Oral Health of Children with Severe Neurological Impairment in Ireland

A thesis submitted in partial fulfilment of the requirements for the degree of Doctorate in Dental Surgery (D. Ch. Dent) in Paediatric Dentistry

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Dr. Robyn Crowley

Supervisor:

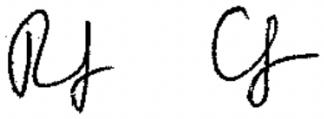
Prof. Anne O'Connell

Trinity College Dublin,
The University of Dublin

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Robyn Crowley

Summary

This thesis comprises two different studies with a shared focus on the oral health of children with severe neurological impairment (SNI). SNI is defined as "a group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment and medical complexity, and where much assistance is required in the activities of daily living. The impairment is permanent but can be progressive or static" (J. Allen et al. 2020). Study One is a cross-sectional study investigating the oral health of children with SNI through a questionnaire and an oral health assessment. Forty-two children and their parents were recruited from Children's Health Ireland (CHI) to take part. All forty-two parents completed the oral health questionnaire and 38 children attended for an oral health assessment appointment. The most common underlying diagnosis was CP. The majority attended a dentist in a hospital setting (60%), rather than in the community. The majority of participants' teeth were brushed with some form of resistance (n=34, 81%) and the most commonly reported perceived barrier to oral health care was "dental centres/units that treat special needs patients are rare and limited". Mean $D_{3vc}MFT+d_{3vc}mft$ was 0.46 (SD=1.6) and mean OHI-S was 1.45 (SD=1.3). There was no difference in $D_{3vc}MFT+d_{3vc}mft$ or OHI-S in those with CP versus genetic diagnoses or in those fed orally and those fed enterally. C-I was statistically significantly higher in those with enteral feeding compared to those fed orally. A preventive treatment need was noted in 100% participants and 11% required dental care under general anaesthesia. These findings highlight the oral health challenges faced by children with SNI and their families, including limited access

to care, limited support for families and reliance on hospital-based services. This study emphasised the need for early referral and better education for both healthcare provider and parents. Study Two aimed to create and assess acceptability of a short educational video demonstrating toothbrushing for parents of children with SNI. Its acceptability was assessed through the Generic Form of the Theoretical Framework of Acceptability (Sekhon, Cartwright, and Francis 2017, 2022). This was completed by 23 HCWs and 20 parents and carers. The video received overwhelmingly positive feedback from both groups with suggestions to use it in waiting rooms in clinics. The results indicate the video is a valuable educational tool, with potential for future refinement based on ongoing feedback.

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Table of Contents

Summary ..... ***II***

Acknowledgements ..... ***IV***

Table of Contents ..... ***V***

List of Tables ..... ***VIII***

List of Figures ..... ***X***

Glossary of Terms ..... ***XI***

1. Literature Review ***1***

1.1 Background **1**

1.1.1 Definition of Severe Neurological Impairment 2

1.1.2 Prevalence in Ireland 5

1.2 SNI-Associated Conditions and Features **5**

1.2.1 Cerebral Palsy 6

1.2.2 Other Conditions and Syndromes 7

1.2.3 Medical Complexity in CP and SNI 9

1.3 Oral Health **15**

1.3.1 Assessment of Oral Health 15

1.3.2 Oral Health of Children with SNI 16

1.3.3 Dental Caries 16

1.3.4 Dental Caries in Children with Special Healthcare needs 17

1.3.5 Dental Caries in Children with Cerebral Palsy 18

1.3.6 Periodontal Health 20

1.3.7 Saliva 21

1.3.8 Tooth Wear 21

1.3.9 Parafunctional habits 22

1.3.10 Malocclusions 22

1.3.11 Dental Development 23

1.3.12 Traumatic Dental Injuries 23

1.3.13 Treatment Need in Children with SHCNs 23

1.4 Dental Care **24**

1.4.1 Dental Care for Children in Ireland 24

1.4.2 Dental Care for Children with SHCNs 26

1.4.3 Complexity of Care 26

1.4.4 Dental Attendance of Children with SHCNs 27

1.4.5 Access to Care for Children with SHCNs 27

1.5 Oral Hygiene for Children 30
1.5.1 Guidelines and Recommendations 30
1.5.2 Oral Hygiene Habits in Children with SHCNs 30
1.5.3 Oral Hygiene Aids 31

1.6 Oral Health Education 32
1.6.1 Video-Based Learning 33
1.6.2 Comparing Different Forms of Oral Health Education 34

2: Introduction to Study One: Oral Health of Children with SNI - A Cross-Sectional Study 37

2.1 Abstract 37

2.2 Background 39

2.3 Study Aims and Objectives 39
2.3.1 Aims 39
2.3.2 Objectives 39

2.4 Materials and Methods 40
2.4.1 Ethical Approval 40
2.4.2 Study design 40
2.4.3 Study population 40
2.4.4 Consent 41
2.4.5 Data Collection 42
2.4.6 Parent Questionnaire 42
2.4.7 Oral Health Assessment 43
2.4.8 Collection of Outcome Variables 46
2.4.9 Attendance 51
2.4.10 Confidentiality 51
2.4.11 Statistical Analysis 51

2.5 Results 53
2.5.1 Recruitment 53
2.5.2 Participant Characteristics 53
2.5.3 Dental Questionnaire 55
2.5.4 Dental Assessment 64
2.5.5 Statistical Analyses 69

2.6 Discussion 71
2.6.1 Oral Health Questionnaire 73
2.6.2 Clinical Assessment 79
2.6.3 Future Considerations and Development of a Care Pathway 87
2.6.4 Transition to Adult Services 92

2.7. Conclusions 93

3. Introduction to Study Two: Oral Health Educational Content 95

3.1 Abstract **95**

3.2 Background **97**

3.2 Study Aims and Objectives **98**

3.2.1 Aims 98

3.2.2 Objectives 98

3.3. Materials and Methods **99**

3.3.1 Educational Video Creation 99

3.3.2 Video Assessment 101

3.3.3 Video distribution 103

3.4. Results **104**

3.4.1 Content Development 104

3.4.2 Healthcare Workers (HCW) 104

3.4.3 Parents/Caregivers 106

3.5 Discussion **109**

3.6 Conclusions **112**

4. References ***113***

5. Appendices ***137***

Appendix 1.1: Study 1- Ethical approval CHI **137**

Appendix 1.2: Study 1 - Ethical Approval Faculty of Health Sciences, Trinity College Dublin **138**

Appendix 1.3: Study 1- Recruitment Poster **139**

Appendix 1.4 Study 1- Participant Information Leaflet **140**

Appendix 1.5: Study 1 – Consent Form **150**

Appendix 1.6: Study 1- Data Collection Form- Questionnaire **153**

Appendix 1.7: Study 1- Data Collection Form- Clinical Assessment **155**

Appendix 2.1: Study 2- Script **158**

Appendix 2.2: Study 2- CHI Consent Form for Recording **159**

Appendix 2.3: Study 2 – QR Code to Access Educational Videos **160**

Appendix 2.4: Study 2 – Ethical Approval CHI **161**

Appendix 2.5: Study 2 – Ethical Approval, Dublin Dental University Hospital **162**

Appendix 2.6: Study 2 – Participant Information Leaflet (HCWs) **163**

Appendix 2.7: Study 2 – Participants Information Leaflet (Parents/Carers) **165**

Appendix 2.8: Study 2 – Consent Form and Questionnaire- HCWs (downloaded from online platform Qualtrics) **167**

Appendix 2.9: Study 2 -Consent and Questionnaire- Parents/Carers (downloaded from online platform Qualtrics) **172**

List of Tables

Table 1-1: Definitions 4
Table 1-2: Classification of cerebral palsy according to motor impairment adapted from Shevell et al. (2009). 6
Table 1-3: GMFCS E&R adapted from Palisano et al. (2007). 7
Table 1-4: A sample of relevant studies investigating caries in children with cerebral palsy. 19
Table 2-1: Inclusion and exclusion criteria. 40
Table 2-2: The Simplified Oral Hygiene Index 48
Table 2-3: The Drooling Severity and Frequency Scale. 49
Table 2-4: The Clinical Oral Dryness Score. 49
Table 2-5: Tooth Wear Index from Whelton et al. (2009). 50
Table 2-6: Participant Characteristics 54
Table 2-7: Previous dental care. 56
Table 2-8: Previous treatment location 58
Table 2-9: Previous treatment received. 58
Table 2-10: Previous dental trauma. 59
Table 2-11: Toothbrushing habits. 60
Table 2-12: Feeding. 61
Table 2-13: Parent-reported oral health status. 62
Table 2-14: Perceived barriers to dental care. 63
Table 2-15: Examination location and supports required. 65
Table 2-16: DMFT+dmft. 65
Table 2-17: P-I, C-I and OHI-S. 66
Table 2-18: CODS and Drooling Score. 67
Table 2-19: Parafunctional habits, n=38. 67
Table 2-20: Examination difficulty. 68
Table 2-21: Identified treatment needs. 68
Table 2-22: Mann Whitney U-Test for DMFT= dmft and other factors. 69

Table 2-23: Mann Whitney U-Test for OHI-S and feeding, diagnosis and hospital stays. 70
Table 2-24: Mann Whiteny U-Test for C-I and feeding, dosgnosis and hospital stays. 70
Table 3-1: Inclusion and exclusion criteria. 101

List of Figures

Figure 2.1: The Denlite® 44

Figure 2.2: Dental tray set-up for dental assessment. 45

Figure 2.3: Patient positioned knee-to-knee. 45

Figure 2.4: Dental charting. 46

Figure 2.5: Identified Treatment Needs. 50

Figure 2.6: Participant recruitment..... 53

Figure 2.7: Appointment numbers. 64

Figure 2.8: Care Pathway for Children with SNI 89

Figure 2.9: Dental Care Pathway for Children with SNI 91

Glossary of Terms

Abbreviation	Description
CEN	Children with Exceptional Healthcare Needs
CHI	Children's Health Ireland
CNNs	Children with Complex Care Needs
CP	Cerebral palsy
GA	General anaesthesia
GDP(s)	General Dental Practitioner(s)
GMFCS	Gross Motor Function Classification System
GORD	Gastro-oesophageal reflux disease
HSE	Health Services Executive
$D_{3vc}MFT$	Decayed to the level of visual dentine cavitation, missing, filled (permanent tooth)
$d_{3vc}mft$	Decayed to the level of visual dentine cavitation, missing, filled (primary tooth)
ICDAS	International Caries Detection and Assessment System
OHE	Oral Health Education
OHI-S	Simplified Oral Hygiene Index
QR	Quick Response
SHCN(s)	Special Health Care Need(s)
SNI	Severe Neurological Impairment
TDI	Traumatic Dental Injury
US	United States
VBL	Video-based learning
WHO	World Health Organisation

1. Literature Review

1.1 Background

Paediatric dentistry is defined as 'the provision of oral healthcare to children and young people from birth until their 16th birthday across primary, secondary and tertiary care settings' (NHS 2023) . It includes, 'oral healthcare for children whose oral health care is complicated by intellectual, medical, physical, social, psychological and/or emotional factors/disability, who are either too anxious or too young to accept routine dental treatment and those with diagnosed special educational needs' (NHS 2023). Oral health is 'the state of the mouth, teeth and orofacial structures that enables individuals to perform essential functions such as eating, breathing and speaking, and encompasses psychosocial dimensions such as self-confidence, well-being and the ability to socialise and work without pain, discomfort and embarrassment' (WHO 2025). Oral health is a critical aspect of overall health for all individuals.

Access to appropriate paediatric dental care is not readily available in the Irish health system and there is a lack of identified pathways for those with the highest care need. It is recommended that a dental home is established for all children by their first birthday (FitzGerald et al. 2017; AAPD 2016, 2018). This is rarely the case for children in Ireland and especially not for those with special healthcare needs. Parents of children with medical complexity frequently report that access to dental care for examination and/or preventive dental care

is not available in their locality. For this reason, children with additional medical needs are more likely to be seen in a hospital setting through referral from their medical team to the dental teams on site. Early recognition and access to preventive dental services seeks to minimise risk of oral disease for all children. Local preventive care from an early age is required.

A significant portion of clinical practice within Paediatric Dentistry requires knowledge and insight into the management of special groups of children who collectively fall under the term children with special healthcare needs. One such group is children with SNI. The researchers clinical experience in hospital-based practice has highlighted the high usage of the medical system by these children, while also revealing the absence of a clear pathway for their oral healthcare. Many of these children are referred to a hospital setting for dental care when concern is expressed by their parents to their medical team. Baseline data for children with SNI is required to investigate their oral health issues, inform planning of services for these children and to support the development of appropriate pathways for their oral healthcare. There is also a need for shared care for these children and improved education amongst colleagues in the medical field on the importance of integrating early preventive oral healthcare.

1.1.1 Definition of Severe Neurological Impairment

SNI is defined as “a group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment and medical complexity, and where much assistance is required in the activities of daily living. The impairment is permanent but can be progressive or static”(Allen et

al. 2020). This term was defined in 2020 through a Delphi consensus led by an Irish group and is therefore a relatively new definition. Prior to this there was no agreed definition for SNI and this term was used to describe many different groups of children (Allen et al. 2020). The advantage of a clear definition is that SNI includes a defined group of patients, with a variety of diagnoses, many of these rare and some individuals with no formal diagnosis. By grouping these children together under the SNI definition, services can be more appropriately planned to suit their shared needs. Many children with SNI are wheelchair users, are fed enterally and need help with everyday activities. Their condition may be congenital or acquired and can be static or progressive (J. Allen et al. 2020).

Children with complex care needs (CNNs) is a similar but distinct term (Brenner et al. 2018). This refers to “multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis” (Brenner et al. 2018). They are ‘individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures’ (Brenner et al. 2018). Children with CNNs definition includes children with SNI but also includes many other children for example children with congenital cardiac disease who do not have SNI (J. Allen et al. 2020).

Children with exceptional healthcare needs (CEN) is another similar term. This is used in Scotland for healthcare provision and is defined as “a child or young person up to age 19 years with severe impairments in four of the following six

categories; learning and mental functions; communication; motor skills; self-care; hearing; vision and enteral feeding, or severe impairment on two categories and require ventilation or CPAP" (NHS Scotland 2024). This definition may be considered one of the closest to SNI but it still will include children with significant medical needs but who do not have SNI.

Table 1-1: Definitions

Term	Reference	Definition
SNI	(Allen et al. 2020)	"a group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment and medical complexity, and where much assistance is required in the activities of daily living. The impairment is permanent but can be progressive or static"
CNN	(Brenner et al. 2018)	"multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They are 'individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures"
CEN	(NHS Scotland 2024)	"a child or young person up to age 19 years with severe impairments in four of the following six categories; learning and mental functions; communication; motor skills; self-care; hearing; vision and enteral feeding, or severe impairment on two categories and require ventilation or CPAP"

It is important to describe children with SNI separately from these other groups as SNI is a more descriptive definition, concerning this particular group of children, many of whom have very rare diagnoses, but all of whom share high medical and oral health needs and complete dependency on full-time care. The

SNI definition allows for more appropriate planning and delivery of oral healthcare.

1.1.2 Prevalence in Ireland

The prevalence of children with SNI in Ireland is unknown and there are no published estimates of prevalence in Ireland or elsewhere since SNI was defined in 2020. There are several studies reporting prevalence of groups of children who may fall under the SNI definition. There is a national estimate for children with ongoing complex needs of 4%, which would equate to 45,325 children aged 0-19 years (HSE 2011; 2009). However, the majority of these children would not fall under the SNI definition. More closely related to SNI is the CEN definition used in NHS Scotland, as described previously. The number of children with CEN in Scotland was 699 in the 2020-2021 CEN Report (NHS Scotland 2022). This also is likely to overestimate SNI.

1.2 SNI-Associated Conditions and Features

Children with SNI have a wide range of underlying diagnoses. The feature that is common to all these children is severe neurological impairment which results in impairment of intellectual function, mobility and communication (Allen 2022). They also have multiple specific medical issues and increased healthcare needs and healthcare utilisation (Allen 2022). The most common underlying diagnosis in children with SNI is cerebral palsy (CP) (Allen 2022). Other less common conditions include Rett syndrome, Angelman syndrome, Wolf-Hirschhorn syndrome, CHARGE syndrome and Trisomy 18.

1.2.1 Cerebral Palsy

CP is defined as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum et al. 2007). CP is most often congenital, but a small number of cases are acquired. The risk of CP is increased in premature births, those born with a low birth weight, multiple births, complicated labour and/or delivery, infections during pregnancy and exposure to toxins (NIH 2024a). The prevalence of CP has been reported as 1.77-3 per 1000 live births in a European population (Sellier et al. 2016). The prevalence of CP in adults in Northern Ireland is 2.38 per 1000 population (McConnell et al. 2020). CP is often classified according to associated motor impairments as seen in Table 1-2.

Table 1-2: Classification of cerebral palsy according to motor impairment adapted from Shevell et al. (2009).

Motor impairment	Description
Spastic	The most common type with stiff, rigid muscle in affected limbs
Dyskinetic/athetoid	Hypotonia with slow uncontrolled writhing movements
Ataxic	Problems with balance and perception
Combined	Combination of the above types

CP can also be classified using the Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997; Palisano et al. 2007). This system has five levels

based on a child's gross motor function and there are different descriptors based on the child's age, as shown in Table 1-3. The system ranges from level I where a child can walk without limitations to level V where the child is transported in a manual wheelchair (Palisano et al. 1997).

Table 1-3: GMFCS E&R adapted from Palisano et al. (2007).

Level	Descriptor
I	Children walk without limitations
II	Walk with limitations
III	Walk using a hand-held mobility device
IV	Self-mobility with limitations, may use a powered wheelchair
V	Transported in a manual wheelchair

Children with CP who also have a diagnosis of SNI are most likely to fall under GMFCS IV and V. In Northern Ireland it was found that just over 35% children with CP who survived beyond age two years had GMFCS of IV or V (NICPR 2016).

There is very little data available on children with SNI, but a large amount of research on general health and oral health of children with CP. This data provides background information to what might be expected in children with SNI.

1.2.2 Other Conditions and Syndromes

SNI can also be associated with a number of other conditions, both genetic and non-genetic. These include Rett syndrome, Wolf-Hirschhorn Syndrome,

Angelman Syndrome, Cockayne syndrome, CHARGE syndrome and Trisomy 18. The first three will be described in more detail.

Rett Syndrome

Rett syndrome is an X-linked neurodevelopmental condition which occurs almost exclusively in females. It is characterised by developmental regression with loss of speech, gait abnormalities, seizures and intellectual disability (Orphanet 2021a). Rett syndrome is usually due to a mutation in the MECP2 gene and the majority of cases are sporadic (NIH 2024b). Children with Rett syndrome develop normally for approximately six months but then their development slows and there is a loss of skills previously acquired (Petriti et al. 2023). An Irish study found that 80% children with Rett syndrome used mainly nonverbal forms of communication and 12% used no communication, verbal or nonverbal (Zade et al. 2024). Rett syndrome affects 5-10 per 100,000 females internationally (Petriti et al. 2023). It is thought that there are approximately 180 people (children and adults) living with Rett syndrome in Ireland (Zade et al. 2024).

Wolf-Hirschhorn Syndrome

Wolf-Hirschhorn Syndrome is a rare chromosomal disorder characterized by specific facial features, growth impairment, hypotonia, seizures and intellectual disability (Orphanet 2021b). It occurs more commonly in females than males with a birth incidence of one in 20,000-50,000 (Orphanet 2021b). It is caused by a deletion of the short arm of chromosome 4 (Orphanet 2021b). The specific facial features seen in individuals with Wolf-Hirschhorn Syndrome include a broad nasal bridge, hypertelorism, a short philtrum, downturned mouth and

micrognathia. Cleft lip and palate may also be a feature. Children with Wolf-Hirschhorn syndrome have severe developmental delay and need much support in daily activities. Most individuals with Wolf-Hirschhorn also have moderate to severe intellectual disability (Orphanet 2021b). Over 90% individuals have frequent, uncontrolled seizures and these generally start by three years of age (Paprocka et al. 2024). Feeding difficulties occur in more than 75% children and skeletal problems are also common (Paprocka et al. 2024).

Angelman Syndrome

Angelman syndrome is a genetic condition characterized by developmental delay, intellectual disability, epilepsy, ataxia and microcephaly (NINDS 2024). The condition is caused by loss of function of the UBE3A gene and affects both males and females equally (NINDS 2024). Children with Angelman syndrome have severe intellectual disability and a motor disorder. They have a characteristically happy demeanour, are easily excited and frequently laugh (Bird 2014). Children with Angelman syndrome often have epilepsy and gastrointestinal problems, including gastroesophageal reflux disease (GORD) and constipation, are also common (Bird 2014). It is thought that there are 250-350 people living in Ireland with Angelman syndrome (Ireland 2024).

1.2.3 Medical Complexity in CP and SNI

Neurological

CP is the most common cause of motor impairment in children (Keogh and Badawi 2006). One third of children with CP also have intellectual disability and 39% children with CP have epilepsy. This varies with the type of CP and its aetiology, with it being more common in those with a more severe motor

impairment (Carlsson, Hagberg, and Olsson 2003). Those with CP who also have epilepsy are more likely to have an intellectual impairment (Carlsson, Hagberg, and Olsson 2003). Speech and language disorders are also prevalent in children with CP with 82% reported as having delayed or disordered speech development (Mei et al. 2020). Hearing and visual impairments are often seen in children with CP (Weir et al. 2018). Autism is also more prevalent in those with CP than children in the general population and a U.S.-based study reported that 7.5% of children with CP in the U.S. are autistic (Durkin et al. 2016).

Gastrointestinal

Gastrointestinal disorders seen in children with CP include dysphagia, GORD and chronic constipation (Erasmus et al. 2012). Dysphagia is reported in 43% of children with CP (Parkes et al. 2010). It is often due to problems in the oral and pharyngeal phases of swallowing. It is thought that individuals with CP may have an impaired ability to coordinate swallowing with breathing (Erasmus et al. 2012). Chronic aspiration due to swallowing difficulties can lead to colonisation of the respiratory tract by pathogenic bacteria which can lead to progressive lung damage (Erasmus et al. 2012). GORD is reported in 51% children with CP and may also lead to chronic pulmonary aspiration in these children (Erasmus et al. 2012). Constipation is also common and reported in 57% of children with severe generalised CP (Veugelers et al. 2010).

Drooling is another issue reported in children with CP related to impaired swallowing. Drooling is defined as “the unintentional spill of saliva from the mouth” (Blasco and Allaire 1992). Its consequences include dry, cracked skin on the face and neck, malodour, damage to books and electronics and social

isolation. Management of drooling is multidisciplinary and there are several strategies. Conservative methods include the use of towelling wristbands, handkerchiefs, waterproofing sewn into clothes, distraction and avoidance of acidic and effervescent foods and drinks (Fairhurst and Cockerill 2011). Oral motor training can enhance oral motor control in some individuals, increase lip closure and promote swallowing (Fairhurst and Cockerill 2011). Injection of Botulinum toxin A into major salivary gland under ultrasound guidance is used to decrease secretion of saliva from the gland and therefore reduce drooling. Other pharmacological techniques include transdermal delivery of hyoscine, hydrobromide and glycopyrronium bromide. Surgical procedures can include submandibular gland relocation surgery (Fairhurst and Cockerill 2011). Some of these techniques may affect a child's caries risk (Corrêa et al. 2021).

Feeding

Children with cerebral palsy often have feeding difficulties. In a Norwegian study it was found that 21% of children with CP had feeding problems and 14% were fed by gastrostomy (Dahlseng et al. 2012). In children with SNI feeding problems may be related to oropharyngeal sensory motor dysfunction, digestive system dysfunction, neuromusculoskeletal and movement dysfunction, as well as other comorbidities (Oftedal et al. 2025). Assessment of nutritional intake and malnutrition is often done by identifying poor growth using growth charts, such as the WHO growth charts. There are CP specific charts available including different charts for those with and without feeding tubes and for the different GMFCS levels (Brooks et al. 2011). Oral feeding is promoted in children with SNI. The Focus on Early Eating, Drinking and Swallowing Toolkit, published in 2022 aims to improve eating, drinking and

swallowing difficulties in children with neurodisability and outlines a range of interventions including modifying the consistency of food and drink, oral and sensory desensitisation, graded exposure to new textures, and modelling (Taylor et al. 2022). This is relevant to the dental practitioner as it may impact oral health of these children as well as their ability to tolerate dental home care and treatment in the dental surgery.

Enteral Feeding

Enteral feeding is defined as “a way of providing nutrition directly into the gastrointestinal tract through an enteral access device that is placed with its tip in the stomach or small intestine” (ASPEN 2025). There are several options including nasogastric which accesses the stomach through the nose, gastrostomy which accesses the stomach through the skin and jejunostomy which accesses the small intestine through the skin (ASPEN 2025). Depending on the child’s swallowing ability, they may receive only medications through their feeding tube, a combination of medications and some nutrition, or all of their nutrition as well as their medications. Blended foods may be prepared by the family at home for their child or commercially available enteral feeds can be used. Children who are exclusively enterally fed may still have some tastes of food in their mouth provided by their family. This is important for the dental team to be aware of as it affects their caries risk. Parents may give children small amounts of tasty foods for the child’s enjoyment and due to the child’s compromised swallowing ability, these foods are likely to remain in the mouth for several hours.

