“Oral Health, Dental Care and Aspiration History of Tube-Fed Children”

Annabelle Frances Carter

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

Supervisors

Dr Richard C. Balmer[1], BDS, M Dent Sci Paediatric Dentistry, FDS (Paed Dent) RCPS, PhD
Dr Francesca Soldani[2] BDS, MFDS RCS Ed, MPaed Dent RCPS (Glasg), FDS (Paed Dent) RCPS (Glasg), MDSc, PGCert HCL
Dr Kate Wildig[3] MBChB FRCPCH MMedSc

1. Department of Paediatric Dentistry, School of Dentistry, University of Leeds, LS2 9LU
2. Bradford Community Dental Service, Bradford District Care NHS Foundation Trust, Horton Park Health Centre, 99 Horton Park Avenue, BD7 3EG
3. Bradford Teaching Hospitals NHS Foundation Trust Top Floor Extension Block, St Luke's Hospital, Little Horton Lane, Bradford, BD5 0NA

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Abstract: Oral Health, Dental Care and Aspiration History of Tube fed children in Bradford

Aim: The study aims were to determine incidence of chest infections (CI) or aspiration pneumonia (AP) for the tube-fed paediatric population known to Bradford Community Dental Service; understand medical characteristics of tube-fed patients in particular those vulnerable to CI/AP; determine the accuracy of dental-medical records taken by dentists; and understand oral health, oral hygiene regimens and dental care of tube-fed children with CI/AP history.

Methods: Retrospective analysis of tube-fed patient records known to Bradford Community Dental Services. The information collated included: medical history, CI/AP episodes, oral health descriptors such as calculus, periodontal disease, caries, treatment received, and oral hygiene regimen.

Results: 92 patients' clinical records were analysed. 53.3% of this sample (49 patients) had a history of CI/AP between 2018-2020. No patients had complete or accurate medical histories in the dental record when compared to the medical records. The following co-morbidities made tube-fed children more vulnerable to CI/AP: being nil by mouth (NBM), having an unsafe swallow, using saliva reducing medication, using prophylactic antibiotics, using medication associated with a risk of gingival hypertrophy, having a history of dental general anaesthetic (GA).

Oral health of tube-fed children with CI/AP was varied; calculus presence was high (65.3% of patients), and caries level was low (12.2%). Oral hygiene levels were variable. Tube-fed children with CI/AP who had unsafe swallow or were NBM had more calculus present, less caries, and were less likely to have had a dental GA, compared to those with a safe swallow or orally fed. Tube-fed children with CI/AP had greater experience of dental GA compared to those without CI/AP.

Conclusions: Tube-fed children have complex medical needs with varying dental needs. Further research is required to understand what dental treatment is in their best interests.

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Abbreviations

AP= Aspiration Pneumonia

BAPEN= British Association for Parenteral and Enteral Nutrition

BDCFT-CDS= Bradford District Care NHS Foundation Trust Community Dental Services

BDSH= British Society of Disability and Oral Health

BSPD= British Society of Paediatric Dentistry

BTHFT= Bradford Teaching Hospital NHS Foundation Trust

CAG= Confidentiality Advisory Group

CDS= Community Dental Service

CI= Chest Infection

CI/AP= Chest Infections /Aspiration Pneumonia

DMFT= decayed missing filled teeth

EHR= electronic health record

GA= General Anaesthetic

GIRFT= Getting It Right First Time

GORD= Gastro-Oesophageal Reflux Disease

HCPs= Health Care Professionals

HRA= Health Research Authority

IT= Information Technology

n= number

NBM= Nil by Mouth

NF= Nissen Fundoplication / Fundoplication procedure

NICE= National Institute for Health and Care Excellence

OH= Oral Hygiene

OHR= Oral Hygiene Regimen

REC= Research Ethics Committee

SALT= Speech and Language Therapy

SIG= Special Interest Group

SPSS= Statistical Package for the Social Sciences

TSL= Tooth Surface Loss

VAP= ventilator-associated pneumonia

CHAPTER 1: LITERATURE REVIEW

1.1. Tube Feeding

1.1.1. Definition of Tube Feeding for the Purposes of this Project

Tube feeding is a term used for patients who are artificially fed via a tube located in the gastrointestinal tract (the stomach, jejunum, or duodenum) to meet a patient's nutritional needs. It is required when a child is unable to meet their nutritional and/or hydration needs orally in a safe way, due to numerous factors (Faculty of Dental Surgery, 2012; GAIN, 2015). According to the most recent data from the British Artificial Nutrition Survey, there were 1336 children reported to be tube-fed in the United Kingdom in 2011 (Smith et al., 2011).

1.1.2. Tube Types

There are different types of feeding tubes that are defined by the site in the gastrointestinal tract, or the shape/mechanism of introducing food. For children, they are inserted endoscopically, radiologically, surgically, or percutaneously in a theatre environment (Faculty of Dental Surgery, 2012; GAIN, 2015). Tube types include:

- Nasogastric tube feeding
    - a narrow tube passed into the nose and down the oesophagus into the stomach allowing the feed to pass directly into the stomach, avoiding the mouth
    - usually, a short-term option for a maximum of six to eight weeks
- Naso-jejunal tube
    - passed into the nose, down the oesophagus, through the stomach, and into the small intestine (the jejunum)
- Jejunostomy tube feeding
    - liquid feed is introduced into the jejunum, a part of the small intestine, using a soft tube either directly into the jejunum or via a gastric port (NHS Quality Improvement Scotland, 2007)
    - a surgical procedure is required, a jejunostomy, which creates a special opening (stoma) to allow artificial feeding
- Gastro-jejunostomy tube
    - inserted through the stomach and then into the jejunum to facilitate longer-term feeding or medicine delivery
- Gastrostomy tube

- feeding tube inserted surgically, usually under general anaesthetic (GA), into the stomach. This is done by a surgical procedure called a percutaneous endoscopic gastrostomy or radiologically, known as a radiologically inserted gastrostomy. This allows liquid feed, fluids, and medicines to be delivered directly into the stomach on a longer-term basis.

1.1.3. Indications for Tube Feeding:

The United Kingdom National Institute of Health and Care Excellence (NICE) clinical guidelines (2021) state tube feeding should be considered if the patient has unsafe swallowing with risk of aspiration, poor nutrition with an inability to consume 60% calorific needs orally, prolonged feeding of over 4 hours a day, weight loss/no weight gain for over 3 months, or weight is below the 2nd percentile for age and sex (NICE, 2021a). Tube feeding is required to help children meet their nutritional needs, prevent dehydration, and allow delivery of medications to help maintain a healthy weight.

Indications for tube feeding in the child population are listed below (Jawadi et al., 2004; Fröhlich et al., 2010; Tutor and Gosa, 2012; GAIN, 2015; Shahid, 2016):

- Children with increased calorific intake requirements e.g., congenital heart disease and cystic fibrosis;
- Children with dysphagia due to neurologic or neuromuscular dysfunction e.g., cerebral palsy, motor neurone disease, muscular dystrophy;
- “Failure to thrive” children who are significantly below the weight of others in their age range;
- Children with anatomical abnormalities and craniofacial anomalies e.g., oesophageal atresia, or acquired via trauma or chemo/radiotherapy;
- Children with a restricted diet e.g., metabolic conditions;
- Children who are severely disabled;
- Orally-averse children e.g. autistic spectrum disorder;
- Children with delayed gastric emptying (gastroparesis);
- Pre-term babies, less than 37 weeks gestational age.

The most common indication for tube feeding is dysphagia (difficulty swallowing), but this is more prevalent in the adult elderly population (Speech Pathology Australia, 2012). There are many causes of dysphagia which can be genetic, developmental, acquired, or even unknown, and the onset can be sudden or gradual. It can be a primary diagnosis or secondary to oral/oesophageal cancer or treatment of a malignancy. For children, common causes of dysphagia are neurologic or neuromuscular dysfunction e.g. cerebral palsy, and risk aspiration or asphyxiation (Calis et al., 2008). Neurologic and neuromuscular dysfunction means children cannot regulate breathing or swallowing, they lack adequate muscle function and coordination, and can also have a weak gag reflex and ineffective cough (Tutor and Gosa, 2012). Tube feeding itself can lead to children having difficulty protecting their airway due to poor coordination between swallowing and breathing (Faculty of Dental Surgery, 2012).

The British Association for Parenteral and Enteral Nutrition (BAPEN) produces a report each decade, which includes the reasons for children who commence tube feeding, the most recent covering the period 2000-2010. In total, 80% of children newly registered on the database were 5 years old and under (Smith et al., 2011). BAPEN places reasons for tube feeding into 4 broad categories within the paediatric population;

1. cancer (6.2% -11%),
2. central nervous system & mental health conditions (such as Cerebral palsy, congenital malformation, epilepsy, Down Syndrome, Congenital Handicap) (30%),
3. non-malignant gastrointestinal disorders (such as Crohn's Disease and Gastro-oesophageal reflux disorder (GORD)) (14%)
4. 'other conditions' (which includes/such as Faltering Growth, Failure to Thrive, congenital cardiac conditions, and respiratory disease like Cystic Fibrosis) (49%).

1.1.4. Co-morbidities of Tube-Fed Children:

Tube-fed children often have complex medical conditions and health needs, which can be either underlying and contribute to the reasons why a child needs artificial feeding, or it can be related to the tube-feeding itself.

Children who cannot feed properly can be at risk of delayed growth, aspiration, and pneumonia (Speech Pathology Australia, 2012). Children with dysphagia are at risk of asphyxiation i.e., choking due to a blocked airway, or aspiration i.e. inhalation of foreign material into the lower

airway. Such aspiration can lead to significant chest infections (CI), respiratory issues, or aspiration pneumonia (AP), which can contribute to significant morbidity and mortality for these patients (Griffiths et al., 2000; Enderby et al., 2013). Aspiration can occur during normal day-day events such as feeding, gastro-oesophageal reflux, washing, poor management of oral secretions, or even toothbrushing (Tutor and Gosa, 2012).

As well as these, there are the wider co-morbidities associated with the concomitant medical conditions to manage (such as syndromes), which makes these children a unique cohort with multiple challenges, often requiring multi-disciplinary care.

1.1.5. Decision to Tube-Feed and Multi-Professional Team Involvement

The decision to initiate tube feeding is a serious one and done via clinical assessment, which should include a full nutritional, physical, and developmental assessment by a multidisciplinary team. This team includes Speech and Language Therapy (SALT), dieticians, paediatricians, paediatric nurses, general medical practitioners, paediatric surgeons, radiologists, physiotherapists, and community health professionals, who also manage these patients once tube feeding has commenced (NHS Quality Improvement Scotland, 2007; Speech Pathology Australia, 2012). Patients may have a fundoplication (NF) procedure, as well as their tube placement, to help prevent acid reflux and GORD. People with reflux have acidic contents from their stomach come back into the oesophagus; a fundoplication surgical procedure stops this as it wraps the top part of the stomach around the lower oesophagus (Hull University Teaching Hospitals NHS Trust, 2020).

SALT is key to diagnostic testing and undertake swallow assessments, which can include a video-fluoroscopy-swallow study and a fibre-optic-endoscopic-evaluation of swallowing or modified barium swallow, which aids diagnosis and assesses the severity of any potential dysphagia, and issues with anatomy or function, and the potential need for artificial feeding (Speech Pathology Australia, 2012). This gives information to decide whether a child needs to be nil by mouth (NBM) due to an unsafe swallow or are allowed oral feeds.

Dieticians are also key team members as they assess patients' nutritional needs. They make decisions with regards to diet modifications, use of thickeners for fluid, patient positioning, and whether tube feeding is required as a temporary or permanent measure. Some tube-fed children

may be completely NBM, some are allowed small oral tasters of food, and others have most of their calorie intake orally and then overnight top-up feeds.

1.1.6. Benefits of Tube feeding

Benefits include improved growth, development, weight gain, and general health, as well as reduced feeding times with some reports of fewer respiratory infections (Mercado et al., 2001; Sullivan et al., 2004; Sullivan et al., 2005; Fröhlich et al., 2010). Improvement in the parent/carer's quality of life has also been reported in the literature (Sullivan et al., 2004; Sullivan et al., 2005).

1.1.7. Risks of Tube feeding

Tube feeding can have negative implications including a worsening of swallow ability and subsequent increased risk of aspiration of food, drink, or saliva, causing AP which has significant morbidity and mortality (Enderby et al., 2013; All Wales Special Interest Group, 2014a). Furthermore, Craig et al., (2003) sent questionnaires to parents of children who were planned to have gastrostomy surgery, they were worried about the loss of oral feeding and the negative psychosocial effects it could have on the child and family. The paper highlighted the need for more practical and emotional support for these children and their carers. NHS Scotland Quality Improvement guidelines (2007) have also recognised the need for more support for the families of children who are tube-fed and have severe disabilities given potential issues around a lack of information on how to deal with complications arising from the tube, the equipment, and lack of fluency of support (Craig et al., 2003; NHS Quality Improvement Scotland, 2007).

1.2. Tube Feeding Comorbidity: Aspiration Pneumonia (AP)

1.2.1. What is Aspiration Pneumonia?

Pneumonia is an "inflammatory condition of the lung parenchyma, usually triggered by bacteria or viruses into the lower airway". It is usually caused by the aspiration of infectious agents from colonising sites such as the oral and nasal cavities and/or upper respiratory tract (Scannapieco et al., 1992; Scannapieco, 1999; Scannapieco and Shay, 2014).

AP is a specific form of pneumonia and can be described as "an infectious process caused by the aspiration of oropharyngeal contents colonised by pathogenic bacteria" (Scannapieco and Shay, 2014). It can be difficult to diagnose and determine from other types of pneumonia/lower

respiratory tract infections with differential diagnoses including dysphagia-related AP, non-dysphagia-related AP, community-acquired pneumonia, healthcare-associated pneumonia, viral respiratory infection, and aspiration pneumonitis (aspiration of gastric contents) (Coyle and Matthews, 2010). Often in the literature, a more generic "pneumonia" terminology is used due to the difficulty of diagnosing and differentiating.

1.2.2. Potential Mechanism of AP Causation

Dysphagia and reduced cough reflex, combined with the accumulation of pathogenic bacteria in the oropharynx due to poor oral hygiene (OH), +/- reduced immunity, +/- changes in lung function (such as being medically compromised or having neuro-muscular conditions), can mean bacteria from the mouth is easily aspirated into sterile lungs. This can lead to the development of AP (Marik and Kaplan, 2003). Pathogens from the oral cavity (which can come from the plaque biofilm) are a source of respiratory pathogens, as they migrate and colonise the oropharynx and subsequently the lungs, due to aspiration in patients with ineffective or unsafe swallowing or a compromised cough reflex. It is hypothesized in numerous studies that migration by aspiration of colonised plaque can lead to pneumonia or respiratory tract infections (Scannapieco et al., 1992; Fourrier et al., 1998; Langmore et al., 1998; Russell et al., 1999; Scannapieco, 1999; Fourrier et al., 2000; Terpenning et al., 2001; Langmore et al., 2002; Mojon, 2002; Marik and Kaplan, 2003; Scannapieco et al., 2003; Munro and Grap, 2004; Jones, 2005; Kikawada et al., 2005; Azarpazhooh and Leake, 2006; Ferozali et al., 2007; Turton, 2008).

1.2.3. Risk Factors for AP

Literature has discussed the causes and risk factors of AP. Langmore et al., (1998) reported that dependency on feeding, dependence on another person to clean the oral cavity, poor oral care, number of decayed teeth, tube feeding, dysphagia, number of medications, and more than one medical diagnosis were important risk factors associated with AP. Other risk factors include; decreased cough reflex; oropharyngeal colonisation of pathogenic organisms with micro-aspiration of saliva/secretions containing these bacterial pathogens; reduced saliva flow, altered saliva composition, poor OH, and medically compromised patients with decreased host defences (Terry and Fuller, 1989; Murray et al., 1996; Langmore et al., 1998; Langmore et al., 2002; Leibovitz et al., 2003; Garcia, 2005; Azarpazhooh and Leake, 2006; Scannapieco and Shay, 2014; Kishimoto et al., 2016).

1.2.4. Tube Feeding as a Risk Factor for AP

Studies have shown tube feeding to treat dysphagia and aspiration of food does not prevent AP and may increase the risk (Finucane and Bynum, 1996; Kikawada et al., 2005; Luk and Chan, 2014), and individuals who are NBM (not partially tube-fed) have a higher incidence of AP (Langmore et al., 2002; Azarpazhooh and Leake, 2006; Kishimoto et al., 2016). However, this evidence is limited to the elderly population. Finucane and Bynum (1996) reported that tube-fed patients had high rates of AP and describe three retrospective cohort studies where several patients developed AP for the first time after tube placement. Feeding tubes do prevent aspiration of food but do not stop the aspiration of oral secretions which can contain high levels of oral bacteria. Literature reports on incidences of AP in tube-fed patients vary and range from 5%-67% but include mostly adults (Finucane and Bynum, 1996; Gavi et al., 2008).

Ferozali et al., (2007) compared the oral flora for adult patients aged 31-79 years who were tube-fed and those fed orally: the highest levels of harmful pathogenic bacteria were found in subjects who were tube-fed, suggesting this could be a source of bacteria for AP and more rigorous mouth care is required for these patients.

1.2.5. Poor Oral Health as a Risk Factor for AP

A systematic review by Azarpazhooh and Leake (2006) reviewed 19 studies regarding the relationship between respiratory diseases and oral health. It highlighted the association between pneumonia and oral health, presence of periodontal pathogens, dental decay, and poor OH via aspiration of oral secretions containing pathogenic oral bacteria. Numerous other studies have shown poor oral health and the presence of oral/dental disease (i.e. presence of periodontal pathogens, cariogenic bacteria, dental decay, and poor OH) are risk factors for the development of and severity of AP, as dental plaque is a unique biofilm of bacteria, which can be a source of respiratory pathogens (Scannapieco et al., 1992; Murray et al., 1996; Fourrier et al., 1998; Langmore et al., 1998; Russell et al., 1999; Scannapieco, 1999; Terpenning et al., 2001; Mojon, 2002; Leibovitz et al., 2003; Garcia, 2005; Terpenning, 2005; Azarpazhooh and Leake, 2006; Awano et al., 2008; Bassim et al., 2008; Garcia et al., 2009; Ortega et al., 2014; Scannapieco and Shay, 2014). This is reinforced by studies showing improvement in OH and professional oral care reduces the incidence of pneumonia and respiratory illnesses (Fourrier et al., 1998; Langmore et al., 1998; Terpenning et al., 2001; Langmore et al., 2002; Mojon, 2002; Leibovitz et al., 2003; Terpenning, 2005; Azarpazhooh and Leake, 2006; Turton, 2008; Maeda and Akagi, 2014).

Oral health determines the amount and type of bacteria that is aspirated by patients and contributes to the development of AP (Awano et al., 2008; Bassim et al., 2008; Ortega et al., 2014). Aerobic oral organisms predominate plaque in a healthy mouth, but in individuals with poor oral health and periodontal disease, the oral biofilm is shifted from gram-positive commensal microbes to gram-negative, anaerobic pathogenic bacteria (Langmore et al., 1998; Terpenning et al., 2001; Mojon, 2002; Terpenning, 2005; Azarpazhooh and Leake, 2006; Ortega et al., 2014). Oropharyngeal colonisation with these gram-negative pathogens, and aspiration of these, are likely to be the cause of AP (Terry and Fuller, 1989; Marik and Kaplan, 2003). Studies have shown lung aspirate samples from individuals with AP contain pathogens found in the oral cavity, periodontal bacteria, and anaerobic organisms such as actinobacillus actinomycetemcomitans, reinforcing oral bacteria to be a cause of respiratory infections such as AP (Fourrier et al., 1998; Mojon, 2002; Leibovitz et al., 2003; El-Solh, 2004; Garcia, 2005; Azarpazhooh and Leake, 2006; Scannapieco and Shay, 2014).

Literature reports that tube-fed children specifically are at increased risk of AP. Researchers propose because these patients are reliant on others for oral care, their OH was often poorer thus they would have an increased reservoir for pathogens. It may be due to a lack of masticatory forces, or reduced saliva flow, thus a reduced level of salivary IgA (a protective enzyme), both of which have a mechanical cleansing effect on the oral cavity, so plaque and calculus can accumulate significantly over all tooth surfaces and oropharynx (Langmore et al., 1998; Dyment and Casas, 1999; Russell et al., 1999; Langmore et al., 2002; Leibovitz et al., 2003; Jawadi et al., 2004; Ferozali et al., 2007; Drummond et al., 2017). In children with poorer OH, anaerobes are found at greater levels in plaque and these periodontal pathogens have been found in aspirates of lungs affected with AP, as discussed in Drummond et al., (2017). Studies show the oral environment of tube-fed children is different from non-tube-fed children, and even when OH is at similar levels to non-tube-fed children they are at increased risk of AP (Dyment and Casas, 1999; Jawadi et al., 2004; Drummond et al., 2017).

In summary, tube-fed children are at particular risk of respiratory infections, such as AP as they have numerous risk factors which can include reliance on parents/carers to clean their teeth, poorer OH due to oral aversion or oral hypersensitivity, reduced swallowing capacity, reduced

masticatory forces, reduced saliva, and increased risk of inhaling contents from the oropharyngeal region.

1.2.6. Recommendation for Better Oral Health Advice and Dental Care for Tube-Fed Patients

Evidence that poor OH is a causative factor of AP, and tube feeding a contributory factor, highlights the need to prioritise OH and dental care for tube-fed patients. Health care professionals (HCPs) need to risk assess patients for AP and try to minimise this risk. The Wales Special Interest Group (SIG), 2014 recommends that dentists should be included in any dysphagia diagnostic care plan. This would enable the oral care risk assessments and oral care plans to be undertaken as soon as possible to minimise the risk of AP (All Wales Special Interest Group, 2014b). To help prevent AP, efforts to educate and train parents, carers, nurses, and others to provide a high standard of day-to-day oral care are needed. Early referral to dentists for treatment of any suspected dental disease is important to ensure the oral environment is as healthy as possible. The risk of AP is reduced by 60% in patients who have a thorough OH regime (Terpenning et al., 2001; Koeman et al., 2006), highlighting the need for robust regular oral care. The need for effective oral health measures in the tube-fed population has been discussed at length in the literature and there has been debate about what measures are most effective. Most of the literature is based on elderly patients and/or patients in intensive care (Fourrier et al., 1998; Langmore et al., 1998; Russell et al., 1999; Fourrier et al., 2000; Terpenning et al., 2001; Leibovitz et al., 2003; Marik and Kaplan, 2003; El-Solh, 2004; Munro and Grap, 2004; Jones, 2005; Kikawada et al., 2005; Awano et al., 2008; Bassim et al., 2008; Luk and Chan, 2014; Maeda and Akagi, 2014; Ortega et al., 2014), not the paediatric population and highlights the lack of evidence base for recommendations in children.

1.3. Oral Health of Tube-Fed Patients in the Literature

There is limited research regarding oral health and oral findings for tube-fed paediatric patients. Much of the research is on adults, thus this research is often extrapolated to the paediatric population. There is even less literature regarding the relationship between the oral health of tube-fed children and AP (Dyment and Casas, 1999; Kim and Emanuel, 2019).

Literature available on tube-fed children discusses lack of feeding orally results in reduced oral stimulus and changes in the saliva. It is also associated with poor OH and increased calculus build-up (Dyment and Casas, 1999; Jawadi et al., 2004; Brown et al., 2006; Hidas et al., 2010; Faculty of

Dental Surgery, 2012; Kim and Emanuel, 2019). To summarise, tube-fed children have higher levels of plaque and calculus than non-tube-fed children (Dyment and Casas, 1999). They also have oral microorganisms that are associated with AP within their saliva (Jawadi et al., 2004). Ensuring the best possible oral health to reduce the plaque, calculus and bacterial levels may reduce AP and thus decrease morbidity and mortality.

1.3.1. Calculus and Oral Hygiene of Tube-Fed Patients

A recurrent finding in studies is that tube-fed children and adults are more likely to have calculus build-up compared to non-tube-fed children (Littleton et al., 1967; Littleton and McCarter, 1967; Klein and Dicks, 1984; Dyment and Casas, 1999; Jawadi et al., 2004; Brown et al., 2006; Hidas et al., 2010; Kim and Emanuel, 2019). The cause of increased calculus levels is unclear. It has been hypothesised it may be due to poorer plaque control and OH measures. But research has shown calculus accumulation is greater and formed at a greater speed for tube-fed children even when OH is optimal or superior (Klein and Dicks, 1984; Dicks and Banning, 1991; Mandel, 1995; Jawadi et al., 2004; Brown et al., 2006; Kim and Emanuel, 2019). This may be due to oral clearance being affected, as the muscles of mastication are not being used (Mandel, 1995). Or it may be due to the pH of saliva being above 5.5 for longer time periods, as there are limited or no fermentable carbohydrates taken orally, which encourages mineralisation of the plaque to form calculus (Hidas et al., 2010; Kim and Emanuel, 2019).

There's a link between abnormal muscle tone and crowding of teeth which can make cleaning more difficult, thus allowing calculus more opportunity to build- up (Mandel, 1995; Dicks and Banning, 1991). This calculus build-up then makes cleaning more difficult around the gingival margin, leading to a greater build-up of pathogens and bacterial loads, which may be harmful if aspirated or inhaled (Jawadi et al., 2004; Hidas et al., 2010). Jawadi et al. (2004), suggested calculus presence in tube-fed children puts the child's systemic health at risk. They found a significant relationship between AP, the presence of calculus, and tube feeding. This poses the question, should removal of plaque and calculus be a priority for dental health professionals to improve their patients' general health, and would removal of such calculus in a conscious but uncooperative patient pose a serious airway risk in patients with unsafe swallow; or would a GA be justifiable even given the inherent risks of a GA?

