietitian or school nurse where it is relevant to the study. I give permission for these individuals to have access to my child's records. ☐
4. I agree to my child taking part in the above study. ☐

Name of child ______________ Date of Birth ______________

Name of parent / guardian ______________ Date ______________ Signature ______________

Researcher ______________ Date ______________ Signature ______________

1 copy for parent, 1 copy for researcher, 1 copy for medical notes

Children's Information Sheet

A project to make a questionnaire to help school nurses know when you need to see the dietitian

Introduction

You have been invited to take part in a project to help make a questionnaire. The information on this sheet will help your mum and dad decide whether or not they would like you to take part. Your mum and dad will be able to ask me any questions or for more information and can take their time to decide whether or not they want you to take part.

Thank you for listening to what my project is about.

Why does the project need to be done?

Dietitians from all over the country are worried that when they see children they already have nutritional problems such as being too big or small, fat or thin. My questionnaire will make sure that children are seen by their dietitian at the right time.
It will take me about 2 years to collect all the information I need to make sure the questionnaire works, however the time I need with you is only about half an hour.

Why have I been chosen?

All children who attend certain schools in Sussex have been asked to take part. In total I need to see 200 children.

Do I have to take part?

The decision is between you, your mum and dad to decide whether you take part. If they say yes you will be given this information sheet to keep and your mum and dad will be asked to sign a form to say its ok. If they change their mind they are able to say no at any time and don't need to say why. A decision to say no or change their minds at any time will not affect your usual appointments with the dietitian.

What will happen if I do take part?

This is what will happen:

- Your school nurse will fill in a questionnaire with your mum and dad at your school medical.
- Within one month of the medical I will meet with your mum and dad to talk about food and nutrition.

What will I have to do?

You would go to your school medical as usual but you don't need to be there for when I meet with your mum and dad, unless you want to of course, then it's quite alright! In the future you may be asked to do this again, but you don't have to of course.

What does the questionnaire ask?

It asks your nurse to tick boxes about your food intake, your shape, eating and drinking, how active you are and your poos! It also asks the nurse to decide whether he or she feels you need to see the dietitian.

If I don't take part what happens?

You will still be seen by your dietitian in the ordinary way which is usually when the school nurse feels you need to. If you already see the dietitian then your appointments will continue as normal.

What are the bad things about taking part?

Your school medical may take a bit longer than usual for the nurse to do the questionnaire, but this shouldn't be more than a couple of minutes.

What are the good things about taking part?

The information that I get from this project will make sure that children get the right advice about food and nutrition at the right time.

What happens when the project finishes?

At the end of the project the questionnaire will be launched to all schools like yours, throughout the country. The questionnaire will then be used by school nurses as part of everyone's annual medical.

Will anyone else know information about me?

All information which I collect about you will be kept in a locked cupboard which only I have a key for, so nobody else will be able to see the information. I will tell your doctor that you are part of my project.

If I want to know more who shall I ask?

You can ask me. My address and telephone number is:

Sarah Almond
Senior Paediatric Dietitian
Royal Alexandra Children's Hospital
Dyke Road
Brighton
BN1 3JN
01273 328145 x 2109
07901 854017

Parent / Guardian Information Sheet

A study to design a questionnaire to help school nurses identify when your child needs to see the dietitian

Introduction

Your child has been invited to take part in a study to help create a questionnaire. The information provided here will help you decide whether or not you would like your child to take part in this. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask me if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish your child to take part.

Thank you for reading this.

What is the purpose of the study?

Dietitians from all over the UK have expressed concern that when children are referred to them they already have nutritional problems such as being overweight, underweight or deficient in certain nutrients. The questionnaire will be a means of making sure that children are referred to the dietitian at the right time before nutritional problems become severe.
It will take about 2 years to collect information from enough children to make sure the questionnaire works, however the time taken with each child is only half an hour.

Why has my child been chosen?

All children with disabilities and / or learning difficulties in East Sussex have been asked to take part. In total 200 children are needed.

Does my child have to take part?

It is up to you to decide whether your child takes part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still able to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care your child will receive.

What will happen if I decide my child will take part?

If you give permission for your child to take part in the study this is what will happen:

- The school nurse will complete a questionnaire with you at your child's annual school medical.
- Within one month of the medical the dietitian will then complete her usual nutritional assessment, you will need to be present at this.

The dietitian will either will either come to your home to your child's school to do the assessment, which ever is the most convenient for you to attend. The assessment is no different to what she usually does and simply involves obtaining information. The dietitian will not have seen the nurses questionnaire until after her nutritional assessment.

You may be asked at a later stage go through this process again.

What will your child have to do?