Respiratory

Respiratory dysfunction is a significant problem in those with CP and is the leading cause of death in children and young people with CP (Allen 2022). It is related to gastrointestinal dysfunction in these individuals, namely dysphagia and aspiration which lead to respiratory damage and disease. Respiratory failure is reported as accounting for 53% of deaths in a Swedish cohort of individuals with CP and was caused by aspiration and/or pneumonia (Himmelmann and Sundh 2015). Lower respiratory tract infections are also more common and more severe in children with CP. Some children are on prophylactic antibiotics during the winter months to prevent aspiration related infections. A Taiwanese study reported that individuals with CP have a 2.5 times greater risk of getting pneumonia than matched peers (Liu, Huang, and Chang 2024).

Aspiration of Oral Pathogens

There is a lot of research on the link between respiratory disease and the aspiration of oral pathogens (Scannapieco and Mylotte 1996; Scannapieco 1999; Gomes-Filho, Passos, and Seixas da Cruz 2010). Oral pathogens have been researched as a source of infection particularly in those with periodontal disease (Scannapieco and Mylotte 1996; Gomes-Filho, Passos, and Seixas da Cruz 2010). There are a number of theories described in the literature on the pathogenesis of this process. The simplest theory involves the direct aspiration of pathogens form the oral cavity into the lungs (Gomes-Filho, Passos, and Seixas da Cruz 2010). These may be periodontal pathogens or respiratory pathogens which have adhered to the dental plaque biofilm (Gomes-Filho,

Passos, and Seixas da Cruz 2010). Another theory involves the high levels of cytokines and bioactive molecules present in periodontal disease which may enter respiratory tissues and alter the epithelium thereby promoting infection (Gomes-Filho, Passos, and Seixas da Cruz 2010). It has been theorised that dental care could reduce or prevent the risk of this occurring in susceptible individuals. Oral care has been shown to reduce incidence of aspiration pneumonia in adult patients receiving enteral nutrition (Maeda and Akagi 2014). The previously mentioned Taiwanese study reported that individuals with CP who attended the dentist at least twice previously were less likely to develop pneumonia than those who never attended the dentist (Liu, Huang, and Chang 2024). A significant relationship has been reported between history of aspiration pneumonia and presence of calculus in special needs children fed by gastrostomy (Brown et al. 2006).

Orthopaedic

Orthopaedic problems are common in children with cerebral palsy and include scoliosis, hip luxations and hip dislocations (Allen 2022). These problems are more common in those with more severe motor impairment and those who are non-ambulatory (Hasler et al. 2020).

Endocrine

Children with CP are at risk of endocrine abnormalities because of the lack of feedback from muscle systems. Growth abnormalities are common and can be related to deficiencies in growth hormone as well as nutritional deficiencies (Hegazi et al. 2012).

Cardiac

Individuals with CP have higher levels of cardiovascular disease (CVD) and CVD-related deaths. This is partly due to reduced mobility secondary to musculoskeletal problems (Mcphee et al. 2019). The risk is greater with age and with more severe CP but CVD-related death was also more common in young people with CP compared to those without CP (Mcphee et al. 2019).

Renal

Urinary tract dysfunction and infections are common in this group. Urinary incontinence is more common in children with CP and they are reported to achieve urinary continence later and more slowly than those without CP (Wright et al. 2016). Severity of motor impairment is associated with continence (Wright et al. 2016).

1.3 Oral Health

1.3.1 Assessment of Oral Health

The Scottish Dental Clinical Effectiveness Programme (SDCEP) describes an oral health assessment and review as involving “a comprehensive assessment of a patient’s social, dental and medical histories and oral health status that leads to diagnosis and risk assessment, followed by personalised care planning and ongoing review” (SDCEP 2012). Oral health can be assessed in many different ways and there is no defined overall measure for oral health specifically. The WHO Oral Health Assessment proformas for children include measurement of dentition status, gingival status, enamel fluorosis, dental erosion, dental trauma, oral mucosal lesions and intervention urgency (WHO 2013).

Oral health assessment is described by the Irish Oral Health Services Guideline Initiative as being completed by a dentist in a dental clinic and involves extraoral and intraoral examination, assessment of soft tissues, plaque levels, signs of trauma, tooth wear, caries and any other pathology and an orthodontic assessment (HSE 2012)

1.3.2 Oral Health of Children with SNI

The oral health of children with SNI is currently unknown. However, likely oral features of children with SNI can be extrapolated from research on other specific groups of children who may fall under the SNI umbrella. Much of this research is based on children with CP. As stated previously, while some children with cerebral palsy have SNI, most do not.

1.3.3 Dental Caries

Dental caries is “a biofilm-induced acid demineralization of enamel or dentin, mediated by saliva” (AAPD 2003). Dental caries is the most common childhood disease in Ireland with 55% of 8-year-olds in Dublin having dental caries to dentine in 2017 (James et al. 2021). The mean $D_{3vc}MFT$ of those with caries was 3.3 (James et al. 2021). Dental caries can be measured using a number of difference indices. DMFT is the sum of the number of Decayed, Missing due to caries and Filled Teeth in the permanent teeth. The index “dmft” denotes the same in the primary dentition (WHO 2013). DMFT is commonly used in research as it is quick and easy to measure. $D_{3vc}MFT$ includes non-cavitated dentine caries as described by James et al. where, “caries is visible as a shadow under the enamel but does not have a detectable cavity through the enamel” (James

et al. 2021). This was used in the most recent Irish research measuring caries in children (James et al. 2021). ICDAS is a more descriptive measure where the caries depth is also measured. It is more descriptive but more difficult and time-consuming to assess (Gudipaneni et al. 2022).

1.3.4 Dental Caries in Children with Special Healthcare needs

Dental caries is a commonly reported finding in children with special healthcare needs. An Irish report from 2009 assessed the oral health of children attending special schools in Ireland and found that 33.5% of five-year-olds attending a day care centre and 27% of five-year-olds with moderate intellectual disability had dental caries (Whelton et al. 2009). For older children, 51.1% of 12-year-olds, and 41.5% of 15-year-olds were caries-free which means over half of 15-year-olds had caries (Whelton et al. 2009). A UK report from 2013 assessed the oral health of five and 12-year-old children attending special support schools. Dental caries was present in 22% of five-year-olds and 29% of 12-year-olds (PHE 2015). An American report from 2021 found that 16% of children and youth with special healthcare needs had dental caries compared to 11% of children and youth without special healthcare needs (Lebrun-Harris et al. 2021).

There are a number of studies investigating caries in children who are fed enterally. Cardona-Soria et al. compared caries levels in children with CP fed enterally and orally and found DMFT scores of 2.81 and 1.09 respectively (Cardona-Soria et al. 2020). There was a significantly higher caries rate in those fed orally. They included over 50 children in each group and included all levels of cerebral palsy and so it is likely that few of the children included would have

SNI (Cardona-Soria et al. 2020). Similarly, Hidas et al. found lower levels of dental caries in children with special needs fed enterally compared to healthy children and compared to children with special needs fed orally (Hidas et al. 2010).

Dental caries has been reported in individuals with Rett syndrome, Trisomy 18 and Angelman syndrome (Mahdi et al. 2021; Fuertes-González, Silvestre, and Almerich-Silla 2011; Bruns, Martinez, and Campbell 2016; de Queiroz et al. 2013). Fuertes-González et al. described dental caries in children with Rett syndrome in Spain (Fuertes-González and Silvestre 2014). These children had lower dmft and DMFT scores than children in the general population. However, this was generally due to lower levels of treated caries but they actually had higher numbers of untreated decayed teeth in both the primary and permanent dentition (Fuertes-González and Silvestre 2014). A case series described dental features in children with Angelman syndrome and reported the presence of the caries and developmental defects of enamel (de Queiroz et al. 2013). Bruns et al. report high levels of caries in individuals with Trisomy 18 (Bruns, Martinez, and Campbell 2016).

1.3.5 Dental Caries in Children with Cerebral Palsy

Dental caries is commonly reported as an oral finding in children with cerebral palsy (Bensi, Costacurta, and Docimo 2020). There is little consistency in the literature regarding the level of dental caries in children with CP compared to the general population with some authors reporting higher levels and others reporting lower levels (Aburahma et al. 2021; Bensi, Costacurta, and Docimo

2020; de Castelo Branco Araújo et al. 2022; Sruthi, Yashoda, and Puranik 2021).

These papers are summarised in Table 1-4.

Table 1-4: A sample of relevant studies investigating caries in children with cerebral palsy.

Author, year	Study type	Location	Participant age	Findings
(Aburahma et al. 2021)	Cross-sectional	Jordan	1.6-11 years	No difference in caries experience between children with CP and age and gender-matched healthy controls
(Bensi, Costacurta, and Docimo 2020)	Systematic review and metanalysis	Included sources from Brazil, China India, UAE, Saudi Arabia, UK, Turkey, Croatia and USA	Children up to age 18 years	Increased caries in the primary dentition in children with CP. No increased prevalence of dental caries in the permanent dentition.
(Zemene et al. 2024)	Systematic review and metanalysis	Africa and Asia	Children	55.6% of children with CP had dental caries
(de Castelo Branco Araújo et al. 2022)	Cross-sectional	Brazil	6-14 years	Significantly higher caries levels in those with CP compared to matched controls
(Sruthi, Yashoda, and Puranik 2021)	Cross-sectional	Bangalore	5-15 years	Caries presence was significantly higher in those with cerebral palsy than controls without cerebral palsy
(Rodríguez et al. 2018)	Cross-sectional	Mexico		DMFT pooled was 6.5 but varied among different CP groups

(Cardoso et al. 2014)	Cross-sectional	Brazil	2-18 years	Dental caries reported in 59.3% of participants
(Asiri, Tennant, and Kruger 2024)	Systematic review	Saudi Arabia	2-18 years	High dental caries rates (ranging between 52.9%- 98.6%)
(Akhter et al. 2019)	Cross-sectional	Bangladesh	2-17 years	Dental caries was present in 55.6% of participants.
(Sedky 2018)	Cross-sectional	Egypt	3-12 years	Dental caries was present in 54.8%. Levels IV and V GMFCS were predictors for dental caries

1.3.6 Periodontal Health

Higher plaque scores and higher gingival index scores have been reported in children and adolescents with cerebral palsy and children with neurological impairment (Aburahma et al. 2021; Bensi, Costacurta, and Docimo 2020; Fregatto et al. 2021). Difficulty maintaining oral hygiene is reported as well as suboptimal oral hygiene habits (Aburahma et al. 2021; Zemene et al. 2024). This could be related to a number of factors including reduced oral clearance, inability to tolerate oral stimulation and motor impairments making toothbrushing more difficult. Children with cerebral palsy are more dependent on caregivers for their oral hygiene and the caregiver burden associated with managing complex medical needs can result in dental care being deprioritised (Aburahma et al. 2021). Children with special healthcare needs fed by gastrostomy have higher plaque scores, calculus and OHI-S scores compared to healthy children and children with SHCNs who are fed orally (Jawadi et al. 2004; Hidas et al. 2010; Fregatto et al. 2021). This is largely due to reduced mechanical

cleansing of the teeth that is associated with the action of chewing and swallowing. These children often have decreased salivary flow, which further impairs the natural removal of food debris and bacteria from the teeth. They also tend to have a higher salivary pH, which can promote the precipitation of minerals and the formation of calculus (Duarte et al. 2023). Gingivitis and periodontal disease are also reported in children with Rett syndrome and Angelman syndrome (Fuertes-González, Silvestre, and Almerich-Silla 2011; Mahdi et al. 2021; de Queiroz et al. 2013).

1.3.7 Saliva

Differences in saliva quality and quantity are often seen in children with SHCNs. Both dry mouth and drooling are seen in children with SNI. Dry mouth may be a side effect of medications or it may be due to neurological conditions affecting saliva production (Feinstein et al. 2020) . Drooling is the unintentional spill of saliva from the mouth and is commonly associated with a neurological disorder (Blasco and Allaire 1992). Cerebral palsy has been reported as the most common cause of drooling in children and interferes with daily activities in 10% of children (Harris and Purdy 1987; Scully et al. 2009).

1.3.8 Tooth Wear

Tooth surface loss due to attrition and erosion is reported in children with SHCN, including cerebral palsy and Rett syndrome (Mahdi et al. 2021; Jan and Jan 2016; Abanto et al. 2014). This can be caused by a number of factors. Erosion can occur due to GORD as well as extrinsic acids (Arvedson 2013). Parafunctional habits as described below can also lead to tooth wear due to attrition.

1.3.9 Parafunctional habits

Bruxism is commonly reported in children with neurological disorders. It is particularly prevalent in children with Rett syndrome and is reported as one of the main features of the condition (NIH 2024b). An Irish study found that 56% of parents reported that their children with Rett syndrome had bruxism (Zade et al. 2024). Mouth breathing and tongue thrust habits are more common in children with cerebral palsy than controls (Almotareb and Al-Shamahy 2024). Tongue thrusting has been reported in Angelman syndrome (Gallo et al. 2012; Murakami et al. 2008).

1.3.10 Malocclusions

Malocclusions are commonly reported in children with CP (Franklin, Luther, and Curzon 1996; Almotareb and Al-Shamahy 2024; Bensi, Costacurta, and Docimo 2020). Most often a class II malocclusion, with increased overjet and proclined maxillary anterior teeth are reported (Franklin, Luther, and Curzon 1996; Almotareb and Al-Shamahy 2024). Children with Angelman syndrome have been reported to have a diastema and wide mouths (Gallo et al. 2012; Murakami et al. 2008). Many genetic conditions associated with SNI have craniofacial features, including Wolf-Hirschhorn syndrome which is characterised by microcephaly and micrognathia and can be associated with cleft lip/palate (Orphanet 2021b). These differences in craniofacial anatomy can contribute to dental malocclusions.

1.3.11 Dental Development

General developmental delay is reported in children with neurological disorders (Allen 2022; NIH 2024b; NINDS 2024). Dental developmental delay may therefore also be expected in these children. Delayed eruption is reported in Wolf-Hirschhorn (Limeres et al. 2020).

1.3.12 Traumatic Dental Injuries

A traumatic dental injury (TDI) is defined as an impact injury to the teeth and/or other hard and soft tissues inside or around the mouth and oral cavity (WHO 2022). The global prevalence of TDI is 15% in the permanent dentition and 23% in the primary dentition (Petti, Glendor, and Andersson 2018). The prevalence of TDIs in individuals with SHCN is higher, reported as occurring in 23% (Devi K et al. 2024). The most common injuries reported are enamel and enamel-dentine fractures (Devi K et al. 2024). It has been reported that individuals with cerebral palsy in particular have a higher chance of TDI. Falls at home were the most common type of injury reported in this group (Silveira, Magno, and Soares 2020; Devi K et al. 2024; Heiden et al. 2024; Bensi, Costacurta, and Docimo 2020).

1.3.13 Treatment Need in Children with SHCNs

It is well documented that children with special healthcare needs have more oral health problems and higher treatment need than those without (Lebrun-Harris et al. 2021; Obeidat et al. 2022; Lewis and Stout 2010). Dental care was reported as the most frequently cited unmet treatment need in children with SHCNs in the US (Lewis 2009). A U.S.-based study reported that 20% of children

with SHCN had dental health needs compared to 12% of those without (Obeidat et al. 2022). They also found that there was an increased prevalence of oral health needs in those affected by poverty and those with higher levels of disability (Obeidat et al. 2022). Another U.S.-based study found that 20% of children with significant SHCNs have unmet dental needs (Nelson et al. 2011). This included a subgroup of children with greater medical complexity (Nelson et al. 2011). Children with SHCNs in Ireland have been reported to have more dental caries and higher unmet dental treatment needs compared to the general population (Whelton et al. 2009).

1.4 Dental Care

1.4.1 Dental Care for Children in Ireland

Dental care for children in Ireland is provided by both the public and the private dental sectors. Health policy in Ireland states all people with a disability in Ireland are entitled to a needs assessment according to the Disability Act 2005 and to provision of identified care needs, which includes dental care. Dental care for children with special needs is the responsibility of the Health Services Executive (HSE) Public Dental Service. The HSE provides emergency dental care for all children up to the age of 16 years (HSE 2024). They also provide appointments for children in certain national school classes as well as those children identified with special needs. Orthodontic treatment is provided for those with a high level of treatment need according to specified criteria (HSE 2024). As this service has limited resources, many families opt for private dental care for their child. This may be with a private general dentist or with a specialist paediatric dentist. There are 14 specialist paediatric dentists in private practice

in Ireland, with the majority located in Dublin. The National Model of Care for Paediatric Healthcare Services in Ireland acknowledged the need for more paediatric dentists in Ireland and the benefit of the appointment of regional consultants in paediatric dentistry (HSE 2016).

The 'Smile agus Sláinte' dental care plan was published by the Department of Health in 2019 (Department of Health 2019). The policy consists of three strategic strands. The first is oral health promotion, which relates to regulations, including the Sugar Tax and alcohol legislation, and community programmes, such as water fluoridation and mouthrinsing programmes. The second strand is service provision. Dental care would be provided by local dental teams for all children under the age of 16 years as well as medical card holders. Individuals would receive 'packages of care' which would be provided by the local dentist. These packages consist of three layers, namely: preventive, routine care and complex care. These would vary according to age. Dental care services for vulnerable people (both children and adults) would be by the local dentist in the first instance, with the option of referral to a community oral healthcare centre if required. Referral for advanced care in secondary and tertiary centres would also be available. The third strand is a clinical surveillance programme. This would enable the programme to be evaluated as well as help with planning for the future. The Smile agus Sláinte programme has not yet been implemented and it is currently unknown if it will be implemented. No planning to increase specialist training in Paediatric Dentistry has occurred either.

1.4.2 Dental Care for Children with SHCNs

Previous studies have reported that the dental care received by children with special healthcare needs is different to the treatment provided to children in the general population (Aburahma et al. 2021; Sevekar, Jha, and Avanti 2021; Hieronymus et al. 2024). Aburahma et al. found that children with cerebral palsy attended the dentist more frequently than children in the general population, but that they experienced less procedural dental treatment and most had only ever had a dental examination (Aburahma et al. 2021). They also reported that only 11% of children with CP had restorations placed by their dentist compared to 76% of healthy children. Similar numbers in both groups however had dental extractions completed (Aburahma et al. 2021). Children with SHCNs are also more likely to experience dental treatment under general anaesthesia and when they do, they have more definitive treatments completed compared to children in the general population (Sevekar, Jha, and Avanti 2021).

1.4.3 Complexity of Care

A number of healthcare systems have developed a case mix tool which can be used to gauge patient complexity. The British model measures six criteria on a four-point scale, namely; ability to communicate; ability to co-operate; medical status; oral risk factors; access to oral care; legal and ethical barriers to care. (BDA 2019). Different weighting is applied to each category, and the six scores are summed to give an overall measure of complexity. The banded total score can then be equated to level of complexity which ranges from ‘standard patient’ to ‘extreme complexity’. Many children with SNI would most likely fall into the ‘extreme complexity’

category as measured by the six criteria, especially due to restrictions in communication, limited ability to cooperate, the impact of their medical status on their dental care as well as oral risk factors. Due to this complexity, children with SNI will most likely require continuing oral healthcare with a professional with additional training and skills commensurate with specialist level paediatric dentist. Currently, in Ireland, dental services for children are not widely available within the local primary care setting and so many children with additional healthcare needs must attend a hospital service for their regular dental care and typically fall between gaps in services as they age .

1.4.4 Dental Attendance of Children with SHCNs

Children with SHCNs are generally reported to have more frequent dental visits than children in the general population but the nature of these dental appointments are different (Lebrun-Harris et al. 2021; Aburahma et al. 2021). Children with SHCNs still have more dental problems and are more likely to have experienced toothache in the past six months compared to those without (Lebrun-Harris et al. 2021; Lewis and Stout 2010).

1.4.5 Access to Care for Children with SHCNs

Dental attendance for children with SHCNs is complicated and may be affected by a number of factors, which both relate to the individual, their family and the service. They face numerous barriers to accessing dental care, resulting in poorer oral health compared to their peers. Ummer-Christian described these barriers in relation to six main areas (Ummer-Christian et al. 2018). “Accessibility” refers to the physical accessibility to the dental clinic building, to

the dental surgery and to the dental chair. This includes the building and the dental chair being wheelchair-accessible. Poor parking facilities, lack of a lift to access a dental surgery upstairs as well as inadequate width of door frames for wheel chairs and power chairs have all been reported (Ummer-Christian et al. 2018; Edwards and Merry 2002; Star et al. 2024; da Rosa et al. 2020). "Availability" refers to the knowledge of a carer to the availability of dental care, as well as the availability of dental services in that area and the availability of both general and specialist dentists (Ummer-Christian et al. 2018). Lack of awareness of the child's dental issues by their carers and not knowing where to go for dental care have been reported as barriers to accessing appropriate dental care for children with SHCNs (Ummer-Christian et al. 2018; da Rosa et al. 2020). It is frequently reported that families find it difficult to find a dentist willing to treat a child with SHCNs (da Rosa et al. 2020; Ummer-Christian et al. 2018; Nelson et al. 2011). This has been investigated in Northern Ireland by Jimoh and Kinirons who carried out a questionnaire-based study of general dental practitioners (Jimoh and Kinirons 2014). They found that behaviour management issues and degree of disability were the most commonly reported factors affecting dentists' willingness to treat patients with SHCNs (Jimoh and Kinirons 2014). It could be presumed that children with SNI would likely fall under the category of those with greater complexity and many general dentists may be unwilling to treat them. Surgery resources and funding issues as well as level of training and clinical experience were also cited as factors (Jimoh and Kinirons 2014). Another Irish study investigating the dental care of adults with special needs found that 66% of dentists treated individuals with SHCNs but 22% reported that treating SHCNs patient was outside their capabilities (G.

Smith, Rooney, and Nunn 2009). It was interesting to note that 41% participants had previous training in treating individuals with SHCNs and 65% were willing to participate in training (G. Smith, Rooney, and Nunn 2009). This may indicate scope for improvement in the Irish setting.

"Accommodations" is the third concept and refers to the planning of appointments and multidisciplinary input. It includes difficulty of securing appointments for children with SHCNs and the often lengthy waiting times to receive an appointment (Ummer-Christian et al. 2018; da Rosa et al. 2020). "Affordability" may also be a barrier to dental care (Ummer-Christian et al. 2018; da Rosa et al. 2020; Nelson et al. 2011). In Ireland, medical care for all children up to age of eight years is freely available within the public system. Dental care is generally not free for children unless provided in a HSE clinic or public hospital. Private dental care with a GDP or paediatric specialist can be costly. "Acceptability" is a commonly reported barrier and relates to the providers awareness, knowledge and skill to provide care for the child with SHCNs (Ummer-Christian et al. 2018). Caregivers may feel the dental practitioner is inadequately trained or lacking experience in treating individuals with SHCNs (Ummer-Christian et al. 2018; da Rosa et al. 2020; Star et al. 2024). The final concept is "appropriateness to need" which refers to the adjustments made within the service to provide a person-centred approach to dental care for the individual with SHCN (Ummer-Christian et al. 2018).

1.5 Oral Hygiene for Children

1.5.1 Guidelines and Recommendations

Irish guidance regarding fluoride use recommends toothbrushing twice a day for all children. For children over two years of age this should be with a fluoride toothpaste containing 1000ppm fluoride – 1500ppm fluoride. It also recommends that toothbrushing is assisted up to age seven years and supervised above age seven years (HSE 2008).

1.5.2 Oral Hygiene Habits in Children with SHCNs

It is reported that oral hygiene habits in children with SHCNs are suboptimal (Whelton et al. 2009). An Irish survey of children attending special schools and day centres reported that most five-year-olds report toothbrushing once per day and higher numbers of 15-year-olds with SHCNs did not brush their teeth compared to 15-year-olds in the general population (Whelton et al. 2009). Aburahma et al. reported absence of toothbrushing in 58% of children with CP compared to 25% of the general population (Aburahma et al. 2021). They also found that most children with CP were reliant on caregivers for toothbrushing (Aburahma et al. 2021). Assisted toothbrushing is recommended for all young children as described above and it has been shown that supervised toothbrushing is also preferable to unsupervised for older children (Toumba et al. 2019; HSE 2008). However, for children with SHCNs long-term assisted toothbrushing is often required. This may be due to problems with manual dexterity as well as lacking the cognitive skills to understand the importance of toothbrushing and remembering to or being physically able to perform

toothbrushing. There may also be other associated conditions that complicate toothbrushing which necessitate assistance such as a hypersensitive gag reflex and oral sensory sensitivity (Sarvas et al. 2024). A U.S.-based study found that half of parents of children with SHCNs reported toothbrushing twice daily and 60% reported using a fluoride toothpaste (Campanaro, Huebner, and Davis 2014). They also reported facilitators and barriers to toothbrushing with the child's cooperation being the most commonly reported facilitator, as well as tooth brushing supplies and ample time. Time constraints, child behaviour and having only one carer available for toothbrushing were all reported as barriers to twice-daily toothbrushing (Campanaro, Huebner, and Davis 2014).

1.5.3 Oral Hygiene Aids

Toothbrushes

A Cochrane review investigated hygiene interventions for adults with intellectual disability and found that the evidence was unclear and further research is needed (Waldron et al. 2019). They found that the multi-sided toothbrush (Dr Barman's Superbrush®) may reduce plaque and inflammation in the medium term greater than a normal manual brush. It was also found that in the long term, training carers in oral hygiene practices coupled with regular dental visits may reduce gingival index and plaque accumulation (Waldron et al. 2019). A realist review by the same authors found that in order for carer-led oral hygiene to succeed, it needs to be supported with adequate resources, clear goals and repeated training (Waldron, MacGiolla Phadraig, and Nunn 2020).