In some studies, tube-fed children with a history of AP have significantly higher levels of calculus than tube-fed children who have not had an episode of AP, which suggests an association between calculus, tube feeding, and AP (Jawadi et al., 2004; Hidas et al., 2010). Conversely, Brown et al., (2006) found a significant relationship between the history of AP and the presence of calculus, but not the amount of calculus for tube-fed children. Kim and Emanuel's (2019) review concluded there was evidence that tube-fed children with a history of AP have higher levels of calculus, poor OH, and plaque accumulation. They found an association between AP and poor oral health, and that tube-fed children have a greater number of respiratory anaerobe bacteria in their oral cavity than other children who aren't tube-fed. There was concern that disruption of this calculus during its removal may trigger an episode of AP, however Jawadi et al. (2004) reported professional calculus removal does not cause AP, but presence of calculus intraorally did.

1.3.2. Tube Feeding and Dry Mouth

Nasogastric tubes can cause open mouth posturing thus causing xerostomia. If this occurs it is important for dental professionals to advise of the relief of dry mouth (Munro and Grap, 2004). Reduced salivary flow, due to lack of oral stimulation has been reported for all types of tube feeding (Shahid, 2016). Some tube-fed children with neuromuscular conditions, such as cerebral palsy, are prescribed medication to control drooling. However, this can reduce saliva production, and causes dry mouth in up to 67% of those who use the medication (Special Pharmacy Service, 2017). Dry mouth reduces the number of protective antibodies in saliva and can increase the number of pathogens in the oral cavity which can lead to an increased risk of AP. In partially-oral-fed individuals, having a dry mouth can also increase caries incidence.

1.3.3. Tube Feeding and Caries

Plaque and saliva from tube-fed patients is less acidogenic and generates less acid when exposed to fermentable carbohydrates according to Littleton et al., (1967), and Littleton and McCarter (1967). Tube-fed children have lower caries levels and lower Decayed Missing Filled Teeth (DMFT) scores compared to the general population (Hidas et al., 2010). If safety allows HCPs such as paediatricians, SALT or dieticians may encourage patients to have some oral feeding i.e., occasional tasters with different tastes and consistencies to engage in important activities such as family mealtimes, help swallowing muscles, or for oral stimulation to reduce oral hypersensitivity. These 'taster' foods are often high in sugar and can increase caries risk,

especially if given at regular intervals, thus regular brushing with fluoride toothpaste is still needed (Maeda and Akagi, 2014).

1.3.4. Tube Feeding: Oral Defensiveness and Hypersensitivity

Oral defensiveness is a phenomenon experienced in tube-fed patients due to reduced oral stimulation as there is nil or minimal oral feeding (Shahid, 2016). This can cause hypersensitivity to toothbrushing and dental examinations, which is reported by parents/carers who have great difficulty in providing daily OH. This impacts the carers' ability to provide appropriate care and thus the child's oral health (Dyment and Casas, 1999; Kim and Emanuel, 2019). This highlights the importance of regular oral stimulation for children who are tube-fed to help develop taste and sensory function. As well as food tasters, OH measures should be part of the oral stimulation (Dyment and Casas, 1999; Byars et al., 2003). The SALT team can be utilised to help with oral stimulation and oral desensitisation programme to reduce associated difficulties.

1.3.5. Tube Feeding and Food Accumulation with Reduced Oral Clearance

If the patient is still partially orally fed, food can collect in the mouth due to reduced muscle tone so usual oral clearance can't occur. This means food remains in the mouth for prolonged periods leading to an increased risk of dental decay, or even inhalation (All Wales Special Interest Group, 2014a; Shahid, 2016).

1.3.6. Tube Feeding and Dental Erosion

Tube-fed children are at greater risk of GORD if they haven't had a fundoplication procedure (Shahid, 2016). Reflux of acidic stomach contents into the oral cavity can cause dental erosion, usually manifested as tooth surface loss (TSL) on the palatal and occlusal surface of teeth. This TSL is exaggerated if the patient grinds their teeth, which can be a phenomenon in children with special and additional needs (Cameron and Widmer, 2013). Reflux of stomach contents could theoretically result in accumulation of food in the oral cavity which if not cleared could then be aspirated in individuals with dysphagia, increasing the risk of AP.

1.3.7. Oral Bacteria in Tube-Fed Children

Tube-fed children have significantly more plaque, calculus, more gram-negative and pathogenic bacteria (species such as Haemophilus influenza, pseudomonas, and streptococcus pneumoniae), compared to non-tube-fed children (Jawadi et al., 2004; Kim and Emanuel, 2019). The microflora

of the oral cavity is different in tube-fed patients, as lack of oral nutrition including carbohydrates means certain bacteria fail to thrive. Plaque samples from tube-fed patients showed lower mutans streptococci and lactobacilli levels (Littleton et al., 1967; Littleton and McCarter, 1967; Jawadi et al., 2004; Hidas et al., 2010).

1.3.8. Overall Oral Health of Tube-Fed Children

In summary, a typical tube-fed child usually presents with large calculus deposits, low caries rate, risk of dental erosion if they have reflux, and is orally hypersensitive and thus has a higher risk of poor oral health (Weitzel et al., 2006; Hidas et al., 2010; Kim and Emanuel, 2019).

Improving OH is one of the most important measures to reduce pneumonia and respiratory infections (Koeman et al., 2006; Ross and Crumpler, 2007) and should be included in the overall healthcare package for tube-fed patients. Unfortunately, it is often seen by some HCPs as a way of improving patient comfort rather than being key to reducing respiratory infections and thus preventing serious illness and reducing mortality (Klein and Dicks, 1984; Lloyd et al., 2011).

1.4. Oral Care and Oral Hygiene Advice for Tube-Fed Individuals

It is important for parents/carers and the dental team to work together to develop a robust, individualised oral healthcare plan for tube-fed patients to reduce any complications or risk factors for respiratory issues, as advocated by the British Society of Disability and Oral Health (BDSH) Guideline for Children with an Impairment or Disability and the Wales SIG for Children with Dysphagia (Griffiths et al., 2000; Faculty of Dental Surgery, 2012; All Wales Special Interest Group, 2014b). This care plan should be created by the multidisciplinary team, involving the dentist, SALT (to assess their swallow and identify whether they are at high or low risk of aspiration), and paediatrician (Griffiths et al., 2000; All Wales Special Interest Group, 2014b).

1.4.1. Deficient Research for Oral Care Advice for Tube-Fed Patients

Research regarding the most effective ways to deliver oral care to tube-fed individuals is scant and limited to patients in acute hospital settings i.e., Intensive Care Units, the elderly, ventilated or stroke patients i.e., not tube-fed children (Durgude, 2011). Literature itself has acknowledged the lack of high-quality evidence for oral care interventions with no trials reporting power calculation for sample sizes thus trials may be underpowered and provide false results on the effectiveness of interventions (Brady et al., 2006). More research is needed regarding the oral

care needs to develop gold standard care for these high need patients to ensure the best outcome for their health (Jones, 2005; Rello et al., 2007; Johnstone et al., 2010; Durgude, 2011). This was highlighted by the most recent research from Kim and Emanuel (2019), who discussed the lack of evidence for tube-fed patients regarding their oral health and hygiene measures. Publications have proven there is a real variety of OH practices with no evidence base on the efficacy or safety for patients (such as the use of sponges instead of toothbrushes), which impacts the quality of effective oral cleaning to reduce the build-up of harmful oral pathogens (Jones, 2005; American Association of Critical Care Nurses, 2010; Lloyd et al., 2011).

Scannapieco et al. (2003) systematic review involving adults and children discovered a link between periodontal disease and pneumonia and found the incidence of pneumonia was reduced by 40% with OH measures including topical chemical disinfection, or mechanical removal of oral pathogens. Azarpazhooh and Leake's (2006) systematic review of multiple studies for the adult population found OH interventions reduced the incidence of pneumonia, with a relative risk reduction that ranged from 34 to 83%, as the interventions reduced colonies of respiratory pathogens. These studies highlight the importance of effective, evidence-based OH measures.

There have been a few documents emerging from care units and SIGs in recent years to provide guidance for delivering evidence-based oral care to help promote the safe management of tube-fed paediatric patients and to prevent oral health issues and respiratory infections. However, these are based on very little evidence as there are few studies outlined above. These include:

- BDSH 2000 guidelines (Griffiths et al., 2000);
- "Caring for children and young people in the community receiving enteral tube feeding" by NHS Quality Improvement Scotland (2007);
- "Mouth care for Children with Swallowing Problems" in April 2014 (All Wales Special Interest Group, 2014b) and;
- "Recommendations for the management of oral healthcare of adults and children with dysphagia" in September 2014 (All Wales Special Interest Group, 2014a)

There is no national guidance for mouth care for tube-fed children from the British Society of Paediatric Dentistry (BSPD). However, there are numerous local patient/carer information leaflets provided by NHS community and hospital trusts including local guidance by Bradford

District Care NHS Foundation Trust Community Dental Services (BDCFT-CDS) (Shahid, 2016), which is relevant to our local population. These local guidelines aimed to improve care and offer an achievable approach to care. Developing the guidance involved a review of the available evidence, with the authors acknowledging a lack of high level, reliable evidence (NHS Quality Improvement Scotland, 2007; Faculty of Dental Surgery, 2012; All Wales Special Interest Group, 2014a; All Wales Special Interest Group, 2014b Lim, 2018).

1.4.2. Attitudes and Knowledge of Carers/Parents to Effective Oral Hygiene Measures

Attitudes to providing thorough and consistent oral care can be a barrier for tube-fed patients achieving optimum OH, as providing oral care safely can be a concern. Carers may avoid oral health care as they strongly dislike it, or lack confidence (Griffiths et al., 2000; Rello et al., 2007; Garcia et al., 2009). It is recognised by numerous publications that mouth care training for carers has been neglected and better training should be provided to improve OH practices (Langmore et al., 1998; Griffiths et al., 2000; Jones, 2005; Azarpazhooh and Leake, 2006; Fiske et al., 2006; Rello et al., 2007; Garcia et al., 2009; American Association of Critical Care Nurses, 2010; Johnstone et al., 2010; Durgude, 2011; Lloyd et al., 2011; All Wales Special Interest Group, 2014a). Nurses and other HCPs can have limited knowledge of the link between poor oral health, dysphagia, and pneumonia without further enhanced training on this subject (Jones, 2005; Rello et al., 2007; Garcia et al., 2009; Durgude, 2011; Lloyd et al., 2011).

Motivation and cooperation from carers/parents are key as to whether an individual oral care plan is a success and is appropriately implemented to get the optimal health benefit for the tube-fed patient. Shahid (2016) suggested the oral healthcare plan could be circulated to the child's carers, school, respite carers, and any others involved in providing oral care for that child to allow ample opportunity for daily oral care to take place (as part of their education and healthcare plan).

1.4.3. Toothbrushing Advice for Tube-Fed Individuals

Regular toothbrushing every 12 hours is important to remove plaque, reduce the bacterial load, prevent dental pain, calculus build-up, and any problems with loss of function, as well as provide valuable oral stimulation in patients at risk of developing oral hypersensitivity (Garcia, 2005; Lindgren and Ames, 2005; NHS Quality Improvement Scotland, 2007; Sjögren et al., 2008; Needleman et al., 2011). This in turn helps prevent oral disease and reduces the risk of AP

(Dyment and Casas, 1999; Sjögren et al., 2008; Turton, 2008; Garcia et al., 2009; American Association of Critical Care Nurses, 2010; Scottish Intercollegiate Guidelines Network, 2010; van der Maarel-Wierink et al., 2013; Drummond et al., 2017). Parents/carers report difficulty providing oral care as tube-fed children become orally hypersensitive and simple oral hygiene like toothbrushing may feel uncomfortable (Idaira et al., 2008). The BDSH guidelines advise a programme of oral desensitisation may be required, after discussing with SALT if the child is orally hypersensitive, to allow for better toothbrushing (Griffiths et al., 2000; Johnstone et al., 2010).

A systematic review by Sjogren et al., (2008) reviewed 5 randomised control trials regarding the preventative effect of OH measures on pneumonia/respiratory infections in the elderly population. These found general OH measures such as toothbrushing were very effective in reducing respiratory infections. It suggested one in ten cases of death from pneumonia in dependent elderly population could be prevented by improving poor OH. Ferozali et al., (2007) assessed the oral environment of 36 non-verbal patients who were either tube-fed, had a hiatus hernia, GORD, or swallowing problems. He assessed different OH interventions and found oral cleaning with a single-use suction toothbrush twice daily with a sodium bicarbonate/1.5% hydrogen peroxide solution and suctioning had the largest reduction in bacteria levels and reduced the risk of AP. A retrospective study by Maeda and Akagi (2014), showed that elderly patients who were tube-fed, and received a daily oral care protocol including tooth and tongue brushing, moisturising the mouth with a glyceryl gel, and a salivary gland massage twice daily, had significantly reduced levels of pneumonia compared to a control group**.**

There is no evidence on the effectiveness of the type of toothbrush that should be used in this population of patients, however, SIGs have advised using modified toothbrushes, such as 3-sided toothbrushes (Collis Curve or Dr. Barman's), finger brushes (which help with patients who bite down or are sensitive), electric brushes, small soft brushes, or suction toothbrushes, as well as mouth rests to allow safe placement of toothbrushes (All Wales Special Interest Group, 2014b; Doğan et al., 2004; Griffiths et al., 2000; Kambhu and Levy, 1993; Lindgren and Ames, 2005; Ferozali et al., 2007; Johnstone et al., 2010; Needleman et al., 2011). Oral suction helps prevent inhalation of toothpaste or saliva secretions (All Wales Special Interest Group, 2014b; Ortega et al., 2014; Shahid, 2016).

1.4.4. Toothpaste Advice and Tube Feeding

Fluoride toothpastes that prevent the build-up of calculus are advised (Brown et al., 2006). Some toothpastes contain foaming agents like sodium-lauryl-sulfate to help remove loosened debris, but using foaming agents can increase aspiration risk, as well as being poorly tolerated by orally hypersensitive children (Jawadi et al., 2004; Brown et al., 2006). Applying sodium-lauryl-sulfate-free (fluoride-containing) toothpaste on a dry toothbrush to reduce the risk of potential aspiration is advised (Davies et al., 2004).

A systematic review compared the effectiveness of triclosan-containing and fluoride-containing toothpastes to improve plaque control and gingivitis. Triclosan is an ingredient that is claimed to reduce calculus build-up. 16 trials were included and found that toothpastes with triclosan were most effective (Davies et al., 2004). Brown et al., (2006) assessed which toothpastes were most effective and safe for tube-fed patients, and found an anti-calculus (i.e., triclosan-containing) toothpaste with low-foaming action significantly reduced supra-gingival calculus accumulation by 56% (Brown et al., 2006). This study had a small sample size of 24, which may be a limitation. Kim and Emanuel's (2019) original study aims were to investigate available evidence that may suggest the use of non-foaming toothpaste reduced AP in tube-fed children due to a reduction of foam created which could have been aspirated. A literature search revealed no relevant papers thus the authors changed their project to a systematic review regarding tube-fed children, their OH, and respiratory health (Kim and Emanuel, 2019). They hope to design future investigative projects to fill these large gaps in knowledge for these children. A service evaluation by Emanuel et al., (2017), reviewed the acceptability of low foaming toothpastes and suction for carers/parents and children with cerebral palsy and swallowing difficulty, and found low-foaming toothpastes were well accepted by carers/parents, they reported due to the low-foam the child was visibly less distressed, some also said it meant they could see the teeth better, and all would recommend its use, although this was a very small sample size of 10. There is limited advice regarding the amount of toothpaste recommended for tube-fed children or children with swallowing difficulties. Lim (2018) advised if there was concern regarding swallow safety for patients with dysphagia of all ages to use a smear of toothpaste. Local BDCFT-CDS advice recommended a smear of paste for under 3-year-olds and a pea-sized amount for 3-6-year-olds, which is in line with the general Public Health England's Delivering Better Oral Health Guidance for all children (Shahid, 2016; Public Health England, 2021).

1.4.5. Chlorhexidine Use and Tube Feeding

Chlorhexidine is a broad-spectrum antibacterial mouthwash or gel, which is effective against gram-positive and negative bacteria (Houston et al., 2002; Grap et al., 2004). Chlorohexidine mouthwash applied via a swab leads to a reduction in plaque formation, thus reduction in respiratory infections and pneumonia, but this has only been proven in intubated patients or those in intensive care units (Fourrier et al., 2000; Koeman et al., 2006; Rello et al., 2007). Koeman et al., (2006) led a randomised control trial that found a 65% reduction in the risk of acquiring pneumonia when using chlorhexidine six hourly for intubated patients. Lim (2018) advised chlorhexidine to be applied with an oral swab if advised by the dental professional for patients with profound dysphagia. The All Wales SIG (2014a) guidelines for patients with swallowing difficulties advise using chlorhexidine gel/spray around teeth, tongue and gingiva twice daily for children over 6 years of age, based on the literature by Johnstone et al. (2010), who appraised studies to make practical recommendations for oral care in paediatric patients in intensive care. Manger et al., (2017) highlighted that use of chlorhexidine reduced the incidence of ventilator-associated pneumonia (VAP), but this evidence was only limited to the elderly, critically ill population. Mouthwash in patients with unsafe swallows is generally not advised, unless specifically prescribed by a dentist as this can pose an aspiration risk if used inappropriately (Jawadi et al., 2004; Brown et al., 2006; All Wales Special Interest Group, 2014a; Shahid, 2016).

1.4.6. Water-based intra-oral moisturiser use and Tube Feeding

All guidelines for tube-fed mouthcare advise the mouth should be kept moist with clean water or saline on a toothbrush every 2-3 hours and apply a water-based moisturiser every 2-3 hours to the lips and inside the mouth (All Wales Special Interest Group, 2014a). Evidence for this is limited to critically ill tube-fed patients with Garcia et al., (2009) having shown that using a water-based intra-oral moisturiser can reduce VAP.

1.4.7. Oral Stimulation and Tube Feeding

Oral stimulation (through tasters and stimulation such as brushing) has been discussed in guidance to maintain some salivary flow, and help prevent poor oral clearance, dental caries, dryness and cracking of the lips, crusting of the tongue, and calculus (Faculty of Dental Surgery, 2012; All Wales Special Interest Group, 2014a) which all can increase risk of AP. It is advised if

brushing is not possible, massaging the mouth, cheeks and facial muscles can improve muscle tone, stimulate saliva flow and desensitise the area, making OH measures easier. A formal oral desensitisation programme, with input from the dentist, SALT, occupational therapist, paediatrician, or other members of the child's multidisciplinary team may be required to reduce oral defensiveness and hypersensitivity and eventually allow thorough toothbrushing (All Wales Special Interest Group, 2014a; Shahid, 2016).

1.4.8. Diet Advice and Tube Feeding

Where there is limited oral intake or "tasters", carers/parents need to check food is not being held in the mouth. Prolonged food contact can increase the risk of caries, particularly if food is sweet and sticky and where saliva production is compromised (Shahid, 2016).

1.5. Tube Feeding and Professional Dental Care

Literature reports that medically compromised patients have more oral health problems, but receive less dental care compared to the general population (Trulsson and Klingberg, 2003). Providing oral care and dental treatment including professional cleaning to tube-fed children is a challenge. This is due to; oral hypersensitivity which can present with an increased gag or biting reflex; poor motor control and coordination; oral aversion; behaviour and cooperation issues due to developmental delays; inability to handle oral fluids which could lead to inhalation, aspiration risk or choking (Dyment and Casas, 1999; Brown et al., 2006; Drummond et al., 2017; Kim and Emanuel, 2019).

Tube-fed children often lack swallowing coordination and have difficulties protecting their own airway (Shahid, 2016). Positioning the child's head and posture is very important to maintain airway protection with the 'neck flexed' position to ensure the neck and head are well supported when performing toothbrushing or dental care, as this can help prevent aspiration (Lindgren and Ames, 2005; Palmer and Metheny, 2008; Sjögren et al., 2008; Durgude, 2011; Needleman et al., 2011). It is advised to be in an upright position or raise the head by at least 30 degrees and to be in the chin down/chin tuck position (van der Maarel-Wierink et al., 2013). Dental treatment should be performed by teams trained in providing specialised dental care (All Wales Special Interest Group, 2014a; All Wales Special Interest Group, 2014b).

Additional recommendations for delivering safe dental care include limiting the water flow from equipment, and careful use of effective suctioning. (Dyment and Casas, 1999; Shahid, 2016; Drummond et al., 2017). Rubber dam use where appropriate can provide improved airway protection (Dyment and Casas, 1999).

Tube-fed children often have limited cooperative ability due to their developmental status and have compromised airway reflexes, with a risk of aspiration, meaning dental treatment can hold a risk to general health or become a life-threatening event if they choke or aspirate. This can be challenging and stressful for dentists and parents/carers alike as there are added risks to any dental intervention. The need for adequate airway protection is paramount – the dental care professional must ensure the airway is protected (Shahid, 2016). For this reason, patients often have to be treated under GA. The risks of GA must be weighed against the benefits and decisions on how to treat patients safely should be done on a case-by-case basis (Dyment and Casas, 1999).

It is estimated Dental GA's put children at a 1:400,000 risk of life-threatening problems during the procedure (Lawson et al., 2017). This is estimated to be much higher for children who already have multiple co-morbidities, such as the tube-feeding cohort. For this reason, there needs to be due consideration given to the provision of Joint GA's. These are when the patient has multiple medical/dental procedures under one GA with more than one surgical specialty in attendance. If feasible to organise, it has the benefit of reducing the number of GAs a patient has by combining different procedures under one GA, which is beneficial to reduce associated risks of GA, as well as reducing lengthy waits these children may otherwise have.

Hidas et al., (2010) recommended that tube-fed patients are seen for frequent calculus removal visits due to the relationship between calculus level and AP. Dyment and Casas (1999) have also recommended children with gastrostomy have cleaning by dental care professionals four times a year. However, if, how, and when to treat such patients is debated in the literature (Dicks and Banning, 1991; Dyment and Casas, 1999; Jawadi et al., 2004; Brown et al., 2006; Hidas et al., 2010; Kim and Emanuel, 2019). Drummond et al., (2017) asked the question of whether scaling in the dental chair by hand or ultrasonic was an appropriate approach to remove calculus in patients with compromised airways-there is a dilemma about how to deliver such care safely,

and whether it is appropriate to expose the patient to either the risks of inhaling a pathogen rich mixture into the lungs created by scaling in the chair (if cooperative) or exposing them to the risks associated with a GA, knowing the calculus is highly likely to recur. Dyment and Casas, (1999) and Jawadi et al., (2004), debated this at length as both treating and not treating tube-fed children can lead to AP. They came to no solid evidence-based conclusion and the question of treatment remains (Dyment and Casas, 1999).

1.5.1. Dental Recall Intervals for Tube-Fed Patients

No specific guidelines exist for the frequency of dental recall visits for tube-fed patients. However, NICE guidelines for Dental Recall (2004) should be applied which states recall interval should be based on dental disease risk. Given these patients are at high risk of oral health issues and the consequence of oral disease puts their general health at risk, it may be prudent to advise the shortest interval between oral health reviews (3 months) (NICE, 2004). Dyment and Casas (1999) advised a recall interval of 3 months, considering the risk of pneumonia and the increased calculus accumulation, to allow for regular monitoring, scaling of calculus where appropriate, and give OH advice. The high speed at which calculus accumulates in these patients should be considered when determining recall intervals for tube-fed patients. (Mojon, 2002; Bassim et al., 2008; Ortega et al., 2014). With the available evidence acknowledging tube-fed children have poorer OH, increased calculus levels and that patients who rely on others for OH have poorer oral health, it seems key that meticulous OH and more regular attendance at the dentist be recommended for tube-fed children (Dyment and Casas, 1999; Jawadi et al., 2004; Tutor and Gosa, 2012).

1.5.2. Role of Dental Care Professionals

Dental care professionals have a key role to play in reducing the risk of AP by improving oral health. This is done by communicating oral health messages with the patient and/or carers, reviewing at regular intervals, giving targeted prevention advice, and treating patients safely and appropriately. Ensuring there is a pathway for patients to receive evidence-based advice, an oral health risk assessment and oral care as required from an experienced dental team is of great importance (All Wales Special Interest Group, 2014a). Considering the lack of studies and literature, there needs to be clear guidance for dental professionals about how and when to treat these patients and a recommended recall interval (Mojon, 2002).

1.6. Accuracy of Medical History of Tube-Fed Patients within Dental Notes

Tube-fed paediatric patients are often a vulnerable and medically complex group seen in the dental setting. The medical history for these patients, including formal diagnoses, swallow safety, and details on feeding, are particularly important given this impact on caries and periodontal risk, what treatments can safely be offered within the dental clinic (without risk of inhalation or aspiration) and allow tailored oral health advice to be given to parents/carers. Dental teams must have accurate medical history information to advise whether it is safe to undertake oral health care given the potential airway risk such care might present in a patient with an unsafe swallow. Anecdotally, the medical reason for a patient being tube-fed is often not readily apparent in the medical history within the dental notes e.g., failure to thrive or unsafe swallow, with parents/carers often uncertain regarding swallow safety.

Locally, BDCFT-CDS relies on a standard medical history proforma completed by the parent/carer, followed by verbal enquiries and clarification by the clinician. With more accurate and comprehensive information, it would be clearer to dentists about what care is feasible and what oral health advice is most appropriate to help improve oral health for these patients.