Your child will need to be present for the school medical which they would usually attend anyway. They do not need to be present for the dietitians assessment as its merely the information about them that we need which we can collect from you. Therefore taking part in the study should not affect your child's usual routine or lifestyle.

What does the questionnaire ask?

The questionnaire has been designed by dietitians who are experts in the nutritional needs of children with special needs.
It asks the nurse to tick boxes about your child's food intake, appearance, activity level, bowel habits and swallowing ability. It also asks the nurse to decide whether he/she feel the child needs to see the dietitian.
After the nurse completes this the dietitian needs to do her assessment too to see if the questionnaire works.

What is the alternative?

Your child can still be referred to the dietitian in the usual way which at present is when the school nurse feels it is appropriate. If your child already sees the dietitian their usual monitoring will continue.

What are the disadvantages about taking part?

The school medical may take a little longer than usual as the nurse completes the questionnaire, but this shouldn't be more than a couple of minutes.

What are the possible benefits of taking part?

The information that we get from this study will ensure future children receive the correct nutritional treatment at the correct time.

What happens when the study finishes?

At the end of the study the final questionnaire will be launched to all schools caring for children with special needs nationwide. The questionnaire will then be used by school nurses each time as part of every child's annual medical.

What if I want to make a complaint?

If you feel your child has been harmed by taking part in this study, you wish to complain or have any concerns about any aspect of the way your child has been approached or treated, the normal National Health Service complaints mechanisms will be available to you.

Will my child's records remain confidential?

All information which is collected about your child during the course of the study will be kept strictly confidential. Any information about your child which leaves the dietitians office will have your child's name removed so that they can not be recognised from it.
Your child's paediatrician will also be informed that the study is taking place.

Who is organising and funding the research?

The study is being organised by Sarah Almond, Senior Paediatric Dietitian at Brighton and Sussex University Hospitals NHS Trust. It is being funded jointly by Brighton and Sussex University Hospitals NHS Trust and Brighton and Sussex Medical School.

Who has reviewed the study?

The following committees have reviewed the study:

- Brighton Local Research Ethics Committee

Who shall I contact for further information?

If you have any questions now or in the future please contact:

Sarah Almond
Senior Paediatric Dietitian
Royal Alexandra Childrens Hospital
Dyke Road
Brighton
BN1 3JN
01273 328145 x 2109
07901 854017

Thank you for considering to allow your child to participate in this study.

Appendix 8

Instruction sheet to support Nutrition Screening Tool

Guidance for completing the Nutrition Screening Tool

Measurements required:

Height : Standing height measure would be ideal however it is anticipated that this may not be possible on many of these children therefore lengths can be measured lying down using a Rollameter. If it is impossible to measure height you may estimate this but please indicate if it is an estimate on the form.

Weight: standing, sitting or wheelchair scales are all fine to use. Please measure their weight without splints, body braces or prosthetic limbs.

Centiles: Please ensure that you are using up to date centile charts. These are the Child Growth Foundation charts which are printed on white card with blue ink for boys and pink ink for girls.

Process:

I will inform you of who has signed a consent form to take part in the study.
All questions on the nutrition screening tool should be completed with the help of the child's parent or carer.
After you have answered questions A to K please answer L which is your own personal judgment of whether you feel the child should be referred to a dietitian.
Please return the completed screening tool in one of the envelopes provided. Only one tool per envelope please. This can be sent in the internal post.
Within one month of the date on the screening tool I will carry out a dietetic assessment. For this the parent or carer and child must be present. I can either do this at school if there is space, or at their home if it is easier.
I will contact them directly to confirm this arrangement.

Guidance notes

Question	Topic	Who assesses	Guidance	How to answer
A	Childs shape	Nurse	Your opinion	Tick one box only
B	Weight centile	Nurse	From growth chart	Tick one box only
C	Height centile	Nurse	From growth chart	Tick one box only
D	Weight for height	Nurse	Your opinion	Tick one box only
E	Bowels	Nurse & parent	Medical fact	Tick one box only
F	Activity	Nurse	Your opinion	Tick one box only
G	Eating & drinking	Nurse & parent	Medical fact	Tick one box only
H	Food intake	Nurse &parent	Your opinion	Tick one box only
I	Fluid intake	Nurse &parent	Your opinion	Tick one box only
J	Swallowing	Nurse & parent	Medical fact	Tick all appropriate boxes
K	Other medical problems	Nurse & parent	Medical fact	Tick all appropriate boxes
L	Your opinion	Nurse	/	Tick one box only

Thank you for agreeing to take part in this study

Appendix 9

3 day food diary

Issued by:

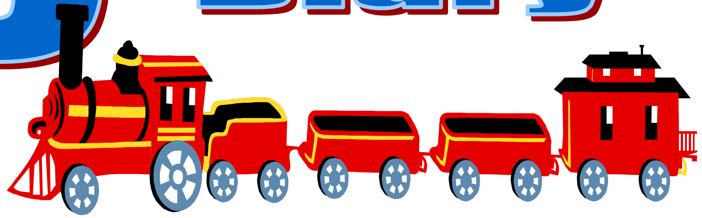
Sarah Almond
Senior Paediatric Dietitian
Chailey Heritage Clinical Services
Beggars Wood Road
North Chailey
Near Lewes
East Sussex
BN8 4JN

Tel 01825 722112 x 7756
Tuesdays & Thursdays only

For dietitians use only

Code _ _ / _ _ _ _

3 Day Food Diary



For nutrition screening tool project

Name ……………………………………………………………………

Date of Birth …………………………………………………

INSTRUCTIONS

1. Please keep this food diary for **3** consecutive days and, where possible, include one day at the weekend.
2. Please only record food and drink **actually** eaten or drunk.
3. Please include **all** snacks, including sweets, crisps and biscuits, as well as **all** drinks.
4. There is no need to weigh your child's food, please write the quantity in most convenient form, for example:

   1 Weetabix
   1 tablespoon mashed potato
   ½ mug of apple juice

5. Please note method of cooking as this can alter the nutritional value of the food, for example:

   boiled
   grilled
   fried

6. Please keep after completion and I will collect it at our appointment.

Thank you for assisting me in this study.

Sarah

Please make any comments below which you feel may have affected your Child's usual eating pattern, for example:

- Went to friend's house for tea
- Was unwell on day 2 and ate very little

DAY ________________________ DATE ________

Time	Quantity	Food & Drink	Comments

EXAMPLE MENU DATE: Tuesday 6th May 2004

Time	Quantity	Food & Drink	Comments
8.00am	3 tablespoons	cornflakes	
	1 teaspoon	sugar	
	½ mug	milk	Aprox 150ml
	1 slice	toast with margarine	Medium sliced loaf with no crusts
	1 teaspoon	marmalade	
	1 cup	tea with milk	
	1 teaspoon	sugar	
10.30am	1 packet (25g)	Wotsits	
12.30pm	1	bread roll with margarine	Thickly spread
	1 dessertspoon	grated cheddar	
	½	tomato	
	1	Kit Kat	2 finger bar
	1 carton	Ribena	
3.30pm	1	apple	
	1 packet	choc buttons	
5.30pm	2 slices	roast chicken	
	2 medium	roast potatoes	
	1 tablespoon	boiled carrots	
	2 tablespoons	gravy	Thinly made

GENERAL QUESTIONS -**please tick (✓)**

1. **Which type of milk is used?**
   - a) Whole (full cream) milk
   - b) Semi-skimmed
   - c) Skimmed
   - d) Other – please specify

2. **Which type of margarine/butter is used?**

   - a) Butter
   - b) Butter spread eg Clover, Utterly Butterly
   - c) Margarine eg Flora, Vitalite
   - d) Low fat spread eg Flora light, Gold
   - e) Other – please specify

3. **How do you spread margarine/butter?**

   - a) Thickly
   - b) Medium
   - c) Thinly

4. ***Do you add any of the following to mashed potato?***

   - a) Milk / cream
   - b) Margarine / butter
   - c) Cheese

5. **Which type of bread do you normally use?**

   - a) Wholemeal
   - b) White
   - c) White & wholemeal mix eg Best of Both
   - d) Other – please specify

DAY ____________________ **DATE** _________

Time	**Quantity**	**Food & Drink**	**Comments**

DAY ______________________ **DATE** _________

Time	**Quantity**	**Food & Drink**	**Comments**

GENERAL QUESTIONS -**please tick (✓)**

6\.

Which types of cold drinks are most commonly used?

- a) Baby squash ☐
- b) Squash ☐
- c) Low Calorie squash ☐
- d) Fizzy drinks ☐
- e) Low Calorie fizzy drink ☐
- f) Pure fruit juice ☐
- g) Fruit drink eg Five Alive ☐
- h) Fruit smoothie ☐
- i) Milk / milkshakes ☐
- j) Other – please specify ______________________

7\. **Is a vitamin or mineral supplement taken?**

If yes, which one ______________________

Daily dose

8\.

Are any protein or calorie supplements taken?

If yes, which one ______________________

How much

9\. **Are any probiotic supplements taken? Eg Yakult, Actimel, Proviva**

If yes, which one ______________________

How much

Appendix 10

Dietetic Assessment proforma

ID Number………………………… **Date - - / - - / - - - -**
Nurse Codes - - - / - - - / - - -
DOB - - / - - / - - -
Decimal Age - - . -

Dietetic involvement:
Sees dietitian regularly ☐
Seen in last 12 months ☐
12 months – 5 years ago ☐
Never seen dietitian ☐

Ethnicity…………………..