Toothpastes

Toothpaste, both the taste and the texture, can be uncomfortable for children with SNI, especially for those with oral aversion or oral sensory problems. There are alternative toothpastes available such as Oranurse® which is flavourless and non-foaming. For children with high caries risk a higher strength fluoride toothpaste may also be prescribed such as Duraphat® 2800ppm Fluoride depending on the child's age.

Other aids

Mouth props and finger props are also helpful for children who tend to bite down when their caregiver is attempting to brush their teeth.

Child positioning

Supine brushing is a very useful position for toothbrushing for children, in particular younger children and infants, as it allows the parent the best visual access. However, this may not be feasible in children with SNI where positioning for adequate management of fluids is critical.

1.6 Oral Health Education

Health education is defined as "the process by which messages aimed at enabling individuals to take greater control over and improve their health are defined" (Levine and Stillman-Lowe 2024). Oral health education (OHE) may be provided by any healthcare professional but is most often provided by the dentist.

Different forms of OHE are available. Traditionally, health education was provided verbally or in leaflet form. More recently there is a wider range of

forms available including audio and audiovisual, such as podcasts, radio, and videos on online platforms including YouTube, Instagram, Vimeo and TikTok. Written information is also still available through books, patient information leaflets (PILs) and online. The evidence for OHE is variable as reported in the systematic review by Hubba and Krishnappa (Habbu and Krishnappa 2015). It is difficult to assess the various OHE interventions due to the range of ways authors measure outcomes, including change in behaviour, change in attitude, knowledge increase and changes in plaque and oral hygiene scores. In general, the literature reports short-term reductions in plaque scores and improved knowledge of participants after OHE (Habbu and Krishnappa 2015).

A recent systematic review by Santos et al. investigated the effectiveness of OHE specifically for caregivers of those with disabilities (Santos et al. 2025). Caregivers included both staff carers and parents caring for individuals of all ages, both children and adults. They found that OHE resulted in improvements in clinical measurements of plaque and oral hygiene scores and well as improved behaviours (toothbrushing quality, frequency and duration) (Santos et al. 2025). OHE is an essential part of preventive dental care. It is necessary for all children and parents and needs to be individualised. For children with special needs it is particularly important that preventive advice is tailored towards the individual and their family (AAPD 2024).

1.6.1 Video-Based Learning

Video-based Learning or VBL is defined as “the knowledge or skills acquired through teaching via Video” (Sablić, Mirosavljević, and Škugor 2021). It is

thought that VBL is particularly useful for practical skills such as health education. It offers increased flexibility in learning as the resource can be accessed anytime and anywhere (Morgado et al. 2024). It is theorised that by involving several senses - visual and hearing - this can increase retention and understanding of knowledge (Morgado et al. 2024; Loy, Underwood, and Stevens 2021). Videos may also increase the uptake among those with low health literacy (Tuong, Larsen, and Armstrong 2014). A recent trial by Demirel et al. found video education preferable to verbal in improving OHI-S scores in children (Demirel et al. 2025).

1.6.2 Comparing Different Forms of Oral Health Education

A systematic review by Loy et al. compared videos and written information for oral health care for parents and children (Loy, Underwood, and Stevens 2021). Three studies were included. Post-education knowledge levels after VBL and written information were assessed in one study which found no significant difference in knowledge acquisition (Lees and Rock 2000). All three studies assessed changes in oral health behaviour. Ramezaninia et al. found improvements in oral health behaviours in all intervention groups at eight weeks – that is for those who received lecture, pamphlet and video education (Ramezaninia et al. 2018). Both Ramezaninia et al. and Yazdani et al. found a significant improvement in oral health behaviours in leaflet and video groups compared to those who received no intervention (Ramezaninia et al. 2018; Yazdani et al. 2009). The review suggested that posting videos online may allow a wider audience to be reached rather than playing these videos in waiting

rooms and videos need to be subject to patient feedback to keep up to date and relevant (Loy, Underwood, and Stevens 2021). A further advantage of video information is the environmental effect as it avoids the need for printing of paper copies and distributing new leaflets as new information comes to light (Loy, Underwood, and Stevens 2021).

The quality of available VBL has been studied by several authors. A review of YouTube videos on oral hygiene instruction found that many were made by lay people and were not evidence based (Smyth et al. 2020). Out of 52 included videos, 20 were made by lay people, primarily bloggers and influencers. Seven videos recommended rinsing with water after brushing and only one advised the correct fluoride concentration to be used. A number of videos contained content that could even be detrimental to oral health (Smyth et al. 2020). Another review investigating smartphone applications found that only two out of 20 commercially available applications on oral hygiene contained accurate information relating to oral hygiene (Sharif and Alkadhimi 2019). Advice regarding the correct fluoride concentration, rinsing behaviours and toothbrushing duration were frequently incorrect or omitted (Sharif and Alkadhimi 2019).

Brushmyteeth.ie was developed by an Irish team including dental health professionals, people with disabilities and general nurses (brushmyteeth.ie 2021). This website is freely available and contains 10 videos demonstrating toothbrushing in different scenarios, with manual, electric and special toothbrushes and for individuals who brush their own teeth, ‘need a little help’

and ‘need a lot of help’. This website contains accurate information and is a valuable resource for children and adults. The key concepts used in the development of the resource are also explained; equality, accessibility, creativity, credibility and inclusivity (brushmyteeth.ie 2021). This resource, however, is primarily aimed at adults and although much of the content is also applicable to children, they are not the primary target audience.

There is currently no educational tool available which appropriately demonstrates toothbrushing for children with SNI, who require lifelong assisted toothbrushing.

2: Introduction to Study One: Oral Health of Children with SNI - A Cross-Sectional Study

2.1 Abstract

Background: There are currently no studies assessing the oral health of children with SNI in Ireland or elsewhere since this term was defined in 2020. ***Aims:*** The aim of this study is to determine the oral health of children with SNI in Ireland, assess parental knowledge and experience of oral care and to evaluate the correlation of oral health variables to the medical data. ***Methods:*** A cross-sectional study design was employed for this study. It consists of two parts, a parental questionnaire and an oral health assessment. Ethical approval was obtained and parental consent. The questionnaire used a previously reported oral health questionnaire (O'Connell et al. 2009; O'Connell et al. 2010). Clinical assessments were completed by two operators, trained and calibrated to measure $D_{vc3}MFT+d_{vc3}mft$. All study data was stored on Redkap and extracted to Microsoft excel for descriptive analysis. Statistical analysis was completed on SPSS using Mann-Whitney U-Test to assess oral health data and medical variables. ***Results:*** Forty-two children aged two to 16 years were recruited. All forty-two parents completed the questionnaire and thirty-eight attended with their child for the oral health assessment. The most common underlying diagnosis was CP. The majority attended a dentist in a hospital setting (n=25, 60%). The majority of participants' teeth were brushed with some form of resistance (n=34, 81%). The most commonly reported perceived barrier to oral health care was "Dental centres/units that treat special needs patients are rare

and limited". Mean $D_{vc3}MFT+d_{vc3}mft$ was 0.46 (SD= 1.6) and mean OHI-S was 1.45 (SD=1.3). There was no difference in $D_{vc3}MFT+d_{vc3}mft$ or OHI-S in those with CP versus genetic diagnoses. C-I was statistically significantly higher in those with enteral feeding compared to those fed orally. A preventive treatment need was noted in 100% participants and 11% required dental care under general anaesthesia. ***Conclusions:*** This study highlights the oral health challenges faced by children with SNI and their families. These include the limited access to care, limited support for families and reliance on hospital-based services. Operative dental treatment received by these children is often invasive emphasising the need for early referral, integrated care pathways and better education for healthcare providers.

2.2 Background

Severe Neurological Impairment in Ireland (SPIRE) is a large multidisciplinary project taking place in Children's Health Ireland involving a group of researchers working with children with SNI. The overall project aims to estimate national prevalence of SNI, assess healthcare use by this group, collect baseline data on feeding, nutrition and growth as well as determine the oral health of these children. It aims to advance understanding of children with SNI and their families as well as their use of healthcare services. This will improve outcomes for these children, assist their parents and allow for future planning of healthcare services. The oral health component described in this thesis forms part of this overall project.

2.3 Study Aims and Objectives

2.3.1 Aims

The aim of this study is to determine the oral health of children with SNI in Ireland, assess parental knowledge and experience of oral care and to evaluate the correlation of oral health variables to the medical data.

2.3.2 Objectives

The objectives of this study are to:

1. Assess oral health through a dental examination.
2. Conduct a parent questionnaire to assess previous dental experience, oral hygiene habits, diet and potential barriers to care.
3. Correlate these findings with medical findings including diagnosis, feeding and hospital stays.

2.4 Materials and Methods

2.4.1 Ethical Approval

Ethical Approval for this research was obtained from The Children's Health Ireland Research Ethics Committee (21st Sept 2022, reference 21.035, Appendix 1-.1) and The Trinity College Dublin Faculty of Health Sciences Research Ethics Committee (8th March 2023, reference 230102 -2150, Appendix 1.2).

2.4.2 Study design

A cross-sectional observational study design has been employed for this study.

2.4.3 Study population

Inclusion and exclusion criteria

The inclusion and exclusion criteria are outlined in Table 2-1 and are identical to the overall SPIRE project.

Table 2-1: Inclusion and exclusion criteria.

Inclusion Criteria	Exclusion Criteria
Children age 16 years and younger.	Acute intercurrent illness.
Attending a neurodisability or paediatric service in Dublin.	Age greater than 16 years at the beginning of the study.
Assessed as fitting the definition of Severe Neurological Impairment by their primary paediatrician.	Parents unwilling or unable to give consent.
	Children subject to a care order.

Recruitment and sampling

A convenience sample of children attending the Neurodisability Service within CHI Hospitals were recruited to the main SPIRE research project through the recruitment posters which were on display in clinical areas in CHI Hospitals

(Appendix 1.3). This was completed by the multidisciplinary team of researchers involved in the SPIRE project, including Dr Siobhán McCormack. There were also recruitment posts on the study's social media platforms, and the project was mentioned to families attending appointments at CHI by staff members. Parents who expressed interest in taking part were provided with an information leaflet to consider (Appendix 1.4).

Sample size calculation

The sample size calculation for the overall SPIRE project was completed by Dr Siobhán McCormack. It was based on an estimate from a similar patient group in Scotland, as there is no published data reporting prevalence of SNI in any population. This Scottish report estimated the prevalence of Children with Exceptional Healthcare Needs (CEN) in Scotland as 0.4 per thousand (NHS Scotland 2024). Based on the Dublin population of 274, 981 children in the 2016 Census, this prevalence estimates 110 children with SNI living in Dublin. To achieve a 95% confidence interval, the sample size for the SPIRE project was estimated to be 86. This is the same sample size for the oral health component of this project.

2.4.4 Consent

Consent for the SPIRE project was obtained by Dr Siobhan McCormack, the lead contact person of the SPIRE team. This included a section on Oral Health – developed by Robyn Crowley (RC) and Anne O'Connell (AOC). Families who expressed interest in participating in the study were provided with a Patient Information Leaflet (PIL) by the SPIRE gatekeeper (Appendix 1.4). They were also provided an opportunity to ask questions. A minimum of one week was

given between giving this information and seeking consent. Families already participating in the overall study were invited to participate in the oral health component and had three options:

1. to opt out
2. to complete the questionnaire only
3. to complete the questionnaire and attend for a clinical oral health assessment.

Parents who consented to participate could choose to withdraw from the study at any time.

2.4.5 Data Collection

Data was collected through the parent questionnaire (Appendix 1.6) and also during the oral health assessment when consent was provided (Appendix 1.7). All families were invited to participate in these two parts but had the option to complete the questionnaire only or to also attend for the dental examination. There was flexibility in the scheduling of the clinical examination to facilitate attendance.

2.4.6 Parent Questionnaire

The parent questionnaire (Appendix 1.6) was developed based on a questionnaire validated previously in a study investigating oral health in children born small for gestational age in Irish children (O'Connell et al. 2009; O'Connell et al. 2010). This questionnaire was modified to include questions used in a survey of children and adolescents with special healthcare needs in Ireland and about barriers to care (Whelton et al. 2009. Additional questions were added relating to oral health issues pertinent for children with SNI

including enteral feeding and saliva management. This was informed by previous publications on oral health in children with CP. A specific question was also included on barriers to care as this also was noted in previous publications on oral health of children with SHCNs (Alfaraj et al 2021). The questionnaire was piloted with volunteer HCWs and parents for length and clarity of language before being finalised.

Completion of Parent Questionnaire during Data Collection

Parents could complete the questionnaire in person before their child was examined with five to ten minutes allowed for completion. Parents who chose not to attend for the dental assessment but requested to complete the questionnaire were sent the questionnaire by post, with instructions to return the completed form to the SPIRE team.

2.4.7 Oral Health Assessment

The clinical assessment was completed in the dental clinic at CHI at Tallaght in the presence of one or both parents. An Oral Health Assessment Form was created (Appendix 1.7) to aid data collection, following a typical paediatric dental assessment. Additionally the form included questions based on known dental issues in this group (identified via clinical experience and during the literature review) such as the Drooling Score. Data was recorded using standardised indices based on previous literature by Whelton et al. as well as additional indices to record oral health issues specific to children with SNI (the Clinical Oral Dryness Score, the Drooling Quotient) (Thomas-Stonell and Greenberg 1988; Osailan et al. 2012; Whelton et al. 2009).

Examiners

Two clinical examiners (RC and AOC) had regular exposure to children with SHCN in a dental setting. Both were calibrated for $D_{vc3}MFT/d_{vc3}mft$ (kappa >0.8). Each child was examined once by one examiner except in the case where two clinicians were required to physically complete the examination. In these cases both AOC and RC examined the child together. Both examiners also assessed the child together when there was uncertainty regarding score for any index and the lower of the possible scores for the queried measure was recorded.

Equipment

The dental assessments were completed using an illuminated dental mirror, the DenLite® (Figure 2.1), blunt ended-probe, toothbrush, finger prop and gauze and the overhead dental light. This set-up is shown in Figure 2.2.

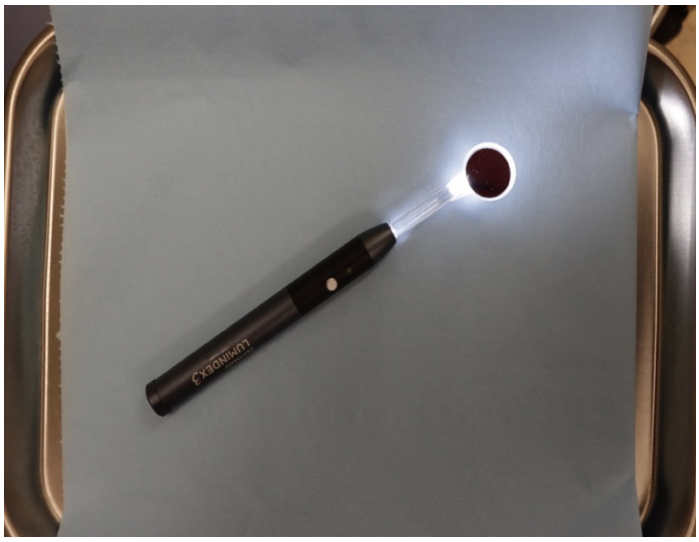


Figure 2.1: The Denlite®

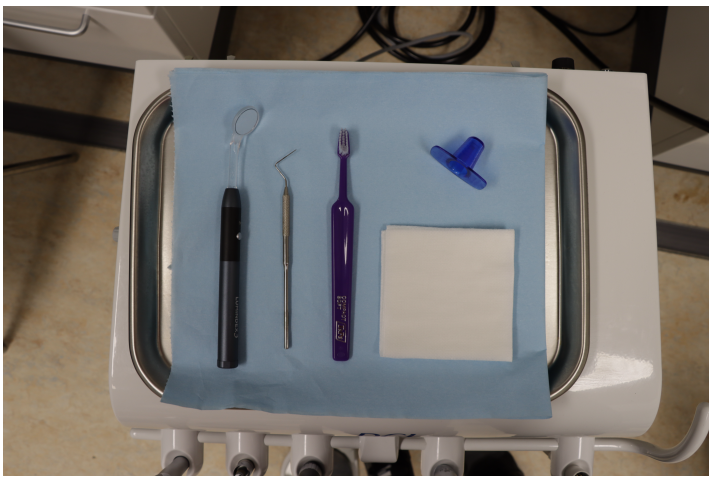


Figure 2.2: Dental tray set-up for dental assessment.

Patient positioning

The decision on positioning was based on parent and clinician preference and was recorded as wheelchair; dental chair; knee to knee or other, with a text box for description of 'other'. The majority of wheelchair users had the assessment completed in their wheelchair, with the chair reclined where possible. Children who were not wheelchair users had their examination completed in the dental chair, in a knee-to-knee position (Figure 2.3) or in their buggy.



Figure 2.3: Patient positioned knee-to-knee.

Dental charting

A standard dental charting was completed for each patient as below (Figure 2.4). This was assessed by one of two examiners and recorded by a dental nurse or dentist who regularly works in the paediatric department in CHI at Tallaght.

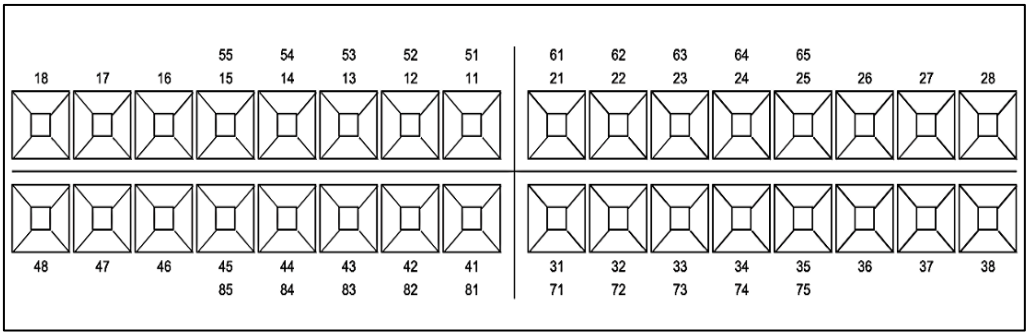


Figure 2.4: Dental charting.

2.4.8 Collection of Outcome Variables

Caries: $D_{3vc}MFT+ d_{3vc}mft$

Teeth were examined with illumination and wiped clean where possible. If the teeth were covered in gross amounts of plaque or food a toothbrush or gauze was used to clean the teeth prior to recording caries. Teeth were recorded as decayed when there was caries to dentine present ($D_{3vc}MFT+ d_{3vc}mft$) described previously in Irish research (James et al. 2018). Teeth were recorded as missing when the tooth was not present and the parent informed us that the tooth had been previously extracted due to dental caries or infection. Teeth were recorded as filled when there was a restorative material present, excluding fissure sealant. Where there was ambiguity about the score for a tooth, for example between a restored tooth or a fissure sealant, the lower of the two scores was used.

Orthodontic Features:

Overjet

Overjet was measured in millimetres with a standard metal ruler from the labial surface of the most prominent maxillary incisor to the labial surface of the mandibular incisors. In cases with a reverse overjet the measurement was given a negative value (Cobourne and DiBiase 2010).

Overbite

Overbite was recorded as the total height of the mandibular incisors overlapped by the maxillary incisors when in full intercuspation as a percentage (Cobourne and DiBiase 2010).

Anterior Open bite

Anterior open bite was recorded where there was no vertical overlap between the anterior teeth (Cobourne and DiBiase 2010).

Crowding

Crowding was estimated as mild (0 to 4mm), moderate (5 to 8mm) or severe (9 mm and above) in both arches (Cobourne and DiBiase 2010). A metal examination ruler which would give accurate measurement, was not used due to the challenging nature of oral examination in these participants.

Spacing

Spacing was recorded as present when there was space present between adjacent teeth, excluding sites where there were missing or unerupted teeth.

Dental Development

Dental development was recorded as normal, delayed or accelerated based on averages for a European population (Cobourne and DiBiase 2010).

Simplified Oral Hygiene Index (OHI-S)

The OHI-S consists of two components; the Simplified Debris Index (DI-S) and the Simplified Calculus Index (CI) (Table 2-2). Each component is measured separately on six tooth surfaces. The scores are added and the total was divided by the number of surfaces scored to given one overall score for each index. The

DI-S and CI-S are combined to estimate the overall OHI-S score (Greene and Vermillion 1964).

Table 2-2: The Simplified Oral Hygiene Index

	Debris Score	Calculus Score
0	No debris or stain present.	No calculus present.
1	Soft debris covering not more than one third of the tooth surface.	Supragingival calculus covering not more than one third of the tooth surface.
2	Soft debris covering more than one third but not more than two-thirds of the exposed tooth surface.	Supragingival calculus covering more than one third but not more than two-thirds of the exposed tooth surface.
3	Soft debris covering more than two thirds the exposed tooth surface.	Supragingival calculus covering more than two thirds the exposed tooth surface or a continuous band of subgingival calculus around the cervical portion of the tooth or both.

Saliva

Saliva Amount and Thickness

Saliva amount was recorded as reduced, normal or excessive based on the clinicians opinion. Saliva thickness was recorded as thick, normal or watery, based on the clinicians opinion.

Drooling Severity and Frequency Scale (DSFS)

The DSFS is a parent-reported measure of drooling. A score is assigned to the severity of drooling and a separate score to the frequency of drooling. These are added to give the overall DSFS (Thomas-Stonell and Greenberg 1988).

Table 2-3: The Drooling Severity and Frequency Scale.

Severity	Score	Frequency	Score
Dry (never drool)	1	Never	1
Mild (wet lips)	2	Occasionally (not every day)	2
Moderate (wet lips and chin)	3	Frequently (part of everyday)	3
Severe (drools to an extent that clothing becomes wet)	4	**Overall score:**	

Clinical Oral Dryness Score (CODS)

The CODS outlines criteria associated with oral dryness. The clinician records the criteria present and the total number of criteria counted is the numerical value for CODS (Osailan et al. 2012)

Table 2-4: The Clinical Oral Dryness Score.

Criteria	Criteria
Mirror sticks to buccal mucosa	No saliva pooling in floor of mouth
Mirror sticks to tongue	Glassy appearance of other oral mucosae
Tongue lobulated/fissured	Debris on palate
Tongue shows loss of papillae	Altered gingival architecture
Frothy saliva	Active or recently restored (< 6 months) cervical caries
Total Score	

Tooth Wear

Tooth wear into dentine was assessed as described previously by Whelton et al. (Whelton et al. 2009). Carious or heavily restored surfaces were not scored and substitution for absent teeth was not used.

Table 2-5: Tooth Wear Index from Whelton et al. (2009).

Score	Criteria
0	No wear into dentine
1	Wear into dentine
X	Could not be scored

Difficulty of the Examination

The degree of difficulty of the examination was based on the clinicians experience. An exam was considered easy if all criteria were measured and moderate if $D_{3vc}MFT+ d_{3vc}mft$ was recorded but not all other criteria were measured. An exam was recorded as abandoned if the $D_{3vc}MFT+ d_{3vc}mft$ was not recorded.

Treatment Need

Treatment need was recorded as the treatment required and the level of intervention were grouped as identified below (Figure 2.5). The clinician recorded the likely location for treatment provision as primary care, secondary or tertiary care and indicated if treatment under GA would be required.

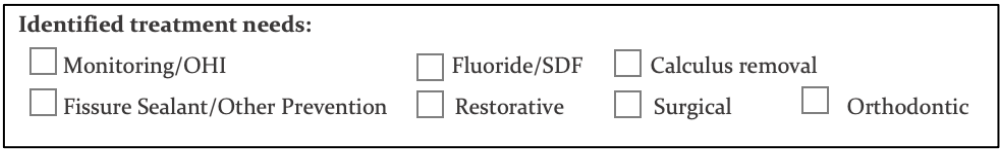


Figure 2.5: Identified Treatment Needs.

2.4.9 Attendance

Appointments were recorded as cancelled if the parents contacted the hospital and cancelled up to the scheduled appointment time. Children were recorded as 'did not attend' (DNA) if they were not brought to their scheduled appointment without cancelling or if they contacted the hospital during or after the designated appointment time. The scheduling of appointments was flexible and agreed with parents in advance to facilitate attendance for the oral health examination.

2.4.10 Confidentiality

The parent questionnaire and assessment form were identified by a unique patient code. On completion, they were placed in a sealed envelope which was stored in a locked cabinet in a locked room. Questionnaires completed without clinical examination were stored in a similar fashion. All paper questionnaires and assessment forms were then inputted to RedKap®, a secure web-based application.

2.4.11 Statistical Analysis

Anonymised data was extracted from RedKap® to Microsoft Excel (Version 16.89.1) by RC and imported to SPSS (Statistical Package for Social Sciences Version 28) by Dr. Bahman Honori, staff statistician at the Dublin Dental University Hospital. Statistical analysis was completed by Dr. Bahman Honori on SPSS. The Shapiro-Wilk test was used to assess for normality. The normality assumption was violated for all groups assessed and therefore the Mann Whiteny U-Test was used to assess for differences in oral health findings

(D_{3vc}MFT+ d_{3vc}mft, OHI-S and C-I) and medical variables (orally fed and enterally fed, CP and genetic diagnosis, and fewer or greater hospitals stays in the preceding two years).