There has been some literature on the accuracy of medical history within dental notes as a research or audit topic. A 1977 study in the US army reviewed 100 medical histories in the dental records and compared them with their medical records, which found 39 discrepancies between the medical and dental records, eleven of these discrepancies were thought to be of major medical significance. As a result, they recommended patients presenting for dental examinations bring their medical records with them (Lewis et al., 1978).

Kovalesky et al., (2019) compared 200 paediatric patients' dental health histories (obtained via parental questioning) with their medical electronic health records (EHR) and found discrepancies in 97.5%, the only ones without errors were children with no relevant past medical history. As a result, they advised dentists obtain medical histories from the patients' doctors or use computer systems that integrate medical records with dental. A cross-sectional study reviewed agreement for medication use in self-reported surveys and the medical EHR in children with Cystic Fibrosis in the dental setting. It showed there was considerable disagreement between the survey and EHR and called for a standardised approach to improve the accuracy of medication data (Banks et al., 2021).

Another study reviewed the correlation of 115 dental-record medical histories with medical records and found a very high discrepancy rate of over 86% (Lutka and Threadgill, 1995). Even a recent study reviewing the medical history of 291 paediatric dental patients found a high rate of error (only 22% matched), showing that despite advances in information technology, this has not improved the situation in healthcare (Claman et al., 2021).

A further recent study reviewed 289 cardiac patients' medical records and dental medical histories and found a 75% discrepancy; they concluded this information gap is due to system-level problems and advised a model for efficient communication between medical and dental providers should be established, particularly for medically compromised patients, otherwise this can threaten the health of such patients (Al Hibshi et al., 2016). Conversely, a study in America found that parents gave certain aspects of their child's medical history (allergies, medications, immunisations, and past hospitalisations) with a 94-99% accuracy (Porter et al., 2000).

There is much debate on the method of attaining the most accurate medical history from patients in the dental setting. Carey and Stassen (2011) assessed the accuracy of medical history taking by dentists using three different methods; a written proforma questionnaire; consultant verbal enquiry; or an electronic questionnaire, to identify any differences or discrepancies between each method in obtaining the medical history. They found a written patient-administered proforma questionnaire, combined with verbal verification by the clinician proved to be the most consistent method for medical history taking, which is the same method used in BDCFT-CDS. This paper reviewed differences in questions asked to get an accurate history rather than the accuracy of the history itself. It did raise the issue that all methods of medical history taking were reliant on the patients' accuracy of recall and understanding medical conditions and diagnoses to answer questions fully, which was a concern as often parents and carers do not know or understand a child's full medical history, particularly when it is complex. This is supported in the literature by Brady and Martinoff (1980) who found that 32% didn't answer the self-reported medical history questionnaires correctly. Another study found that 25% of patients didn't answer correctly, and for paediatric dental patients' failure to report rates of parents ranged from 40-60% and were higher for medically compromised children (Fenlon and McCartan, 1992; Schwarz et al., 2004).

Rudman et al., (2010) advocated integrating medical and dental records to avoid discrepancies between notes, improve quality of care, improve safety, and reduce costs. Jones et al., (1999) discussed the feasibility and attitudes towards creating an integrated medical-dental record and found that 87% of dentists and 68% of doctors supported the idea. A 3-year prospective study by Haughney et al., (1998) to integrate medical and dental records in primary care found a reduction in discrepancies, safer care, and increased dental appointment attendance in an under 5-year-old population.

1.7. Conclusions of Literature Review

When completing a full search of the available literature only six papers were found that were relevant to the specific cohort of patients of interest i.e., the oral health of tube-fed paediatric patients (Dicks and Banning, 1991; Dyment and Casas, 1999; Jawadi et al., 2004; Brown et al., 2006; Hidas et al., 2010; Kim and Emanuel, 2019). Most other literature available involved elderly tube-fed populations, critically unwell intubated patients or individuals who had dysphagia but were not tube-fed, which had to be extrapolated. This highlights a gap in research and literature about this patient cohort.

Limited evidence available shows that tube-fed patients suffer worse oral health and are at risk of increased plaque and calculus levels, tooth erosion, xerostomia, and crowding. Increased plaque and calculus levels can be due to; oral hypersensitivity which makes brushing more difficult; poorer OH practices as they rely on carers/parents; issues around patient cooperation; and reduced saliva levels and muscle tone.

1.8. Rationale for Project

The most recent systematic review of the literature regarding the effects of OH on respiratory health of tube-fed children summarised available evidence, which was from only 2 articles (Kim and Emanuel, 2019). The literature review presented here mirrors their conclusions: there is limited evidence around OH practices to reduce AP in tube-fed children with further research advised. In addition, the literature (Dyment and Casas, 1999; Hidas et al., 2010; Kim and Emanuel, 2019) advises of a paucity of guidelines for the oral care of tube-fed children, and the need for evidence-based treatment guidelines to optimise care for these children. The current project will hopefully add to the limited body of literature by investigating the dental health, OH,

and past dental treatment of tube-fed children. Textbox 1 provides a clinical incident that illustrates the difficulties HCPs have managing these complex patients, which inspired this project.

The need for further research to support treatment and care recommendations is clear. We are aware these paediatric tube-fed patients are more complex to manage and if not cared for appropriately may have an oral environment that could have significant consequences on a patient's mortality, morbidity, and quality of life due to the risk of significant CI/AP. It seemed of interest to investigate the adverse respiratory outcomes these patients suffer, to assess the respiratory infection incidence in our local Bradford population, as well as the patient's oral health and dental history to help build on the limited body of evidence. This in turn may encourage guidelines or a local protocol to be created for this challenging cohort of patients, for whom regular reviews and good dental care should be a priority. It may also improve our knowledge of the challenges these patients face in their dental and general health by assessing their medical and dental histories, which will serve as a good basis for oral health conversations.

The literature surrounding medical and dental records described siloed systems, operating in isolation with resulting discrepancies. This is despite the management of this patient cohort calling for multi-disciplinary care and collaboration of multiple HCPs for the patient's benefit. Locally there was interest as to whether the dental team was gaining an accurate medical care record for the patient during their dental visits.

Children with feeding difficulties are amongst the most vulnerable seen by dentists with numerous medical health challenges and specific dental health issues. Calculus formation is the most common manifestation creating a strong clinical dilemma in addressing the disease in a safe way, given many of these children have an unsafe swallow and a GA is high risk with concern that failing to intervene can place these children at increased risk of CI/AP through the inhalation of infected material. Understanding the risk factors within this population for both the acquisition of oral disease and its consequences will clearly aid in targeting prevention. A review of the literature identified scant information and evidence regarding the oral health issues, possible implications on general health and subsequent oral care management of the paediatric tube-fed population.

Textbox 1: Real-Life Scenario

A parent expressed concern at the appearance of calculus on the patient's teeth and asked if it could be removed. The dentist explained as the patient had an unsafe swallow, safely removing this without impairing the child's respiratory health or risking aspiration of any secretions or calculus and protecting the airway adequately was not possible. The dentist discussed the only way to safely do this whilst adequately protecting the airway would be under GA, however the risks of the GA such as post-operative CI, or even death outweighed the benefits of removing the calculus. The dentist informed the parent to contact the dental team should the patient need a GA for another procedure to see if a joint GA was feasible. The father asked if he could 'chip off' the calculus with a spoon at home, which the dentist strongly counselled against. Shortly after, the patient was admitted to Leeds General Infirmary due to a serious CI and AP. A chest X-ray identified a piece of dental calculus in the lung. It came to light this was likely due to the father using a teaspoon to remove the calculus.

1.9. Aims of the Study

The study aims were:

- Describe the characteristics (medical) of tube-fed children in the local Bradford population, and in particular characteristics that risk children vulnerable to getting chest infections and/or AP.
- Determine the accuracy of the dental-medical record, taken by dental care professionals compared to the actual medical record.
- Determine the incidence of Chest infections or Aspiration Pneumonia within the local tube-fed population in Bradford, Yorkshire, known to BDCFT-CDS.
- Describe the oral health, oral healthcare regimens, and dental care of tube-fed children in the local Bradford population with a history of chest infections or aspiration pneumonia

Chapter 2: MATERIALS AND METHODS

2.1. Ethical Approval

Ethical approval was granted through the Research Ethics Committee (REC), Health Research Authority (HRA) (number 249799). Confidentiality Advisory Group (CAG) approval was applied for and granted by HRA. This was necessary as part of the project involved having access to Bradford Teaching Hospital NHS Foundation Trust (BTHFT) dietician's database of tube-fed patients to identify the study sample of tube-fed children known to both BTHFT and BDCFT-CDS. The researcher was not part of the direct care team at this point thus full permissions were required (CAG number 19/CAG/0227). Appendices show approval letters, patient information leaflets, and forms for the study.

2.2. Sample Selection

This project was undertaken within the Bradford child tube-fed population. The study sample was identified by access to the BTHFT Dietician's locally devised 'Tube-Fed Database', a database of paediatric patients who are tube-fed in Bradford.

2.2.1. Identifying the Study Population

Patients' NHS numbers from the BTHFT tube-fed database were cross-referenced with BDCFT-CDS electronic patient record database (R4) to identify which patients were already known to the CDS and had attended the CDS for dental appointments within the last 36 months. The study sample, therefore, consisted of patients known to both services (BTHFT dieticians and BDCFT-CDS).

2.3. Inclusion Criteria:

- aged between 2-16 years old (i.e., <16 years);
- artificially tube-fed (via Gastrostomy, Jejunal tube, Gastro-jejunal tube);
- known to BDCFT-CDS and BTHFT;
- received a dental check-up in BDCFT-CDS within the last 36 months (2018/2019/2020).

2.4. Exclusion Criteria:

- 16 years old and above, and under 2 years old.
- not tube-fed at the time of the most recent dental appointment.
- nasogastric tube feeding (i.e., very short-term tube feeding).

- patients for whom it is impossible to find or access medical and dental notes (e.g., incomplete clinical records, lost notes).
- not been seen by the CDS for over 36 months (i.e., before 2018).

2.5. Data Protection

The BTHFT Dieticians Tube-fed database was shared electronically using a secure nhs.net to nhs.net email account, via an encrypted, password-protected document and stored for the duration of the project on a CDS password-protected computer, within an encrypted document. All research data was kept securely by the researcher. Electronic data was stored on password protected encrypted computer files. The data obtained was anonymised to ensure no data could be identifiable. Data will be stored securely and accessed up to 3 years after thesis submission and then be destroyed securely.

2.6. Study Design

The study was a retrospective case note analysis of tube-fed paediatric patient records within Bradford (UK). This was split up into two parts as outlined below.

2.6.1 Stage 1 Protocol

An audit and retrospective analysis of medical and dental notes of tube-fed children known both to the medical team at BTHFT and BDCFT-CDS. The "Medical History" Section of the Dental Notes at BDCFT-CDS was reviewed and compared to the actual medical record at BTHFT and checked for omissions or discrepancies. The accuracy of this medical history-taking by the dental team was checked by cross-referencing and comparing the data sets with the patients' medical hospital electronic records from BTHFT. See Table 1 for Data Collection Sheet of Dental Medical History and Medical Record and Discrepancies.

2.6.2. Stage 1 Data Collection

Data was collected retrospectively from patient electronic records (BDCFT-CDS: R4/BTHFT: SystmOne).

Table 1. Data Collection Sheet for Medical History Accuracy. Summary of Information Collected from Dental Medical History and Medical Record, with omissions and discrepancies checked.

Patient ID:	Medical Notes	Dental Notes	Discrepancies? (Y/N and how)	Omissions in Dental Notes?
Consultant/name of lead doctor and other HCPs				

Medical diagnoses				
Medications (number and type)				
Type of tube feeding				
Duration of tube feeding (i.e., date of tube placement)				
Reason for tube feeding (e.g., failure to thrive, unsafe swallow, other)				
Safety of swallow				
NBM, or tasters (consistency of tasters), or oral feeding with top-up feeds via tube				
Dietician and advice given around oral intake				
Previous GAs/operations (date, reason, inc. Dental GA)				
History of non-elective admissions				
History of AP/CI (including dates)				

2.6.3. Medical Diagnoses

The Medical History in the Medical notes for this cohort of patients was often long, complex, and involved multiple diagnoses, multiple conditions, and in some patients' conditions so rare they were unknown or undiagnosed genetic/neurodegenerative/neuromuscular/neurological conditions. Medical Diagnoses were categorised into 10 categories based on a combination of the BAPEN report on tube feeding and NICE guidelines on indications for tube feeding (Smith et al., 2011; NICE, 2021) and were as follows:

1- Neuromuscular Conditions (such as Congenital myopathy, myotubular myopathy, cerebral palsy, muscular dystrophy, undiagnosed neuromuscular condition, cerebral palsy and epilepsy, Battens and epilepsy, arthrogryposis);

2- Severely disabled;

3 - Syndromes (Down and Pierre Robin);

4 - Orally Averse (Autism or feeding difficulties);

5 - Metabolic Conditions (such as Galactosaemia, Congenital Hyperinsulinaemia, Pompes Disease, Metachromic Leukodystrophy);

6 - Neurological Conditions (Epilepsy and Road Traffic Accident-causing brain damage);

7 - Failure to Thrive;

8 - Gastro-Intestinal Conditions;

9 – Cardiac Conditions;

10- Cystic Fibrosis.

2.6.4. Stage 2 Protocol

Patients identified in Stage 1 as having a history of AP or CI (from their medical notes) within the time frame specified i.e. (2018/2019/2020), had their electronic dental notes reviewed for the time period of 12 months before this via a retrospective case note analysis.

2.6.5. Stage 2 Data Collection

Data for this stage was collected retrospectively from the patient dental electronic records (BDCFT-CDS: R4). Table 2 shows a summary of the dental data collected from the dental record, i.e., the data collection sheet.

Table 2: Data Collection Sheet for Dental Variables from Dental Record

Dental Data Set	Patient 1	Patient 2
Clinician Grade		
Any complaints (C/O)		
Oral hygiene regime (including Toothbrush type, frequency, toothpaste type, supervised/completed by parents/carers)		
Diet reported		
Dental treatment history/previous experience/past dental history (prior to 2018)		
Oral hygiene		
Periodontal health		
Calculus levels		
Tooth wear levels (TSL)		
Caries		
Cooperation/examination quality		
Orthodontic findings		
Dental diagnoses		
Decay risk noted		
Periodontal disease risk		
Dental treatment needs (if any)		
Treatment options discussed (if required)		
Oral hygiene advice given		
Any dental care completed (if yes, how)		
Any history of Joint GA care		
Recall interval advised		

2.6.6. Pilot Data Collection Forms

The data collection forms and processes were piloted. Ten sets of notes were used to pilot the data collection forms and minor modifications were made thereafter.

2.7. Data Analysis and Statistical Methods

Data was collected, collated, and analysed via a secure, password-protected Microsoft Office Excel Spreadsheet. It was also analysed on Statistical Package for the Social Sciences (SPSS) software. Descriptive statistics were used as part of the analysis of the quantitative data including means and standard deviations. Qualitative or categorical data were summarised using proportions, percentages, and frequencies. Statistical analysis was completed to compare medical histories of tube-fed patients with and without a history of CI/AP to identify co-morbidities of tube-fed patients, in particular respiratory health, which is one of the aims of this study.

Tube-fed patients who had CI/AP were compared to those without CI/AP, to see if there were any associations with the following variables: being NBM, having a fundoplication procedure, unsafe swallow, history of dental GA, taking saliva reducing medication, taking prophylactic antibiotics, taking medication associated with gingival enlargement. This was to assess if any of these characteristics made tube-fed children more vulnerable to getting CI/AP.

Data was statistically analysed, with the guidance of a statistician, to assess for associations between oral health and the following for all tube-fed patients with a history of CI/AP: duration of artificial tube feeding, being NBM, having a fundoplication procedure, unsafe swallow. Other correlations and relationships were analysed including the use of medications associated with gingival enlargement, use of prophylactic antibiotics, use of saliva reducing medications, and dental health data sets.

There was no control group when looking at dental data and dental history with statistical analysis of dental data limited to the 49-patient sample who had CI/AP. The following groups were compared:

- NBM versus not NBM (oral fed): were reviewed to see associations between; calculus presence, dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

- Patients with Safe Swallow versus Unsafe swallow were reviewed for associations between; calculus present, dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

- Patients with NF versus no NF were reviewed to see associations between; calculus present, dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

- Patients taking medication related to gingival hypertrophy versus those not taking these medications were reviewed to see associations between; calculus present, dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

- Patients taking prophylactic antibiotics versus those not taking these were reviewed to see associations between; calculus present, dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

- Patients taking secretion reducing medication versus those not taking these medications were reviewed to see associations between; calculus present, dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

- Patients with calculus present versus calculus absent were reviewed to see associations between; dental caries, enamel defects, periodontal disease, previous dental GA, difficulty brushing, limited cooperation, age, and duration of tube feeding.

This statistical analysis used Chi-Squared, Fishers Exact, and Independent t-tests where appropriate, which were completed using SPSS software. Chi-squared and Fishers exact tests were used to test for association between 2 categorical variables (e.g., chest infection/no chest infection and unsafe swallow/safe swallow, safe swallow/unsafe swallow and periodontal disease present/absent). Independent t-test was used to compare the difference between 2 quantitative variables (e.g., duration of tube feeding). Significance was predetermined at the $P < 0.05$ level.

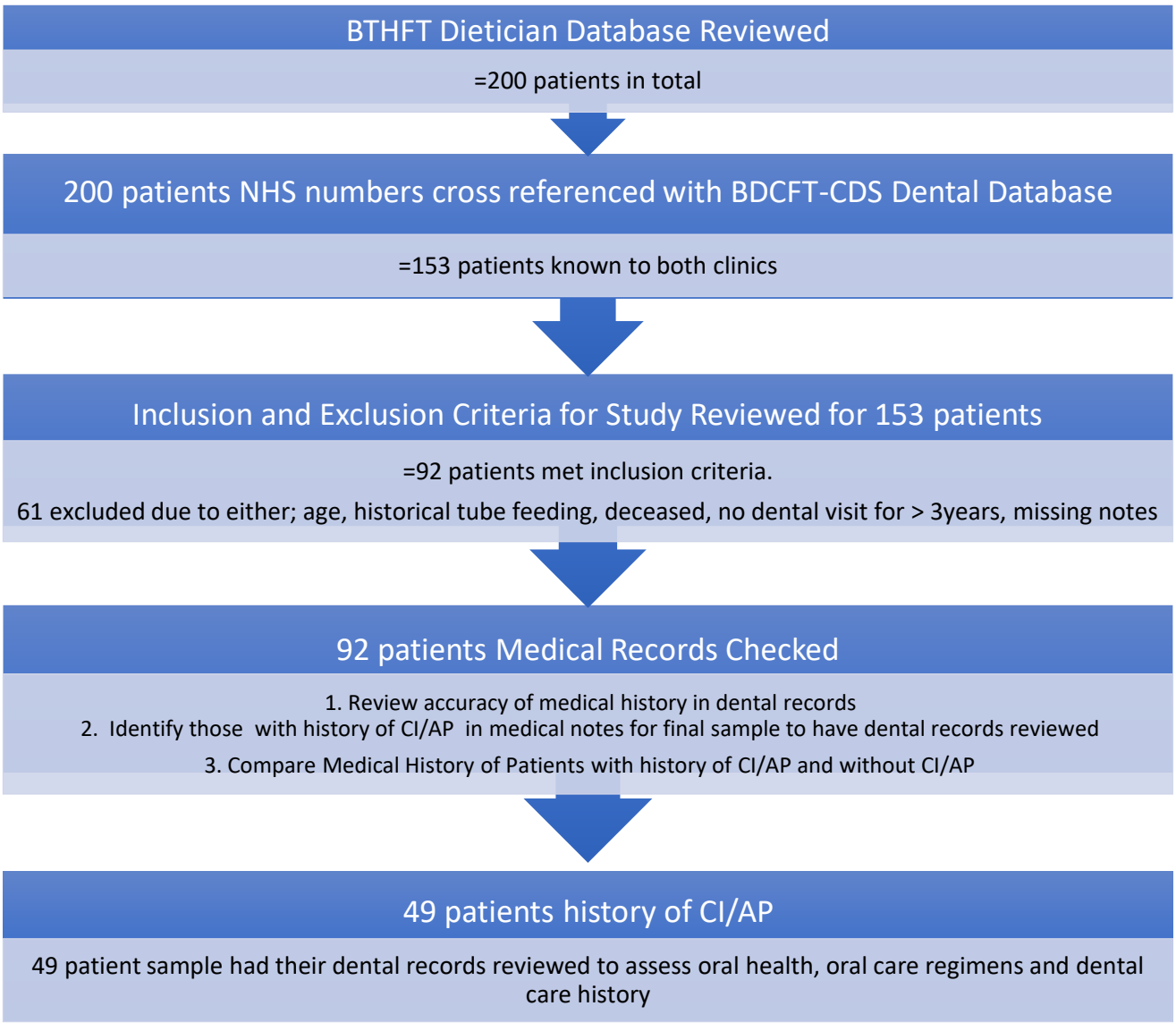
CHAPTER 3. RESULTS

3.1. Sample Size

In total 200 tube-fed patients were known to the BTHFT dietician team with 153 patients known to both BTHFT and BDCFT-CDS thus 76.5% of tube-fed patients were known to BDCFT-CDS. Within the 153 sample, after reviewing the inclusion and exclusion criteria, 61 patients did not meet the inclusion criteria, thus our total sample size was 92.

92 patient medical records were reviewed to assess the history of CI/AP, as well as reviewing the accuracy of medical record-keeping compared to the BDCFT-CDS medical history. 49 of these 92 medical records had patients with a history of CI/AP between 2018-2020 (53.3%), thus their dental notes were reviewed in detail to assess their oral health and dental history. Figure 1 shows a flow chart of the sample size at each stage of the study.

Figure 1: Flow chart of the cohort in the study



Of note, 10 additional patients had a history of CI/AP but were excluded, as the infections were before 2018. Furthermore, 1 patient had CI within the specified time frame but was excluded from the study as the dental notes were missing from the patient record.

3.2. Accuracy of Medical History in Dental Notes of 92 Patient Sample

There were large discrepancies in the information recorded and the accuracy of the medical history taking recorded in the BDCFT-CDS electronic patient record system (R4) compared with that in the BTHFT medical notes.

As a whole data set, **no patients** had complete and accurate medical histories in the BDCFT-CDS dental notes compared to the medical BTHFT records (Table 3).

Table 3: Accuracy of Medical Record in Dental Notes for Patient Sample

Medical Information Reviewed	Number and Percentage (%) of dental notes that contain **the same** (i.e., accurate) information compared to Medical Notes	100% standard for accurate dental records met?
Diagnoses Recorded	5 (5.4%)	No
Medication Recorded	33 (35.9%)	No
HCPs listed	2 (2.2%)	No
Date of tube placement	17 (18.5%)	No
Type of Tube placed	17 (18.5%)	No
Reason for tube feeding noted	25 (27.2%)	No
Safety of Swallow	36 (39.1%)	No
Feeding Habits (NBM, Tasters)	83 (90.2%)	No
Dietician Advice Recorded	71 (77.2%)	No
Admissions for Operations/ GA's	29 (31.5%)	No
History of CI/AP	41 (44.6%)	No

3.3. Sample of Tube-Fed Patients

The results are presented in the following formats:

- 92 total patient sample (i.e., all tube-fed children both with and without a history of CI/AP);
- the 49 patients who had CI/AP and 43 patients who had no CI/AP for a comparison.

Any statistically significant differences ($p<0.05$) found between each group will be specified.

3.3.1. Demographics: Age

Table 4 summarises the age across the total 92 patient sample who were tube-fed and known to BDCFT-CDS, 49 patient sample who had a history of CI/AP between 2018-2020, and 43 patient

sample who had no CI/AP history between 2018-2020. There was little difference in ages between the samples.

Table 4: Summary of Age of patient population as of November 2020

Current Age	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average (mean)	9.75 years	9.6 years	9.5
Standard Deviation	3.0	3.1	3.3

3.3.2. Demographics: Gender

The male: female split is summarised in Table 5. There was little difference in the gender split between CI/AP and non-CI/AP tube-fed patients.

Table 5: Gender of Sample Breakdown

Gender	Total Patient Sample (n=92) [% and number n]	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Male	60.9% (n=56)	57.1% (n=28)	65.1% (n=28)
Female	39.1% (n=36)	42.9% (n=21)	34.9% (n=15)

3.3.3. Medical History: Main Medical Diagnosis

The major diagnoses in the patients' medical history were ordered into ten main categories (organised by the researcher with the guidance of BAPEN and NICE categories) (Smith et al., 2011; NICE, 2021). The main diagnoses are summarised in Table 6. A higher proportion of patients had neuromuscular conditions such as cerebral palsy in the sample with CI/AP, compared to the 43 sample with no CI/AP.