Paediatrician: ……………………………………………..
Name of School …………………………………………

Relevant Social Information

Time:
Medial notes………..mins
Food diary…………..mins
Consultation…………mins
Meal obs……………..mins
Total…………mins

Relevant Medical History (K):

Relevant Diagnosis (K):

Clinical signs of malnutrition:

Oedema	☐	Wiry hair	☐
Hepatomegaly	☐	Loss of skin pigment	☐
Dermatitis	☐	Moon face	☐

▸ Regular Medications

Name	Dose	Nutritional Side Effects
…………………………	……….	……………………………….
…………………………	……….	……………………………….
…………………………	……….	……………………………….
…………………………	……….	……………………………….

▸ Relevant Blood Test Results

Date	Result	Indication
………….	………	……………………………….
………….	………	……………………………….
………….	………	……………………………….
………….	………	……………………………….

▸ Anthropometry (A,B,C,D)

Height / Length: ……………cm Centile……………. % for age……..

If estimated – please describe: Ht age………….

Mid Parental Height………………..cm Range ………….cm - ……………..cm

Scoliosis / kyphosis: Yes ☐ No ☐

Weight: …………………Kg Centile………….. % for Ht……….

If estimated – please describe: % for age……..

Weight History: BMI ……….kg/m^2 Percentile ……………….

Lower leg Length: ………………mm

Knee Height: ………………mm

Upper arm length ……………..mm

MAC ……….mm Centile

TST ………..mm Centile

MAMC ………cm Centile

▸ Oral motor skills (J)

Sensory impairment	A	☐	Food escaping through nose	O	☐	Difficult to open/close mouth	A OP	☐	Needs familiar carer	A	☐
Food loss	OP	☐	Difficult to bite / chew	OP	☐	Bite reflex	OP	☐	Tongue thrust	OP	☐
Recurrent chest infections or known resp difficulties	O OP P	☐	Level of arousal inconsistent	All	☐	Changes in resp rate, skin colour or temperature	O OP P	☐	Altered voice quality	O OP P	☐
Coughing	O	☐	Choking	O	☐	Reflux / vomits	O	☐	Poor dentition	OP	☐
Gagging / facial grimacing during the meal	OP	☐									

▶ Activity (F)

Does the child have CP?	Yes	☐	No	☐				
Distribution of CP	Monoplegia	☐	Diplegia	☐	Quadriplegia	☐		
Type of CP	Spastic	☐	Ataxic	☐	Athetoid Dyskinetic	☐	Athetoid Hypotonic	☐
Mobility	Fully mobile	☐	Walking with aid	☐	Wheelchair	☐	Bed bound	☐

▶ Communication - Redway scale

Pre-intentional	0	☐	Intentional	1	☐	First meanings	2	☐
Formal language	3	☐	Language for learning	4	☐			
Regular SALT for communication		Y ☐		N ☐				

▶ Dietary Analysis (H)

collected by: 3 day Food Diary ☐ 3 x 24 hour recall ☐

▶ Analysis	**Actual**	**RNI (age)**	**LR NI age**	**RNI Ht age**	**LRNI Ht age**
Energy Kcal					
Protein g					
Fluid ml					
Na mmol					
K mmol					
Fibre g					
Calcium g					
Iron mg					
Zinc mg					
Vitamin A µg					
Folate µg					
Vitamin C mg					

▶

Is fluid lost when drinking? Yes ☐ No ☐

Does child dribble excessively? Yes ☐ No ☐

▶ Fluid intake (I)

Good ☐ Average ☐ Poor ☐

▶ Food intake (H)

Eats large meals and snacks	☐
Average sized meals and snacks	☐
Average sizes meals no snacks	☐
Frequently leaves food	☐
Eats very little	☐

Time taken to eat school meal……….. mins

▶ Eating & Drinking Skills

Can feed self	☐	Needs to be fed	☐
Needs help	☐	Nil by Mouth	☐

▶ Bowels (E)

Bristol Stool Chart scores:

Type 1	Type 2	Type 3	Type 4	Type 5	Type 6	Type 7
☐	☐	☐	☐	☐	☐	☐

Stool Frequency:

Once a week	Every 2-3 days	Once a day	2-3 times a day	>4 times day
☐	☐	☐	☐	☐

Regular bowel medication:

▶ Mental Health (K)

Any behavioural / emotional issues effecting mealtimes e.g. venues, environment, eating with others, etc.?

▶ Dietitian's Assessment (L)

1. This child does not need to be referred to the dietitian 1☐
2. This child should be monitored and may need to be referred to a dietitian. 2☐
3. This child needs to be referred to a dietitian 3☐