2.5 Results

2.5.1 Recruitment

Sixty-six patients in total were recruited for the overall SPIRE project and invited to take part in the dental component. Forty-two patients were recruited to take part in the dental component and all 42 completed the oral health questionnaire. Thirty-eight also attended for a dental examination as shown in Figure 2.6.

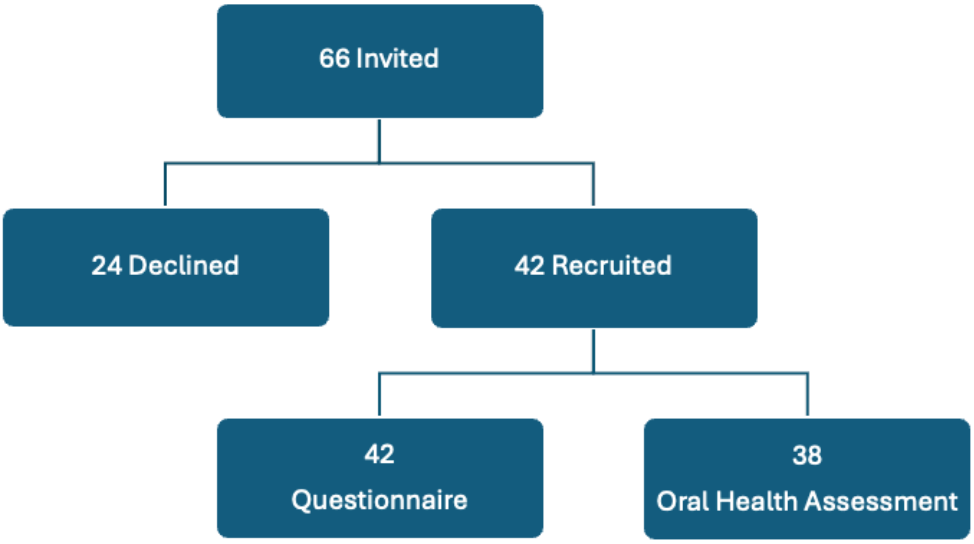


Figure 2.6: Participant recruitment.

2.5.2 Participant Characteristics

Participant characteristics are displayed in Table 2-6. Nineteen males (45%) and 23 (55%) females participated. Their ages ranged from age two years to sixteen years. The mean age was 8.6 years and the median age was eight years. The most common diagnosis was cerebral palsy (45%) and 55% were diagnosed with

a genetic condition. Four participants had Rett syndrome, two had Wolf-Hirschhorn syndrome and two had Angelman syndrome. Twenty-five participants (60%) were enterally fed at the time of recruitment, two (5%) had been previously and 15 (36%) had never required enteral feeding. Thirty-two (76%) participants had been hospitalised within the past two years. The mean number of days spent in hospital in the two years preceding their recruitment for the project was 18 days, but ranged from one to 100 days. Seventeen participants (40%) had epilepsy and six participants previously had epilepsy (14%). No epilepsy had been diagnosed in 43% of children.

Table 2-6: Participant Characteristics

Characteristic	**n**	**%**
Gender		
Male	19	45
Female	23	55
Age	**years**	
Min-Max (years)	2-16	
Mean	8.56	
Median	7.95	
Primary Diagnosis	**n**	**%**
Cerebral Palsy	19	45
Genetic syndrome/condition	23	55
Rett syndrome	*4*	10
Wolf-Hirschorn syndrome	*2*	5
Angelman syndrome	*2*	5
Sotos syndrome	*1*	2
CHARGE syndrome	*1*	2
Patau syndrome	*1*	2
Langer- Giedion syndrome	*1*	2
Cornelia de Lange	*1*	2

Trisomy 18	*1*	2
Menke-Hennekam syndrome	*1*	2
Cockayne syndrome	*1*	2
Other genetic diagnoses	*7*	17
Enteral Feeding	**n**	**%**
Yes	25	60
No, previously	2	5
No, never	15	36
Hospitalisations in the preceding two years	**n**	**%**
Yes	32	76
No	10	24
Number days spent in hospital of those who were hospitalised in the preceding two years n=32		
Min-Max (days)	1-100	
Mean (days)	17.6875	
Median (days)	7	
Epilepsy	**n**	**%**
Yes, currently	17	40
Yes, previously	6	14
No, never	18	43
Unknown	1	2

2.5.3 Dental Questionnaire

Forty parents completed the questionnaire in its entirety. Two parents did not answer one question, which asked parents to rate their own oral health. All other questions were answered by all 42 parents.

Previous dental appointments

Answers regarding previous dental appointments and treatment are displayed in Table 2-7. The mean age for first dental visit was four years, and this included the 10 participants for whom this was their first dental appointment. Ten participants (24%) had never attended a dentist before and 33% of participants attended the dentist every six months. The majority of participants attended the dental team in association with their medical team in a hospital setting (n= 25, 60%). Twenty-two participants (52%) had previously attended their local HSE dental clinic. The main reason for attending a dentist previously or for attending as part of the study, was for a regular check-up (n=39, 93%). This was followed by concerns regarding grinding (n=9, 21%), calculus (n=7, 17%) and concerns about eruption of teeth or tooth position (n=7, 17%).

Table 2-7: Previous dental care.

Question	**Answers**	
Age at first dental visit		
Min-Max	1-12 years	
Mean	4 years	
Median	4 years	
How often does your child attend the dentist?	**N**	%
Never before	10	24
Every 6 months	14	33
Every year	13	31
Rarely or when there is a problem	5	12
Where does your child attend for dental care?		
HSE clinic	22	52
Private GDP	8	19

Hospital	25	60
What was the reason for previous dental appointments?		
Regular check-up	39	93
Concerns about grinding	9	21
Concerns about drooling	4	10
Calculus or tartar	7	17
Erupting teeth and/or tooth position	7	17
Pain	2	5
Tooth decay	2	5
Bleeding gums	4	10
Dental Trauma	2	5
Swelling	1	2

Previous Dental Treatment

The majority of participants had previous dental treatment completed in their own chair (wheelchair or powerchair) (n=24, 57%). Five participants had previous dental care under general anaesthesia. The research team did not have access to these notes but all five parents reported extractions, two had fissure sealants and two had a cleaning. These four children were some of the older children who attended, with two aged 11 years, one aged 13 and two aged 16 years. One of these children had cerebral palsy and the other four children had genetic conditions (Wolf-Hirschhorn, Chromosome 1q deletion, Sotos syndrome and Cockayne syndrome). Four of these five children were enterally fed at time of recruitment.

Table 2-8: Previous treatment location.

Location of treatment	n	%
Participant's own wheelchair	24	57
Dental chair	7	17
Knee-to-knee	3	7
Buggy	2	5
Parent's lap	2	5
Inhalation sedation	0	0
General anaesthesia	5	12

Previous treatment provided as recalled by the parent is displayed in Table 2-9. Just over half of participants (52%) participants had received previous dental treatment of some kind, with 47% in total receiving any type of preventive care (including brushing instructions, cleaning, fluoride varnish and fissure sealants).

Table 2-9: Previous treatment received.

Treatment	n	%
Preventative total	18	47
Brushing instructions	16	38
Cleaning	7	17
Fluoride varnish application	9	21
Fissure sealants	5	12
Restorative		
Fillings	3	7
Stainless steel crowns	0	0
Surgical		
Extractions	8	19
No previous treatment	20	48

Dental Trauma

Seven participants (17%) had experienced previous dental trauma. Thirty-three participants had not had previous trauma and two parents did not answer this question. Most traumas were as a result of a fall from the participant's wheelchair as shown in Table 2-10. Parents were asked what they did and were able to give multiple answers. Most parents provided first aid at home, visited the child's GP and/or the hospital. Only one parent reported bringing their child to the dentist.

Table 2-10: Previous dental trauma.

Cause	**N=7**	**%**
Falls	5	71
Toys	1	14
Self-inflicted	1	14
What did you do?		
First aid at home	2	29
Attend GP	2	29
Attend dentist	1	14
Attend Hospital	2	29
Nothing	1	14

Toothbrushing

Toothbrushing was most often performed by the participant's mother (n=38, 90%) and the majority of participant's teeth were brushed with some form of resistance (n=34, 81%). Most participants had their teeth brushed once per day (n=21, 50%), followed by at least twice (n=15, 36%) per day. The majority of parents reported that they had never been shown how to brush their child's teeth (n=24, 57%). Most participants were using a fluoridated (n=38, 90%) and

flavoured (n=32, 76%) toothpaste. Three participants (7%) were not using toothpaste.

Table 2-11: Toothbrushing habits.

Questions		
Who brushes your child's teeth?	**n**	**%**
Mother	38	90
Father	19	45
Sibling	1	2
Other caregiver	5	12
The child	1	2
Are your child's teeth brushed..?		
Without resistance	8	19
With resistance	24	57
Requires second person	5	12
Cannot be brushed	5	12
How often are your child's teeth brushed?		
Less than once/week	3	7
2-6 days/week	3	7
Once/day	21	50
Twice/day or more	15	36
Has anyone ever showed you how to brush?		
Yes	16	38
No	26	62
Toothpaste type		
Fluoridated	38	90
Not fluoridated	1	2
Flavoured	32	76
Unflavoured	7	17
No toothpaste	3	7

Feeding

Twenty-five participants were enterally fed at the time of the study. However three parents still reported giving food by mouth more than four times per day to their enterally fed child. The majority of those not enterally fed (n=17) had food more than six times per day (n=13). Food was used as a reward for all children with 31% parents reporting using food as a reward sometimes and 7% reported using it daily as a reward. The majority of children (61%) drink water and the next most common drink was juices (43%) followed by milk (39%). One parent reported that their child was given carbonated drinks, despite being enterally fed. Only one parent reported currently bottle feeding their child. Questions regarding feeding are displayed in Table 2-12.

Table 2-12: Feeding.

Enterally feeding	**n=42**	**%**
Yes	25	60
No (never or previously)	17	40
Frequency of food per day	**n=42**	**%**
<3	21	50
4-6	6	14
>6	15	36
Food as a reward	**n=42**	**%**
No	26	62
Sometimes	13	31
Often (daily)	3	7
Drinks	**n=42**	**%**
Water	17	40
Milk	11	26
Juices	12	29
Carbonated drinks	1	4

Bottle use	n=42	%
Never	37	88
Yes, previously	1	2
Yes, still uses	4	10

Parent-reported oral health

Four parents rated their child's oral health as excellent and 19 as very good. This is compared to five parents who reported their own oral health as excellent and 18 as very good. Six parents reported their child's oral health as fair or poor whereas only two parents reported their own oral health as fair and no parent reported their own oral health as poor. Parents were also asked how often they themselves visit the dentist; 13 reported visiting every six months, 17 attend once a year and 12 attend only rarely or when there is a problem. These results are displayed in Table 2-13.

Table 2-13: Parent-reported oral health status.

	Excellent	Very good	Good	Fair	Poor	Not answered
Child	4	19	13	3	3	0
Parent	5	18	15	2	0	2

Perceived Barriers to Dental Care

Participants were asked if they had problems in the past accessing dental care for their child. Eighteen parents responded that they had and the remaining 24 responded that they had not. However, when asked to review the potential barriers listed below, only eight participants responded that these were not reasons for not attending the dentist. Table 2-14 shows parents perceived

barriers to oral care. The most highly reported barriers were that 'Dental centres/units that treat special needs patients are rare and limited" and "Dentist unwilling to treat or inadequately trained in treating patients with special needs".

Table 2-14: Perceived barriers to dental care.

	Major reason	Minor reason	Not a reason	Not sure
Dentist unwilling to treat or inadequately trained in treating patients with special needs	16	2	23	1
Dental clinic environment, colours, light and design are disturbing to special needs persons	1	3	35	3
Dental clinic waiting area and general services (example: toilets) are not suitable	1	5	32	4
Dental clinic is not equipped to facilitate treatment of special needs individuals	8	4	27	3
Dental staff are not friendly or do not know how to manage special needs individuals	2	6	31	3
Patient has communication difficulties with the dentist during treatment visits	5	4	32	1
Medical health status of the patient hinders him/her from receiving immediate dental care	2	3	36	1
Patient needs informed consent from his physician or needs hospitalization	0	0	40	2
Patient is afraid of the dentist	0	2	37	3
Patient unable to sit on the chair or cooperate with the dentist	8	8	24	2
Patient's dental condition was not serious enough to see a dentist	0	3	37	2
Dental centres/units that treat special needs patients are rare and limited	18	3	20	1
Difficulty in getting appointments	7	3	30	2
No time to visit the dentist	0	6	34	2

Cost or financial difficulty	0	1	39	2
Transportation difficulty	0	1	39	2
Dental clinic is too far away	1	1	38	2

2.5.4 Dental Assessment

Attendance

For a total of forty-two participants eighty-four appointments were booked. Thirty-eight appointments were attended. Sixteen appointments were cancelled by the parent. No appointments were cancelled by the dental team. Thirty appointments were not attended without cancelling.

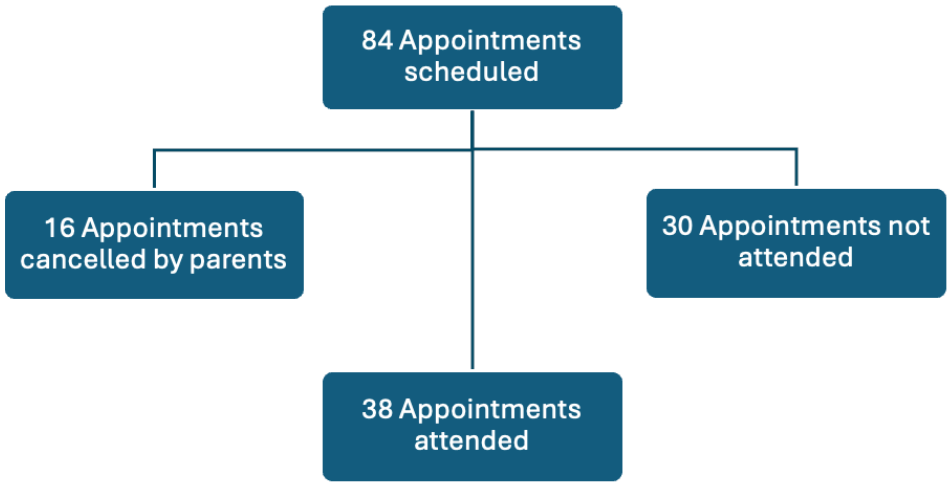


Figure 2.7: Appointment numbers.

Patient assessment

Most participants were seen in their own wheelchair (74%) and required some form of stabilisation for the dental examination (76%), with 82% participants requiring the use of a mouth prop for the assessment as displayed in Table 2-15.

Table 2-15: Examination location and supports required.

Examination location	Wheel chair	Dental chair	Parent's lap	Knee-to-knee	Buggy
N (%)	28 (74%)	4 (11%)	3 (8%)	1 (3%)	2 (5%)
Holding required	**Yes**		**No**		
N (%)	29 (76%)		9 (24%)		
Mouth prop used	**Yes**		**No**		
N (%)	31 (82%)		7 (18%)		

$D_{3vc}MFT+ d_{3vc}mft$

$D_{3vc}MFT+ d_{3vc}mft$ was recorded in all but one participant. No patient had missing or filled teeth despite parental report of extraction history. This is likely due to age, and extractions completed on primary teeth with permanent successors since erupted. Thirty-four participants were caries free. Four participants had at least one tooth with caries into dentine. One participant had eight teeth with dentine caries and a PUFA score of three (presence of pulpal involvement (P/p), ulceration (U/u), fistula (F/f), and abscess (A/a)). All other patients (n=37) PUFA score was zero. The mean $D_{3vc}MFT+ d_{3vc}mft$ score was 1.46 with a standard deviation of 1.6, as displayed in Tale 2-16.

Table 2-16: $D_{3vc}MFT+ d_{3vc}mft$.

Measure	Min-Max	Mean (SD)	Median
$D_{3vc}MFT+ d_{3vc}mft$	0-8	0.46 (1.6)	0
PUFA/pufa	0-3	0.1 (0.5)	0

OHI-S

OHI-S was measured in 35 participants and ranged from 0-3, with a mean of 1.5 and standard deviation 1.3 as shown in Table 2-17.

Table 2-17: P-I, C-I and OHI-S.

Measure	Min-max	Mean (SD)	Median
P-I	0-6	1.45 (0.6)	1.33
C-I	0-2	0.9 (1.2)	0.7
OHI-S	0-6	1.5 (1.3)	1.3

Orthodontic exam

Overjet was recorded in 10 participants and ranged from 0-10mm. Overbite was measured in 13 participants, with the majority recording no overbite or an anterior open bite (n=12). Presence of a crossbite was assessed in 24 participants. Three participants had an anterior crossbite and two had a posterior crossbite. Crowding was assessed in 32 participants and the majority had no crowding (n=19). Eruption sequence was assessed in 32 participants and most had a normal eruption sequence (n=23). Eight participants were dentally delayed for their chronological age and one was advanced. Orthodontic features are displayed in Table 3.10.

Saliva

Saliva was of normal amount and normal consistency in the majority (n=20 (53%), n=23 (61%)). Saliva amount was recorded as reduced in four participants (11%) and excessive in 14 (37%). Saliva thickness was recorded as watery in six participants (16%) and thick in nine (24%). One child was found to have a dry mouth and scored two on the CODS. All other children scored zero as shown in

Table 2-18. A DSFS of greater than one was recorded in 35 out of 38 participants. The mean DSFS was 5.2 as shown in Table 2-18.

Table 2-18: CODS and DSFS.

Measure	Min-max	Mean (SD)	Median
CODS	0-2	0.05 (0.32)	0
DSFS	0-9	5.15 (2.51)	5

Parafunctional Habits

Parents reported grinding for 24 participants and non-nutritive sucking habits in 18 as shown in Table 2-19. Sucking habits included a range of items including soother (n=1), thumb (n=1), fingers (n=1), ChewyTubes® and other soft objects (n=9).

Table 2-19: Parafunctional habits, n=38.

Habit		N	%
Grinding	Yes	24	63
	No	14	37
Nonnutritive sucking habits	Yes	18	47
	No	20	53

Tooth wear

Tooth wear into dentine was noted in 10 (40%) of participants who were assessed. No child had pulp exposure or secondary decay is association with the tooth wear.

Examination Difficulty

The majority of examinations were reported as moderately difficult (n=25), or difficult (n=9). Three examinations were easy and one was abandoned without measuring $D_{3vc}MFT+ d_{3vc}mft$, as displayed in Table 2-20.

Table 2-20: Examination difficulty.

Degree of difficulty	No. participants	%
Easy	3	8
Moderate	25	66
Difficult	9	24
Abandoned	1	3

Identified Treatment Needs

Treatment needs were identified in all 38 participants. The most common treatment need noted was for preventive care including OHI, fluoride application and fissure sealants. A total of seven participants required extractions (n=3) or restorations (n=3) or both (n=1). Most participants (76%) were suitable for treatment in a primary care setting. Four participants required dental treatment in a tertiary care setting under general anaesthesia. Identified treatment needs are listed in Table 2-21.

Table 2-21: Identified treatment needs.

Treatment type	Treatment	N	%
Preventive			
	OHI	38	100
	FV or SDF	7	18
	Calculus removal	30	79
	FS	8	21
Restorative			

	SSCs or composite restorations	4	11
Surgical			
	Extractions	4	11
Suggested location of treatment			
	Primary care	29	76
	Secondary Care	5	13
	Tertiary care/hospitalisation	4	11
	General anaesthetic required	4	11

2.5.5 Statistical Analyses

D_{3vc}MFT+ d_{3vc}mft

The Shapiro Wilk test was used to assess normality. All p-values were less than 5% indicating violation of the normality assumption. Therefore the Mann-Whitney U Test was used to assess for differences in D_{3vc}MFT+ d_{3vc}mft in different groups of children with SNI as shown in Table 2-22. It was found that there was no difference in D_{3vc}MFT+ d_{3vc}mft in those enterally fed versus those orally fed (z=-0.39, p=0.85), those with CP or a genetic condition (z=-1.13, p=0.56) or those with more or less hospital stays in the preceding two years (z=-0.28, p= 0.89).

Table 2-22: Mann Whitney U-Test for D_{3vc}MFT+ d_{3vc}mft and other factors.

Factors		Total N	Median (IQR)	z	p
Feeding	Oral	16	0 (0)	-0.39	0.85
	Enteral	22	0 (0)		
Diagnosis	CP	17	0 (0)	-1.13	0.56
	Genetic	20	0 (0)		

Hospital stays	<5 nights	17	0 (0)	-0.28	0.89
	>5 nights	21	0 (0)		

OHI-S

Differences in OHI-S and C-I was also analysed between the same groups, as shown in Table 2-23. This data was also nonparametric and the Mann Whitney U-test was used. Enterally-fed children had a significantly higher C-I compared to those fed orally (z=2.3, p=0.02). However, there was no difference in OHI-S between these two groups. There was also no difference in OHI-S or C-I in those with an underlying genetic diagnosis or a diagnosis of CP, or those with greater number of nights spent in hospital in the preceding two years.

Table 2-23: Mann Whitney U-Test for OHI-S and feeding, diagnosis and hospital stays.

Factors		Total N	Median (IQR)	z	p
Feeding	Oral	13	1 (1.5)	1.15	0.26
	Enteral	22	1.4 (1.42)		
Diagnosis	CP	16	1.41 (2.24)	0.84	0.42
	Genetic	19	1.33 (1)		
Hospital stays	<5 nights	17	1.5 (1.16)	-1.21	0.23
	>5 nights	19	1 (2)		

Table 2-24: Mann Whiteny U-Test for C-I and feeding, diagnosis and hospital stays.

Factors		Total N	Median (IQR)	z	p
Feeding	Oral	13	0.5 (0.58)	2.3	0.02*
	Enteral	22	1 (1.04)		
Diagnosis	CP	16	0.5 (1)	-0.62	0.57
	Genetic	19	0.83 (1.3)		
Hospital stays	<5 nights	16	0.58 (1.19)	0.017	1.00
	>5 nights	19	0.83 (1.33)		

2.6 Discussion

This is the first study to investigate the oral health of children with SNI. Forty-two parents completed the oral health questionnaire and 38 of these brought their child for an oral health assessment.

The sample of this population was small and smaller than the estimated sample size for the overall SPIRE project. It is currently unknown how many children are living with SNI in Ireland and the original estimate may have been an overcalculation. One component of the SPIRE project is estimating prevalence of SNI. Only 66 children were identified as having SNI and were invited to participate in the SPIRE project. Out of these 66, 42 agreed to participate in the dental health component. More participants may have been recruited to the oral health component of the project by making this a multicentre study. Although children attending other centres for their medical and/or dental care were invited to participate, they had to attend this one centre for the oral health assessment. Those who attended elsewhere for medical and/or dental care may have been reluctant to attend an extra appointment in an unfamiliar setting. More may have participated if the oral health assessment could have been completed in their local dental clinic or in the hospital or healthcare centre where they attend their paediatrician. It is also known that children with complex needs often attend many medical appointments and therefore dental care is competing against their many other healthcare needs (Sarvas et al. 2024). Appointments were co-ordinated with medical colleagues but unfortunately given clinical time and other commitments the research team

could only assess these participants on certain days. Greater flexibility from the research team may also have facilitated a better range of appointment days and times, and possibly increased recruitment for the oral health assessment. Furthermore, parents of children with complex needs may not prioritise dental care or see it as important, given all their other medical needs. Increased awareness of the importance of dental care as part of their healthcare may also have increased the recruitment numbers.

Cerebral palsy was the most frequent underlying diagnosis in the sample (45%), consistent with its prevalence as the leading diagnosis among children with SNI (Allen 2022). It is known that CMC, which includes children with SNI, have a much greater number of hospital visits compared to other children, up to seven times higher and 76% of our participants had been hospitalised in the past two years (Kuo et al. 2015). Epilepsy was common in this group with 54% with a current or past diagnosis of epilepsy. The variety of underlying diagnoses, the prevalence of epilepsy and the number of hospital stays give an insight into the overall medical complexity of these children. This complexity affects their oral health through oral features of conditions and through side effects of medications. Indirectly the burden of care associated with complex medical conditions may also have an effect.

Our sample consisted of slightly more females (55%) than males (45%). This may be due to the several genetic conditions which have X-linked inheritance and

affected males have a more severe type and do not survive, for example Rett syndrome, which was diagnosed in four participants in our study

2.6.1 Oral Health Questionnaire

The questionnaire was completed by the parents of all 42 participants. Most children had their teeth brushed by their mother once to twice per day (86%), but a small number of participants had their teeth brushed less that once per week (7%). This is similar to findings in previous research, both in Ireland and abroad on toothbrushing in children with special needs (Whelton et al. 2009; Zhou, Wong, and McGrath 2019). The use of fluoridated toothpaste was higher in our sample compared to other studies with 90% parents reporting using a fluoride containing toothpaste and only three participants were not using toothpaste (Zhou, Wong, and McGrath 2019; Hashemipour, Zeyghami, and Rajaee 2024). Tooth brushing was completed with some form of resistance in 81% participants and for five participants, their parent reported that their teeth could not be brushed. Toothbrushing can be particularly challenging for these children due to factors such as oral sensitivities, overactive gag reflex, impaired swallowing reflex, and involuntary movements. Additionally, children with SNI often rely entirely on their caregivers for oral care.