Table 6: Primary Medical Diagnoses of Patients

Main Diagnosis % and number (n)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Neuromuscular condition such as Cerebral Palsy	51.1% (n=47)	67.3% (n=33)	32.5% (n=14)
'Complex severe disability'	15.2% (n=14)	8.2% (n=2)	30.2% (n=13)
Syndromes (Down or Pierre Robin)	8.7% (n=8)	10.2% (n=5)	7% (n=3)
Feeding difficulties and orally averse	6.5% (n=6)	2% (n=1)	11.6% (n=5)
Metabolic conditions such as Galactosaemia	6.5% (n=6)	2% (n=1)	9.3% (n=4)
Neurological conditions (Epilepsy)	5.4% (n=5)	2% (n=1)	2.3% (n=1)
Cardiac condition	2.2% (n=2)	2% (n=1)	0

"Failure to thrive"	2.2% (n=2)	2% (n=1)	4.7% (n=2)
Gastro-intestinal disorder	1.1% (n=1)	0% (n=0)	2.3% (n=1)
Cystic fibrosis	1.1% (n=1)	2% (n=2)	0% (n=0)

3.3.4. Overall Sample Medications

Table 7 illustrates a summary of medication numbers and types across the sample population. On average patients with CI/AP were taking 8 medications (range 0-21), which was more than those without a history of CI/AP, who took an average of 6 (range 0-13).

Medications of note were:

- Medications that can cause gingival enlargement as a side effect (such as tacrolimus, amlodipine, or sodium valproate), which could contribute to gingival health issues and plaque, and bacteria build-up.
- Prophylactic antibiotics to prevent CIs.
- Saliva and Secretion reducing medications e.g., hyoscine or glycopyrronium bromide (which may help reduce the risk of aspiration of secretions).

Table 7: Summary of Medication Numbers and Types across sample population

	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average number of Medications Taken	7 (range 0-21)	8 (range 0-21)	6 (range 0-13)
Standard Deviation	4	5	3
Percentage and Number (n) Taking Gingival Enlargement Medication	30.4% (n=28)	34.7% (n=17)*	21% (n=9)*
Percentage and Number (n) Taking Prophylactic Antibiotic Medication	42.4% (n=39)	59.2% (n=29)**	23.3% (n=10)**
Percentage and Number Taking Secretion Reducing Medication	n=28 (30%)	n=19 (38.8%)*	n=9 (20.9%)*

*Significant according to chi squared test ($p<0.05$)

**Significant according to chi squared test ($p<0.001$)

The Chi-squared test indicated the following:

- an increased number of patients who had CI/AP were taking secretion reducing medication ($p=0.041$). Thus, patients using secretion-reducing medication were more likely to have a history of CI/AP.

- an increased number of patients who had CI/AP were taking prophylactic antibiotics (p=0.001). Thus, patients taking antibiotics were more likely to have had CI/AP.
- an increased number of patients who had CI/AP were taking medication associated with gingival hypertrophy (p=0.01). Thus, patients taking medication associated with gingival hypertrophy were more likely to have CI/AP.

3.3.5. Health Care Professionals (HCPs) Involved in Care

Patients had numerous HCPs e.g., doctors, dieticians, occupational therapists, physiotherapists, who looked after them as part of the wider team. All patients in the sample had a paediatrician, dietician, and SALT as part of their care team. A breakdown of the average (mean) number of HCPs across the tube-fed patient samples is summarised in Table 8. There were similar number of HCPs involved in care for the 49 CI/AP patient sample and 43 non-CI/AP patient sample.

Table 8. Number of HCPs involved in Care for Tube-fed Population

Number of HCPs	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average (Mean)	8	9	8
Range	4-12	5-12	4-12
Standard Deviation	1.98	1.6	2.1

3.3.6. Feeding Tube Type

There were a variety of artificial feeding tubes patients had fitted, the majority had a gastrostomy tube (Table 9).

Table 9: Tube Types across sample population

	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Tube Type	Percentage (%) and Number (n)	Percentage (%) and Number (n)	Percentage (%) and Number (n)
Gastrostomy Tube	93.4% (n=86)	91.8%(n=45)	95.3% (n=41)
Jejunal Tube	3.3% (n=3)	4.1% (n=2)	2.3% (n=1)
Gastro-Jejunal Tube	3.3% (n=3)	4.1% (n=2)	2.3% (n=1)

3.3.7. Age at Initial Tube Placement

The average age at tube placement for the total 92 patient sample was 2.75 years (33 months). For the 49-patient sample who had CI/AP, the average age at initial tube placement was 6 months older at 3.25 years (39 months). Table 10 summarises tube patient age for the sample.

Table 10: Age of patient at initial tube placement across sample population

Age at Tube Placement (months)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average (Mean)	33	39	30
Range	1-125	1-125	1-118
Standard Deviation	27	30	26

Independent t-test showed no significant difference between the age of tube placement between patients with and without a history of CI/AP (>0.05).

3.3.8 Duration of Tube Feeding

At the time of data collection (November 2020) the average time patients in the 92-total sample had been tube-fed was 83 months, this was similar to both the CI/AP and no CI/AP sample (Table 11).

Table 11: Summary of Duration of Tube Feeding in patient samples

Age at Tube Placement (months)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average (Mean)	83	82	83
Range	31-169	31-169	29-153
Standard Deviation	33	35	31

3.3.9. Number of Tube Changes or Replacements

Since the initial tube placement, some patients had tube replacements, revisions or changes (Table 12). Comparison of the tube changes across the samples were similar.

Table 12: Tube Replacements in patient samples

Tube Replacements	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average Number of tube changes	0.8 (range 0-5)	1 (range 0–5)	0.6 (range 0-2)
Any number of Tube Replacements (TOTAL)	62% (n=57)	65% (n=32)	58% (n=25)
No Replacements	38% (n=35)	34.7% (n=17)	41.9% (n=18)
One Replacement	51.1% (n=47)	49% (n=24)	53.5% (n=23)
Two Replacements	5.4% (n=5)	6.1% (n=3)	4.7% (n=2)
Three Replacements	4.3% (n=4)	8.2% (n=4)	0
Five Replacements	1.1% (n=1)	2% (n=1)	0

3.3.10. Reason for Tube Feeding

The reason for tube feeding provided in the medical notes varied (Table 13).

Table 13: Reason Stated for Tube Feeding in patient samples

Reason for Tube Feeding Percentage (%) and Number (n)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Unsafe swallow	34.8% (n=32)	44.9% (n=22)	23.2% (n=10)
feeding difficulties/poor weight gain	51.1% (n=47)	34.7% (n=17)	69.8% (n=30)
unsafe swallow and feeding difficulties	8.7% (n=8)	12.2% (n=6)	4.7% (n=2)
unsafe swallow and failure to thrive	2.2% (n=2)	4.1% (n=2)	05 (n=0)
poor fluid intake	1.1% (n=1)	2% (n=1)	0% (n=0)
oral aversion	1.1% (n=1)	2% (n=1)	0% (n=0)
no record	1.1.% (n=1)	0% (n=0)	2.3% (n=1)

3.3.11. Fundoplication (NF)

1/3rd of patients had a NF. A higher proportion of patients with CI/AP had NF at a later date, rather than at the same time as tube placement, compared to those without CI/AP (Table 14).

Table 14: Number of Patients who underwent a NF in patient samples

NF Percentage (%) and Number (n)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Total Patients who had NF	33.7% (n=31)	36.7% (n=18)	30.2% (n=13)
NF at time of tube placement	15.2% (n=14)	10.2% (n=5)	20.1% (n=9)
NF at later date	18.5% (n=17)	26.5% (n=13)	9.3% (n=4)
No NF	66.3% (n=61)	63.2% (n=31)	69.8% (n=30)

3.3.12. Safety of Swallow

Table 15 shows the swallow safety across the sample. There was a significant association between unsafe swallow and CI/AP (p=<0.001), thus patients with CI/AP were more likely to have an unsafe swallow.

Table 15: Swallow Safety in patient samples

Swallow Safety % and number (n)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Unsafe	58.7% (n=54)	81.6%* (n=40)	32.5%* (n=14)
Safe	39.1% (n=36)	18.4% (n=9)	62.8% (n=27)
No Record	2.2% (n=2)	0%	4.7% (n=2)

*Significant according to chi squared test (p<0.001)

3.3.13. Feeding Habits

Dietician advice and feeding habits for the patient samples are shown in Table 16. Feeding habits varied across the sample. A higher proportion of children were NBM in the CI/AP sample. For one

patient (1%) the child's parent was still feeding the patient orally despite dietician advice that they should be NBM.

Table 16: Summary of Feeding Habits in patient samples

Feeding % and Number (n)	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
NBM	36.9% (n=34)	55.1%* (n=27)	16.2% (n=7)*
Occasional Oral Tasters	35.9% (n=33)	30.6% (n=15)	41.9% (n=18)
Oral (with Top-up Tube Feeds)	27.2% (n=25)	14.3% (n=7)	41.9% (n=18)

*Significant according to chi squared test ($p<0.001$)

This was simplified into patients who were NBM versus not NBM for statistical analysis. Using the Chi-Square test, there was a significant difference between being NBM and orally fed, and experience of CI/AP. Thus, there was a significant association between being NBM and having CI/AP ($p=<0.001$) i.e., if you were NBM, you were more likely to have a history of CI/AP.

3.3.14. Number of GA's and Dental GA's

All patients in the sample had one or more operations, with an average of 4 for those with a history of CI/AP and fewer (3.5) for those with no history of CI/AP (Table 17). Of note, 62% (n=57) of patients had more than one operation for tube changes of the total 92 patient sample.

Table 17: Summary of GA's performed in patient samples

	Total Patient Sample (n=92)	CI/AP Sample (n=49)	No CI/AP Sample (n=43)
Average (mean) number of GA operations per patient	4	4	3.5
Range of GA operations	1-10	1-10	1-9
Standard Deviation	1.9	1.9	1.9
Number (n) and Percentage of Patients who had a Dental GA's	17% (n=16)* (N.B. 8 were Joint GA)	24.5% (n=12)* (N.B. 6 were Joint GA)	9.3% (n=4)* (N.B. 2 were Joint GA)

*Significant according to chi squared test ($p<0.05$)

The Chi-squared test indicated a significant difference between Dental GA history and patients with and without a CI/AP ($p=0.034$). Thus, a history of Dental GA meant you were more likely to have had CI/AP.

3.3.15. Number of CI/AP episodes for patient sample with history CI/AP

The patients who had a history of CI/AP tended to have recurrent episodes over the time period reviewed (2018-2020) (Table 18).

Table 18: Number of CI/AP Episodes in 49 Patient sample

	Number of CI/AP
Average (Mean)	4
Range	1-13
Standard Deviation	2.7

3.4. Dental History and Oral Health Information of patients with history of CI/AP

The dental data results below in section 3.4 relates to the 49-patient sample who had a history of CI/AP.

3.4.1. Number of Dental Appointments Reviewed

Some patients had multiple CI/AP over the time period assessed, thus there were multiple dental appointments to review, 102 in total. The average number of dental appointments for the time period reviewed for these patients was 2 (range 1-5; Standard Deviation 1.1).

3.4.2. Clinicians involved in care

During the study period, tube-fed patients saw a range of clinicians from consultants, specialists, trainees and dental officers (Table 19).

Table 19: Grade of Clinicians seen during period of study

Grade of Clinician	Percentage Patients Seen %
Consultant	64.7%
Paediatric Specialist	7.8%
Senior Dental Officer	17.6%
Dental Officer	9.8%
Specialty Registrar Trainee	1%

3.4.3. Patient Complaints at Appointments

At tube-fed patients (with a history of CI/AP) appointments, parents/carers dental complaints and concerns for their children were as follows:

- **no complaints**: 52% (n=53)
- **periodontal health** related
    - 19.6% (n=20)
        - 9.8% n=10 gums bled when brushing,
        - 6.8% n=7 complained of calculus build up,

        - 2% n=2 complained of red inflamed gums
        - 1% (n=1) 'gums look thick'.
- **oral hygiene** related
    - 13.7% (n=14)
        - 8.8% (n=9) complained of difficulty brushing teeth
        - 2.9% (n=3) complained of bad breath
        - 2% (n=2) complained of black staining on teeth with difficulty brushing
- **orthodontic** related
    - 4.9% (n=5)
        - 3.9% (n=4) teeth crowding
        - 1% (n=1) front teeth stick out too much
- **behaviour** related
    - 3.9% (n=4)
        - 2.9% (n=3) tooth grinding
        - 1% (n=1) excessive drooling
- **oral medicine** related
    - 2% (n=2)
        - 1% (n=1) ulcers
        - 1% (n=1) oral thrush
- miscellaneous
    - 2.9% (n=3)
        - 1% (n=1) tooth crumbling but no pain
        - 1% (n=1) for undefined pain query if oral cause
        - 1% (n=1) parent worried about patient aspirating teeth due to unsafe swallow

3.4.4. Past Dental History

Patients with a history of CI/AP had limited interventional dental treatment at the BDCFT-CDS. Past dental history describes any treatment completed on these patients in the past, including beyond the period of study i.e., before 2018. Greater than two thirds of patients had previous treatment limited to examinations and prevention (69.4%, n=34). A few had limited treatment in the dental chair (4%, n=2). Some had had a dental GA for dental treatment (26.5% n=13). A summary of past dental treatment is presented in Table 20. For the 13 patients who had a dental GA, the treatment completed under GA is summarised in Table 21.

Table 20: Summary of Past dental treatment for 49 tube-fed sample with CI/AP history

Past dental history	Number	Percentage %
Examination and verbal preventative advice only	34	69.5%

Examination and verbal preventative advice and ultrasonic scale in the dental chair	1	2%
Examination and verbal preventative advice and polishing in the chair	1	2%
Examination and verbal preventative advice and dental treatment under GA (Total)	13	26.5%

Table 21: Summary of Treatment under GA for the 13 patients who had a Dental GA

Type of Treatment under GA	Number	Percentage %
Comprehensive Care (including scaling, restorations, fissure sealants, extractions)	5	10.2%
Extractions under GA	2	4.1%
Joint GA	6 (1 had examination only, 5 had comprehensive care)	12.2%

Chi-square test of tube-fed CI/AP patients indicated that tube-fed patients were more likely to have a dental GA if they were partially orally fed (Chi-square =8.01 p=0.005). This is in keeping with the fact that NBM patients have less decay thus likely to require less treatment.

The Chi-square test indicated that tube-fed children with CI/AP were less likely to have had a GA for dental treatment if there were taking secretion-reducing medication (Chi-Square=4.94. p=0.026).

3.4.5. Treatment Completed During the Period of Study

Over the period of study, 49 patients with a history of CI/AP had 102 appointments. This section describes any treatment the patients had during this time and shortly before they suffered CI/AP i.e., any dental appointments 12 months before having CI/AP were reviewed. The majority of appointments were prevention only (88.2% n=90). For restorations, no Local Anaesthetic was used. Table 22 summarises the treatment completed over the 102 dental appointment records reviewed.

Table 22: Treatment Completed over the 102 appointments during the period of study

Treatment completed	Number	Percentage %
Prevention Only	90	88.2 %
Prevention and Scale in the chair	3	2.9%
Prevention and GA waiting list	1	1%
Prevention, scale and composite restoration	1	1%
Prevention, temporary restoration with Glass Ionomer and GA waiting list	1	1%

Prevention and Glass Ionomer temporary restoration	1	1%
Hall Technique Crown	1	1%
No record	4	3.9%
Total	102	100%

3.4.6. Treatment options discussed by dentists

During the period of study, the dental care professional discussed aspiration risk for treatment in the dental chair and that dental treatment in clinic would not be safe at 26.5% (n=27) of appointments. At 26.5% (n=27) appointments dentists discussed treatment under GA, at 23.5% (n=24) appointments dentists discussed Joint GA, and at 28.4% (n=29) appointments dentists discussed the prevention-only approach.

3.4.7. Oral Hygiene Regimen (OHR)

Patients OHR varied greatly i.e., how often they had their teeth brushed, the type of toothbrush, and toothpaste they used.

Toothpastes: For 90.2% (n=92) of patient appointments, patients were using toothpastes that complied with guidance in the literature (Davies et al., 2004; Jawadi et al., 2004; Brown et al., 2006; Shahid, 2016). There was no note of any triclosan-containing toothpastes being used, which can reduce calculus accumulation. Table 23 summarises the type of toothpaste used by the patients.

Table 23: Toothpaste type for 49 tube-fed patient sample with a history of CI/AP

Toothpaste type	Number	Percentage %
Non-foaming	19	37.7%
Fluoride >1000 ppm	13	26.5%
Fluoride <1000 ppm	2	4.1%
Fluoride 2800ppm	2	4.1%
No paste (Sterile Water)	1	2%
No record in notes	12	24.5%
Total	49	100%

Toothbrushes: It was difficult to get a complete picture of toothbrushes tube-fed children with a history of CI/AP used, as over two thirds did not have a record of this in their dental records (n=33, 67.4%). Table 24 is a summary of the toothbrush type recorded in the patient notes.

Table 24: Toothbrush Type of 49 tube-fed patient sample with history of CI/AP

Toothbrush type	Number	Percentage %
No Record	33	67.4%
Manual Brush	6	12.2%
Electric Brush	4	8.2%

Two Brushes	2	4%
Dr Barman 3-sided Brush	1	2%
Mouth Sponges	1	2%
Cotton wool roll	1	2%
Towel	1	2%
Total	49	100%

To summarise, 8.2% (n=4 of 49) patients' notes had recorded 'gold standard oral hygiene practices' i.e., had their teeth brushed twice daily, with a fluoride toothpaste (which was non-foaming paste), with an appropriate toothbrush and were supervised.

Brushing Frequency: Only 34.7% (n=17) of tube-fed patients with a history of CI/AP had their teeth brushed twice daily as per standard advice (Shahid, 2016) (Table 25).

Table 25: Summary of Brushing Frequency Recorded for 49 tube-fed sample

Brushing Frequency	Number	Percentage %
Twice daily	17	34.7%
Once daily	22	44.9%
Less frequently that once a day. i.e. "rarely"	6	12.2%
No Record	4	8.2%
Total	49	100%

Brushing Supervision: 34 patients (69.3%) had their teeth brushed by parents/carers. There was no record either way for 14 patients (28.6%). 1 patient (2% sample) had unsupervised brushing recorded in their dental notes.

Brushing Difficulty: 51% (n=25) parents/carers reported they struggled to brush their child's teeth.

Use of Suction Whilst Brushing: Only 4 patients (8.2%) parents/carers used suction whilst brushing. The rest of the sample population had no record of using suction, with the advice being to use suction to reduce aspirating toothpaste/oral secretions (Shahid, 2016).

3.4.8. Cooperation

Patients had a range of cooperative ability for dental examinations and treatment, with most patients having limited cooperation (Table 26).

Table 26: Summary of Cooperative Ability for 49 tube-fed sample with CI/AP

Cooperation Recorded	Number	Percentage %

Limited	35	71.4%
Fair	6	12.2%
Good	3	6.1%
Excellent	1	2%
No Record	4	4%
Total	49	100%

3.4.9. Dental Recall Interval

The dental recall set by dentists varied, the average (mean) interval set was 6 months. A summary of Dental Recalls is shown in Table 27.

Table 27: Dental Recalls Set for 49 tube-fed sample with history of CI/AP

Recall Interval	Number	Percentage %
3 months	8	16.3%
4 months	4	8.2%
6 months	34	69.4%
9 months	2	4.1%
12 months	1	2%
Total	49	100%

3.4.10. Calculus Presence

The majority of patients had calculus on examination in their dental record (n=32, 65.3%) (Table 28).

Table 28: Calculus Recorded for 49 tube-fed sample with CI/AP history

Calculus Present	Number of Patients	Percentage %
Yes	32	65.3%
No	7	14.3%
No record in notes	10	20.4%
Total	49	100%

The level of calculus visible e.g., minimal, moderate, gross, generalised, localised was not routinely recorded in a standardised way, thus was difficult to summarise. For this reason, it was omitted from the results and analysis.

The Chi-squared test, reviewing the difference between calculus presence and safety of swallow showed a significant difference (p=0.017). Patients had increased calculus incidence with unsafe swallow (more than expected). Therefore, there was a relationship between unsafe swallow and calculus present. In addition, the following was noted:

- Tube-fed children with CI/AP who were NBM were more likely to have calculus according to the Chi-squared test (Chi square=8.53, p=0.03) compared to those who had orally feeding;
- Tube-fed children with a history of CI/AP who were taking medications associated with gingival hypertrophy were more likely to have calculus according to the Chi-square test (Chi square=15.0, p=<0.001), compared to those not taking these medications;
- Tube-fed children with a history of CI/AP who were taking secretion reducing medication were more likely to have calculus according to the Chi-square test (Chi square=9.23, p=0.002), compared to those not taking this medication type;
- Tube-fed children with a history of CI/AP, who had calculus present, were less likely to have had a GA for dental treatment according to the Chi-square test (Chi square=10.4, p=0.001);
- Tube-fed children with a history of CI/AP who have periodontal disease were significantly more likely to have calculus present according to the Chi-square test (Chi square=20.8, p <0.001).

An independent-samples t-test was conducted to compare the mean age of tube-fed patients with CI/AP (in months) with calculus present or absent. There was a significant difference in the ages of patients with calculus (Mean=101.2, SD=34.7) and without calculus (Mean=73.5, SD=43.0), p=0.01, meaning that older patients were more likely to have calculus present.

An independent-samples t-test was conducted to compare the duration of tube feeding of tube-fed children with CI/AP (in months) with calculus present or absent. There was a significant difference in the duration of tube feeding with calculus (Mean =62.4, SD =38.9) and without calculus (Mean =46.8, SD =4.4), p=0.044, meaning that patients who have been tube-fed for longer are more likely to have calculus present.

3.4.11. Periodontal Disease

Dentists recorded that over half (57.1%, n=28) of tube-fed patients with a history of CI/AP had periodontal disease as a diagnosis during the period of study (Table 29).

Table 29: Number of Patients with Periodontal Disease for 49 tube-fed sample with a history of CI/AP

Periodontal Disease present?	Number of Patients	Percentage %

Yes	28	57.1%
No	12	25.5%
No Record	9	18.4%
Total	49	100%

3.4.12. Periodontal Status and Type of Periodontal Disease

The specific type and diagnosis of periodontal disease, or periodontal status of the patient is summarised in Table 30. Unfortunately, 18.4% (n=9) patients had no record of periodontal health in the records.

Table 30: Periodontal Status and Diagnosis for 49 tube-fed sample with CI/AP history

Periodontal Diagnosis	Number of Patients	Percentage %
Plaque and Calculus induced Gingivitis	20	40.8%
Plaque induced Gingivitis	5	10.2%
Gingival Hypertrophy	3	6.1%
Healthy Gingiva/NAD	12	24.5%
No record either way	9	18.4%
Total	49	100%

3.4.13. Oral Hygiene

Oral hygiene recorded in dental notes for tube-fed patients with a history of CI/AP was varied, with no obvious majority or trend (Table 31).

Table 31: Oral Hygiene for 49 tube-fed patient sample with CI/AP history

Oral Hygiene Recorded by Dentist	Number	Percentage %
Very Poor	3	6.1%
Poor	16	32.7%
Fair	14	28.6%
Good	10	20.4%
Excellent/Very Good	2	4.1%
No Record	4	8.1%
Total	49	100%

3.4.14. Caries Presence

The majority of patients in the tube-fed patient sample with a history of CI/AP had no active caries during the period of study (87.8%, n=43). 12.2% (n=6) had caries during the period of study, and all these 6 patients were partially orally fed. Also, of note:

- Tube-fed children (with a history of CI/AP) with a safe swallow were more likely to have dental caries according to Fishers exact test (p=0.02) when compared to those with an unsafe swallow;

- Tube-fed children, with a history of CI/AP who are NBM, were less likely to have dental caries according to Chi-Square test (Chi Square=15.3, p<0.001), compared to those who have some oral feeding.
- Tube-fed children (with a history of CI/AP) who had a NF procedure were less likely to have dental caries according to Fishers exact test (p=0.03), compared to those who had not had a NF;
- Tube-fed children with a history of CI/AP, who were taking prophylactic antibiotics were less likely to have caries according to Fisher exact test (p=<0.001), compared to those who were not taking prophylactic antibiotics;
- Tube-fed children with a history of CI/AP, who were taking medications associated with gingival hypertrophy were less likely to have decay according to Fisher Exact test (p=0.029), compared to those not taking this medication type;
- Fisher's Exact test showed that tube-fed children with a history of CI/AP who were taking secretion reducing medication were less likely to have decay (p=0.01 significance) when compared to those not taking this medication type.

3.4.15. Tooth Surface Loss (TSL)

It was difficult to determine the levels of TSL as most patients (94%, n=46) had no record in the dental notes either way. Two patients (4.1%) had evidence of TSL (erosion). TSL presence, distribution, or levels were not routinely recorded in a standardised way

3.4.16. Dental Anomalies Present

There were few patients who had a dental anomaly recorded (a total of 20.4%, n=10), however, these patients tended to have multiple anomalies (Table 32).

Table 32: Breakdown of Dental Anomaly Types for the 49 tube-fed sample with CI/AP

Anomaly Type	Number	Percentage %
Delayed dental development	8	16.3%
Enamel defects	8	16.3%
Hypodontia	2	4.1%
Microdontia	1	2%
Fused primary tooth	1	2%
Infra-occluded primary molars	1	2%
No anomaly recorded	39	79.6%

3.4.17. Oral Medicine Diagnoses

There were minimal oral medicine-related diagnoses in the dental records; two patients (4.1%) had ulceration during the period of study and one patient had an oral candida infection (2%).

3.4.18. Other Dental Diagnoses

Two patients (4.1%) had a diagnosis of dental trauma during the period of study.

3.4.19. Orthodontic Findings

Orthodontic findings were not routinely recorded in a standardised way. 20 patients (40.8%) had no record of orthodontic findings. 11 patients (22.4%) were in the primary dentition, so this was not applicable. A summary of orthodontic findings is shown in Table 33.