The mean age for the first dental visit in this cohort was four years of age. This is much later that the recommended age for a child's first dental visit which is by age one year (FitzGerald et al. 2017; AAPD 2016, 2018). Only two participants (4.7%) had their first dental visit by age one, despite their early entry into the medical system. In the U.S., Collie et al. reported that 13% of children with

SHCNs were brought to the dentist by their first birthday but there is no comparable Irish data (Collie et al. 2024). The oral health assessment appointment was the first dental visit for 10 participants in this study, and a further five participants reported only attending the dentist rarely or when there is a problem. One participant's first dental visit was not until the age of 12 years. In Ireland all children are scheduled to be seen by the HSE during their primary schooling and therefore before the age of 12 years. Children with special healthcare needs are given priority but the lack of paediatric dentists in community clinics may be one reason why local access is not possible or not encouraged and referral to the hospital service is preferred. It could also be possible that due to medical complexity or illness this child who was 12 years old at their first dental assessment never attended through the primary school system

Collie et al. (2024) reported that most children with SHCNs in the U.S. were brought to a paediatric dentist. This was not recorded in the present study but unlikely to be the case in Ireland where there is a shortage of paediatric dentists, and they are generally seen on a referral basis from a GDP. Dental attendance is generally reported as greater in children with special healthcare needs compared to healthy children in the general population (Aburahma et al. 2021; Lebrun-Harris et al. 2021). In this study 33% reported attending the dentist every six months and 31% every year. This is much lower than that reported by Collie et al. who reported that 81% children attended every six months and a further 7% attended annually (Collie et al. 2024). However, Collie et al. reported on children with special healthcare needs, a broader population than children

with SNI. Chi et al. (2014) suggested that increased caregiver burden may be associated with reduced preventive dental visits, so the children with the most complex needs may attend less preventive appointments and have a higher attendance at emergency and secondary or tertiary dental care centres (Chi, McManus, and Carle 2014). This may be the case for children with SNI who often have many several competing healthcare needs. In our sample, the majority (60%) of participants were attending a dentist in a hospital setting and fewer were attending primary care.

Given this low attendance at primary care, it is unsurprising that only 18 participants (43%) had received any kind of preventive dental care, including 16 (38%) who had been demonstrated toothbrushing. This is lower than preventive care reported previously in children with SHCNs by Lebrun-Harris et al. in the U.S. who found that 50% children with SHCNs had received fluoride varnish, fissure sealant application and/or toothbrushing instruction (Lebrun-Harris et al. 2021). When children with special needs do attend the dentist, they receive different dental care to healthy children. Previous extractions were more common than having had previous restorative treatment in this sample (19% compared to 7%). This finding is supported by previous research where children with special healthcare needs have more extractions and less restorative care than children in the general population (Aburahma et al. 2021; Sevekar, Jha, and Avanti 2021; Al-Ogayyel and Al-Haj Ali 2018). This may be in part due to the extent of caries on presentation, as well as the need for advanced pharmacological behaviour management techniques. Dentists are

more likely to provide definitive treatment including extractions over pulp treatments when a child's treatment is completed under general anaesthesia .

The most cited reason for seeking dental care included general check-up followed by concerns about tooth grinding, tooth position and calculus. The most common reason for seeking dental care for children with SHCNs was for a check-up (Collie et al. 2024) followed by pain or an observed dental cavity in that study (Collie et al. 2024). Dental decay or pain was an uncommon reason for attending the dentist in our sample reported by only 7% parents, maybe due to the child being unable to report oral pain.

Dental trauma is common in individuals with SHCNs and reported in 23.7% by Devi et al. (Devi K et al. 2024). It is particularly prevalent in those with movement or coordination disorders (Devi K et al. 2024) with prevalence estimates ranging from 11% to over 57%, depending on the study and severity of CP (Heiden et al. 2024; Cardoso et al. 2015; Bagattoni et al. 2017). Seven participants (17%) in this study reported previous dental trauma. This is likely lower than studies looking at children with SHCNs or CP because all participants in this study were either wheelchair users or using a buggy and limited mobility therefore may be less likely to suffer trauma compared to children who are ambulatory.

It is well-documented in the literature that children with special needs encounter numerous, often overlapping barriers to receiving necessary oral care (da Rosa et al. 2020; Ummer-Christian et al. 2018). The low rate of

preventive care reflects a lack of primary care for this group of children with only 52% having ever attended a dentist in the community primary care setting. When asked about various potential barriers to care, 50% participants responded that “Dental centres/units that treat special needs patients are rare and limited” was a perceived barrier. The second most cited reason was that they thought the “Dentist is unwilling to treat or inadequately trained in treating patients with special needs”. Irish research into dentist willingness and training revealed that the greater the level of disability the less willing dentists are to treat these patients (Jimoh and Kinirons 2014). These provider-related barriers might indicate that parents bring their child to a hospital dentist due a lack of appropriate of local support. Affordability did not seem to be a barrier for this group with just one parent reporting is as a minor reason why they might not bring their child to the dentist. This is likely because dental care for children with special needs is usually provided without charge by the HSE, which may not be the case in other countries where cost is commonly reported as a perceived barrier (da Rosa et al. 2020). Key barriers reported in the literature include child stress and anxiety (Star et al. 2024) and sixteen parents in this study reported that their child was ‘unable to sit on the chair or cooperate with the dentist’ as a perceived barrier to care. Greater education of primary care providers and availability of specialist-led services may provide support to parents so that their child’s co-operation should not preclude dental care. Burden of care is also cited in the literature as a reason for missed or cancelled appointment but only six parents reported a lack of time to visit the dentist as one of their perceived barriers (da Rosa et al. 2020). Despite this however, there were a high number of cancelled and missed appointments in the present study.

This highlights the challenging nature of care for these children and the need for regular local support from a young age to encourage familiarity with the dental team.

Parents reported their child's oral health as similar to their own. Parents were not aware of their child's oral health status with three of the four parents of children with caries reported their child's oral health as good. Of the four children with dental caries, one parent reported bringing their child to a dentist every year, one every six months and two rarely/when there is a problem. This may reflect a lack of dental awareness as well as lack of appropriate local care and highlights the need for better education of GDPs.

Recall bias is always a limitation with a questionnaire which asks participants about past experiences. Parents were asked about their child's first dental visit, the reasons for previous dental visits and about previous dental trauma. It is likely that many parents will not accurately recall this information, especially when they are recalling an event that happened many years previous. Parents may also be reluctant to always tell the truth when asked by the dental team member about oral health care. Some parents may be inclined to answer how they believe they should answer. For example, they may say that their child's teeth are brushed twice per day because they know this is the correct answer but in reality, their child's teeth are only brushed once per day at most.

2.6.2 Clinical Assessment

Attendance at dental appointments was a challenge for this group. When scheduling appointments for these children a date and time was arranged and agreed with the parent but there was still a very high rate of missed appointments. Despite parents reporting in the questionnaire that time and other appointments were not a barrier, this would suggest otherwise. Eighty-four appointments were scheduled in total for the 38 children who participated in the oral health examination. Thirty appointments were not attended without cancelling. A further 16 appointments were cancelled by parents and 38 were attended. This high rate of missed appointments may reflect competing demands for a child with SNI.

Most children were examined in their own wheelchair or powerchair and with stabilisation by the parent and with the use of a finger prop. This reflects the challenging nature of assessment for these children and the need for dentist to be trained to manage these children.

This is the first research to measure dental caries in children with SNI, and it is important to note that this data is not directly comparable to any other data as it is specific to this unique cohort of children. Four out of the 38 children examined had at least one tooth with caries to dentine. Mean $D_{3vc}MFT+d_{3vc}mft$ was 0.46 and ranged from 0-8. There were no differences in $D_{3vc}MFT+d_{3vc}mft$ in those with different underlying diagnoses, in those fed enterally versus orally or those with greater numbers of hospital stays. Compared to the available and most recent Irish data this study presents a low caries level in children with SNI

compared to children in the general population (ames et al. 2021). James et al, also using the D_{3vc}MFT index, reported the presence of caries in 55% of 8-year-olds in Dublin (James et al. 2021). This is much greater that that found in our study. These assessments were also clinical only, without the use of radiographs and carried out in a school setting and not in a dental clinic (James et al. 2018).

In 2002, Irish children attending special schools and day centres were examined using the D_{3vc}MFT index to measure dental caries (Whelton et al. 2009). They reported a much higher level of dental caries compared to this study with 27-33.5% 5-year-olds and 42-51% of 12-year-olds having dentine caries. This study looked only at children attending special schools and day centres and this group of children are likely to be very different from the group in the present study. The study included 653 children in total. Although some of the children included may have had SNI, it is likely that they would have constituted only a very small percentage of the sample.

As described previously there are varied reports in the literature on caries in children with CP, with some authors reporting higher levels of dental caries compared to children in the general population and others reporting lower levels (Zemene et al. 2024; Bensi, Costacurta, and Docimo 2020; Asiri, Tennant, and Kruger 2024; de Castelo Branco Araújo et al. 2022; Akhter et al. 2019; Rodríguez et al. 2018; Cardoso et al. 2014). This data is also not directly comparable to children with SNI as children with SNI would likely make up only a very small portion of the sample of those with CP. Sedky et al. reported that children with CP with higher levels of motor impairment denoted by GMFCS

scores IV and V, had higher caries rates (Sedky 2018). They found over 50% had caries at the level of cavitation to dentine (Sedky 2018). This is interesting as children with CP and SNI would have GMFCS scores of IV and V, yet a much lower level of caries was noted in this group. This may be because only 45% of our sample had CP and overall, a high proportion were enterally fed.

Children who are fed enterally generally have lower levels of caries compared to children in the general population and compared to children with SHCNs fed orally, although this was not found in the present study (Cardona-Soria et al. 2020; Hidas et al. 2010). Cardona-Soria et al. compared caries levels in children with CP fed enterally and orally and found DMFT scores of 2.81 and 1.09 respectively. There was a significantly higher caries noted in children fed orally. They had a large sample size, of over 50 in each group and included all levels of cerebral palsy and so it is likely that few of the children included would have SNI. Hidas et al. similarly, found lower levels of dental caries in children with SHCHs fed enterally compared to those fed orally and compared to healthy children (Hidas et al. 2010). This was not found in our study and may be due to a number of factors. Firstly, this was not the aim of this project, and the sample size is small and was not devised with this in mind. Furthermore, a number of parents reported that although their child was enterally fed, they had several tastes of food throughout the day, and these tastes are often of tasty, sweeter foods. This was not accounted for in our analysis. The time since enteral feeding began or ended was also not accounted for and children were divided into the two groups based on their current feeding status.

$D_{3vc}MFT+d_{3vc}mft$ was used to measure dental caries as it is quick, simple and has been used in previous research investigating caries in Irish children (James et al. 2021; Whelton et al. 2009). Other indices such as ICDAS could not have been used accurately given the difficulty in examining these patients. It is possible that the dental caries rates would be higher in this group if enamel caries was also included and if radiographs could be taken to identify interproximal caries. It also would not have been possible to expose radiographs for these children in the dental clinic setting due to their cooperative ability.

Difficulties with home oral care was reflected in the high OHI-S scores with a mean OHI-S of 1.5. Irish data by Whelton et al. shows that children with special needs require more professional intervention for oral hygiene than children in the general population (Whelton et al. 2009). This study measured oral hygiene by recording the need for intervention as needing oral hygiene only, oral hygiene and cleaning or urgent referral for intervention. This is subjective, based on the assessor's opinion and so difficult to compare to the present study. However, it does reflect that children with special needs and their families do need great support to maintain oral hygiene. We found that children with SNI fed enterally had a statistically significant higher C-I compared to those fed orally which has been reported previously (Hidas et al. 2010). This may be due to a lack of chewing which would mechanically remove deposits from the tooth surface, as well as differences in saliva, lack of muscle tone and malocclusions. This high level of calculus in children with SNI is important for the dental team to be aware of because of the relationship between periodontal pathogens and respiratory disease. It is thought that the inhalation of oral pathogens, which

occurs more readily in those with greater plaque and calculus deposits can lead to aspiration pneumonia in susceptible individuals, mainly those with a compromised swallowing ability, including children with SNI (Scannapieco and Mylotte 1996; Gomes-Filho, Passos, and Seixas da Cruz 2010; Brown et al. 2006).

Orthodontic features were difficult to assess in this group and were recorded for less than half of participants. This is due to the need for a patient to stay still, to keep a certain posture and the need for a measurement with a ruler to accurately record many orthodontic features. Also, the orthodontic features were recorded after caries and oral hygiene and so, for the more difficult children to examine, cooperation was often lost by this stage. The most commonly recorded feature was reduced overbite or anterior open bite. These features are commonly reported in children with CP, who often have an open mouth posture which is related to low muscle tone (Franklin, Luther, and Curzon 1996; Bensi, Costacurta, and Docimo 2020). One quarter of participants had delayed dental development which is commonly seen in children with special needs or with generalised delayed development.

Drooling is highly prevalent among children with special needs, especially those with CP. Studies report that between 58% and 94.5% of children with CP experience drooling, with severity and frequency often linked to the degree of motor impairment and younger age groups (Tahmassebi and Curzon 2003; Harris and Purdy 1987; Blasco and Allaire 1992; Scully et al. 2009). Our sample found 92% reported drooling with a mean DSFS of 5.2, which is at the upper

limit of what was reported previously. This may be explained by drooling being more common with more severe forms of CP, as well as other conditions with greater oromotor dysfunction in children who may also have SNI. Whelton et al. reported the presence of drooling in 12-36% children in Irish special schools and day centres, with lower numbers in 12-year-olds compared to five-year-olds. This is much lower than found in our sample, which highlights the difference in the two populations in these studies, children with SNI compared to children with special needs.

Parafunctional habits—such as bruxism, NNSHs and object biting—are common in children with special needs, particularly those with neurological impairments including cerebral palsy (Tuncer et al. 2023; Almotareb and Al-Shamahy 2024). In this cohort 63% parents reported that their child either was a day time or night time tooth grinder, similar to the 52.4% reported by Tuncer et al. in children with cerebral palsy (Tuncer et al. 2023). Almost half (47%) of this sample had a NNSH which is lower than that reported in a population of children with cerebral palsy and Trisomy 21 (Carneiro et al. 2017). This may be because many children with SNI are not able to hold a soother or other object with their hand or in their mouth for sucking. Children with SNI also have reduced oral motor function, some with little sucking ability. Parafunctional habits may contribute to tooth wear in all children and the literature reports this as more prevalent in children with special needs, particularly those with CP (Pope and Curzon 1991; Du et al. 2010). Studies have found that up to 48% of children with CP exhibit tooth wear, with significant associations to factors such as GORD and bruxism (Shaw, Weatherill, and Smith 1998; Abanto et al. 2014).

Whelton et al. measured tooth wear in 12 and 15-year-old children and reported tooth wear into dentine present in 6% 12-year-olds and 7% 15-year-olds. Our level of 40% is much greater than that reported by Whelton et al. and closer to previous reports in children with CP of 48-63% (Abanto et al. 2014; Du et al. 2010). Du et al. similarly recored presence of tooth wear when there was 'loss of enamel involving dentine' whilst Abanto et al used the Smith and Knight index to measure wear which includes enamel wear (Du et al. 2010; Abanto et al. 2014; Smith and Knight 1984;). Other more descriptive methods including the Smith and Knight Index are available to measure tooth wear but require greater clinical time and cooperation from the partcipants and were deemed not appropriate for this study (Smith and Knight 1984; Bardsley, Taylor, and Milosevic 2004).

Treatment was planned for all children assessed by the research team. The three children requiring restorations and one of the children requiring extractions only were planned for dental treatment under general anaesthesia. Treatment under general anaesthesia is often needed for children who cannot cope with dental treatment in the dental chair due to the severity of their disease or condition or due to their difficulty tolerating invasive dental treatments (Heidari et al. 2022). Completing dental care under general anaesthesia for children allows the dentist to accurately assess, diagnose and treat dental conditions and provide a high standard of definitive care. Although, it is important to note that some children with complex medical conditions may not be suitable for treatment under general anaesthesia and this would include some children with SNI. This is another reason why early and regular preventive

care is particularly important for these children. Four children were planned for care under general anaesthesia and a further five reported previous care under general anaesthesia. One of the children who had previous dental treatment under GA and required further care under GA. This child was 16-year-old and the only examination that was abandoned. It has been reported that children with more complex medical backgrounds are more likely to require repeat general anaesthetics for dental treatment (Guidry et al. 2017). In total eight children or 21% required general anaesthesia for dental care. In Ireland, access to general anaesthesia services for dental treatment is limited and has been reported previously as 'inadequate' and in 'urgent need of expansion' (Whelton et al. 2009). Whelton et al. estimated that 22% children with SHCNs require sedation or general anaesthesia for dental care, similar to this group of children with SNI. Therefore, it is important that these children are linked in with primary dental care services early to prevent or reduce this need. It also highlights the importance of clear referral pathways to secondary and tertiary care when required.

The difficulty in assessing these children in the dental clinic is reflected in the need for finger props in 82% and some form of holding/additional support in 76%. Assessments were recorded as moderately difficult or difficult in 34 participants (89%). One assessment was abandoned without recording of $D_{3vc}MFT+d_{3vc}mft$. Both assessors were present for this patient's oral health assessment and once it was observed that several extractions were required the examination was stopped due to participants difficulty with assessment and for the safety of the assessors and the participant's parent. Comprehensive

examination and treatment under GA therefore were planned for this participant.

The difficulty in assessing the study participants was another limitation in this study. This may have introduced measurement bias and affected the outcome measures. To minimise this, caries was defined as at the level of cavitation to dentine or visual caries to dentine. This can be identified quickly and without radiographs. Many outcome measures were not recorded for all participants due to the participants' cooperative ability. It might be presumed that the more challenging a participant was to assess, the more challenging home care and the provision of preventive care at the dentist would be and then potentially the greater the oral heath need. This however remains unknown. This could have been overcome by offering advanced pharmacological behaviour management techniques to ensure every participant was thoroughly assessed. This however would not be ethical, and children were only planned for advanced behaviour management following their assessment when it was deemed necessary to prevent or eliminate infection.

2.6.3 Future Considerations and Development of a Care Pathway

The baseline data collected in this research is highly valuable as the first to describe the oral health of this patient cohort. This data can be used for the development of a care pathway for children with SNI, who often face complex medical and oral health challenges. Integrating their oral health

care into their overall medical management from an early age is essential to ensure it is recognised as an integral part of their care. The inclusion of a paediatric dentist within the Neurodisability care pathway would be ideal, with oral health evaluated on a regular basis. Integrated care pathways co-designed with patients, families and carers offer the most effective way to deliver prevention services and optimal oral healthcare and to adapt care according to their particular additional oral healthcare needs.

An ideal care pathway for children with SNI could follow the ‘hub and spoke model’ with a centralised specialist hospital, and regional primary care centres. This model of care has been described previously in the Irish healthcare system for the care of children with cleft lip/palate and children with 22q11 deletion (HSE 2016; HSE National Rare Diseases Office 2023). Specialist services including a consultant paediatric dentist would be centralised in the one hospital where multidisciplinary medical and dental care would be provided. Shared care with community services including paediatric dentistry as well as GMP, dietetics, speech and language therapy and occupational therapy would help overcome some of the perceived and actual barriers to care. Some patients however due to medical complexity might require their dental home to be within the hospital service on a long-term basis. This would need to be assessed on a case-by-case basis. A care pathway model is displayed in Figure 2.8.

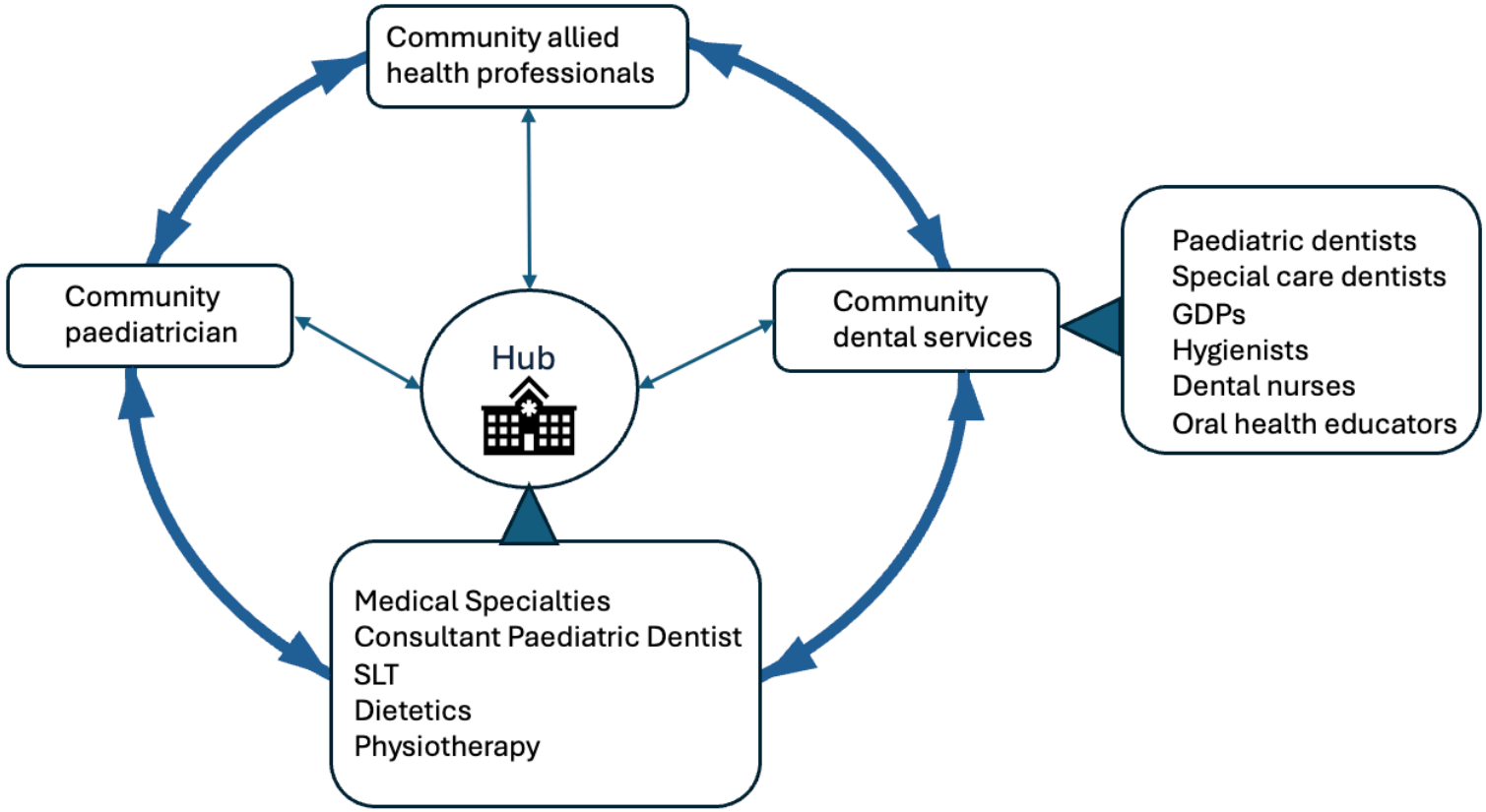


Figure 2.8: Care Pathway for Children with SNI

A more detailed model of the dental service within this care pathway is displayed in Figure 2.9, with the centralised consultant paediatric dentist at the specialised hospital and regional primary care services with a team of dental health professionals available to provide individualised care in the most appropriate setting. An ideal service would have seamless access to specialist paediatric dentists, special care dentists, general dentists, hygienists and dental nurses.