Table 33: Summary of Orthodontic Findings within Patient Sample

Orthodontic findings	Number	Percentage %
Crowding	7	14.3%
Class 2 Division 1 Incisor relationship	5	10.2%
Class 3 Incisor relationship + Hypodontia	2	4.1%
Anterior open bite	1	1%
Anterior cross bite	1	1%
Class 1 incisor relationship	1	1%

3.4.20. Caries and Periodontal Disease Risk

The caries and periodontal disease risk were categorised as low, medium or high risk (Table 34).

Table 34: Summary of Caries and Periodontal Risk Categories

Caries Risk	Number	Percentage %
High caries risk	11	22.5%
Medium caries risk	5	10.2%
Low caries risk	33	67.4%
Total	49	100%
Periodontal Risk		
High periodontal risk	9	18.4%
Medium periodontal risk	24	49%
Low periodontal risk	15	30.6%
No record of risk	1	2%
Total	49	100%

3.6. Summary of Statistical Analysis for Medical History Variables of Tube-fed Patients

From statistical analyses where the 49 CI/AP patient cohort was compared with the 43-patient cohort with no history of CI/AP from 2018-2020, a significant association was found between:

1. CI/AP and being NBM (p=<0.001)

2. CI/AP and safety of swallow (unsafe swallow) (p =<0.001)
3. CI/AP and history of Dental GA (p=0.034)
4. CI/AP and use of secretion reducing medication (p=0.041)
5. CI/AP and use of prophylactic antibiotics (p=0.001)
6. CI/AP and use of medication associated with gingival hypertrophy (p=0.01)

Therefore, the following co-morbidities in this sample resulted in a higher risk of CI/AP:

- Being NBM (rather than orally fed)
- Having an unsafe swallow
- Using saliva reducing medication
- Using prophylactic antibiotics
- Using medication with a risk of gingival hypertrophy
- Having a history of Dental GA

3.7. Summary of Statistical Analysis for Tube-fed Patients with CI/AP, with their Dental Findings

The following significant associations were found for the 49-patient data who all had a history of CI/AP:

1. Safety of swallow and Calculus Present (p=0.017) (i.e., if have an unsafe swallow, more likely to have calculus present)
2. Swallow Safety and Caries Presence (p=0.02) (i.e., if have a safe swallow, more likely to have decay)
3. Safe swallow and History of Dental GA (p=<0.001) (i.e., if have a safe swallow, more likely to have had a GA for dental treatment)
4. NF and Decay. (p=0.03) (i.e., have less tooth decay if had a fundoplication procedure)
5. NBM and Calculus Present (p=0.03) (i.e., if NBM, have more calculus)
6. NBM and Decay (p<0.001) (i.e., if NBM, have less decay)
7. NBM and History of Dental GA (p=0.005) (i.e., if not NBM, more likely to have GA for dental treatment)
8. Medications associated with Gingival Hypertrophy and Calculus presence (p=<0.001) (i.e., if on medication, more likely to have calculus)
9. Medications associated with Gingival Hypertrophy and Decay Presence (p=0.029) (i.e., if on medication, less likely to have decay)

10. Prophylactic Antibiotics and Decay presence (p=<0.001) (i.e., if using antibiotics, less likely to have decay)
11. Saliva Reducing Medication and Calculus (p=0.002) (i.e., if taking saliva reducing medication, more likely to have calculus)
12. Saliva Reducing Medication and Decay (p=0.001) (i.e., if on medication, less likely to have decay)
13. Saliva Reducing Medication and Previous Dental GA (p=0.026) (i.e., if on medication, less likely to have had a GA)
14. Saliva Reducing Medication and Limited Cooperation (p=0.041) (i.e., if not on medication, more likely to have limited cooperation)
15. Calculus present and Periodontal Disease (p<0.001) (i.e., if have calculus, more likely to have periodontal disease)
16. Calculus present and Previous Dental GA (p=0.001) (i.e., if have calculus, less likely to have had a GA)
17. Calculus present and Age of Patient (p=0.01)
18. Calculus present and Duration of Tube Feeding (p=0.044)

Chapter 4. DISCUSSION

This section will have the following structure: a discussion of; the methodology, sample population, the medical history findings, the accuracy of the medical-dental record, the dental findings for tube-fed children with CI/AP, the implication of study findings, recommended actions, study limitations, and areas of future research.

4.1. Methodology

4.1.1. Sample Selection

Patients included in the study were all those children who were currently tube-fed, between 2-16 years old, were under BTHFT dietician care, and were cared for by BDCFT-CDS. Feeding via a nasogastric tube was excluded because these were children tube-fed in the short-term only, and thus were less likely to have prolonged effects of tube feeding.

Initial data collected included age, gender, and medical history in the dental clinical notes and medical records, to understand the medical health of the patient cohort, and identify those with a history of recurrent CI or AP requiring medical attention within the last 36 months. These patients with a history of CI/AP would then serve as our cohort of patients who had their dental records reviewed.

The data collection then involved the dental history available in the dental notes to understand the specifics of the patient cohort (i.e., the dental health of tube-fed patients with a history of CI/AP). Patients were excluded from the study if they had not received a dental check-up with BDCFT-CDS in the last 36 months, as this would mean we would not know their oral health status in the months prior to the CI/AP.

4.1.2. Diagnoses

Different types of CIs are difficult to diagnose accurately, particularly the different types of pneumonia, which is recognised in the literature (Couriel, 2002). Issues include difficulty in differentiating the cause, and different ways of categorising (e.g., community-acquired pneumonia vs hospital-acquired vs aspiration vs viral vs lower respiratory tract infection). It is also difficult to determine if the patient developed AP by aspirating substances from the oral cavity such as plaque or calculus or aspirating other substances from several other routes, including aspiration of saliva, toothpaste, bathwater, food tasters, or gastric reflux.

Ways of naming and diagnosing respiratory infections were inconsistent in medical records, thus it was decided any type of CI diagnosis should be included and deemed sufficient for dental notes to be checked. It was recognised patients could have had less severe respiratory issues that were managed by long-term prescription of prophylactic antibiotics, which could be a limitation of the study.

4.1.3. Interpretation of Notes

The review of both medical and dental notes was purely retrospective of appointments that had happened before November 2020 and relied upon the accuracy and detail given by the HCP providing care and writing the notes. A review of the dental notes was thorough, with every clinical entry analysed within the specific timeframe for all patients (i.e., dental appointments 12 months prior to CI/AP episode). Descriptions of treatment completed, the appearance of teeth/periodontium, oral health diagnoses, and observations of OH and calculus levels were taken as the exact wording of the clinician notes entry.

4.1.4. Pilot Study

The data collection Excel spreadsheets (for medical history data collection and dental history data collection) were piloted for 10 patient records to check ease of use. Following this, minor amendments were made, including the addition of “history of Joint GA” to the data collection sheet; this was something deemed to be of significant interest to the study to determine the utilisation of joint GA’s.

The pilot study also revealed it would take significant time to review the medical history from the centralised electronic system at BTHFT (SystmOne). The transition from paper notes to an electronic system in 2018 meant all previous paper notes and letters were uploaded and scanned as PDFs in no logical order such that the researcher found the medical notes a significant challenge to navigate.

4.1.5 Permissions and Timelines

REC approvals were challenging, as this project spanned two different Trusts, and involved a University site sponsor where data was securely stored. As such this study became multi-site and required more assurances. (BTHFT, BDCFT, and the University of Leeds).

This project not only required REC approval via HRA but also CAG approval, which wasn't advised as a requirement until after REC approval was granted. CAG approval was required because the researcher required access to the dietician database to discover the number of tube-fed children in the local area (Bradford), which included patients not in the direct care of the researcher. CAG approval process was lengthy, with long delays in response from the CAG team office due to short staffing and illness resulting in a delayed project start i.e., application to approval resulted in almost a 6-month delay.

4.1.6. Impact of COVID

COVID-19 significantly impacted the ability to complete the project as intended. This included: limited access to clinics for data collection, long-term shielding of these vulnerable patients; closure of clinics, and abandonment of routine check-ups.

The original methodology included a prospective element of the study: an examination of all tube-fed patients by the chief investigator and supervisor in BDCFT-CDS within 6 months to collect specific and reproducible data. Unfortunately, COVID meant this was abandoned. This element would have helped overcome limitations of retrospective data collection identified, e.g., past notes being incomplete or inaccurate, allow standardisation of dental descriptors, reduced biases, and allow for 2 groups (tube-fed children with CI/AP and those without) to have dental data statistically analysed and relationships identified.

4.2. Discussion of the sample population

Before ethical approvals, it was unknown what the total sample size would be, given permission was required to access the dietician database. There has been limited research on this specific cohort of patients with previous studies regarding the oral health of tube-fed patients having very small sample sizes: Jawadi et al., (2004) reviewed 27 patients in a study to compare oral findings of special needs children with and without a gastrostomy, Brown et al., (2006) had 24 patients reviewing the use of anti-calculus toothpaste and calculus levels for tube-fed patients, Klein and Dicks (1984) assessed 21 patients (adults and children) calculus accumulation, Hidas et al. (2010) reviewed 12 children's DMFT, calculus levels and saliva, Dicks and Banning (1991) assessed 15 tube-fed children and adults calculus accumulation.

It was deemed prudent to use the maximum number of patients who were known to both BTHFT and BDCFT-CDS to give the most accurate picture of the oral and respiratory health of tube-fed children in the local population, and to assess the accuracy of medical history taken by dentists within the BDCFT-CDS. After consulting a statistician within the University of Leeds, it was agreed that as this was an exploratory study, it would use descriptive statistics, and thus no power calculation was necessary. The total sample size was dependent on the number of patients known to both BTHFT and BDCFT-CDS meeting the inclusion criteria as detailed in the methods.

There was a total of 200 tube-fed patients known by BTHFT dieticians. When cross-referencing these patients with the BDCFT-CDS database, there were 153 patients known to both, thus 76.5% of tube-fed patients were known to the CDS at one point in time. 47 tube-fed paediatric patients out of the 200, (23.5% of the total of tube-fed children in Bradford) were not known to Bradford-CDS. This does pose a question as to where these patients receive dental care, as they are typically medically complex, require specialist care, and are not usually seen in primary care by General Dental Practitioners due to complicating factors such as cooperative ability and unsafe swallow. It may be these children are seen in primary care, or not seen by a dentist at all which would be more of a concern. This coincidental finding has been flagged and has an action plan.

4.2.1. Discussion of Sample Demographics (Gender and Age)

4.2.1.1 Gender

Of the 92 children sample, there were more males than females (56: 36 split) which was 60.9% of the sample. In the 49 children sample who had CI/AP, there were also more males (28: 21 split) which were 57.1% of the sample. It was difficult to determine whether this was representative of the wider tube-fed population, as these demographics had not been collected in the most recent BAPEN survey of tube-fed patients, nor could such demographics be found in smaller United Kingdom-based studies (Smith et al., 2011). It was however a comparable figure to the smaller tube-fed studies, where there were consistently more males than females: Hidas et al., (2010), had an 8:4 split (66.7% males), Brown et al., (2006) had a 15:9 split (62.5% males), Jawadi et al., (2004) had an 18:9 split (66.7% males). The most recent Italian survey of tube-fed children in 2016 had a different male: female split of 43:57 (Lezo et al., 2018).

4.2.1.2. Age

The average age for the 92 children sample with CI/AP was 9.75 years, which was similar to the 49 patients with CI/AP at 9.6 years. The most recent BAPEN survey does not provide any demographic data on UK tube-fed children (Smith et al., 2011). Previous tube-fed child studies had a range of ages, with the averages being 7.4 years in Jawadi et al., (2004); 4.04 years in Hidas et al., (2010); and 7.2 years in Brown et al., (2006).

4.2.2. Discussion of CI/AP Incidence

In total, 49 patients i.e., 53% of the 92-total patient sample had CI/AP during the period of study 2018–2020. These 49 patients tended to have multiple infections in this time frame, with an average of 4 CIs, range 1-13. This highlights how if these children have CI/AP, they are likely to be recurrent, which can come with significant morbidity, and can be a significant burden for the parents/carers and healthcare system.

There is very little literature on tube-fed children and CI/AP as highlighted in the literature review. It is discussed that tube-fed children may be more prone to CI/AP and have an increased incidence relative to the rest of the child population, however, it has never been quantified, and is difficult to do direct comparisons, particularly as these children are medically complex and have multiple disabilities; finding a comparable control group to analyse has been a challenge for researchers previously. Dyment and Casas (1999) discuss gastrostomy tubes in children are associated with AP, particularly children with neuromuscular impairments and an impaired swallow reflex. They also mention there are no mortality statistics for tube-fed children regarding CI/AP. Aspiration is reported in up to 89% of tube-fed adults (Blumenstein et al., 2014), however, this has not been evaluated in children. The most recent systematic review for tube-fed children with swallowing difficulties found good evidence of an association between gastrostomy tube feeding and AP. The review found a higher prevalence of pneumonia and oro-motor dysfunction in gastrostomy-fed children (Kim and Emanuel, 2019). This was based on literature specific to tube-fed children with a profound disability or neurodevelopmental issues (Eyman et al., 1993; Strauss et al., 1997; Sullivan et al., 2005).

The project has described the medical characteristics of tube-fed children vulnerable to getting CI/AP. This was done via comparing the 49 tube-fed patients with CI/AP history, with the 43

patients within the total sample who had not had CI/AP and by statistical analysis of the two groups, as discussed below in section 4.3.

4.2.3. Tube Feeding and CI/AP Association

Literature has shown some level of association between tube feeding and CI/AP, however mostly in those with unsafe swallow reflex and profound disabilities. Eyman et al., (1993) reviewed children with profound disabilities and found those who were tube-fed were surviving 4-5 years longer than those without, and pulmonary issues were the most likely cause of death for all these children. Strauss et al., (1997) reviewed 4,921 disabled children retrospectively and found tube feeding had increased mortality via respiratory infections due to recurrent aspirations. Tube feeding doubled the risk of mortality in these children with neurological impairment (relative risk of mortality increased by 2.1). Tube feeding is often more beneficial to these children, as it allows safe feeding and adequate nutrition. It may in fact reduce AP for children, especially those with severe disabilities, as there is less risk of aspirating food if it were given orally (Sullivan et al., 2004; Sullivan et al., 2005). This highlights how complicated the relationship is between tube feeding and respiratory health and it is a careful balance of risks versus benefits to recommend tube feeding.

Oral health variables, such as calculus or poor OH, and links to CIs have been discussed in literature by Dyment and Casas (1999), Jawadi et al. (2004), Brown et al., (2006), and Hidas et al., (2010). These papers also ask key questions about how to improve oral and respiratory health outcomes for such patients, though unfortunately these have still to be answered. One of the reasons for this could be difficulty in the ethical design of any studies which could answer such questions, the limited numbers and cohort of child patients that are tube-fed, and the general lack of research that has been undertaken in this field over the last 3 decades.

4.3. Discussion of Medical History of Tube-Fed Children

One of the study's aims was to assess the medical history of the local tube-fed population to determine characteristics in their medical history that makes tube-fed patients more vulnerable to CI/AP. To do this, the total sample medical history notes were reviewed (n=92) and statistical analysis was subsequently completed of 49 patient cohort with CI/AP versus the 43-patient cohort without CI/AP.

4.3.1. Safety of Swallow

Safety of swallow is a vital piece of information within the medical notes the dental team should know. Firstly, swallow safety determines whether the patient has any food or tasters orally-they are often NBM due to the risk of aspirating food-which can alter the oral microflora and the acidity in the mouth and can increase the risk of caries and/or dental erosion. Secondly, swallow safety can also determine if the patient silently aspirates secretions such as saliva, or other products like bathwater, which can contribute to AP or CI.

In addition, swallow safety also dictates how dentists can safely treat patients. Having an unsafe swallow means it is not safe to do any interventional treatment in the dental chair, even a hand-scale or placing fluoride varnish can put the child at risk of aspirating or inhaling secretions, which then puts them at increased risk of AP. Knowledge of swallow safety also dictates what preventative oral care HCPs can advise to parents/carers e.g., using a suction toothbrush, head in a chin-tuck position with low-foaming toothpaste. Often, if patients with an unsafe swallow require dental treatment, the only way to do this safely to protect the airway is via a GA.

For the 92-total tube-fed patient sample, 58.7% (n=54) had an unsafe swallow. The sample results for patients with an unsafe swallow were higher than the BAPEN classification of "swallowing disorder" which has 20% of the total UK tube-fed population of 1336 patients between 2001-2010 (Smith et al., 2011).

A higher proportion of tube-fed patients with CI/AP (49 patient sample) had an unsafe swallow at 81.6 % (n=40). Children with unsafe swallow had a higher incidence of CI, which was a statistically significant association ($p=<0.001$). This is in line with and adds to the body of literature that discusses unsafe swallow mechanisms can cause AP/CI, most of which is adult-only research (Langmore et al., 1998; Russell et al., 1999; Terpenning et al., 2001; Langmore et al., 2002; Mojon, 2002; Marik and Kaplan, 2003; Scannapieco et al., 2003; Kikawada et al., 2005; Ferozali et al., 2007). It is beneficial to confirm this within the tube-fed child population as there haven't been many studies to assess this specific population. Only a couple of child-centric papers have discussed this both of which are reviews of the literature (Dyment and Casas, 1999; Kim and Emanuel, 2019).

4.3.2. Medications Taken

Tube-fed children are on multiple medications to manage multiple co-morbidities. On reviewing the specific medication list of each patient, three groups of medications were considered to be of interest and potential dental significance; those which reduced oral secretions and drooling (glycopyrronium bromide and hyoscine patches), those that could cause gingival enlargement (calcium channel blockers for high blood pressure, certain anti-epilepsy drugs, immuno-suppressants for post organ transplantation to reduce transplant rejection), and prophylactic antibiotic used to reduce the chance of recurrent respiratory infections and subsequent hospitalisations.

This is pertinent to consider as a high proportion of our tube-fed patients take these medications for neuromuscular conditions affecting oro-motor skills such as Cerebral Palsy (affecting 55% (n=51) of our local population), recurrent seizures (affecting 47% (n=43) of our population), and 1% (n=1) patient with an organ transplant. The researcher reviewed differences in the number taking these medications in the CI/AP group and non-CI/AP group to further analyse this. No other studies in the literature review medication taken and its impact on oral health or CI/AP so discussion on this aspect is limited.

4.3.3. Secretion-reducing Medications

30% (n=28) of the total sample patients took hyoscine or glycopyrronium bromide. A higher proportion, 38.8% (n=19), of CI/AP patients took secretion-reducing medication, compared to fewer without CI/AP at 20.9%. These medications reduce saliva flow, oral secretions, and drooling. It is often used for patients with neuromuscular dysfunction such as cerebral palsy (Cameron and Widmer, 2013). This may help reduce silent aspiration of saliva as secretions are reduced, thus potentially reducing the incidence of AP, but can have a negative impact on dental and oral health by causing a drier mouth. If saliva is reduced, the protective moisturising effect is reduced which means there is reduced oral clearance, reduced buffering capacity to neutralise harmful acids in the mouth which can lead to either erosion or tooth decay and reduced saliva antibodies which are key to fighting infection and reducing bacterial and viral loads in the mouth. Reduced saliva and oral moisture can also lead to gingival inflammation, increased bacterial load, and even dental caries if the patient is orally fed at any point. The impact of reduced saliva may be in fact amplified as Brown et al., (2006) states gastrostomy feeding is associated with reduced saliva flow. Taking such medication may reduce the risk of significant CI by reducing fluids that

could be aspirated but have an adverse effect on oral health. However, more patients took this medication and had CI/AP, which was statistically significant. The Chi-squared test showed an increased number of patients who had CI/AP who were taking secretion-reducing medication ($p=0.041$). Thus, patients taking medication associated with reducing secretion were more likely to have a history of CI/AP.

A study of oral health in elderly people in a nursing home concluded that reduced saliva flow allows oral bacteria to become more pathogenic and increases the likelihood of CI/AP (Russell et al., 1999; Jawadi et al., 2004). A similar study has not been carried out on the child population. Another consideration is the CI/AP may be due to the unsafe protective mechanism of swallowing itself and other medical diagnoses, rather than the medication itself. Dicks and Banning (1991) advised further studies into saliva flow, pooling, and composition are required to review its impact on oral health for tube-fed children, particularly calculus build-up. A study of this nature has not yet been completed.

Further statistical analysis found that tube-fed children with a history of CI/AP who were taking secretion-reducing medication were more likely to have calculus according to the Chi-square test ($p=0.002$). Previous studies have discussed increased calculus levels for tube-fed children but have not understood its causation (Klein and Dicks, 1984; Dicks and Banning, 1991; Dyment and Casas, 1999; Jawadi et al., 2004, Hidas et al., 2010). A few theories have been discussed which include increased calculus (even with good OH) may be due to lack of oral function and mastication according to Dicks and Banning (1991) and Jawadi et al., (2004), or when the saliva is over a critical pH for a sustained period (Hidas et al., 2010), but this specific novel finding connecting medication use has not been discussed in the literature prior.

4.3.4. Prophylactic Antibiotics

42.4% (n=39) of the total sample took prophylactic antibiotics as part of their medications. These patients often take these over the winter months to reduce the incidence or severity of respiratory infections, or the need to be admitted to hospital, so patients taking these are known to be at risk of CI/AP. This may have affected our results by reducing the number of CI/AP incidences recorded for each patient. Respiratory infections are a known common cause of death for patients with mental disabilities (Dyment and Casas, 1999). Antibiotics may change the flora of the plaque biofilm or the type of oral bacteria present, thus it may impact the oral health of

these patients inadvertently, such as potentially reducing the number of cariogenic pathogens, therefore reducing the caries incidence and rate. Hidas et al., (2010) completed a study reviewing the saliva composition of tube-fed children with disabilities with matched control groups of disabled orally fed children and found tube-fed children had the lowest levels of lactobacilli and mutans streptococci, which are bacteria associated with caries. This study didn't consider the medical history of these children or medications taken or their impact, which would have been interesting to note. Jawadi et al. (2004) reviewed saliva composition between three groups; tube-fed children with AP, tube-fed children without AP, and controls without AP, and found significant differences in bacterial saliva composition (such as H. Influenzae) but could not draw on its significance or find a role of this bacteria in AP. It also did not consider medication effects thus this element was overlooked.

A higher proportion of patients with CI/AP were prescribed prophylactic antibiotics (59.2% n=29), compared to those with no CI/AP (23.3%, n=10), which reinforces they are prescribed for patients who are known to suffer from respiratory infections. The Chi-squared test showed a significant association between patients who had CI/AP and taking prophylactic antibiotics (p=0.001). This is not a novel finding, as it is likely they take antibiotics because of the history of recurrent CI/AP but reinforces respiratory infections are a significant co-morbidity for this cohort of patients.

4.3.5. Medications associated with Gingival Hypertrophy

30.4% (n=28) of the total sample were taking; tacrolimus, amlodipine, lamotrigine, topiramate, or sodium valproate, which are known to have a potential adverse side effects of gingival hypertrophy. This could contribute to gingival health issues, lead to plaque build-up and cause periodontal disease. Such bacterial build-up could be harmful especially if aspirated and lead to respiratory infections.

Enlarged gingiva is more difficult to clean and more at risk of plaque and calculus accumulation, which can affect gingival health. This could also impact respiratory health if the bacteria in the plaque biofilm are more pathogenic and if such bacteria are aspirated due to unsafe swallow. Previous literature by Terry and Fuller (1989) and Dyment and Casas (1999) also reported that bacteria associated with AP are found in higher amounts in people with gingival hypertrophy. A higher proportion of patients who had CI/AP were on medications that can cause gingival hypertrophy (34.7%, n=17), compared to those with no CI/AP (21%, n=9). This leads to a new

finding to add to the literature, that tube-fed children taking these medications associated with gingival hypertrophy were more likely to have a history of CI/AP, with a significant association found using Chi-Squared test p=0.001. The effect of this medication on tube-fed patients and their oral health has not been reviewed before, with no information on its effects available.

4.3.6. Health Care Professionals

The average number of HCPs the total sample of patients had was 8 (range 4-12). For the CI/AP cohort, this average was higher at 9 (range 5-12), but there were no statistical differences between CI/AP and no CI/AP. These numerous HCPs can often lead to numerous appointment demands on the parents/carers. Within each appointment it is likely information and advice is given to parents/carers about how to best care for their child. The numerous demands, medical care burden, and information overload may be a reason why dental care and daily OH are low on their priority list and may explain the oral health of such patients.

Each patient contact provides the opportunity to ensure good preventative oral healthcare and support is there for the families of these children. There may be missed opportunities to be checking in 'holistically' with these patients, to see if they have any concerns/issues, or to be able to offer guidance or support or signpost them to appropriate care pathways within our dental appointments. It may be beneficial to try to raise awareness regarding the importance of good OH and dental care with other HCPs or at other hospital appointments. This lack of awareness and education regarding the importance of oral health for paediatric patients in hospitals has been acknowledged and led to a national campaign in England called "Mini Mouthcare Matters" (Health Education England, 2020). This programme aims to improve HCP awareness of the importance of oral health for children admitted to hospital for over 24-hours. It wants to "empower medical and allied medical healthcare professionals to take ownership of the oral healthcare of any paediatric in-patient" by simple measures such as providing toothbrushes and including oral healthcare as part of their basic general care (Health Education England, 2020).

4.3.7. NF Procedure

33.7% of the total patient sample had undergone a NF procedure, there were no significant differences in the CI/AP patient group versus the non-CI/AP group. This procedure helps prevent GORD (Hull University Teaching Hospitals NHS Trust, 2020), which is a common finding in tube-fed children (Dyment and Casas, 1999), and thus reduces silent aspiration or inhalation of gastric

contents which can have negative consequences on patient's respiratory health. Reflux can also lead to dental erosion (Dyment and Casas, 1999). Due to limited note-taking of dental erosion and no prospective study, it was not possible to statistically analyse dental erosion, thus findings around this aspect were absent.

4.3.8. Diet, Oral intake, and Feeding Habits

Whether the patient is NBM or has food (either in taster form or meals) is key information for dentists to have and accurately record. Similarly, to an unsafe swallow, this information can affect treatment decisions and preventative advice given. Inaccurate information can leave the patient vulnerable to aspiration and its consequences such as AP if dental treatment is undertaken or even if preventative care such as fluoride varnish is applied. It helps determine dental decay risk, which can impact what recall interval is given to the patient.

Results found dentists were not always accurately recording whether these children were NBM, their oral intake, or swallow safety, with 61% (n=56) dental notes being inaccurate regarding their swallow safety and 10% (n=9) dental notes being inaccurate regarding their oral intake (i.e., there was no record, or what was recorded was incorrect compared to the medical record). It would also be beneficial for dental care professionals to record in detail what the child's feeding habits were and have access to what the dietician/SALT had advised. This would help the dental team understand if parents/carers were following HCP advice and allow them to reinforce diet advice to reduce caries risk e.g., advising tasters or snacks which were lower in sugar, and advising on the frequency. It would also flag if there were any discrepancies between official HCP advice and the actions of the parents/carers.

A higher proportion of tube-fed children with CI/AP were NBM, this was a statistically significant finding. There was an association between CI/AP and being NBM ($p=<0.001$), thus tube-fed patients who were NBM were more likely to have a history of CI/AP. A possible reason for this is if you are NBM you are more likely to have an unsafe swallow mechanism. It could be these children are "silent aspirators", and aspirate oral secretions containing pathogens which could lead to the significant CI/AP, which is discussed in the literature (Dyment and Casas, 1999).

4.3.9. Number of Tube Replacements

62% (n=57) of the total sample had one or more tube replacements or revisions. 65% (n=32) of CI/AP sample, some having multiple replacements over time. To replace, revise or change a tube a child must undergo a GA, this could provide an opportunity for the dental team to join the GA to examine the child or complete treatment in a safe controlled environment where the airway is protected. The literature recommends frequent calculus removal to reduce the risk/frequency of AP (Hidas et al., 2010) because there is a relationship between calculus level and AP but not between AP and calculus removal itself (Jawadi et al., 2004). So ideally the dental team joining a GA that is already happening would be beneficial and less risky than attempts to scale in the dental chair or a second GA with its associated risks.

4.3.10. General Anaesthetics

Tube-fed children had multiple GAs for numerous reasons, including tube replacements. There were no statistically significant differences between the number of GAs in either those with or without a history of CI/AP.

There was a significant association between children with CI/AP and a history of dental GA ($p=0.034$). More children with a CI/AP had undergone a dental GA (24.5%) compared to those with no history of CI/AP (9.3%). This is a new finding which has not been discussed in literature before. It is difficult to deduce the causation of this, only there is an association. However, potential reasons for this, considering there is no association between the number of GA's and CI/AP, could point to the fact that dental GA for dental treatment is usually undertaken due to a diagnosis of dental disease or poor oral health e.g., caries or periodontal disease. Thus, it may be possible to assume poor oral health in tube-fed children may be linked to CI/AP.

For these reasons, it would be pertinent to advocate and recommend joint GAs for dental treatment wherever possible, reducing the number of GAs. This would seem potentially feasible, as these children have undergone an average of 4 GAs in the study. It also correlates with a national agenda about best utilising GA services with increased demand and waiting list pressures across the NHS for better patient care, called the Getting It Right First Time (GIRFT) report for improved hospital dental care (Jones, 2021).

4.4. Discussion of Medical History Accuracy Within Dental Records

Assessment of the quality of medical record taking for tube-fed paediatric patients attending the BDCFT-CDS identified whether dental professionals at the CDS were accurately documenting tube-fed patients' medical history in their electronic dental records when compared to their actual medical history in their medical notes. Accuracy of the medical history taken by dentists is important as it can inform dentists what care is safe and feasible in the dental clinic and what oral health advice is most appropriate to help improve the oral health of these patients. Thus, facilitating safe, appropriate, and optimal oral healthcare for tube-fed patients.

Results showed none of the patients' dental-medical history records were accurate and complete, 100% of notes had discrepancies. The medical and dental record notes did not correlate. This included only 36 (39.1%) patients dental notes having swallow safety accurately recorded, which was a concern as swallow safety dictates how a patient can be safely treated.

Numerous studies, even in recent years (spanning 1978-2021) found similar results, that there was a high rate of discrepancy, which highlight this is an ongoing problem to fully integrate a universal healthcare record across different healthcare providers, despite calls for improved information technology (IT) and information sharing. The high rate of discrepancy in accuracy between the medical records and dental medical history may be due to either (1) recall of parents/carers not knowing full medical history, (2) dental professionals not asking the right questions, (3) poor documentation, (4) a combination of the discussed. Recall of medical history knowledge demands a high level of parent awareness, as highlighted in Theis et al., (2010). This leads to a debate as to whether the emphasis should be placed on the dental care professional to ensure they are obtaining accurate notes rather than relying on the recall of a parent who may not know the finer detail of the child's medical condition, which is often complex. It highlights the need for better crosslinking and connected medical data sharing, to allow for better patient care. For such patients, the dentist in the CDS (which is a different healthcare Trust and works in silo from BTHFT) must either access the BTHFT patient record system which only a limited number of dentists can access, or contact the paediatrician/general medical practitioner for a summary of the medical history and clarification of specific elements, both of which are time-consuming.

The need for better IT systems that can create a shared care record across different healthcare settings has been advocated in numerous NHS documents, including "Use of Technology to

Improve Services", and "Multidisciplinary Team Working". Both documents recognise significant barriers and challenges to implementing such but advocate for its implementation due to the ability to access better information more efficiently to save time and money, so HCPs can make better decisions about care for improved health outcomes (NHS Institute for Innovation and Improvement, 2017; NHS Institute for Innovation and Improvement, 2008).

Determining the accuracy of the dental-medical record was an audit and quality improvement project within itself. Results will be shared with the clinical lead and dental team within the CDS, and a specific action plan formulated to ensure this improves. The poor accuracy is due to poor communication, poor IT systems, and reliance on parent recall. Also, the NHS electronic patient record computer programme the researcher accessed to gather this data on medical history summaries, medication lists, admissions for CI/AP, emergency admissions, GA operations, was very disorganised, with paper notes being uploaded to the system on PDFs without any logical order. This meant collecting key medical data sets was very time-consuming. It is important to note the Trust (BTHFT) transitioned to the electronic patient record system in 2018-2019. Notes prior to 2018/9 were scanned in no logical order, however, it is hoped that notes from 2019 onwards will be all electronic thus much better organised and easy to navigate. This project may create a conversation as to how we can improve technology and communication between specialties, Trusts, and HCPs for the overall health benefit of the child.

4.5. Discussion of Dental findings for Patients with CI/AP

The assessment of CI/AP history of the 92 patients identified 49 paediatric tube-fed patients who had CI/AP within the time frame specified. This allowed a detailed case series review of the 49-paediatric tube-fed patients and their dental history within the CDS.

4.5.1. Dental Complaints of Tube-Fed Patients with CI/AP

When dental appointment notes were reviewed, there was a variation in parent/carer concerns at appointments, with no trends apparent. Over half (52%) of parents/carers had no complaints about their child's oral health. The largest concern for parents/carers was related to periodontal health with 19.6% voicing concerns at appointments, such as gums bleeding and calculus accumulation. This being the second most common concern (after no concerns) was no surprise as calculus accumulation is a known problem, as supported by previous literature by Klein and Dicks (1984), Dicks and Banning (1991), Jawadi et al., (2004) and Brown et al., (2006) who found

tube-fed patients had higher levels of calculus. Dyment and Casas (1999) recognised high levels of calculus and periodontal disease in tube-fed patients compared to a control population who were not tube-fed. The number of complaints regarding this was lower than the researcher expected, particularly when there were 65% of patients who had visible calculus and 53% with periodontal disease recorded. Oral findings (such as periodontal health and calculus presence) in the examination notes suggest there perhaps should have been some concerns raised by parents. This may have been because they were unaware of problems, lacked knowledge/education, or accepting of the "status quo" with problems having been long-term issues with a limited scope of being able to do anything to resolve in the dental setting.

The third most common concern from patients was related to OH at 13.7% (e.g., difficulty brushing), this is not a surprise as reported in previous literature, these patients either have a neurological impairment that affects cooperative ability to cope with such tasks and many suffer from oral hypersensitivity due to the lack of oral stimulation from food (Dyment and Casas, 1999; Kim and Emanuel, 2019).

4.5.2. Past Dental History of CI/AP Patients

The past dental history discussed here is the previous dental treatment received prior to the period of study (prior to 2018). Very few patients with a history of CI/AP had received any dental treatment in the chair. Only 2 (4%) had a scale or polish in the chair. This is likely due to cooperation issues limiting what could be done, as these children have complex medical needs. As well as this, a large proportion of children had an unsafe swallow meaning it would be unsafe to treat without airway protection.

Most patients had examinations and prevention only (69.5%), despite 65.3% having calculus present, which dentists would usually remove for cooperative patients with a safe swallow to reduce the risk of periodontal disease. This demonstrates the dental team have a minimal intervention approach to treatment which was likely due to cooperative ability (71.4% having limited cooperation recorded) and unsafe swallow (81.6% patients), limiting treatment feasibility in the chair. This is because dental treatment can risk patients inhaling oral fluids/debris etc. and cause AP (Dyment and Casas, 1999; Kim and Emanuel, 2019), which must be avoided.

Over a quarter (26.5%, n=13) had treatment under GA previously, signifying a large proportion requiring treatment for dental disease in a controlled environment. Only one patient (2%) had an examination under GA, which was a joint GA. This proves there is a dental treatment need for a significant number of these patients, for which treatment in the chair is either not possible due to cooperation, inappropriate due to the extent of care required, or unsafe owing to swallow safety and aspiration risk of fluid or debris created by dental treatment.

Chi-square test of tube-fed CI/AP patients indicated tube-fed patients were more likely to have a dental GA if they were partially orally fed i.e., not NBM (p=0.005). This is in keeping with the fact that NBM patients have less decay thus likely to require less treatment for this. This also may tie in with the statistically significant finding that if patients had a safe swallow, they were more likely to have a dental GA (p=<0.001): this is because patients with a safe swallow are more likely to be partially oral fed (having cariogenic carbohydrates) thus are more prone to caries. If they have caries, they are more likely to have a treatment need and thus have a dental GA. Despite the fact a safe swallow means they are more likely to be able to be safely treated in the dental chair, the amount of treatment required or the cooperative ability of such patients who usually have multiple disabilities can preclude this.

There was a significant finding in the relationship between calculus and previous dental GA, if patients had calculus, they were less likely to have had a dental GA (p=0.001). This may be explained by the fact that if they had been treated under a GA, they had their calculus removed, thus at the time of examination, there was less calculus present. No other studies have reviewed this aspect thus further comment is not possible.

A Chi-square test indicated tube-fed children with CI/AP were less likely to have had a GA for dental treatment if they were taking secretion-reducing medication (p=0.026). This is an interesting finding, as these patients also are statistically significantly more likely to have limited cooperation for dental treatment in the clinic and more calculus. However, there was a statistically significant finding that if they are taking these medications, they are less likely to have decay which may explain the fact that in absence of noticeable disease (such as decay) it is difficult to justify a dental GA, and calculus presence is not a justification for GA. There is no literature on this to comment further.

4.5.3. Joint General Anaesthetics

6 patients had 'joint' GAs for dental treatment. A joint GA is when a patient has one GA for more than one procedure, by different surgical specialty teams, aiming to reduce the number of anaesthetics and hospital admissions, and the associated morbidity and mortality risks, such as nausea, vomiting, respiratory infections, headaches, blindness or death. The researcher considered whether there were missed opportunities for joint GAs for patients who had multiple medical GAs and either had such poor cooperation a thorough dental examination was not possible or had calculus present, but swallow safety would not allow for safe removal in the dental chair.

Joint GA's may prove a more efficient and effective use of theatre and hospital time/resources and reduces risks to the patient. For example, if a patient requires a GA for dental treatment and a GA for a tube change, they may have two separate shorter GAs at two different times, but this impacts the families and patients who require more time off school, parents/carers require more time off work, they are exposed to anxiety-inducing GA procedures twice, and associated risks. However, a 'joint GA' means two surgical specialties need time to coordinate so their treatment to be undertaken under one longer GA.

A joint GA allows the dental team to undertake care that may have not been possible otherwise when considering risk-benefit analysis and decision making if the GA would have to be planned for dental care alone. It would never be deemed suitable or appropriate to have a GA just for an EUA or scaling alone in absence of signs or symptoms, but often these are invaluable in uncooperative patients where an examination or treatment by any other means would be impossible and potentially unsafe without airway protection and may allow the dental team to diagnose dental disease or allow a full mouth prophylaxis to reduce the bacterial load which in theory could be aspirated. Undergoing GA can also affect the patient's lung health, thus increasing risks to respiratory health further. CIs are a known risk post-GA, and it is listed as such by the Royal College of Anaesthetists (2017), as the anaesthetic affects the normal way in which phlegm is moved from the lungs. This is important to consider in this already vulnerable cohort of patients, who are prone to multiple respiratory infections.

Due to lack of integration and communication issues, no mechanisms exist which inform different HCPs a GA is taking place without the medical teams directly and personally contacting the dental team and vice versa. A recommendation could be to review a mechanism for this, to allow for more integrated care, which is in line with the GIRFT report for hospital dentistry, which advocates reducing the number of GA's, thus reducing the risk of morbidity and mortality, and the emotional, social and psychological costs associated with repeated hospital admissions (Jones, 2021).

When reviewing the medical records many of these children have undergone multiple GA's, with a mean of 4 GA's (range 1-10). This may be a wasted opportunity to combine procedures, involve different specialties, and reduce risks. Or allow for a short dental examination on these patients, especially where one has not been possible due to limited cooperation. This is relevant to the population studied as 68.6% (n=70) patient appointments noted poor cooperation and a limited incomplete examination only possible.

4.5.4. Dental Care at CDS appointments during the Period of Study

The actual care completed at the appointments reviewed was very limited. Most patients (88.2%) had examination and prevention only. 2.9% involved a scale in the chair, 1% appointments involved scaling and a restoration, and 3% involved placing a temporary restoration or Hall crown. Any further treatment that had previously been undertaken and was extensive was completed under GA. This is significant as this dental care could act as an opportunity for patients to aspirate debris from the mouth such as saliva secretions, oral bacteria, and calculus, and potentially contribute to the development of AP/CI's.

2 patients who had dental interventions (1 for a temporary restoration and then placed on the GA waiting list for extensive care, and 1 for a Hall crown) had an unsafe swallow noted in their medical history, which would put them at risk of aspiration and CI/AP which they subsequently went on to have within 6 months of the dental appointment. The dentists in these cases were aware of the swallow safety and had documented in notes a discussion of treatment options with risks and benefits with the child's carer to come to the decision to treat in the chair. There are no clear guidelines or guidance or evidence regarding the treatment of these patients i.e., whether to intervene and risk an aspiration event or leave dental disease untreated. Dentists in this situation must use their own judgement, which goes against the usual principle of 'evidence-

based dentistry', but with the lack of any available evidence, it is the best they can do. They are in a difficult position of not knowing whether to intervene or not, regarding what is in the patient's best interests for their dental and overall health and wellbeing and thus are often having to provide care on a case-by-case basis.

There are no studies that have investigated this before. However, the dilemma of treatment risk versus benefit is acknowledged and discussed in the literature, and appreciate there is no clear-cut answer or evidence about whether intervention or non-intervention is more beneficial, and no solid conclusions have been made (Klein and Dicks, 1984; Dyment and Casas, 1999; Brown et al., 2006; Kim and Emanuel, 2019).

However, Jawadi et al., (2004) suggested that professional calculus removal didn't seem to aggravate AP, but instead would reduce the calculus which seems to be a significant risk factor for poor respiratory health. The authors recognised assumptions had been made and advised a larger study was needed before regular professional scaling could be recommended. This study failed to discuss the difficulties of such children accepting care for such treatment (Jawadi et al., 2004). Hidas et al., (2010) took on board the findings of Jawadi et al. (2004) and concluded it was better to scale calculus frequently to reduce the frequency of AP, as there was a relationship between calculus level and AP, but not between AP and calculus removal. Klein and Dicks (1984) and Dicks and Banning (1991) were the only studies that were interventional i.e., did a scale (other than examinations of the subjects) as part of their study, but did mention the study size was limited as only a select few could cope with any treatment. These studies were also not limited to children.

4.5.5. Preventative Advice Given

All patients had preventative advice delivered during appointments which is encouraging, however, due to the limited detail provided in dental notes, it was difficult to assess what specific advice was given or whether it was tailored to the patients' needs or in line with local tube feeding preventative guidance (Shahid, 2016). 80% (n=39) of patients had minimal detail, just "prevention delivered" or "Diet advice and Oral Hygiene Instruction given" with no further detail in the notes, thus further analysis was not possible.

<u>Toothpaste Advice</u>

14.3% (n=7) of patients had non-foaming toothpaste recommended by the dentist, despite 81.6% having an unsafe swallow, and this being a recommendation for patients with an unsafe swallow, or those struggling with neurological deficit or oral hypersensitivity. However, there is a paucity of evidence or literature about the benefits of such pastes (Brown et al., 2006; Kim and Emanuel, 2019). Kim and Emanuel (2019) aimed to investigate the use of low-foaming toothpastes for tube-fed patients via a systematic review, as it may reduce the risk of aspiration but there were too few papers on this topic, so they had to change their project.

Interestingly, very few patients were advised to use anti-calculus, triclosan-containing toothpastes (4.1%, n=2). These toothpastes help improve OH and may reduce calculus build-up thus, in theory, reduce the incidence of AP (Brown et al., 2006; Kim and Emanuel, 2019), however evidence of its effect is very limited. Brown et al., (2006) completed a small double-blind crossover randomised trial of 24 tube-fed children, comparing the effect of an anti-calculus toothpaste, with one containing fluoride only, and found significantly reduced supra-gingival calculus from baseline by 58% for the anti-calculus paste.

2% (n=1) patient had 2800ppm high strength fluoride toothpaste prescribed, which is recommended for high caries risk patients over 10 years old in the delivering better oral health national guideline (Public Health England, 2021). This is a lower number than expected, bearing in mind that 14.3% (n=7) of patients were over 10 years old and were categorised as high caries risk by the dentist. This may be because these children were advised low foaming or flavourless or triclosan-containing toothpaste ahead of the priority for caries prevention.

<u>Toothbrushing Advice</u>

A small proportion (14% n=7) of patients had toothbrush advice documented in the notes: 8.2% (n=4) had a Collis curve/Dr. Barman's super brush recommended, 4.1% (n=2) of patients had a mouth prop or 2nd brush to use as a mouth prop recommended as the child would clamp down when brushing.

Difficulty brushing is an issue for over half (51%) of the children who are tube-fed with CI/AP as reported by parents in this study. Comments in the patients' notes from parents/carers included "clamps down on brush", "gags" and "a real struggle". Klein and Dicks (1984) commented on

difficulty brushing for these patients due to concern with swallowing and being physically compromised. This is echoed in literature such as Dyment and Casas (1999), and Brown et al. (2006) research which involved 2 groups of tube-fed children having their teeth brushed twice daily with different toothpastes, the caretakers reported difficulty brushing due to associated neuro-disabilities and oral hypersensitivity (hypersensitivity being due to lack of oral stimulation with food). Carers often needed to resort to immobilisation to complete brushing (Dyment and Casas, 1999; Brown et al., 2006). Dyment and Casas (1999) review on tube-fed patients discussed oral hypersensitivity and difficulty brushing which is often due to a neurological deficit which can mean OH is poorer. The authors suggested an oral desensitisation programme or more support with brushing may help improve OH and thus reduce bacteria load and reduce CIs. Dentists may play a role in prescribing oral stimulation via encouraging OH at home (Dyment and Casas, 1999) but it is difficult to tell if dentists at BDCFT-CDS are doing this due to a lack of detailed information within patient notes.

4.5.6. Dental Treatment Needs and Options Discussed during the Period of Study

The treatment needs of tube-fed patients were more difficult to identify retrospectively by reviewing the dental notes due to the quality of note-taking. One patient was placed on a waiting list for GA (for examination and comprehensive care). Some dentists at appointments had discussions regarding scaling of calculus or thorough examination would be ideal to ensure optimal oral health, however, a GA for this purpose only was not justified when weighing up the risks and benefits, especially if perfect OH is not adhered to post-GA, calculus could rapidly build up again. Dyment and Casas (1999) discuss this difficult balancing act of risk–benefits of dental treatment under GA where the airway is protected and dental scale can occur to reduce the pathogenic bacteria count over the risk of the GA itself, which must be done on a case-by-case basis. Klein and Dicks (1984), Brown et al., (2006), and Hidas et al., (2010), echo this, and advise frequent calculus removal visits to reduce the risk of AP but doesn't discuss the difficulties of doing this safely for this cohort of patients. They do mention occasionally GA may be necessary to achieve this but suggest no further guidance or discuss the nuances of this risk-benefit debate (Klein and Dicks, 1984; Brown et al., 2006; Hidas et al., 2010). Kim and Emanuel (2019) systematic review on the effects of OH on respiratory health of tube-fed children also summarises this dilemma well of what is more beneficial to these patients: leaving calculus which is an AP risk versus removal in the chair which is an aspiration risk versus removal under GA where GA is a risk but does not give any further answers.

Of note, 50% of dentists at appointments discussed the potential of a joint GA in the future and its benefits so advised the parents/carers to contact the dental team if the patient had a GA operation planned for another procedure to see if the dental team may be able to coordinate and plan care for the patient whilst under this GA for another procedure.

4.5.7. Oral Hygiene Regimen of Patients During Period of Study

Oral hygiene regimens (OHR) include information on important factors involved in maintaining a healthy mouth i.e., brushing frequency, the type of toothbrush and toothpaste used, whether the brushing was completed by the parent/carer or supervised, and if suction was used. A good OHR can help reduce dental issues such as plaque, calculus formation, and caries (if not NBM). Reducing the oral bacterial load is key to reducing the AP risk. Determining a patient's OHR allows tailored, preventative advice to be given and helps inform the risk of caries, periodontal disease, and tooth wear which determine recall intervals. Patient's reported OHR varied greatly in the study.

4.5.7.1. Record of Toothpastes used by patients

For 9.8% (n=10) of patient appointments, patients were using toothpastes that are not gold standard and not recommended i.e., no toothpaste or child strength fluoride toothpaste. There was no note of triclosan-containing toothpastes being used. 36.3% used a non-foaming fluoride paste. 24.5% did not have this information recorded. No parents or carers were using chlorhexidine products.

4.5.7.2. Record of Suction used by patients

Very few patient notes (8.2%) reported using suction whilst tooth-brushing. Suction is important for patients with an unsafe swallow as can help reduce the risk of a child inhaling the toothpaste/plaque/saliva debris mix produced during brushing, thus potentially reducing AP (Emanuel et al., 2017). This may have some connection to AP incidence but was not investigated further due to omission in notes.

4.5.7.3. Record of Toothbrushing

Only 41.2% of patient notes indicated they brushed their teeth twice daily which is the gold standard. 37% brushed less frequently and 11.8% (n=12) had no detail on the frequency of

brushing, making it hard to analyse further. Infrequent brushing may make children more likely to have an accumulation of pathogenic bacteria that could be inhaled and put them at risk of AP/CI.

The majority 79.4 % of patients had no record of the type of toothbrush. For the remaining 20.6%, there was a real variety of brushes and equipment used; in 3% of patient appointments, parents/carers used something we would not recommend using (a sponge, cottonwool roll, or towel). Due to the absence of data, it was difficult to analyse this further, but the use of inappropriate brush may mean brushing is less effective and increase oral pathogens.

68.7% (n=70) had tooth-brushing supervised or completed by parents/carers which is recommended as these patients often have a physical or neuro-disability and are unable to brush effectively, 2% (n=2) reported to be unsupervised, 29.4% had no record. Further analysis of this is difficult due to the missing data.

4.5.7.4. Record of OHR Summary compared to "gold standard" advice

The recommended best available evidence-based oral hygiene advice is to brush twice daily, with a small-headed manual/electric or super-brush and adult strength fluoride toothpaste. Non-foaming and/or flavourless toothpaste can be recommended if the patient has an unsafe swallow or struggles with taste or is orally hypersensitive. A triclosan-containing toothpaste is also recommended if there is calculus build-up as this reduces calculus accumulation. Supervised brushing is always recommended for children, especially those with additional needs. As well as this, suction may be recommended if the child has an unsafe swallow and is at risk of aspirating secretions produced during brushing. (Griffiths et al., 2000; Brown et al., 2006; All Wales Special Interest Group 2014a; All Wales Special Interest Group, 2014b; Shahid, 2016; Lim, 2018). Only 8.2% (n=4 of 49) patients' notes had recorded "gold standard advice" with their OHR i.e., it was recorded they brushed twice daily, with a fluoride toothpaste which happened to be non-foaming, with an appropriate toothbrush and were supervised.

Data recorded on the OHR undertaken by patients and parents/carers were often variable and incomplete, and dental care professionals failed to fully document how often the patient brushed and what toothbrush and toothpaste they used. This meant we could not get a clear picture of

the OHR. This highlights a need for the CDS team to be more consistent with their documentation.