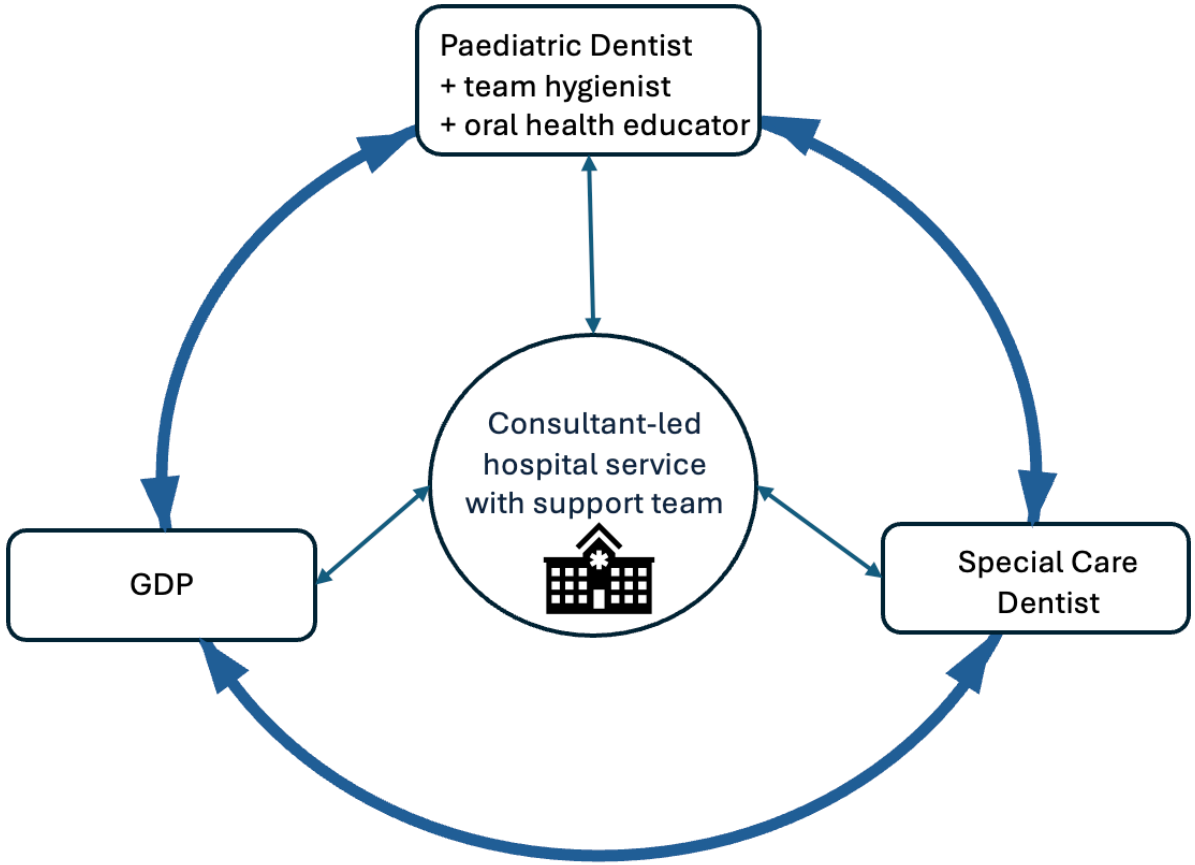


Figure 2.9: Dental Care Pathway for Children with SNI

2.6.4 Transition to Adult Services

Transition is 'the planned, gradual process of moving from child-focused healthcare to adult services for young people with long-term health conditions' (CHI 2025). This should be a part of the care pathway for children with SNI, who will continue to need specialist care throughout life, as their survival is extended with improved early medical care. Transition often begins at age 12 and continues for several years to age 16 or 18 years. There is guidance available from the HSE and NICE on the medical transition process (HSE 2024; Singh et al. 2016). A Key Worker should be identified at age 12 years and introduced to the family (HSE 2024). This Key Worker stays with the family throughout the transition process and liaises between the paediatric and adult medical services. The paediatric service complete readiness checklists with the child and family in the years leading up to the transition and then produces a Transition Document to facilitate the final transfer of care to adult services. This works well in the medical field where adequate specialists exist in the Public Health Service. In an ideal model a special care dentist in the adult hub would take over from the paediatric dental consultant. This special care team would similarly share care with community special care dentists. This is not available at present but may develop if or when 'Smile agus Slainte' is implemented to assure equitable oral health outcomes for these children as they age and mitigate systemic impacts from poor oral health across their life-course.

2.7. Conclusions

This is the first study to investigate the oral health of children with SNI. Children with SNI and their families face significant challenges maintaining oral hygiene at home. Parents are not equipped appropriately with the individualised knowledge and tools necessary to support their child's home oral care. Access to early preventive care is limited and local dental care for these children is often unavailable. Most children attend a dental team at a hospital setting with parents reporting mainly provider-related barriers to oral health care. Attending appointments is also difficult for these children, requiring dental teams to be flexible in their approach.

Dental caries is generally not a significant problem for most children with SNI, but issues related to oral hygiene, calculus and oral function are more prevalent. When these children require operative dental treatment for dental caries, it is often more invasive with extractions being more common than restorative procedures. While prevention and oral health care can be provided in a primary care setting for the majority of children with SNI, these children should be under the care of a specialist paediatric dentist due to their overall complexity.

There is a clear need for the development of integrated care pathways for managing these children's oral health as well as their general health. Shared care involving specialised hospitals and primary care centres provides the optimal approach for achieving integrated oral health services that are fit for purpose. Enhancing the education of both medical and dental teams involved in their care is essential, along with fostering interdisciplinary collaborations.

Early referral and the creation of integrated care pathways from medical teams to primary dental services as well as clear pathways to secondary and tertiary dental services are also critical for improving these children's oral health care.

3. Introduction to Study Two: Oral Health Educational Content

3.1 Abstract

Background: Families of children with SNI report great difficulties maintaining oral hygiene at home. There is also a need for appropriate resources to assist them. The dental team, together with their medical and dietetics colleagues, created a dental health educational video to address this. This video was then assessed for acceptability by parents and carers of children with SNI and HCWs. ***Aims:*** This study sought to create and distribute oral health educational content to parents of children with SNI and to assess its acceptability. ***Methods:*** The educational video was created in association with medical and dietetics colleagues and with support from a HSE Sparks Seed Grant. Two parents and their children with SNI took part in the recording alongside two HCWs. The video was edited several times and reviewed by the dental and medical teams as well as the parent participants. A questionnaire of acceptability was developed using the Generic Form of the TFA by Sekhon et al. (Sekhon, Cartwright, and Francis 2017, 2022). Ethical approval was obtained. The questionnaire was completed anonymously on the online platform Qualtrics. Data was extracted to Microsoft excel for analysis. ***Results:*** Video recording was completed in one afternoon. Five video and voice call sessions as well as two team meetings were required for editing. The final video is three minutes in length. The acceptability questionnaire was completed by 23 HCWs and 20 parents and carers. The overall response from HCWs was positive. Two HCWs

responded negatively to the question, “Did it take much effort to access and watch the videos?” with “it took a huge amount of effort”. The 20 parents/carers responded very positively to the videos with no negative responses. Suggestions from HCWs and parents/carers in the free comments section indicated that the video would be useful if used as educational tool in a clinical setting, particularly while patients are waiting for appointments. ***Conclusions:*** The educational video was very well accepted by both HCWs and parents and carers. If there is additional feedback in the future the content should be revisited. The value of the video in improving knowledge gained could also be measured in the future.

3.2 Background

Over the course of Study One the researchers got to know many families of children with SNI. It quickly became clear that there were no resources available to support home oral care for these children and their families. They also reported difficulty in accessing a local dentist and in attending dental appointments, with 55% of oral health assessment appointments made for these children not attended. Every child assessed required preventive management, in addition to some need for treatment. Most parents reported that they had never been shown how to brush their child's teeth. Families of children with SNI require individualised instructions to suit their unique needs. Maintaining oral hygiene at home can be a great challenge and many families have never been shown how to achieve adequate oral hygiene or made aware of the tools available to assist them. An oral health educational video was planned to teach parents about toothbrushing for children with SNI, to show the different techniques that may be useful, and to share the tools that are available. The video was targeted towards parents and carers of children with SNI but can also benefit parents of all children with additional needs or in cases where toothbrushing is challenging. This video can be accessed by all involved in the care of these children and provided to families by any member of the dental team, as well as by their medical team, with whom they are likely to be in more consistent contact.

3.2 Study Aims and Objectives

3.2.1 Aims

The aims of this project were to create and distribute oral health educational content to parents of children with SNI and to assess its acceptability.

3.2.2 Objectives

The objectives of this project were to create a short educational video demonstrating toothbrushing and to use a questionnaire to assess its acceptability amongst parents/carers and HCWs.

3.3. Materials and Methods

3.3.1 Educational Video Creation

Funding

Funding was received through a special HSE Sparks funding grant, by the Dietetics Team at CHI at Tallaght.

Storyboard

A storyboard was created by the researchers as an overview of the video. This facilitated communication with the videographer in the early stages of planning.

Video Content

Video content was based on available guidance on toothbrushing for children (Toumba et al 2019; HSE 2008) and toothbrushing individualised who are enterally-fed (CREST 2004).

Script

The script (Appendix 2.1) was written by RC and AOC and was reviewed by postgraduate student peers of RC. After adjustments, the script was reviewed by non-HCW family and friends of RC, followed by parent volunteers. The script was written in plain English following available advice on health literacy in the Irish population (HSE 2017).

Participants

Two parents and their children were invited to take part in the video. They were contacted by the study gatekeeper and were under no obligation to participate.

Both parents agreed to take part with their children. Two members of staff (RC, AOC) agreed to act as dentist and dental nurse for the video recording.

Consent

Written consent to be recorded was sought from the two dental team members and the two parent volunteers on the day of recording by Dr Siobhan McCormack using the CHI Communications Consent Form (Appendix 2.2).

Recording

The dental team and the videographer prepared the location and practiced before recording with the children. A recording session was completed with each child and their parent, and one further session was required recording scenes without participants.

Video drafts

The video was formatted by the videographer. The layout of the script was adjusted to fit the images captured, as in some instances recording was very challenging due to patient behaviour and coping ability. Preliminary drafts were created and refined by RC and AOC before appraisal by members of the Dublin Dental University Hospital paediatric team; Daithí McGrory, Isabel Olegario, Aisling Cant and Rona Leith. Further adjustments were made, and the video was then viewed by one of the parent volunteer actors. The script was finalised, and the voiceover was added to the visuals. The finalised video with voiceover was viewed and approved by Dr Siobhan McCormack.

Distribution

The completed video was uploaded to Google Drive account belonging to RC and QR codes were developed which linked to the site. These QR codes were

provided to parents of children with SNI and any other parents attending the dental or medical clinics in CHI who would benefit from them (Appendix 2.3)

3.3.2 Video Assessment

An anonymous survey was planned to determine the acceptability of the finalised video from two perspectives, HCWs and parents and carers. A survey of acceptability was developed based on the Theoretical Framework of Acceptability (TFA) (Sekhon, Cartwright, and Francis 2017, 2022). The survey uses the Generic Form of the TFA (Sekhon, Cartwright, and Francis 2022). This consists of five components which make up acceptability. There are one to two questions per component and each is adapted to fit the instrument being tested. There are two surveys- one for healthcare professionals and one for parents. The questions and answers are similar but with some slight changes in wording.

Ethical approval

Ethical approval was sought from the CHI Research Ethics Office and granted on 1st December 2024 (Appendix 2.4). Ethical approval was then sought from the Dublin Dental University Hospital Research Ethics Committee and granted on 8th April 2024 (Appendix 2.5).

Participants

Inclusion and Exclusion Criteria

Table 6.1 shows the inclusion and exclusion criteria for both HCWs and parent participants.

Table 3-1: Inclusion and exclusion criteria.

Inclusion Criteria	Exclusion Criteria

Parents of paediatric patients attending CHI at Tallaght who have been given the dental educational videos as part of their care plan, and Healthcare professionals involved in the care of children attending CHI at Tallaght, Who: Have the capacity to give consent Speak English Can use a smartphone or other device	Parents/guardians: their child is over 16 years of age Healthcare professional: not involved in the care of children below age 16 years Those who are unwilling/unable to give consent Those who do not speak English. Those who do not have access to a smart device.

Recruitment

Healthcare Workers

HCWs were informed of the project by the Dental team at CHI at Tallaght. Any healthcare professional interested in taking part contacted the dental team and were provided with access the video and the HCW-PIL (Appendix 2.6).

Parents

Recruitment was carried out by the Dental and Medical Teams at CHI at Tallaght. Every parent who met the above inclusion criteria over the three week recruitment phase were invited to participate. Those who expressed interest were provided with a PIL (Appendix 2.7).

Consent

The consent process followed the CHI anonymous survey guideline and consent was gained from each participant before starting the survey on the online platform (Appendices 2.6 and 2.7).

Completion of the Questionnaire

The survey was completed online on Qualtrics®, which is a secure, online, GDPR compliant platform for anonymous surveys. It does not record any participant details or web address.

Data Analysis

The collected data was extracted from Qualtrics® to Microsoft Excel (version 16.89.1) for analysis.

3.3.3 Video distribution

After confirming acceptability of the video it was finalised and the process to make it more widely available is underway in coordination with the CHI Communication Team.

3.4. Results

3.4.1 Content Development

Content was developed and assessed as described in the Materials and Methods section. Minor changes were introduced to simplify language and to improve clarity for all ages and levels of literacy after reviewing with our parent participants. Video recording took three hours in total. This was followed by editing by the videographer independently and then three separate 30 minute sessions between RC and the videographer on voice call and video call. After the voiceover was added to the visuals, two further 20 minute sessions between RC and the videographer were required before the video was sent to the research team and selected staff members. Some minor edits were then completed by the videographer and the video was finalised. The finished video is three minutes in length.

3.4.2 Healthcare Workers (HCW)

Twenty-three HCWs took part. All 23 completed consent on Qualtrics and answered all eight questions as displayed in Figure 3.1. Five of the questions elicited overwhelmingly positive responses and three questions had some neutral responses (grey area). The only negative response from HCWs was where two respondents replied to the question, ‘ Did it take much effort to access and watch the videos?’ with ‘it took a huge amount of effort’. These respondents did not elaborate on their response in the comments section.

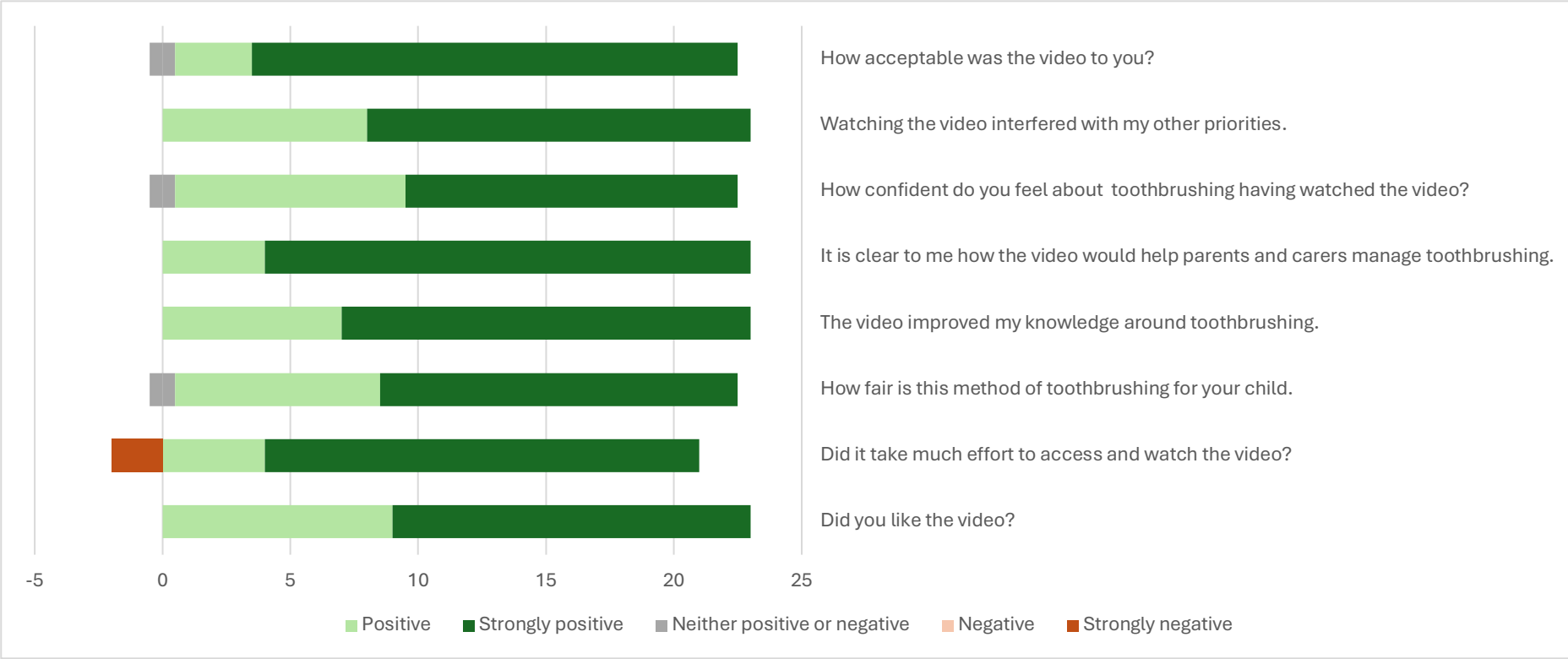


Figure 3.1: HCP questionnaire results.

HCWs had the option of submitting any 'further comments' in a free text box at the end of the questionnaire. These comments are displayed in Table 3-2.

Table 3-2: Further comments submitted by HCWs.

Comment
Very helpful should be in as many waiting rooms as possible
Great resource for parents of all children but especially those with additional needs
Forceful brushing find bit hard
Great to give patient's waiting for appointments
Very informative and succinct!
I'm a paediatric nurse- this is a great to give parents while waiting for appointments/ waiting for their children
Love the video but I don't know if all parents are good with phones and QR codes
Very informative video, Would be extremely helpful to parents/carers of children.
Great video- good idea to give to patients waiting for hospital appointments
Excellent resource for parents well done

3.4.3 Parents/Caregivers

Twenty parents and caregivers participated. All 20 participants gave consent and completed all eight questions. These results are displayed in Figure 3.2. There was an overall positive response from parents and carers. Five questions elicited entirely positive responses and two questions had a small number of neutral responses. There were no negative responses to any of the questions from parents and carers.

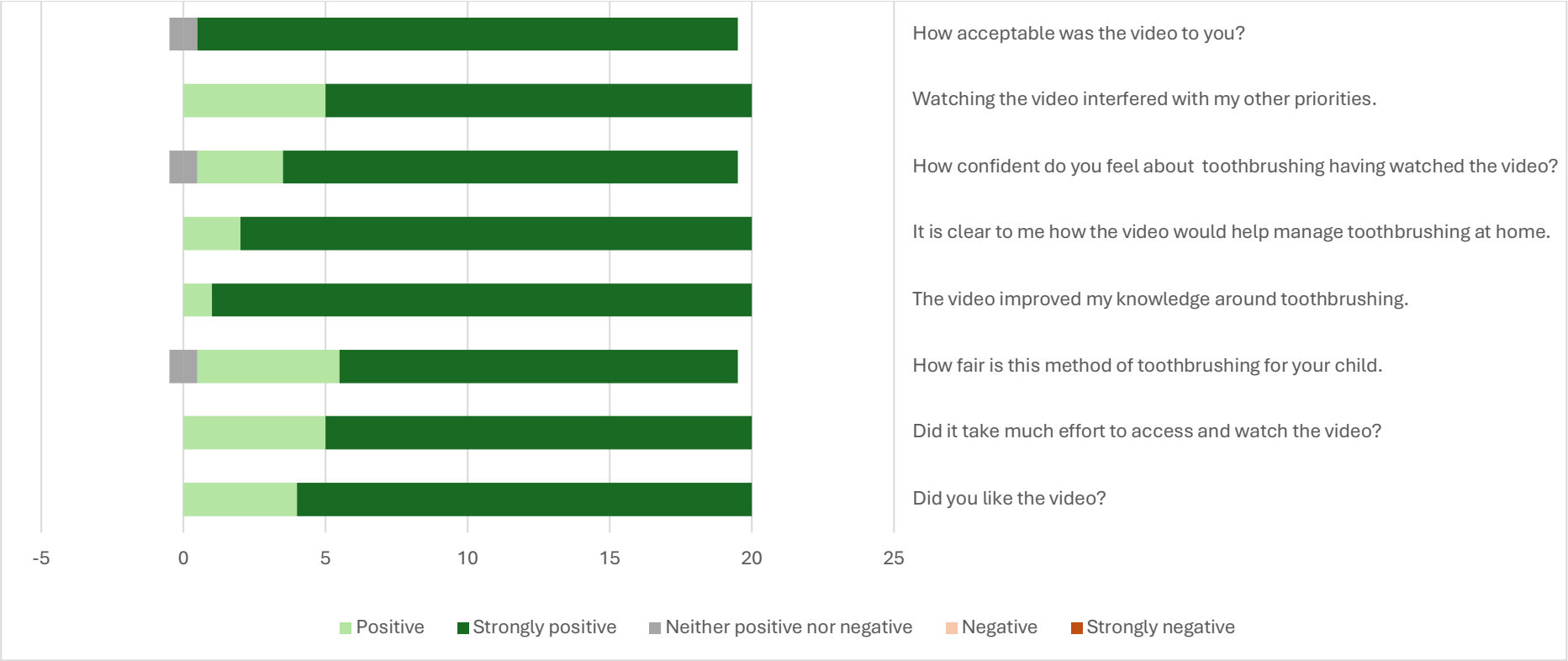


Figure 3.2: Parents/carers questionnaire results.

Eleven of these participants submitted comments in the free text section as displayed in Table 3-3.

Table 3-3: Further comments submitted by parents/carers.

Comment
Good to actually see amount of toothpaste
Nice and short
Good that it showed how much toothpaste to use
Great to see amount of tooth paste
The toothpaste label guide was helpful as well as the amounts to use.
Like that it's a video and not it a leaflet!
Would be great to have this available for parents in waiting rooms!
Nice to see what to look for in tooth paste and amount of fluoride
Easy to watch while waiting for my child's appointment
Love the video , a nice change from having to read information
Nice to actually see someone acknowledge how hard this can be, it's so hard to brush my sons teeth. He is 10 years old with intellectual disability

3.5 Discussion

The educational video produced was available through a QR code and is now in the process of being uploaded to CHI media platforms to make it more widely available to both HCWs and parents and caregivers. It lasts three minutes, six seconds, and emphasises various oral hygiene practices specifically for children with SNI. It is also helpful for all those caring for children who need their teeth brushed for them. Overall the educational video was very well accepted by both HCWs and parents and carers. Participants could see how it would help with toothbrushing and felt that it improved their knowledge around toothbrushing.

There are a number of methods reported in the literature to assess educational content that is created for patients. These include knowledge content, quality, understandability, knowledge acquisition, change in behaviour (Loy, Underwood, and Stevens 2021). This study measured acceptability of the dental health educational video using the Generic Form of the Theoretical Framework of Acceptability (TFA) (Sekhon, Cartwright, and Francis 2017, 2022). The TFA assess acceptability against 10 constructs: affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and self-efficacy (Sekhon, Cartwright, and Francis 2017). The Generic Form of the TFA is adaptable and can be used in a range of healthcare settings (Sekhon, Cartwright, and Francis 2022). It is quick for participants to complete and produces measurable responses. The reason the generic form of the TFA was chosen for this study is because it is informed by research, has been used previously in healthcare research and can easily be used in the future to assess

or compare other educational content. There were no issues with the TFA, and all questions were answered by all participants. Some individuals also made suggestions in the free text section.

The TFA has been used in healthcare research to assess acceptability of programmes, interventions and services (Paynter et al. 2023; Timm et al. 2022; Smyth et al. 2024). Some authors have used the TFA to assess acceptability using both a questionnaire and interviews (Smyth et al. 2024). This was not done in the current study due to both time and resource implications, though this would lead to greater insight into participants responses.

The results of this study show a very high acceptance rate amongst both parents and carers and HCWs. The only negative response was from HCWs, where two respondents commented that 'it took a huge amount of effort' to watch the video but failed to elaborate on their answer in the comments section. This was not reported by any parent or caregiver participant. Watching the video requires access to a smartphone and to the internet as well as the ability to scan QR codes. The use of QR codes is increasingly common, especially since their widespread use during and after the COVID-19 pandemic. It has been reported that younger people and those more confident with technology are more likely to feel confident in scanning QR codes (Singh, Brand, and Steenkamp 2025). Research by Singh et al. found that 80% of participants were willing and 85% were able to scan a QR code to access a PIL (Singh, Brand, and Steenkamp 2025).

Suggestions from HCWs and parents/carers indicated that the video would be useful if used as educational tool in a clinical setting, particularly while patients are waiting for appointments. Research has shown that patient education videos shown in waiting rooms are generally useful. They have been shown to improve patient knowledge, satisfaction, and influence health behaviours (Saeed et al. 2024; McNab and Skapetis 2019; Berkhout et al. 2018). Replacing general television programs in waiting rooms with healthcare educational videos could be a straightforward way to emphasise the importance of oral hygiene, particularly for families with children who frequently attend medical appointments and face a high healthcare burden.

One limitation of this study is the sampling method used. Sampling bias may have been introduced by using convenience sampling as it is more likely that parents and carers who are more engaged with healthcare for their child were more likely to participate. Similarly, for HCWs, those more interested in dental care were more likely to take part. The video uses members of the dental team as the actors. Parents and HCWs who know the dental team in the video may be more likely to give positive or complimentary responses leading to reporting bias. This effect was reduced by making the questionnaire completed anonymous.

This video was created to assist families of children with SNI and all families of children with special needs. A further more detailed video could be created to specifically demonstrate toothbrushing for a child who is enterally-fed. This could demonstrate more aids that are available for families and carers, such as

suction and suction toothbrushes (CREST 2004; NHS 2025; NHS 2025). There is current guidance available from CREST and the NHS Mouth Care Matters. The National Oral Health Office is currently creating guidance which will describe the use of suction as part of oral care for care staff in residential and acute settings for adults (HSE 2023). Once published this guidance could also be used to inform a future video. This may also be of benefit to parents for improved oral homecare in children with SNI.

3.6 Conclusions

The oral health educational video was very well accepted by both HWCs and parents/carers indicating that the content was accessible, engaging, and relevant to the intended audience. However, as with any educational resource, it is important to remain responsive to ongoing feedback. It would also be beneficial to revisit and, if necessary, revise the content to ensure it remains accurate, up-to-date, and aligned with best practices. Consideration should be given to evaluating its effectiveness in improving knowledge retention and understanding among parents/carers in the future also.

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5. Appendices

Appendix 1.1: Study 1- Ethical approval CHI

Children's Health Ireland

CHI Research Ethics Office
Email: ethics.committee2@olchc.ie
Tel: 01-409 6307 / 6243

Dr Siobhan McCormack
Clinical Research Fellow in Neurodisability
Children's Health Ireland at Tallaght
Dublin 24

21st September 2022

REC REF: **21.035**

SPIRE (Severe neurological imPairment In iREland): prevalence, healthcare utilisation and a consensus-based clinical dataset
Principal Investigator: Prof Denise McDonald, Dr Joanne Balfe
Co-investigators: Dr Suzanne Kelleher, Dr Louise Baker, Dr Siobhan McCormack, Dr Ciara McDonnell, Dr Shoana Quinn, Maeve Graham, Roisin Kelly, Leah Craigie, Dr Charlotte Wilson, Prof Anne O'Connell, Dr Robyn Crowley, Prof Nicholas Allen

Dear Dr McCormack,

The CHI Research Ethics Committee at a meeting which took place on 20th September 2022, reviewed the following documentation in relation to the requested amendment to the above named study:

- Amendment form SPIRE study- oral health
- SPIRE amended ethics application - oral health CI with tracked changes
- SPIRE Dental Visit - Data collection
- SPIRE Oral Health - Questionnaire to all parents

The requested amendment is **APPROVED.**

I wish you continued success with this study and should you require any assistance in the future please do not hesitate to contact me.

Yours sincerely,

Dr Eugene Dempsey
CHI Research Ethics Officer

Cc: Prof Denise McDonald, Consultant Paediatrician, CHI at Tallaght
Dr Joanne Balfe, Consultant Paediatrician, CHI at Tallaght

CRA Registered Charity Number (RCN): 20202295 **Revenue Charitable Status CHY:** 22235
Board Members: Prof James Browne (Chairman), Mr Con Cronin, Ms Mary Cryan, Mr Liam Dowdall, Prof Martin Elliott, Ms Catherine Guy, Dr Anne Kilgallen, Dr Gavin Lavery, Ms Brigid McManus, Mr Turlough O'Sullivan, Mr Sean Sheehan

Appendix 1.2: Study 1 - Ethical Approval Faculty of Health Sciences, Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Dr Robyn Crowley,
Division I,
Dublin Dental University Hospital,
Lincoln Place,
Dublin 2

8th March 2023

Ref: 230102 -2150
Title of Study: Status of oral health in children with SNI achieved via SPIRE study (Severe neurological imPairment In iREland): prevalence, healthcare utilisation and a consensus-based clinical dataset

Dear Dr Crowley,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in March 2023. We are pleased to inform you that the above project has ethical approval to proceed.

This study has been ethically approved. We would advise you to seek review and comments on your DPIA from the DPO if required prior to study commencement.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

We wish you every success with this study and should you require any assistance in the future please do not hesitate to contact us.

Yours sincerely,

Jacintha O'Sullivan

Prof. Jacintha O'Sullivan
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Foirgneamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

Appendix 1.3: Study 1- Recruitment Poster







Research Invitation

Study title: SPIRE (Severe neurological imPairment In iREland): prevalence, healthcare utilisation and a consensus-based clinical dataset

Does your child fit the criteria for Severe Neurological Impairment (SNI)?

Children with SNI have disorders of the nervous system resulting in severe movement and learning difficulties, complex medical care needs and require much assistance with daily tasks.

Would you like to help advance knowledge and improve care delivery for children with SNI by participating in a research study?

CHI researchers are looking at how children with SNI use healthcare services and are gathering baseline data on their diagnoses, symptoms, diet, and growth measurements with an aim to improve care, quality of life and reduce unplanned hospital attendances.

Would you like more information?

If you would like more information about participating, or are unsure if your child fits criteria for SNI, please ask a member of staff or email spirestudy@tuh.ie

Appendix 1.4 Study 1- Participant Information Leaflet







Parent Information Leaflet - Baseline dataset and healthcare use in Children with Severe Neurological Impairment

Study title: SPIRE (Severe neurological imPairment In iREland) - CONCEPT (CONsensus- based Clinical datasEt, Prevalence and healthcare uTilisation)

Site	**CHI at Tallaght, Temple Street and Crumlin**
Principal Investigator(s) and Co-Investigator(s) (insert names, titles and contact details)	Prof Denise McDonald Consultant Paediatrician CHI at Tallaght Tallaght University Hospital Dublin 24 01 414 2000 And Dr Joanne Balfe Consultant Paediatrician CHI at Tallaght Tallaght University Hospital Dublin 24 01 414 2000
Data Controllers	Prof Denise McDonald Dr Joanne Balfe And Dr Siobhan McCormack Research Specialist Registrar CHI at Tallaght
Data Protection Officer	**CHI Temple St site Data Protection Officer:** Mr Alan McKenna

Introduction:

You are being invited to take part in a research study of Children with Severe Neurological Impairment that is being led by Prof Denise McDonald and Dr Joanne Balfe at CHI Tallaght, Temple Street and Crumlin.

Before you decide whether or not you wish your child to take part (consenting for your child), you should read the information provided below carefully and, if you wish, discuss it with your family, friends, or GP. Take time to ask questions - don't feel rushed, and don't feel under pressure to make a quick decision. You should clearly understand the risks and benefits of this study so that you can make a decision that is right for you. This process is known as "informed consent". Changes in Irish data protection law with the introduction of GDPR, requires that you are provided with all of the detailed information you need to make your decision. This is known as 'Explicit Consent' and this information leaflet aims to give you clear and detailed information so you can give your Informed and explicit consent upon participating in the baseline dataset and healthcare use study for Children with Severe Neurological Impairment.

This leaflet has five main parts:

Part 1 – The Study
Part 2 – Data Protection
Part 3 – Costs, Funding and Approval
Part 4 – Future Research
Part 5 – Further Information

Part 1 – The Study

Why is this study being done?

We are doing this study in an effort to improve the health and wellbeing of those with Severe Neurological Impairment (SNI) through understanding how children with SNI use healthcare services and inclusion of baseline data in a dataset for children with SNI. This study will help us clarify the number of young people in Ireland that fulfil the definition of SNI and the issues they experience, and give service providers the information they need to plan the necessary services and appropriate allocation of resources. In our work over the years with children and families with this condition we are frequently asked if certain problems and illnesses are more common for children with SNI, how these are likely to change over time, and how best to prevent and manage them. In some areas we have some understanding of the answers and for other aspects unfortunately the information is not yet available. However, by you agreeing to work with us by participating in the dataset and to giving us permission to contact you and meet you and your child, to gather more information and measurements, we may be able to answer these questions more reliably for families in the future.

Why have I been invited to take part?

You are invited to take part in the baseline dataset and healthcare utilisation aspect of the study if you have a child with SNI who is attending one of the three CHI Children's Hospitals (Tallaght, Temple St or Crumlin) for primary paediatric care.

Do I have to take part? Can I withdraw?

No, this is entirely voluntary, you do not have to participate at all and do not have to give any reasons why you might choose not to. You can withdraw and this will not have any impact on your future medical care.

What happens if I change my mind?

You can change your mind at any point, and we will not contact you further again. You do not have to give any reason for that.

How will the study be carried out?

This study will take place from September 2021 for two years, but we expect to be enrolling children with SNI from January 2022 to Spring 2023. The study will be run from CHI hospitals at Crumlin, Temple Street and Tallaght but all children will be invited to attend a once-off visit to CHI Tallaght.

The study involves agreeing that the research team can look at your child's hospital records to gather the information they need, answering some questionnaires on medical background, symptoms and diet, and attending one visit to CHI Tallaght for growth measurements and nutrition assessment and blood tests- but the blood tests will only be as part of usual care for SNI and not extra sampling.

We hope to enrol about 80 children with SNI in this study, and the more children that are included the more helpful our results will be.

Are there any benefits to taking part in this research?

Taking part in this study may not directly benefit you but we plan to use the information that is collected to enable us to provide realistic data to enable planning of our services and national services for the future health and wellbeing of children with SNI and their families. This may develop into a long-term research project, so the benefits of the research may not be seen for several years. Currently we do not know exactly the number of children with SNI in Ireland, what their underlying diagnoses are, how much contact with healthcare services they have, which symptoms they experience and how best to prevent and manage health complications. This vital information will greatly support the planning of appropriate services and resources, and lead to improved care and reduced unscheduled hospital attendance for this group of children. When appropriate services and optimisation of care is provided to children and their families in relation to health and development, their quality of life is enriched.

Are there any risks to me or others if I take part?

As there is no medication or treatment being given, and no examinations or tests outside of what could be considered routine clinical care and best practice, no harm is anticipated for your child/you from participating in this study. The risk would be from inadvertent access to your/your child's personal data which we take great care to prevent as we will outline later in this leaflet.

What will happen to me if I decide to take part?

To participate in this study is to allow details about your child to be recorded along with details of other children who have Severe Neurological Impairment. Their name will be de-identified in a way that we call pseudo-anonymised, and fully anonymised (made fully unidentifiable) before any research work is produced, so that they cannot be identified by anyone but the principal researchers.

The clinical details recorded will be in line with international agreement on the most important details to collect on children with SNI, examples of which would include: any specific diagnoses (e.g. neurological or metabolic) that your child may have, any other medical and birth history or problems, the symptoms your child experiences, medications, details of how your child is currently and has previously been fed, ethnicity, your child's gender, the name of the consultant responsible for your child's care, and whether there is a family history of neurodevelopmental conditions. We will access your child's medical records so we can collect baseline information and record how often you attend healthcare services.

By agreeing to participate in this study you are also giving us your permission to contact you by phone to arrange for you to complete some questionnaires and symptom and feeding records and follow up with you about how you are getting on with these. We will also schedule to meet you at a dedicated clinic visit in CHI at Tallaght at a time and day that is convenient for you.

At this visit we will record some clinical information related to your child's condition including measures of their growth and nutrition, and we will arrange some blood tests in our blood-test department. The blood tests will not involve extra blood taking other than at a frequency that would normally be recommended for your child- if you attend Tallaght usually this will be a routine visit and if you attend other centres this will be instead of your next routine blood tests with the results going back to your primary paediatrician. We do not anticipate that any child will get any duplicated blood testing done just for the study. Our blood tests, which would be about a teaspoon or two of blood in total, are done by specialist staff skilled in taking blood from children and every effort will be made to minimise distress but there is always a chance of there being difficulty in taking samples, discomfort and bruising. We will also ask you to bring a urine sample on the day and will provide you with equipment to collect this in advance.

During the study, you will remain under the care of your usual paediatrician, local teams and GP and you will continue to be looked after them afterwards also.

What will happen to my Samples and Data?

Your identity will remain confidential. Your name will not be published or disclosed to anyone. Your child's name will not be put on the dataset. All information will be pseudo-anonymised using a unique study ID number "key" code for your child.

Your child's data will be fully anonymised before we publish or present any findings and all results will be aggregated (this means all data from all participants presented together so as not to pertain to any individual). The coded data collected from this study may be utilised for further relevant studies by the researchers or partner research teams but only if approved by an ethics committee and will only be reported in an anonymous way.

We will store your data confidentially, using a locked cabinet in a locked room for any paper data and an approved, secure data management system (REDCAP) for computerised data. Only the researchers will know where the data is and have keys or passwords to access it.

You child's blood samples will be analysed in Tallaght Hospital and routine labs used by Tallaght Hospital all the time as part of clinical care (These include St Vincent's in Dublin and UCL London). The results will be given to the study researchers who will also send them to your usual paediatrician so they can be used in the care and monitoring of your child's heath. No samples are stored and they are destroyed after analysis as standard.

The blood tests do not include any genetic or DNA testing.

What happens if something goes wrong when I'm taking part in the study?

In the unlikely event that you are harmed in any way, the researchers on this study are covered by standard malpractice insurance and the hospital's indemnity scheme. This insurance would cover you if you are injured as a result of taking part in this study.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The overall outcomes of the study will be published in medical journals and presented at national and international conferences. No information which reveals your identity will be disclosed.

The individual baseline data that is collected is not communicated back to participants, but it can be requested if desired. It does not include any information that is not in your medical records and available to you, or that you tell us about. The results of the laboratory tests on blood and urine are sent to your usual paediatrician so that they can be used as part of your routine care.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Your identifying data (names, date of birth, address, and phone number) will be required but will not be stored with your clinical data, which will be pseudonymised using a study ID number as outlined.

The clinical details recorded, using the pseudonym, will be in line with international agreement on the most important details to collect on children with SNI, which includes: any specific diagnoses that your child may have, any other medical and birth history or problems, the symptoms your child experiences, medications, details of how your child is currently and has previously been fed, ethnicity, your child's gender, the name of the consultant responsible for your child's care, and whether there is a family history of neurodevelopmental conditions.

We will access your child's medical records so we can collect this information and record how often you attend healthcare services.

The information you give when you complete some questionnaires on your child's history, health and symptom and feeding records as well as the measures of their growth and nutrition and results of the nutrition and bone health blood and urine markers also form part of your child's data in the dataset. All of these will be recorded under the pseudonym and not your child's identifying details.

What will happen to my personal data?

The purpose of collecting your data is to store information securely on a dataset (which is similar to an electronic filing cabinet) to enable us to reach our research outcomes and better understand the health and needs of children with SNI.

Your personal data will be processed (includes collecting, recording, organising, combining and anonymising data) only as is necessary to achieve the objective of the health research and will not be processed in a way that damage or distress will be caused to you.

We will pseudonymise your data to enable the research outcomes, and fully anonymise data to present the overall research findings. We intend to keep the baseline data securely to enable us to add to it, if you agree in the future to the collection of further data (such as updated growth measurements or symptom data) over time. It would be stored in a pseudonymised format. If you want us to delete your data after this baseline study, please let us know and we will delete your electronic data from the secure system and shred any paper data before confidentially disposing of it.

We may use, or be asked to use, anonymised data for national and international studies with our research collaborators and we would like to obtain your permission to do this. We will only do so when we believe the study is well-organised, the results are likely to be useful and if an ethics committee approves it. Any information we provide will be processed to fully anonymise the participant and will

be aggregated to ensure that individual patients cannot be identified. Including Irish-based data for international studies (most of which are based in the UK and North America) is important as the number of children with SNI in Ireland is low and we will be able to compare with other countries and join our data to make more powerful conclusions on the results. No data will be shared with commercial entities.

We will ask you in the consent form if you agree to the use of your data in future studies and if you agree to be contacted again to be invited to provide further data. You do not have to agree to this and do not have to give any reasons for your choice.

Who will access and use my personal data as part of this study?

Your personal data will be accessed only by the research team, which includes the principal investigators Prof Denise McDonald and Dr Joanne Balfe and the researcher Dr Siobhan McCormack. A small part of the data relating to gut health and bone health will be analysed with the assistance of CHI paediatricians, Dr Shoana Quinn and Dr Ciara McDonnell who are expert in these areas. This data will be pseudonymised and not contain identifying details. The nutrition components will be reviewed with the dietetics team of CHI Tallaght, led by Paediatric Dietitian Manager Meave Graham. The laboratory staff that analyse the blood and urine samples will have only the minimum identifiers that they require to run the samples so that they can be used as part of clinical care.

When the data has been anonymised it will be shared with Prof Nicholas Allen of NUI Galway, who is an academic supervisor in this study, for collaboration, and the overall research in an anonymous way will form part of publications in the medical literature and presentations at paediatric conferences.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

- Identifiable personal data will only be contained in a "key" of study ID numbers, stored on a separate computer in a locked principal investigator office and not in the dataset.
- Information in the dataset will be pseudonymised using the study ID and not personal identifying details.
- During this study any paper data will remain stored in a locked filing cabinet in a locked room.
- Electronic data will be stored on an approved, secure data management system.
- Only the researchers of this study will know where the data is and have keys or passwords to access it.
- All persons carrying out the research are bound by a professional code of secrecy to ensure confidentiality

However, if something did go wrong, we would follow established procedures to tell you as soon as we are aware and report it to the data protection officers.

What is the lawful basis to use my personal data?

By law, we can use your personal information for scientific research and in the public interest. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations. The name of the law is The European General Data Protection Regulation (GDPR).

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research.

You can exercise these rights by contacting the study doctors Prof Denise McDonald or Dr Joanne Balfe or the CHI Temple St Data Protection officer Alan McKenna, CHI Temple St, Dublin 1 01 878 4200 or Children's Health Ireland Data Protection Office, Block A, Herberton, St James's Walk, Rialto, Dublin 8. Website: https://www.olchc.ie/About-Us/Privacy-Statement-GDPR/

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

The study has obtained ethical approval from the joint ethics committees of CHI Crumlin, Temple St and Tallaght. Approval was granted on September 9th 2021.

Who is organising and funding this study? Will the results be used for commercial purposes?

This research is undertaken by The Department of Developmental Paediatrics and Neurodisability, Children's Health Ireland at Tallaght, Temple St and Crumlin by Prof Denise McDonald, Dr Joanne Balfe and MD researcher Dr Siobhan McCormack. Dr McCormack's salary is supported by the CHI Children's Health Foundation as part of new and emerging service development and patient impact initiatives for Children's Health Ireland Complex Care Programme (CHICC-P). The results will not be used for commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying patients to take part in the study.

Part 4 – Future Research

Will my personal data be used in future studies?

We may use, or be asked to use, anonymised data for future national and international studies that relate to the current study on SNI and we would like to obtain your permission to do this. This may be by CHI researchers or research partners with institutions we are linked with because they have an interest and expertise in children with SNI. We won't be asking for your consent again but would only use or share this anonymous data when we believe the study is well-organised, the results are likely to be useful and if an ethics committee approves it.

Any information we provide will be processed to fully anonymise the participant and will be aggregated to ensure that individual patients cannot be identified. We will uphold the same confidentially and security measures applying to your data in this study. No data will be shared with commercial entities. If you wish to withdraw from your anonymised data partaking in future studies, you can indicate that on the consent form or let us know.

We would also like your permission to contact you again to see if you would agree to provide further or updated information to add to your baseline data for possible future research related to this study. You would not have to agree to it at the time we ask and if you would prefer not to be contacted at all in relation to this you can indicate that on the consent form.

Part 5 – Further Information

Who should I contact for information or complaints?

You can get more information on this study by discussing it with your healthcare team or by contacting:

Prof Denise McDonald/Dr Joanne Balfe
SPIRE study
Children's Health Ireland at Tallaght
Tallaght University Hospital
Dublin 24
Email: spirestudy@tuh.ie

If you have any further questions about the study, your participation or if you want to opt out of the study, now or at any time in the future, please contact us. You can rest assured it won't affect the quality of any treatment you may get in the future.

You can also contact: CHI Temple St Data Protection officer Alan McKenna, CHI Temple St, Dublin 1 or CHI Data Protection Officer Ms Meiread Ashe, Board Secretary and Data Protection Officer, Children's Health Ireland, Block A, Herberton, St James's Walk, Rialto, Dublin 8

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Email: info@dataprotection.ie

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.
If you are taking part, we will contact you to arrange the study questionnaires and hospital visit at a time and day that is convenient for you.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.

Appendix 1.5: Study 1 – Consent Form

Children's Health Ireland

NUI Galway
OÉ Gaillimh

PATIENT CONSENT FORM FOR BASELINE AND HEALTHCARE USE DATA

Study title: SPIRE (Severe neurological imPairment In iREland): prevalence, healthcare utilisation and a consensus-based clinical dataset

Centre ID
Identification Number for study

Please initial each appropriate box

General	Yes	No
I confirm I have read and understood the **Information Leaflet** for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.		
I understand that this study **is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason**. I understand that deciding not to take part will not affect my future medical care.		
I understand that my child's **medical notes and records** may be looked at by Dr Siobhan McCormack, Prof Denise McDonald and Dr Joanne Balfe at Tallaght/Temple Street/Crumlin hospital where it is relevant to the research to get baseline health information. I agree that these individuals can access my child's records. I understand that all information will be kept private and confidential and that my name will not be disclosed.		
I give permission for researchers of this study to look at the hospital/clinical information system to get information about my child's **healthcare use**. I have been assured that information will be kept private and confidential.		
I consent to completing the questionnaires on my child's health and feeding. I have been assured that information will be kept private and confidential.		
I consent to a visit to CHI Tallaght Hospital with my child to have growth measurements and a nutrition focused assessment done, *as well as blood samples at a time that it is in keeping with my child's routine blood tests.*		
I understand that I **will not be paid for taking part in this study**.		
I know how to contact the research team if I need to.		
I agree to take part in this research study having been fully informed of the **risks and benefits** which are set out in full in the information leaflet which I have been provided with.		
I agree to being contacted by researchers by phone as part of this research study.		
I agree that my GP and primary consultant will be informed of my child's participation in the study.		

Data Processing	Yes	No
I agree to have my data processed (includes collecting, recording, organising, combining and anonymising data) as part of this research study as described in the patient information leaflet		
I acknowledge that the above described consent to the processing of my child's personal can be withdrawn any time (without giving reason) by sending an email to dataprotection@olchc.ie		
I agree to allow personal information, which would be in an anonymised and aggregate format, to be shared with third parties including national and international research partners and academic research institutions for the purpose of research in Severe Neurological Impairment, as described in the Information leaflet. I understand that the data from this research would only be presented or published in a fully anonymised way.		
I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.		
I understand that there are may not be **direct benefits to me** from participating in this study, but that my involvement will allow realistic data to enable planning of appropriate services and resources for the future health and wellbeing and improved care for children with SNI and their families. I understand that **results from analysis of my personal information will not be given to me**.		
I understand that **I can stop taking part in this study** at any time without giving a reason and this will not affect my future medical care.		

FUTURE USE OF INFORMATION		
RETENTION OF RESEARCH SAMPLES IN THE FUTURE	***Yes***	***No***
*I give permission for my personal information to be stored for possible future research **related** to the current study on Severe Neurological Impairment **without further consent** being required but only if the research is approved by a Research Ethics Committee. I understand that the data from this research would only be presented or published in a fully anonymised way.*		
*I agree to be contacted again to be invited to provide further data for possible future research **related** to the current study on Severe Neurological Impairment. This might include updated growth measurements or data on symptoms, for example. I understand that **further consent** would be required again to provide more data and further parent information would be provided.*		

BIOLOGICAL SAMPLES	***Yes***	***No***
I agree to have blood samples collected from my child looking at nutritional and bone health as described in the Information leaflet. I also agree to provide a urine sample. I understand that the researchers do not wish for any child to have extra blood sampling other than at a frequency that would normally be recommended for my child as part of their clinical care. The risk of taking blood samples has been explained to me.		
I understand that my biological samples will be disposed of in a lawful and respectful way.		

I understand that I can stop taking part in this study and request withdrawal of my laboratory results at any time until they are fully anonymised without any negative impact on my medical care.		
*I understand that results from the **analysis of my samples will not be given to me** but understand that results will be sent to my child's primary consultant.*		
I understand that I will not be paid for the use of my samples.		