4.5.8. Diet/Feeding Habits of Patients

55.1% reported their children were NBM, and 28.6% reported they had tasters (daily or occasionally), which consisted of custard, yoghurt, pudding, thickened fruit juice, ice cream, banana puree, porridge with sugar. The tasters listed tended to be highly cariogenic with high sugar content, except for pureed banana. 14.3% reported they were having mostly oral intake and using the tube for top-up feeds. For one patient (1%) a parent was going against professional dietician and SALT advice by giving his child regular oral feeds when the patient should be NBM due to an unsafe swallow. This could be of serious concern (and a potential child protection issue), as it may lead to increased incidence of aspiration, inhalation, or gastro-oesophageal reflux and respiratory health implications such as AP/CI. This child had in fact suffered from frequent CI's and feeding against professional advice may have contributed to these. There was comment in the notes the dentist had advised to stop oral feeding and had contacted the medical team to alert them of this.

4.5.9. Cooperation of Patients

At each appointment, dentists should try to note the cooperative ability, as it aids future appointment preparation. Over two-thirds (68.6%) of patients had limited cooperation, and 11.8% had no record of cooperation. Cooperation of these patients is often reported to be limited because a lot have neuromuscular conditions or are severely disabled with limited mental capacity. Cooperation can impact the ability to perform dental care including examinations, tooth-brushing, and scaling. It influences what practical preventative advice can be given. It is often why many of these patients have GA for any invasive treatments (as well as unsafe swallow).

This limited cooperation noted should be taken into consideration when reviewing these results, as it is likely the examination quality was affected, where the ability to take radiographs, a Basic Periodontal Examination, or diagnose caries, calculus levels, TSL, or periodontal disease may have been compromised. Only one patient out of the 49 was able to tolerate dental bitewings in the chair, which means others could have interproximal dental decay which was undetected as X-rays

were not feasible due to their limited cooperation, thus accurate diagnoses regarding caries incidence, interproximal calculus, and alveolar bone levels were not possible.

To get a thorough examination so the study could have high-quality, reliable, consistent data would be extremely difficult, as dentists would never force or physically restrain children. The use of physical holding techniques is only done when there is a clear clinical need for the dental team to do so and would not be done for a routine examination. It would have not been possible to exclude patients with “limited cooperation” otherwise there would have had an extremely small sample size of 14 patients.

Cooperation is a limiting factor within a study by Dicks and Banning (1991) which mentions and echoes our results that cooperation was limited. Their study evaluated calculus accumulation of tube-fed patients and required patients to be cooperative enough to undergo OHI, scaling, and dental examinations. Only 15 patients out of a total of 44 (34%) were considered cooperative or healthy enough to tolerate the treatment involved.

4.5.10. Dental Recall Intervals Set

The recall interval the dentist decides upon is dependent on several factors, including the calculated risk of oral disease likely to occur if the patient goes unchecked, the concern of late diagnoses of dental disease, and potential litigation. Dentists usually decide this based on NICE Clinical Guidelines for Dental Recall (National Institute for Health and Care Excellence, 2004). The shorter the recall recommended between appointments, the more concerned the dentists are that the patient is at risk of dental disease and wants to review the patient, as well as this, the review allows dental care professionals to deliver preventative advice to help improve a patient’s oral health at more frequent intervals. Six months was the most common recall chosen by dentists (69.4%). The spread of recall intervals shows there is no clear agreement on what the best interval for these patients is and it may be up to individual assessment by the dentist. There is an argument that more frequent recall should be recommended as treating these patients for dental disease is very complex, so reviewing more frequently before problems arise is beneficial as well as an opportunity to deliver oral health advice and highlight the importance of oral health which can impact respiratory health. There is an opposing argument to lengthen the recall interval, as these patients are often NBM, the decay risk is low, the parents/carers are already

over-burdened by medical appointments, and frequently reviewing these patients might impact on BDCFT-CDS service capacity.

No literature for tube-fed children discusses recalls or gives recommendations regarding the frequency of visits. Jawadi et al. (2004) found dental visit frequency had no relationship to AP, however, advised a larger study size over a more prolonged period. Hidas et al. (2010) stated it was important to establish protocols for follow-up visits due to the high rate of calculus accumulation and that calculus is related to AP. They recommended "frequent" visits but did not define what frequent was. They recommended guidelines be created for the frequency of dental visits for tube-fed children. Dyment and Casas (1999) recommended that tube-fed children had dental appointments 4-times a year for calculus removal to reduce AP risk. According to this literature, the 6-month recalls set for most of the CDS patients is not enough. Guidance for recall intervals for these vulnerable children would be welcomed, as this project will not be able to provide this.

4.5.11. Calculus Presence

Almost 2/3rds (65.3%) of tube-fed patients with CI/AP had calculus present. Incomplete dental records meant there were no results for 1/5th of patients. The large proportion of patients with calculus is in keeping with all previous studies on tube-fed children, who reported higher numbers of tube-fed patients having calculus. It is difficult to comment on this within the BDCFT-CDS population, as there is no control group the author can compare with to discuss if this is higher or lower than the general child population.

It would be sensible to suggest poorer OH leads to increased plaque, which would then lead to calculus, however, studies have shown increased calculus even when OH is excellent (Dicks and Banning, 1991; Jawadi et al., 2004; Hidas et al., 2010). A critical review of the oral health of tube-fed children by Dyment and Casas (1999) summarised available evidence at the time and concluded that tube-fed children had higher calculus levels. This was found in a more recent literature review by Kim and Emanuel (2019) where high levels of calculus were found in tube-fed children. Jawadi et al. (2004) compared oral health of 27 special needs children who were tube-fed, to 27 patients who were orally fed, and found tube-fed patients had significantly more plaque and calculus p=0.001 despite good OH. Hidas et al., (2010) compared 12 tube-fed patients

with 2 other groups (17 'healthy' patient group and 16 children with disabilities but not tube-fed) and found calculus levels were significantly higher in tube-fed patients p=<0.05.

Klein and Dicks (1984) and Hidas et al., (2010) found that calculus accumulation was more rapid in tube-fed patients, even when OH levels were at the same level. Klein and Dicks (1984) study examined tube-fed adults, not children, but found much higher levels of calculus (p<0.0001). Dicks and Banning (1991) compared 15 tube-fed special needs adults with 15 non-tube-fed special needs adults and reviewed their calculus accumulation. It found that calculus build-up was more rapid even if OH was better for adults. The study discussed the lack of understanding of mechanisms around rapidity of calculus accumulation for tube-fed patients, proposed it may be due to lack of mastication, but suggested more research was required to see if the increased calculus accumulation affects oral health and how to deliver preventative care for such patients (Dicks and Banning, 1991). This is yet to be investigated and understood, as no further literature has done so. There have been some theories, as summarised in Kim and Emanuel (2019) including chewing fibrous food may physically remove plaque (a theory from Jawadi et al., (2004)), or lack of oral feeding means oral pH remains above 5.5 leading to rapid plaque mineralisation (Mandel, 1995; Hidas et al., 2010; Kim and Emanuel, 2019).

These theories may explain this study's finding that there is a statistically significant finding that if a tube-fed child was completely NBM, they were more likely to have calculus (p=0.03). This may also explain the statistically significant finding of having an unsafe swallow, you are more likely to have calculus (p=0.017) as these patients with an unsafe swallow are mostly NBM, and there is clear evidence in Jawadi et al. (2004) who reviewed 27 tube-fed patients with a 27-patient control group and found significantly higher calculus levels in the tube-fed children despite similar OHRs. No other literature has found this or explained this, other than these patients lack oral function, leading to increased plaque and subsequent mineralisation, causing calculus (Jawadi et al., 2004).

There was a significant association found between calculus presence and the duration of tube feeding i.e., the longer the patient was tube-fed, the more likely they were to have calculus (p=0.044); this is a new finding, not mentioned in literature and is most likely due to prolonged lack of oral function meaning there has been longer for calculus to accumulate. There was a

significant association between calculus presence and previous dental GA (p=0.001) (i.e. if there's calculus, the patient is less likely to have had a GA for dental treatment). No other studies have looked at this element before, however, an explanation could be that a past dental GA removes the calculus via a full debridement, thus meaning that less calculus has re-accumulated. There was a statistically significant relationship between medications associated with gingival hypertrophy and calculus for tube-fed children (i.e. if taking this medication, more likely to have calculus, p=<0.001). This can be explained generally as if these medications cause hypertrophy, which means plaque is more difficult to remove, meaning it has more chance of being in the mouth for longer and mineralised into calculus, which is a known risk (Gopal et al., 2015). There is a relationship between secretion-reducing medication and calculus (if you're taking secretion-reducing medication, you're more likely to have calculus) (p=0.002), which may not be linked to the medication itself, but perhaps the fact these children are likely severely disabled and have difficulty brushing thus increased plaque and calculus accumulation.

The level of calculus e.g., minimal, moderate, gross, generalised, localised was not routinely recorded in a standardised way, and for 29% of patients, it was not noted, which made it difficult for the researcher to statistically analyse this or make meaningful conclusions.

4.5.12. Periodontal Disease

Periodontal health is of great interest. Unfortunately, 18.4% of patients had no record of periodontal health in their notes. Over half (57.1%) had periodontal disease noted in the dental records. Most of the periodontal disease diagnoses were gingivitis (89.3%), with only 10.7% having gingival hypertrophy. There are no investigations or studies in recent literature about the periodontal disease of tube-fed children. Dyment and Casas (1999) support this and reports no evidence of periodontal disease (only calculus accumulation and OH) and no periodontal indices had been reported or recorded in any study for tube-fed patients. No other literature has reviewed gingival health, loss of attachment, or periodontal indices for tube-fed children. It is recognised how difficult it would be to perform an accurate periodontal examination due to the cooperation of patients, even if the prospective element of the proposed research would have taken place, which is a significant limitation for future studies.

4.5.13. Oral Hygiene (OH)

Oral hygiene is important to note as it indicates how well the patient or parent/carer is managing tooth-brushing. Optimal OH reduces the risk of periodontal disease, calculus build-up, decay, and in unsafe swallow patients reduces the risk of aspirating saliva that contains a high bacterial load, which can contribute to AP/CI (Langmore et al., 1998; Murray et al., 1996; Dyment and Casas, 1999; Langmore et al., 2002; Kim and Emanuel, 2019). The need for exemplary OH has been recognised across all literature to reduce the chance of CI/AP and improve any oral health-related issues in this complex cohort of patients (Klein and Dicks, 1984; Dyment and Casas, 1999; Hidas et al., 2010).

There were no trends for OH recorded for these patients, with no clear majority. Poor/very poor OH was the most common group in our results at 36.7%, this was in keeping with the expectation that tube-fed patients are more orally hypersensitive with gag reflexes, rely on carers for brushing, are less cooperative due to their complex disabilities, and have poor motor control, which makes thorough brushing more difficult (Dyment and Casas, 1999; Brown et al., 2006). Dicks and Banning (1991) in their study discussed the fact cooperation does limit the ability to perform a thorough OH program. Previous literature states tube feeding is associated with poor OH in children due to reduced salivary flow (Dyment and Casas, 1999; Jawadi et al., 2004; Brown et al., 2006). This was also supported by Klein and Dicks (1984) who found that tube-fed non-ambulatory patients (adults and children) had poor OH.

4.5.14. Oral Hypersensitivity (OHS)

Oral hypersensitivity affecting tube-fed patients is something commonly reported in the literature, due to lack of oral stimulation and disabilities (Dyment and Casas, 1999; Brown et al., 2006). This can be linked to difficulty accepting OH measures such as tooth brushing or dental care, which can, in turn, lead to poor oral health, higher bacterial levels, and risk AP/CI. The retrospective nature of the project meant it was difficult to fully assess OHS, as notes lacked this detail. OHS was assessed by reviewing whether parents/carers reported difficulty brushing in the clinical notes, and the exam quality. This meant there were some assumptions made that difficulty brushing and examination quality was due to hypersensitivity rather than mental capacity or lacking cooperative ability, which needs to be considered, as it may not be a true reflection of hypersensitivity. 51% of patients' parents/carers reported difficulty brushing. Cooperation (as mentioned previously) was limited for 71.4% of patients. Due to the lack of

information in dental notes, it is difficult to discuss this, and no further analysis was completed on this element.

4.5.15. Caries

Generally, a review of the notes revealed a low caries rate with 6 patients (12.2%) having caries present. This finding supports all previous literature on tube-fed persons. There is only one child-centric study by Hidas et al., (2010) who found a lower DMFT score in tube-fed patients when comparing 12 tube-fed children with 16 disabled but orally fed and 17 healthy children. However, tube-fed children in Hidas et al., (2010) study were completely NBM which is not comparable to our population. Kim and Emanuel (2019), and Jawadi et al. (2004) also discuss this low caries incidence. This 12.2% figure for caries was much lower than the 36.0% figure reported in all 5-year-olds in Bradford local authority from the 2019 Oral Health Survey of 5-year-olds (Public Health England, 2020).

All patients with caries recorded had food orally, and all NBM patients were caries-free which was expected. Statistical analysis in this study found a significant relationship between caries and swallow i.e. if you have a safe swallow, you're more likely to have decay ($p=0.02$), as well as caries and being NBM i.e. if you are NBM you are less likely to have had decay ($p<0.001$) which further supports and adds to the literature. This is because there is no fermentable carbohydrate intake orally, which leads to less cariogenic bacteria and less acid formation which causes decay. This is discussed in Hidas et al., (2010) who found Streptococci mutans and Lactobacilli counts in tube-fed patients to be very low when compared to non-tube-fed disabled children.

Statistical analysis showed there was an association between NF and decay. i.e., if a tube-fed patient with a history of CI/AP had a NF they were less likely to have tooth decay ($p=0.03$). It could be because the reduced acid reflux means the patients' oral pH was always higher than the critical pH needed for the carious process, or these patients were ones at risk of silent aspirating thus they were NBM thus no oral intake of cariogenic food substances. Or if a patient had acid reflux (i.e., no fundoplication), it may result in a food bolus being pouched in the mouth for prolonged periods which may increase caries. It is difficult to fully explain the reasons for this, and this is a new finding.

Statistical analysis found that tube-fed children with CI/AP who were taking secretion-reducing medication were less likely to have decay (p=0.001 significance), which is an interesting association, as it could be assumed less saliva leads to a dry mouth which can increase caries risk (NICE, 2021b). A dry mouth means there is a reduced protective effect of saliva (i.e., few immunoglobulins, lesser clearing effect, and less buffering capacity) which increases the risk of caries. However, in this study use of these medications was associated with reduced caries, this may be because the children taking these types of medication are more medically compromised and less likely to have a safe swallow for such secretions thus are more likely to be NBM. This association has not been established before and no other study has investigated this relationship. It is an association and does not establish causation, so no further speculation will be made.

Further statistical analysis revealed that tube-fed children with a history of CI/AP, who were taking medications associated with gingival hypertrophy were less likely to have decay according to Fisher Exact test (p=0.029). Whilst it is known that tube-fed children, in general, have higher calculus levels (Dicks and Banning, 1991; Dyment and Casas, 1999; Jawadi et al., 2004; Hidas et al., 2010; Kim and Emanuel, 2019), this is a new association found, which has not been reviewed before, with no literature discussing this. This could also be because these children are more likely to be severely medically compromised and NBM, in which case less likely to have decay This is an association, not causation so will not be further discussed.

Unsurprisingly, statistical analysis showed that tube-fed children with a history of CI/AP, who were taking prophylactic antibiotics were less likely to have caries according to Fisher's exact test (p=<0.001). Whilst it is known that tube-fed children, in general, have less caries often due to reduced oral feeding, the association with antibiotic use has not been discussed before. This could be linked to antibiotics altering the microflora, which is known to reduce caries incidence in cystic fibrosis patients who are on long-term antibiotics to reduce complications (Chi, 2013), or linked to this group being more likely to be NBM, however, this is a new finding for tube-fed patients with CI/AP and has not been discussed in the literature before.

It is important to note that as bitewing radiographs were not possible in all but one patient (due to cooperative ability), it is difficult to guarantee all teeth declared caries-free were so, as visual examination does not prove this, a combination of radiographic and clinical examination would

be the only way to rule out any interproximal tooth decay in dentitions with closed contact points.

4.5.16. Dental Anomalies and Enamel Defects

16.3% of patients had enamel defects such as hypomineralisation. There have been no studies relating to tube-fed children who have reviewed this before, so further comment is difficult. This figure is lower than 28% of the general child population in the 2013 Child Dental Health Survey (Health and Social Care Information Centre. 2015). It is not known why but may be worth reviewing anomalies further.

4.5.17. Tooth Surface Loss (TSL)

TSL was expected in tube-fed patients, as Dyment and Casas (1999) suggested that GORD incidence is high in this population, thus intrinsic erosion could have contributed to tooth-wear, however, calculus deposits may minimise or hide acid reflux effects. TSL was not routinely recorded in notes: only 2 patients out of 49 had TSL present and noted, 1 patient (2%) had no TSL recorded as being present in notes and 94% (n=46) had no record, either way, thus no real conclusions regarding TSL and tube feeding can be made.

4.5.18. Orthodontic Findings

Orthodontic findings were not routinely recorded in a standardised way, which made them difficult to analyse. 20 patients (40.8%) had no record of orthodontic findings. 11 patients (22.4%) were in the primary dentition, so this was not applicable. 14.3% had crowding recorded in the notes, Crowding is a common finding in disabled children (Dinesh et al., 2003), and is associated with conditions such as down syndrome and cerebral palsy often thought to be due to poor muscle tone (Kuter, 2021).

4.6. Implications of findings

This study provided insights into the medical history of tube-fed children in the local population and the characteristics that make them vulnerable to CI/AP, which has not been previously reported. This will hopefully help increase awareness of this issue and risk factors within the dental community.

The lack of evidence or literature on these children reveals the limited information dental care professionals must use to make decisions about their dental care, which is not without risk. The debate continues regarding to treat or not to treat tube-fed patients to remove calculus deposits, and what is more detrimental to their general health. Further research is required, though as highlighted in research in this population is challenging due to limited patient cooperation for complete and reproducible examinations to be carried out in addition to the complexities of accurate medical history information due to non-integrated medical/dental notes and ethical implications of interventional studies.

The need for more coordinated and interdisciplinary care in the local area was revealed in numerous parts of the study to benefit patient's quality of life including better referral pathways from medical teams to dental teams for tube-fed children; better information sharing between HCPs; highlighting to the dental team when a GA may be taking place for the potential of a joint GA to be coordinated and vice versa.

The discrepancy between dental-medical history in the dental notes and the medical record was revealed. This highlights wider issues with coordination of notes, and the need for an integrated electronic patient record to help improve and coordinate care. Action plans will be set in motion to locally improve the quality of the dental-medical history taking. This includes improved note-taking of medical history by dentists on their dental records, this could also include information sharing from the paediatrician and other HCPs where appropriate or a medical history note proforma to ensure all relevant data is captured.

There is a clearer picture of the dental characteristics of tube-fed patients with CI/AP. As well as this, there is evidence to strengthen the argument that calculus, which is more likely to be present in NBM patients or those with unsafe swallows, is associated with CI/AP incidence. However, without a control group with dental data collected it is difficult to make solid conclusions from these observations.

The study has not been able to provide advice on dental treatment, recall intervals, or change preventative advice given. But it has helped build a more complete picture of what the oral health findings are of tube-fed children with CI/AP; it is the largest study sample of its kind, which

has collected a large amount of dental data, albeit retrospectively due to circumstantial challenges. It did find that note-taking around prevention given by the dentist was often vague with improved note-taking required.

Ensuring regular dental reviews and easy access to dental care is in place for this cohort of tube-fed patients is important, as highlighted by patients' complex medical histories, CI/AP risk, and increased calculus accumulation. This would also allow trained experienced dental professionals to monitor and treat the accumulation of calculus and give OH advice/support to families and carers.

4.7. Recommended Actions from the Study

From this research, recommendations can be made as follows:

Strengthen existing referral pathways and links to the CDS from dieticians, paediatricians, and other HCPs such as SALT to ensure all tube-fed children are consistently receiving appropriate oral healthcare and prevention.

Improved rollout and awareness of "mini mouth care matters" and oral prevention within the medical profession, including out-patient settings, to help improve oral health. This may increase the number of opportunities preventative oral health advice is given, as well as educating parents/carers on the link between oral health and respiratory health.

Improved communication and information sharing of medical and dental history between HCPs. This is likely to involve a review of how different HCPs can access a centralised database of patient information for better, shared communication regarding patients' medical information/care which would help improve care and be a more efficient use of clinician time. At present, only a small number of CDS dentists have access to the centralised NHS medical record hub to review other HCP notes so wider access amongst dentists is advocated.

Ensure improved note-taking by dental professionals at BDCFT-CDS for dental prevention to include what specific preventative advice was given and to raise awareness of the local prevention guidelines.

Explore oral desensitisation training or awareness with the SALT team or dental team for orally hypersensitive children (where feasible and if capacity allows in the service). This may help improve the cooperation of children for toothbrushing and in turn improve their oral health.

Improved utilisation of joint GAs to see if more dental care, such as debriding calculus, can be carried out. This may help improve the oral health of tube-fed children.

4.8. Limitations of Study

The retrospective nature of the study means that many elements the researcher aimed to collect data regarding, such as tooth erosion, and periodontal health were incomplete or missing from the notes, as the method was reliant on the quality of multiple dental care professionals note-taking. Record-keeping quality was very variable and information bias could likely affect the results. This could have impacted data analysis for statistics, which is at risk of being skewed or inaccurate in the face of incomplete/missing notes e.g., 1/5th of notes did not have a record of calculus being absent/present, and TSL was not recorded in 94% of results. Multiple dental care professionals had differing styles and standards of the depth and detail their clinical notes provided, meaning there were no standardised descriptors of categories such as calculus levels and OH and some descriptors were often missing completely. This made it very difficult to categorise such descriptors into a meaningful scale for analysis of results.

There were no standardised use of scales or descriptors in records such as cooperation, TSL, or OH. For example, the description of OH was very varied, some dentists used different descriptors such as fair, very poor, poor, average, suboptimal, good, very good, and excellent. There is no way of standardising this retrospectively, but the author had to categorise and scale these descriptors, which was challenging because where did “suboptimal” fit into the scale? These measures are very subjective too, which is difficult to standardise. Also, lack of calibration of any scale meant the meaning of results is limited e.g., what makes OH fair, compared to average or good? This would have been overcome by the prospective examination element with a calibrated scoring system that was planned but not possible.

Description of levels of calculus had significant variation (due to being retrospective) so the researcher had to make a more basic bimodal measure of calculus present or absent. This

limitation had been identified by the researcher and was going to be overcome by the prospective element of the study.

As mentioned previously, the study should have had a prospective element, which had ethical approval. The appendices show the patient information leaflets and consent and assent forms that would have been used and were approved by the HRA as well as the HRA and CAG approval letters. This would have been a clinical dental review and oral examination (during their routine check-up) for at least 50 tube-fed children over a 6-month period to assess their oral health status, record more detailed and calibrated oral health indices, and record issues these patients or parents/carers face. For 10 patients, the research supervisor was going to re-assess the children for inter-rater reliability of data descriptors and scales. This would have overcome the issues with poor or incomplete notes. This would have been able to provide data on both types of tube-fed patients: both with and without a history of CI/AP, which would have allowed us to have 2 groups as a comparison for statistical analysis of dental data for tube-fed patients with and without CI/AP. It may have been possible for associations to be made about the dental health that could be linked to CI/AP risk. e.g., tube-fed patients with dental decay were more likely to have CI/AP. However due to the COVID-19 pandemic, this part of the project was not possible to complete, the CDS became an urgent care centre, and these children were vulnerable, thus were all asked to shield long term, making the project impossible to complete in the time frame required.

Confounding factors are variables we cannot account for. They are underlying and often unknown differences in the baseline characteristics of our cohort such as complexities within the medical history which may have contributed to issues with cooperation and toothbrushing or incidences of CIs. Therefore, we can't prove a cause and effect between dental variables and CI incidence, as there are too many confounding factors to account for and that may contribute to this due to the complexity of these patients. We cannot account for the differences in baseline medical history or patient characteristics which may in fact lead to the increased number of CIs. We cannot control these confounding factors for the patients, so a comparison like this would never be possible. Hence why this study is only going to be possible to be a descriptive exploratory study.

A further limitation is that these patients are difficult to assess and examine as they are often severely disabled, lack cooperative ability, and are challenging to treat, so the quality of previous dental examinations and data collected could be compromised.

A significant limitation of this study is having no control group to compare any of the oral health findings. Dental notes were only reviewed if the patient had been found to have had a CI/AP. It would have been beneficial to have dental data for 2 cohorts of patients, one being a control group. A control group could have been either:

1. Collecting oral health data and findings from tube-fed patients who had not suffered from CI/AP between 2018- 2020, or
2. Collecting oral health data and findings from a group of non-tube-fed child patients in the BDCFT-CDS to compare the findings.

Not having any control group significantly limited what could be done with the data statistically and how it could be interpreted, particularly with the dental data. Statistical analysis of dental data was limited to the 49-patient sample who had CI/AP. Advanced statistical analysis, such as logistical regression analysis was not possible. A change to the study design was not feasible due to time constraints with the COVID-19 pandemic having prevented the prospective element of research which would have provided data for both groups and thus a 'control'.

4.9. Future Areas of Research

Because this is such an understudied population and area, there is a wealth of potential research studies from this project, as listed below.

Collecting retrospective dental data for the 43 patients with no CI/AP acting as a control group so dental variables could be further analysed.

Completing the prospective element: i.e. a study with a "control" group, by assessing the dental health of those tube-fed children with AP/CI and those without CI/AP. This may then be able to answer the question of dental characteristics which put tube-fed children at risk of CI/AP, and in turn, be able to provide dental care recommendations for them. This could also be done with the whole 92-patient sample, or an even larger sample size by using multiple sites.

A study to be able to provide evidence-based guidelines of frequency of recall and dental care recommendations, with the possibility of relating these to outcomes on respiratory health. This has also been highlighted as an area of need by other studies (Dyment and Casas, 1999; Jawadi et al., 2004; Hidas et al., 2010).

A study to understand the reason for increased calculus build-up, often despite superior OH, has been identified in previous studies as an area we lack knowledge in (Klein and Dicks, 1984). Understanding this mechanism could help inform us of the best prevention and treatment for these children.

Kim and Emanuel (2019) suggested future research to review the efficacy of certain toothpastes, comparing chlorhexidine gel vs non-foaming vs anti-tartar vs normal paste to understand the best way of removing rapid calculus build-up and thus reducing the incidence of CIs. It would be beneficial to not only do this but also investigate the efficacy of other elements of OH to see if one is more beneficial for these children in reducing plaque and calculus build-up and respiratory health outcomes, such as the use of different toothbrushes (electric, 3-sided, manual).

Further investigation is required into the impact of removing calculus versus not removing it on oral health and respiratory health for these patients. I.e., which poses a greater risk for general health, and whether professional scaling to remove calculus should be recommended. This is an area highlighted by other studies also (Jawadi et al., 2004; Brown et al., 2006).

A questionnaire or focus group of tube-fed parents/carers regarding their attitude to oral health, dental appointments, and difficulties/challenges with maintaining oral and dental care would be beneficial, this may help inform policy such as recall interval and prevention advice.

Another future project could review the confidence and competence of dental care professionals giving OH advice and oral desensitisation programmes to this cohort of tube-fed children, to help improve guidance.

A review of joint GA opportunities locally or nationally would help understand the treatment pathway, challenges, and barriers experienced by the medical and dental team in organising this,

and help improve this to enable better, more integrated care. This may allow researchers to utilise this resource more and share best practice guidance with other centres.

A study to establish the link between poor dental health and tube feeding with AP, which has been established in adults, but not children. This is discussed in Dyment and Casas (1999) but has still not been investigated in the paediatric population.

Chapter 5. CONCLUSION

Under the conditions of the project, the following conclusions were made:

This research has produced wide-ranging data showing tube-fed children have complex medical needs, and are under the care of multiple HCPs, with varying dental needs.

Reviewing medical records and statistical analysis found that tube-fed patients with a history of CI/AP were more likely to have the following characteristics in their medical history:

- be NBM rather than orally fed;
- have an unsafe swallow;
- take secretion-reducing medication;
- take prophylactic antibiotics;
- take medications associated with gingival hypertrophy;
- have a history of dental GA.

The study has highlighted the lack of comprehensive and accurate medical history within the dental notes, which would benefit from improved information sharing. The dental-medical record was inaccurate and had discrepancies compared to the actual medical record.

The incidence of CI/AP for tube-fed children in Bradford was 53.3%. (49 out of 92 between 2018-2020). These patients had multiple infections within this time frame (average of 4, range 1-13).

Oral health of tube-fed children with CI/AP was varied; calculus presence was high (65.3% of patients), and caries level was low (12.2%). Oral hygiene was variable. Tube-fed children with CI/AP who had unsafe swallow or were NBM were more likely to have calculus present, have less caries, and were less likely to have had a GA for dental treatment, compared to those with a safe swallow or orally fed. Tube-fed children with CI/AP had greater experience of dental GA compared to those without CI/AP.

The oral hygiene regime reported was varied, and rarely followed “gold standard” advice, this needs to be investigated further as to barriers to a better regimen for parents/carers.

Our knowledge of these children is limited due to the paucity of research/studies, particularly surrounding oral health, dental care, and relationship with respiratory disease. These children will continue to present to dental teams, who need to be equipped with the knowledge to understand what dental treatment is in their best interests for their overall health; this continues to be challenging and requires further research.

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Appendix 1: Clinical Advisory Group Approval

Health Research Authority
Skipton House
80 London Road
London
SE1 6LH

Tel: 020 797 22557
Email: cag@hra.nhs.uk

27 May 2020

Dr Frankie Soldani
Consultant in Pediatric Dentistry
Bradford Community NHS Trust
Horton Park Health Centre
Dental Department
Bradford
BD7 3EG

Dear Dr Soldani

Application title:	**Oral Health, Dental Care and Aspiration History of Tube Fed Patients**
CAG reference:	**19/CAG/0227**
IRAS project ID:	**249799**
REC reference:	**20/YH/0002**

Thank you for submitting a **research** application under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support') to process confidential patient information without consent.

Supported applications allow the controller(s) of the relevant data sources, if they wish, to provide specified information to the applicant for the purposes of the relevant activity without being in breach of the common law duty of confidence. Support provides a lawful basis to allow the information to be processed by the relevant parties for the specified purposes without incurring a breach of the common law duty of confidence only. Applicants must ensure the activity remains fully compliant with all other relevant legislation.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Health Research Authority on whether application activity should be supported, and if so, any relevant conditions. This application was considered at the CAG meeting held on 05 December 2019. The application was considered via the precedent set process under category four: time limited access to undertake record linkage/validation and to anonymise the data.

This outcome should be read in conjunction with the provisional support letter dated 16 December 2019.

Health Research Authority decision

The Health Research Authority, having considered the advice from the Confidentiality Advisory Group as set out below, has determined the following:

1. The application to allow the disclosure of confidential patient information from Bradford Teaching Hospitals NHS Foundation Trust to Bradford Community Dental Service (Bradford District Care NHS Foundation Trust), to enable an eligible patient cohort to be identified for inclusion in the study is conditionally supported, subject to compliance with the standard and specific conditions of support.

Please note that the legal basis to allow access to the specified confidential patient information without consent is now in effect.

Context

Purpose of application

This application from Bradford Community NHS Trust set out the purpose of medical research which aims to determine the oral health of tube-fed children, oral health care regimens, dental care history and identify the dental treatment needs of the local tube fed paediatric population in Bradford.

The patient cohort will be identified using the Bradford Royal Infirmary's locally devised tube-fed database. This dataset will be cross-referenced with the Bradford Community Dental Service database to identify individuals who are already known to the dental service. Patients known to both services would become part of a retrospective case note review, which will inform the study. Support is sought to legitimise access to electronic patient records within the Bradford Teaching Hospitals NHS Foundation by the student applicant. This database will include wider clinical records for patients who are not directly within the care of the applicant for dental treatment. Section 251 support is sought to legitimise the applicant's access to these wider clinical records to enable the eligible patient cohort to be identified. Following the identification of the patient cohort, the requirement for support will cease as only patients within the direct clinical care of the applicant will continue to be included in the study.

The study also involves a secondary element where a sub-cohort of 50 of the identified patients would undergo an additional clinical examination to assess their oral condition. This element is out of scope for the CAG application as consent will be sought from the patient's parent/guardian and assent from the patient for their participation.

A recommendation for class 1, 3, 4, 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential patient information requested

The following sets out a summary of the specified cohort, listed data sources and key identifiers. Where applicable, full datasets and data flows are provided in the application form and relevant supporting documentation as this letter represents only a summary of the full detail.

Appendix 2: HRA Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Annabelle Carter
Paediatric Dentistry Department, University of Leeds
The Worsley Building
Claredon Way, Leeds
LS2 9LU

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

30 June 2020

Dear Miss Carter

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Oral Health, Dental Care and Aspiration History of Tube Fed Patients in Bradford**
IRAS project ID:	**249799**
Protocol number:	**n/a**
REC reference:	**20/YH/0002**
Sponsor	**University of Leeds**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix 3: Data Collection sheet for Medical History Accuracy

Patient ID Number:				
Data Set	Medical Notes	Dental Notes	Discrepancies? (Y/N and how)	Omissions in Dental Notes?
Consultant/name of lead doctor and other Health Care Professionals				
Medical diagnoses				
Medications (number and type)				
Type of tube feeding				
Duration of tube feeding (i.e. date of tube placement)				
Reason for tube feeding (e.g. failure to thrive, unsafe swallow, other)				
Safety of swallow				
Nil by mouth, or tasters (consistency of tasters), or oral feeding with top-up feeds through tube				
Dietician and advice given around oral intake				
Previous General Anaesthetics/ operations (date and reason, inc. Dental GA)				
History of non-elective admissions				
History of aspiration pneumonia or significant chest infection (including dates)				

Appendix 4: Data Collection sheet for Dental History Data

Dental Data Set	Patient 1 (ID)	Patient 2 (ID)
Clinician Grade		
Any complaints (C/O)		
Oral hygiene regime (including Toothbrush type, frequency, toothpaste type, supervised/completed by parents/carers or not)		
Diet reported		
Dental treatment history/ previous experience/ past dental history prior to 2018		
Oral hygiene		
Periodontal health		
Calculus levels		
Tooth wear levels (TSL)		
Caries		
Cooperation/ examination quality		
Orthodontic findings		
Dental diagnoses		
Decay risk noted		
Periodontal disease risk		
Dental treatment needs (if any)		
Treatment options discussed (if required)		
Oral hygiene advice given (if any by dentist)		
Any dental care completed (if yes, how)		
Any history of 'joint' GA care		
Recall interval advised		

Appendix 5: Patient Participant information sheet for 5–10-year-olds

NHS
Bradford District Care
NHS Foundation Trust

| V2 19/06/19

Participant Information Sheet (for children 5-10 years)

What does tube feeding do to my mouth and teeth?

We at the Community Dental Service in Bradford are asking if you and your parents would like to take part in a research study. Before you decide, it's important you understand what the study is about and what it will mean if you take part. If something doesn't make sense, or if you have any questions, you can ask your parent/carer to give us a call and we can discuss it with you and your parent/carer. Thank you for reading this.

What is research? Why is this project being done?

Research is a way we try to find out answers to questions we are not sure about. This research project is being done to look at your mouth, your teeth and your gums.

What we eat, and how we brush our teeth can affect our teeth and mouth. Because you don't always eat with your mouth, but have your food through your special tummy-tube, we want to look at what your teeth and gums look like.

Who is doing the project?

Annabelle Carter and Frankie Soldani, two of the dentists who do check- ups at the clinic, are doing the project. The project is part of some research Annabelle is doing to be a special dentist just for children.

Why have I been asked to take part?

You have been asked to take part because you have a special tummy- tube to help you eat.

Did anyone else check the project is okay to do?

Before the project is allowed to start, it had to be checked by a group of people to make sure the project is fair. That group of people said it was okay for us to do this project.

Do I have to take part in the project?

No you don't. It is your choice whether you want to take part and you can always change your mind.

What will happen to me if I take part?

You will come to your dental check-up like normal.
We will check if you are happy to take part in the project and ask you and your parent/carer to sign a form.

Like normal, the dentist will ask you and your parent/carer if you have had any problems with your mouth or teeth since your last visit, if you have any worries about your teeth, how often your brush your teeth, and the normal questions they ask at every dental check-up appointment.
The dentist will look at your mouth, count your teeth, check how clean your teeth are, and check your gums.
At the end of your visit the dentist will talk about what they have seen with you and your parents.

Will anything about the project upset me?
We will do the usual check-up to count your teeth and check how clean your teeth are, just like the last visit when your dentist counted your teeth. This won't be anything new or different from before.

Will taking part help me?
The study will not help you right now, but it will help us know more about children who have a tummy-tube and how this may affect their mouth and teeth.

What happens when the project stops?
The project will be talked about and written down, but no one will know you took part.

If I don't want to take part in the project, will you treat me differently?
No one will treat you differently. You will have the same dental check-up and same advice as any one coming to see the dentist.

What do I do if I don't want to take part in the project anymore?
Just tell your parent/carer and the dentist that you don't want to take part anymore. You don't have to give a reason. It is YOUR choice. We do keep your dental check-up on our computer system, as we would normally do, but won't use any of your information in the project.

Will my information be kept private? Will anyone else know I am taking part?

All your information will be kept private, on a computer with a password only the dentist that looks after you knows.

What happens if I find out I have problems with my teeth that I did not know about?

Just like any person coming to visit the dentist, we will tell you and your parents about any problems we have found with your teeth or gums and how we can help to fix them.

Who has looked at this project?

Before any project like this is allowed to go ahead, it has to be checked by a group of people called the Research Ethics Committee. They make sure the project is fair. This project has been looked at by the Dental Research Ethics Committee at the University of Leeds.

Who should I ask if I have any further questions?

If you have any questions, talk to your parents first. You can also contact the dental team, in Bradford:

Annabelle Carter on

Specialist Registrar in Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust.
Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250
Annabelle.carter@nhs.net

Or Frankie Soldani, Academic Supervisor for the research project on:

Dr Frankie Soldani
Designation: Consultant Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust.
Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250
Frankie.soldani@bdct.nhs.uk

Or Dr Richard Balmer, Academic Supervisor for the project on:

Richard Balmer
Consultant Paediatric Dentistry
University of Leeds, School of Dentistry
r.c.balmer@leeds.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 6: Patient Participant information sheet for 11–15-year-olds

NHS
Bradford District Care
NHS Foundation Trust

V3 30/07/2019

Participant Information Sheet (11-15 years)

WHAT EFFECT DOES TUBE FEEDING HAVE ON YOUR MOUTH HEALTH?

We at the Community Dental Service in Bradford are asking if you and your parents would be interested in taking part in a research study. Before you decide, it's important you understand what the study is about and how it would involve you. If you have any questions, please let us know and we can discuss it with you and your parents. Thank you for reading this information.

Why are we doing this research?

This research is to look at teeth and gum health of young people who are tube-fed.

What we eat and how we brush our teeth can affect our teeth and gums. Because you don't always have food through your mouth, but have it through your tummy tube, we want to look at what your teeth and gums look like. As your mouth might be more sensitive, you teeth and gums may be slightly more difficult to brush and the amount of saliva you have may be different. These things can affect the amount of tooth decay and the health of your gums. Looking at this in more detail may help us understand how tube feeding affects the mouth, as no-one has looked at this properly before for young people.

Who is doing the study?

Annabelle Carter and Frankie Soldani, two of the dentists at Horton Park and Westbourne Green dental clinics are doing the study.
The study is part of a Masters by research degree which Annabelle is doing as part of her training to be a Specialist Dentist for Children.

Who has made sure that the study is done properly?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is alright to do. This study has been checked by the Yorkshire Research Ethics Committee.

Why have I been asked to take part?

You have been invited to take part because you are tube-fed, and come for regular check-ups at the dentist.

What will be involved if I take part in this study?
You will have your check-up appointment as usual.

At this visit, you and your parents will have the chance to ask any further questions, then you and your parents sign a form that lets us know you are both happy to take part in the study.

Annabelle (the dentist), will ask you and your mum/dad/carer all the usual questions that are asked at your dental check-ups, so things like how many times a day your teeth are brushed and if there are any worries you or your parents have about your teeth.
Annabelle will have a look in your mouth, count your teeth, look at your gums, check if you have any wear on your teeth and look at how clean your teeth are.

For a small number of patients in the study (5-10 people), Frankie Soldani (another dentist) will count your teeth as well, and check your gums, to double check. This should take an extra 5 minutes.

Once you have had your check- up we will use the information, such as tooth and gum health, in the study.

Will taking part in the study help me?
The study will not help you right now, but it will help us understand more about the mouth health of young people who are tube-fed.

If I don't want to take part, will you treat me differently?
No one will treat you differently. You will have the same dental check-up and same advice as as you would normally receive when you come to see the dentist.

What do I do if I agree to take part and later change my mind and don't want to take part in the research anymore?

Just tell our parent/carer and the dentist that you don't want to take part anymore. You don't have to give any reason. It is YOUR choice.
Information from your dental check-up will still be kept on our computer as part of your dental record/notes, like after any dental check-up for anyone, BUT we won't use it for the research.

Will my information be kept private? Will anyone else know I am taking part?
All your information will be kept private. We will only tell you and your parent/carer what your teeth and mouth look like (and this will be on the day of the check - up). No one else will

know you were in the study other than the dentists (Annabelle and Frankie) who have seen you for your check-up.

Information about your teeth and mouth will be kept on our safe computer system, which only other dentists who may see and look after you will look at. The form you sign will be kept with your notes in a locked cabinet in our dental clinic. Any information about you which leaves the clinic will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the study?

The results and findings of the study will be written up in an essay so that people can read about it, but they won't know that you were in the study. All results will be kept anonymous, so no one reading this will know what your own dental health was. If you want a copy of the essay, you can ask the dental clinic at your next check-up.

Who has reviewed this study?

Before any research is allowed to go ahead, it has to be checked by a group of people called the Research Ethics Committee. They make sure the research is fair. This study has been reviewed by the Dental Research Ethics Committee at University of Leeds.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. Please contact Annabelle Carter in the first instance. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the dental clinic.

Who should I ask if I have any further questions?

If you have any questions, talk to your parents first. You can also contact the dental team, in Bradford:

Annabelle Carter
Specialist Registrar in Paediatric Dentistry
Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250
Annabelle.carter@nhs.net

Or Dr Frankie Soldani, NHS Supervisor for the project:
Dr Frankie Soldani, Consultant in Paediatric Dentistry
Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250
Frankie.soldani@bdct.nhs.uk

Or Dr Richard Balmer, Academic Supervisor for the project:
Dr Richard Balmer, Consultant in Paediatric Dentistry
University of Leeds, School of Dentistry
r.c.balmer@leeds.ac.uk

Appendix 7: Participant information sheet for parent and/or carer

Bradford District Care
NHS Foundation Trust

V4 02/07/2019

Parent/Legal Guardian Information Sheet

What effect does tube feeding have on oral health and dental treatment?

We would like to invite you and your child to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it will involve.

One of our team will go through this information with you and answer any questions you may have.

Talk to others about the study if you wish.

Part 1 tells you about the purpose of this study and what will happen to you and your child if you take part

Part 2 gives you more detailed information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you want your child to take part.

Part 1 – to give you first thoughts about the project

1. What is the purpose of the study?

This research is to look at the oral health of young people who are tube fed.

We know that children who are tube fed have higher calculus (tartar) levels in the mouth and usually a lower decay rate as the fact they are tube fed can change the oral environment. As well as this, children who are tube fed can develop oral hypersensitivity, making toothbrushing more difficult. We want to explore this further and look at how tube feeding can affect oral health, such as tooth decay, oral hygiene, gum health and tooth wear levels. This may help us better understand how tube feeding affects the mouth, as no -one has looked at this properly before, and help us deliver a better dental service.

2. Why have we been chosen?

Your child has been chosen because he/she has an artificial tube to help with feeding, and they are seen by our dental team.

3. Who is doing the study?

Annabelle Carter, Trainee Paediatric Dentist is doing the study, as part of a masters in research degree (University of Leeds). Frankie Soldani, Consultant in Paediatric Dentistry is overseeing the study.

4. Do we have to take part?

No. It is up to you and your child (wherever possible) to decide if you wish to join the study or not. We will explain the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. If your child is able to understand the research and is happy to take part and can write their name, they will be asked to sign an assent form with you, if they want to.

You will be given a copy of the information sheet and the signed consent/assent forms to keep for your records.

You are free to withdraw at any time, without giving a reason. This will not affect the standard of care your child receives.

5. What will happen to my child if we agree take part?

This study involves a dental check-up/examination, where one dentist (Annabelle Carter) will do a dental examination of your child, and record dental findings such as number of teeth, health of gums, levels of plaque, levels of calculus (tartar), extent of tooth wear, health of soft tissues such as the tongue and cheeks. As well as this, the dentist will ask routine questions about toothbrushing and oral - hygiene measures. This is all routine care that would usually happen at a check-up appointment.

For a small number of patients (5), a second check-up will be done by Frankie Soldani (Consultant in Paediatric Dentistry) to double check the teeth and gum health.

The study duration is the usual time required to perform a dental check-up (i.e. the length of the dental check-up appointment is usually 20-30 minutes), which is done at your child usual dental clinic.

The care your child receives will be unaffected by your decision to enter or not enter the study.

6. What will we have to do?

Attend your routine dental check-up as normal. Annabelle Carter, the dentist will ask you routine questions at your check-up, just like at any dental check-up appointment. This includes any concerns you have about your child's teeth/mouth, how they are managing with toothbrushing, how you are keeping the mouth/teeth clean, and checking your child's medical history.

7. What are the possible disadvantages or risks of taking part?

The dental check-up appointment may take an extra 5 minutes if Frankie Soldani is required to check your child's teeth. If not, there are no disadvantages - all care received will be the same as normal.

If we do find something during the dental check-up that may affect your child's dental health we will immediately discuss this with you as normal.

There are no risks to your child taking part, your child would have received a routine dental check-up regardless, and we are using anonymised information from the check-up to help our study.

8. What are the possible benefits of taking part?

The information we collect may help us to understand the oral health of patients who are tube fed better in the future. Taking part in the study may not benefit your child.

9. Are there any side effect of taking part in the study?

No there are no side effects, and the treatment (dental check-up) your child will receive will be no different.

10. Can I withdraw from the study at any time?

Yes you can, if you change your mind, all you would need to do is call the clinic and tell them. You do not need to give a reason. All data collected will be removed from the study, but a record of the dental check-up will be kept on our dental electronic record system, as it is part of your child's clinical record.

11. What happens when the research study stops?

We will collect all the information together and see if this extra information allows dentists to manage tube-fed patients better.

12. Will my child's taking part in the research project be kept confidential?

Yes. We will follow ethical and legal practice and all information about your child will be handled in confidence. The details are included in Part 2.

13. Contact for further information

If you would like any further information about this study you can contact:

Name: Dr Frankie Soldani
Designation: Consultant Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2 - More details: Information you need to know if you still want to take part.

1. **What if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the research team who will do their best to answer your questions.

Name: Dr Frankie Soldani
Designation: Consultant Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250

Name: Annabelle Carter
Designation: Specialist Registrar in Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250

Complaints
If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. Please contact Annabelle Carter 01274259250 in the first instance. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the clinic.

2. **Will taking part in this study be kept confidential?**

All information which is collected about your child during the course of the research will be kept strictly confidential. Any information about your child which leaves the clinic will have their name and address removed so that your child cannot be recognised from it. Once the study is complete all information will be kept in your child's confidential notes.

Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 2018.

University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from your child's medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Leeds will keep identifiable information about you for 3 months after the study has finished.
Your rights to access, change or move the information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
You can find out more about how we use your information by contacting the persons described below in section 7.

Information is kept strictly confidential, and we adhere to specific rules. Here is the link to the University privacy statement for research participants, which you may want to read: https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf.

Bradford District Care Trust will keep your childs' name, date of birth, and contact details confidential and will not pass this information to University of Leeds. Bradford District Care Trust will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the

quality of the study. Certain individuals from University of Leeds and regulatory organisations may look at your medical and research records to check the accuracy of the research study. University of Leeds will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, date of birth or contact details.
Bradford District Care Trust will keep identifiable information about your child from this study [for 12 months after the study has finished.

3. Will any tests be done?

No extra tests outside of those required by the dentist for your child to have a usual check-up, such as Dental Xrays, will be done.

4. What will happen to the results of the research study?

When the study has finished we will present our findings to other dentists, and we may put the results in dental journals that dentists read. The findings will be kept anonymous, which means that your child will not be able to be identified from any results.

5. Who is organising and funding the research?

Annabelle Carter, dentist and speciality trainee is organising the research. It is part of her Masters by research project at the University of Leeds so there is no external funding.

6. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed by Dental Research Ethics Committee, University of Leeds.

7. How can we find out more about research?

If you agree to take part, would like more information or have any questions or concerns about the study please contact

Name: Dr Frankie Soldani
Designation: Consultant Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250
Frankie.soldani@bdct.nhs.uk

Or
Annabelle Carter, Specialist Registrar in Paediatric Dentistry
Clinic/Department: Community Dental Service. Bradford District Care NHS Foundation Trust. Horton Park Health Centre. 99 Horton Park Avenue. BD7 3EG
Tel: 01274259250
Annabelle.carter@nhs.net

Or
Richard Balmer, Consultant Paediatric Dentistry
University of Leeds, School of Dentistry
r.c.balmer@leeds.ac.uk

If you and your child decide to take part in this study, you will be given this information sheet and signed consent and assent forms to keep.

Thank you for taking the time to read this information sheet

Appendix 8: Participant Consent form

NHS
Bradford District Care
NHS Foundation Trust

[Version 1, 30/4/19]

Centre Number: BDCT

Study Number: IRAS: 249799

Patient Identification Number for this trial:

CONSENT FORM

Title of project: **Oral Health, Dental Care and Aspiration History of Tube Fed Paediatric Patients within Bradford**

Name of Researcher: Annabelle Carter

	Please initial box
1. I confirm I have read and understand the information sheet dated ..... (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these Individuals to have access to my records.	☐
4. I agree to take part in the above study.	☐

----------	----------	----------
Name of Patient	Date	Signature
----------	----------	----------
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix 9: Participant Assent form

ASSENT FORM FOR CHILDREN

(Can be completed by child and their parent/guardian)

NHS
Bradford District Care
NHS Foundation Trust

Oral Health, Dental Care and Aspiration History of Tube Fed Paediatric Patients within Bradford

Child (or if unable, parent on their behalf)/young person to circle all they agree with:

Do you understand what this project is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand? Yes/No

Are you happy to take part? Yes/No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name _____

Date _____

The doctor who explained this project to you needs to sign too:

Print Name _____

Sign _____

Date _____

Thank you for your help