Patient Name (Block Capitals)	Patient Signature	Date
Translator Name (Block Capitals)	Translator Signature	Date
Parent Name	Parent Signature	Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.
I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

Name (Block Capitals)	Qualifications	Signature	Date

Appendix 1.6: Study 1- Data Collection Form- Questionnaire

ORAL HEALTH QUESTIONNAIRE

DENTAL VISIT

A - PREVIOUS DENTAL EXPERIENCE

1 At what age did your child visit the dentist for the first time? _____ (months/years)

2. How often does your child visit the dentist?

☐ Never visited the dentist before ☐ Every 6 months ☐ Every year ☐ Rarely/when there is a problem

3. Where does your child visit the dentist?

☐ HSE dental clinic ☐ Private GDP/Own dentist ☐ Public Hospital (e.g. CHI at Tallaght)

4. What was the reason for previous dental visits? Select **all** that apply.

☐ Regular check-up ☐ Grinding ☐ Drooling ☐ Calculus/Tartar ☐ Erupting teeth/teeth position

☐ Pain ☐ Tooth decay ☐ Bleeding gums ☐ Dental Trauma ☐ Swelling

5. Select what treatment was provided by your dentist up to now. Select all that apply.

☐ Brushing instructions ☐ Fissure sealant ☐ Fluoride application ☐ Fillings ☐ Crowns

☐ Removal of tooth (extraction) ☐ Cleaning ☐ None

6. How was the treatment carried out? Select **all** that apply.

☐ In the dental chair ☐ In the child's wheelchair ☐ Other: _____

☐ General Anaesthesia (GA) ☐ Nitrous oxide/laughing gas

7. Has your child received trauma to the mouth/teeth/face? ☐ Yes ☐ No

8. Type of trauma: _____

9. What did you do? ☐ Nothing ☐ First aid at home ☐ Attend hospital ☐ Attend GP ☐ Attend dentist

B - ORAL HYGIENE HABITS

10. Who brushes your child's teeth? ☐ Mother ☐ Father ☐ Sibling ☐ Other caregiver

11. Has anyone demonstrated how to brush your child's teeth? ☐ Yes ☐ No

12. Which of the following applies? My child's teeth:

☐ are brushed without resistance ☐ are brushed with resistance

☐ requires a second person to brush ☐ cannot be brushed

13. How often are your child's teeth brushed?

☐ Less than once a week ☐ 2-6 days a week ☐ Once a day ☐ Twice a day or more

14. What toothpaste is used when brushing their teeth?

☐ No toothpaste ☐ Flavoured toothpaste ☐ Unflavoured

15. Does it contain fluoride? ☐ Yes ☐ No

C - DIETARY HABITS

16. Does your child eat/drink anything by mouth?

☐ Yes, all food/drinks ☐ Yes, only some food/drinks but mainly PEG fed ☐ No, exclusively PEG fed

17. How many times a day does your child have food/drinks in their mouth? ☐ <3 ☐ 4-6 ☐ >6

18. Do you usually use food as reward/comfort? ☐ No ☐ Sometimes ☐ Often

19. What drinks does your child usually have? ☐ Water ☐ Milk ☐ Juices ☐ Fizzy drinks

20. Does/did your child use a bottle at bed/night-time? ☐ No ☐ Yes, no longer uses ☐ Yes, still uses

D – BARRIERS TO CARE

21. Have you had problems getting a dentist to see your child? ☐ Yes ☐ No

22. Which of the following factors play a role in accessing dental care for your child?

Difficulties in Accessing Dental Care	Major Reason	Minor Reason	Not a reason	Do not know
Dentist unwilling to treat or inadequately trained in treating patients with special needs				
Dental clinic environment, colours, light and design are disturbing to special needs persons				
Dental clinic waiting area and general services (example: toilets) are not suitable				
Dental clinic is not equipped to facilitate treatment of special needs individuals				
Dental staff are not friendly or do not know how to manage special needs individuals				
Patient has communication difficulties with the dentist during treatment visits				
Medical health status of the patient hinders him/her from receiving immediate dental care				
Patient needs informed consent from his physician or needs hospitalization				
Patient is afraid of the dentist				
Patient unable to sit on the chair or cooperate with the dentist				
Patient's dental condition was not serious enough to see a dentist				
Dental centres/units that treat special needs patients are rare and limited				
Difficulty in getting appointments				
No time to visit the dentist				
Cost or financial difficulty				
Transportation difficulty				
Dental clinic is too far away				

E – ORAL HEALTH RATING

23. How would you rate **your child's** oral health? ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

24. How would you rate **your** oral health? ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

25. How often do you visit the dentist?

☐ Never visited the dentist before ☐ Every 6 months ☐ Every year ☐ Rarely/when there is a problem

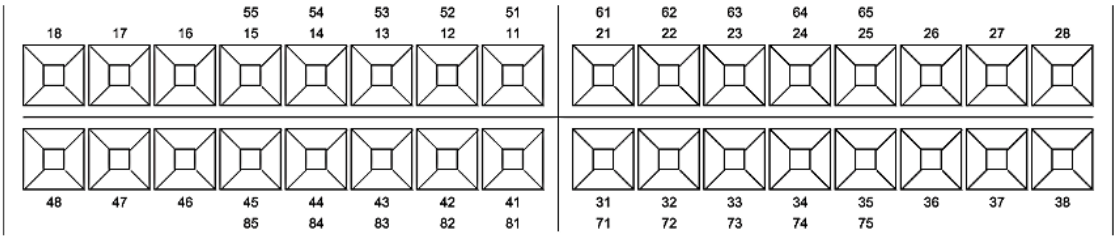
Appendix 1.7: Study 1- Data Collection Form- Clinical Assessment

F – DENTAL EXAM

Examined in: ☐ Dental Chair ☐ Wheel chair ☐ Caregiver laps ☐ Other: _____

Parent assistance needed: ☐ Yes ☐ No **Finger prop needed:** ☐ Yes ☐ No

EO/IO Abnormalities: _____



DMFT INDEX: _____ Decayed: _____ Missing due to caries: _____ Filled:_____ PUFA: _____

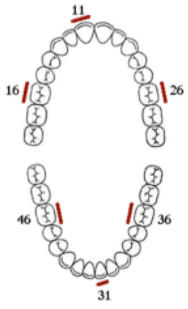
dmft INDEX: _____ Decayed: _____ Missing due to caries: _____ Filled:_____ PUFA: _____

ORTHO FEATURES: Overjet: _____ Overbite: _____ Cross bite: ☐ None ☐ R ☐ L ☐ A

Crowding: ☐ Spaced ☐ Mild ☐ Moderate ☐ Severe

Eruption sequence: ☐ Normal ☐ Delayed ☐ Accelerated

PLAQUE/DEBRIS INDEX: ___/____=



Debris Score	Criteria
1	Soft debris covering <1/3 exposed tooth surface or presence of extrinsic stains
2	Soft debris >1/3 and <2/3
3	Soft debris >2/3 tooth surface

Calculus score	Criteria
1	Supragingival calculus covering <1/3 exposed tooth surface
2	Calculus >1/3 and <2/3 or flecks of subgingival calculus
3	Calculus >2/3 tooth surface or band subgingival calculus

CALCULUS INDEX: ___/____=

G – SALIVA

SALIVA AMOUNT: ☐ Reduced ☐ Normal ☐ Excessive

SALIVA THICKNESS: ☐ Thick ☐ Normal ☐ Watery

CLINICAL ORAL DRYNESS SCORE: _____

✓	CRITERIA	✓	CRITERIA
	Mirror sticks to buccal mucosa		No saliva pooling in floor of mouth
	Mirror sticks to tongue		Glassy appearance of other oral mucosa, especially palate.
	Tongue lobulated/fissured		Debris on palate
	Tongue shows loss of papillae		Altered/smooth gingival architecture
	Frothy saliva		Active or recently restored (last 6 months) cervical caries (> 2 teeth)

Jager et al., 2018

DROOLING SCORE: _____

	SEVERITY: _____		FREQUENCY: _____
1	Dry (never drools)	1	Never drools
2	Mild (wet lips only)	2	Occasionally drools
3	Moderate (wet lips and chin)	3	Frequently drools
4	Severe (wet clothes)	4	Constantly drools
5	Profuse (wet clothing, hands, trays, objects within reach)		

Thomas-Stonell & Greenberg 1988

H – TOOTH WEAR

History of grinding/bruxism: No ☐ Yes ☐ Day ☐ Night ☐

Non-nutritive oral habits: ☐ Hard objects ☐ Soft objects ☐ Other: _____

Tooth wear worst score per quadrant:

☐ UR: ___
☐ UL: ___
☐ LR: ___
☐ LL: ___

Score	Criteria	*Modified O'Brien 1995*
0	No wear into dentine	
1	Dentine just visible (including cupping) or dentine exposed for less than 1/3 of surface	
2	Dentine exposure greater than 1/3 of surface	
3	Exposure of pulp or secondary dentine	

I – DEGREE OF DIFFICULTY IN THE EXAMINATION

Difficulty in the assessment: ☐ Easy ☐ Moderate ☐ Difficult ☐ Abandoned

J – IDENTIFIED TREATMENT NEEDS

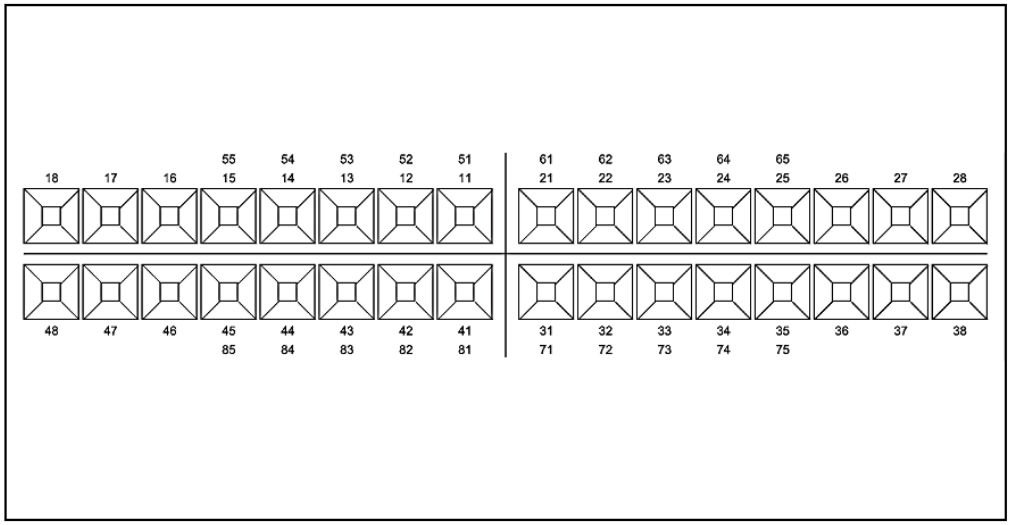
Radiographs required: ☐ **Yes** ☐ **No**

Identified treatment needs:

☐ Monitoring/OHI ☐ Fluoride/SDF ☐ Calculus removal

☐ Fissure Sealant/Other Prevention ☐ Restorative ☐ Surgical ☐ Orthodontic

Planned treatment:



Most appropriate location if treatment required:

☐ Primary care ☐ Secondary care ☐ Hospitalisation

GA required:

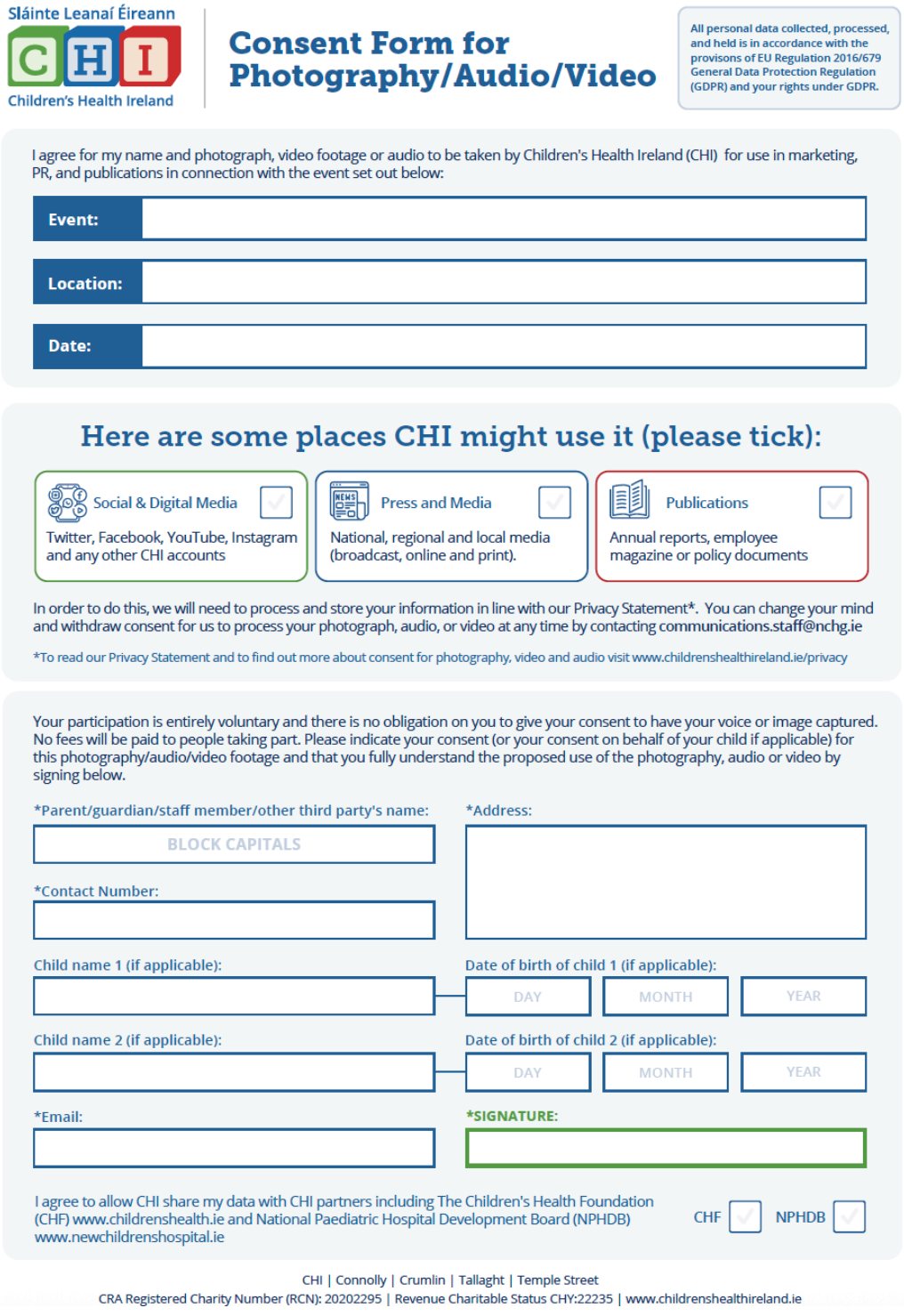
☐ Yes ☐ No

Appendix 2.1: Study 2- Script

SCRIPT- Dental Video version 06

It is really important that your child's teeth are kept clean, today we're going to show you how to brush your child's teeth and what to expect when you and your child visit the dentist. We hope you enjoy it!	*Snippets of views from the video for the intro*
Start brushing your child's teeth as soon as the first tooth comes in. It is good to use a soft toothbrush. Brush all surfaces of each tooth and brush all four corners in the mouth. Remember up, down and all around. It is helpful to lift your child's lip while brushing so that you can get the brush all the way to where the tooth meets the gum and you can check that the gum look light pink and healthy For children aged under 2 years just use a toothbrush with water, unless your dentist advises otherwise. For children aged 2 years and older use a small amount of toothpaste grain of rice sized amount For older children use a pea sized amount Brushing should last 2-3 minutes and when finished your child should not rinse with water or mouthwash. Encourage your child to spit out the leftover toothpaste or you can wipe it away. Remember spit, don't rinse!	*Scene: Dentist, parent and young child, dentist brushing childs teeth, then parent takes over* *Shows dentist or parent lifting the lip* *Show plain toothbrush, no toothpaste* *Stop video to show picture of correct amount* *Show correct amount again* *Video shows mother wiping away excess toothpaste*
There are lots of different toothpastes for sale, with different flavours including unfavoured The amount of fluoride in the toothpaste is what is important. This is written in the ingredients. We are checking that it says 1450ppm F Special toothbrushes can also help when brushing your childs teeth- they can be electric or multisided like this. Fingerprops can be useful especially if your child tends to bite down on the toothbrush, or you can use a second toothbrush to act as a prop. Ask your dentist where to purchase these. Distraction is also helpful when brushing- you can sing a song or pay some music	*Video shows table of toothpastes, - oranurse etc* *Video zooms on ingredients showing 1450ppm F* *Video shoes barmanns* *Video shows finger prop* *Then shows dentist using fingerprop for the older child*

Appendix 2.2: Study 2- CHI Consent Form for Recording



Sláinte Leanaí Éireann
CHI
Children's Health Ireland

Consent Form for Photography/Audio/Video

All personal data collected, processed, and held is in accordance with the provisons of EU Regulation 2016/679 General Data Protection Regulation (GDPR) and your rights under GDPR.

I agree for my name and photograph, video footage or audio to be taken by Children's Health Ireland (CHI) for use in marketing, PR, and publications in connection with the event set out below:

Event:

Location:

Date:

Here are some places CHI might use it (please tick):

☐ Social & Digital Media
Twitter, Facebook, YouTube, Instagram and any other CHI accounts

☐ Press and Media
National, regional and local media (broadcast, online and print).

☐ Publications
Annual reports, employee magazine or policy documents

In order to do this, we will need to process and store your information in line with our Privacy Statement*. You can change your mind and withdraw consent for us to process your photograph, audio, or video at any time by contacting communications.staff@nchg.ie

*To read our Privacy Statement and to find out more about consent for photography, video and audio visit www.childrenshealthireland.ie/privacy

Your participation is entirely voluntary and there is no obligation on you to give your consent to have your voice or image captured. No fees will be paid to people taking part. Please indicate your consent (or your consent on behalf of your child if applicable) for this photography/audio/video footage and that you fully understand the proposed use of the photography, audio or video by signing below.

*Parent/guardian/staff member/other third party's name:
BLOCK CAPITALS

*Address:

*Contact Number:

Child name 1 (if applicable):

Date of birth of child 1 (if applicable):
DAY MONTH YEAR

Child name 2 (if applicable):

Date of birth of child 2 (if applicable):
DAY MONTH YEAR

*Email:

*SIGNATURE:

I agree to allow CHI share my data with CHI partners including The Children's Health Foundation (CHF) www.childrenshealth.ie and National Paediatric Hospital Development Board (NPHDB) www.newchildrenshospital.ie

CHF ☐ NPHDB ☐

CHI | Connolly | Crumlin | Tallaght | Temple Street
CRA Registered Charity Number (RCN): 20202295 | Revenue Charitable Status CHY:22235 | www.childrenshealthireland.ie

Appendix 2.3: Study 2 – QR Code to Access Educational Videos



Appendix 2.4: Study 2 – Ethical Approval CHI

Sláinte Leanaí Éireann
Children's Health Ireland

CHI Research Ethics Office
Email: ethics.committee2@childrenshealthireland.ie
Tel: 01-409 6307 / 6243

Dr Robyn Crowley
Postgraduate Student Paediatric Dentistry
Children's Health Ireland
Dublin 24

1st December 2024

REC REF: **REC-521-24**

Parents and Healthcare Professionals Acceptance of a Dental Health Education Tool
Principal Investigator: Prof Anne O'Connell
Co-investigators: Dr Robyn Crowley, Dr Daithi Hugh McGrory

Dear Dr Crowley,

Your application for the above-named study was first reviewed by the CHI Research Ethics Committee on the 19th November 2024. Further to your correspondence dated 29th November 2024, I can confirm that all of the minor comments raised by the CHI REC have been successfully addressed.

This project is **APPROVED** with the expectation that it is conducted as stated in the reviewed application. An annual report for this project should be submitted to the CHI Research Ethics Office on or before the anniversary of this approval.

I wish you every success with this study and should you require any assistance in the future please do not hesitate to contact me.

Yours sincerely,

Dr Eugene Dempsey
CHI Research Ethics Officer

Cc: Prof Anne O'Connell, Consultant Paediatric Dentistry, CHI at Tallaght

CRA Registered Charity Number (RCN): 20202295 **Revenue Charitable Status CHY:** 22235
Board Members: Prof James Browne (Chairman), Mr Con Cronin, Ms Mary Cryan, Mr Liam Dowdall, Prof Martin Elliott, Ms Catherine Guy, Dr Anne Kilgallen, Dr Gavin Lavery, Ms Brigid McManus, Mr Turlough O'Sullivan, Mr Sean Sheehan

Appendix 2.5: Study 2 – Ethical Approval, Dublin Dental University Hospital

Subject:
Ethics Application "Parents and Healthcare Professionals Acceptance of a Dental Health Education Tool" has been approved

Message:

Dear Robyn Crowley

The following ethics application has been approved and an approval letter can be downloaded from the attachment section of the application' Please note the Application Number for reference below:

- Title: Parents and Healthcare Professionals Acceptance of a Dental Health Education Tool
- Reference No: 4134

Please do not respond back to the email.

TCD Ethics Application System

Send At:
08/04/2025 7:07:54 AM

Appendix 2.6: Study 2 – Participant Information Leaflet (HCWs)

Sláinte Leanaí Éireann
CHI
Children's Health Ireland

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Participant Information Leaflet- Healthcare Workers

Study Title: Survey of Parents and Healthcare Providers Acceptance of Dental Health Education Video

Principal Investigator: **Prof Anne O'Connell**
Co-investigator: **Dr Robyn Crowley and Dr Daithi Hugh McGrory**
Contact Details: **Robyn.Crowley@dental.tcd.ie**
Anne.oconnell@tuh.ie

What is the purpose of this survey?
We are doing this study to find out what parents and health care professionals opinions are of the dental health educational content we provide to families. This will help us improve the educational content we provide to patients and their families.

We hope to enrol more than 20 participants in this study, and the more people that are included the more helpful our results will be.

This study will form part of Robyn Crowley's Clinical Doctorate in Paediatric Dentistry.

Why am I being asked to take part?
You are invited to take part in this project because you are a healthcare professional who works with children in CHI at Tallaght.

Do I have to take part?
No, your participation is completely voluntary and you will not be asked for your name or for any other identifying information.

If I take part, what will I be asked to do?
Once you have read this information leaflet and you are interested In taking part, the dental team will provide you with the dental education video. After watching the video you are asked to complete a short questionnaire online. There is a QR code at the end of this leaflet which allows you to access the survey. Using the camera function on your phone scan the QR code and a link to the anonymous survey will then appear.

Will the data be confidential?
Yes, this survey is completely anonymous. Your answers will be treated confidentially and the information you provide will be anonymous within any publications or reports. Your anonymous data will be held securely and can only be accessed by the listed investigators. All data will be deleted when the study and any subsequent publications or reports are completed, this process usually takes about 5 years.

Any Questions?
If you have any questions or concerns on any aspect of this study, you can contact Robyn Crowley at Robyn.Crowley@dental.tcd.ie

Sláinte Leanaí Éireann
Children's Health Ireland

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

After reading the Participant Information Leaflet if you would like to take part please scan the QR code below to begin the anonymous survey!

Appendix 2.7: Study 2 – Participants Information Leaflet (Parents/Carers)

Sláinte Leanaí Éireann
Children's Health Ireland

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Participant Information Leaflet- Parents

Study Title: Survey of Parents and Healthcare Providers Acceptance of Dental Health Education Video

Principal Investigator: **Prof O'Connell**
Co-Investigator: **Dr Robyn Crowley and Dr Daithi Hugh McGrory**
Contact Details: **Robyn.Crowley@dental.tcd.ie**
Anne.oconnell@tuh.ie

What is the purpose of this survey?
We are doing this study to find out what parents and health care professionals opinions are of the dental health educational content we provide to families. This will help us improve the educational content we provide to patients and their families.

We hope to enrol at least 20 participants in this study, and the more people that are included the more helpful our results will be.

This study will form part of Robyn Crowley's Clinical Doctorate in Paediatric Dentistry.

Why am I being asked to take part?
You are invited to take part in this project because you have been provided with a copy of the dental health education video by the dental team.

Do I have to take part?
No, your participation is completely voluntary and you will not be asked for your name or for any other identifying information.

If I take part, what will I be asked to do?
Once you have read this information leaflet and you are happy to proceed, you will then be asked to complete a short questionnaire. There is a QR code at the end of this leaflet. Using the camera function on your phone scan the QR code. A link to the anonymous survey will then appear.

Will the data be confidential?
Yes, this survey is completely anonymous. Your answers will be treated confidentially and the information you provide will be anonymous within any publications or reports. Your anonymous data will be held securely and can only be accessed by the listed investigators. All data will be deleted when the study and any subsequent publications or reports are completed, this process usually takes about 5 years.

Any Questions?
If you have any questions or concerns on any aspect of this study, you can contact Robyn Crowley at Robyn.Crowley@dental.tcd.ie.

Sláinte Leanaí Éireann
Children's Health Ireland

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

After reading the Participant Information Leaflet if you would like to take part please scan the QR code below to begin the anonymous survey!

Appendix 2.8: Study 2 – Consent Form and Questionnaire- HCWs (downloaded from online platform Qualtrics)

Toothbrushing Survey- HCPs

Start of Block: Participant Information

You have been invited to take part in this anonymous online survey as you expressed interest in the project to the Dental Team here in CHI Tallaght. You received access to our Dental Health Video education tool and the following survey asks you for your feedback on this education tool.

As the survey is entirely anonymous, we ask that you do not identify yourself, any staff members or any children in your answers.

The goal of this research is to improve the access and quality of the educational tools we use here in the Dental Department and we appreciate your input into helping us reach that goal.

Prior to completing the survey questions, please read the accompanying participant information leaflet and ensure to complete the following consent section.

End of Block: Participant Information

Start of Block: Consent

Prior to proceeding, your consent is required. Please read the following and tick the check boxes if you agree with the following statements:
I have read and understand the study Participant Information Leaflet (PIL).

○ Yes

I understand that this survey is intended to be anonymous and should not identify any particular individual.

○ Yes

I understand that should I provide my name or other identifiable information, my responses may be linked to me.

- Yes

I understand that if I include any identifiable information, this will be anonymised by the researchers.

- Yes

I understand that on completion of this survey I am providing consent for the use of this data.

- Yes

I understand that on completion of this survey, as everything is anonymised it will not be possible to have my specific responses removed from the pooled data.

- Yes

End of Block: Consent

Start of Block: Survey Questions

Q1 Did you like or dislike the video?

- Strongly dislike
- Dislike
- No opinion
- Like
- Strongly Like

Q2 How much effort did it take to access and watch the video?

- ○ No effort at all
- ○ A little effort
- ○ No opinion
- ○ A lot of effort
- ○ Huge effort

Q3 How suitable is this method of toothbrushing for children?

- ○ Very unfair
- ○ Unfair
- ○ No opinion
- ○ Fair
- ○ Very fair

Q4 The video improved my knowledge around toothbrushing.

- ○ Strongly disagree
- ○ Disagree
- ○ No opinion
- ○ Agree
- ○ Strongly agree

Q5 It is clear to me how the video would help parents and carers manage toothbrushing.

- ○ Strongly disagree
- ○ Disagree
- ○ No opinion
- ○ Agree
- ○ Strongly agree

Q6 How confident do you feel about toothbrushing having watched the video?

- ○ Very unconfident
- ○ Unconfident
- ○ No opinion
- ○ Confident
- ○ Very confident

Q7 Watching the video interfered with my other priorities.

- ○ Strongly agree
- ○ Agree
- ○ No opinion
- ○ Disagree
- ○ Strongly disagree

Q8 Overall how acceptable was the video to you?

- ○ Completely unacceptable
- ○ Unacceptable
- ○ No opinion
- ○ Acceptable
- ○ Completely acceptable

Q9 Do you think it is preferable to receive dental health education material in a different format (such as handouts)?

- ○ Yes
- ○ No

If yes what format do you think is preferable? _____

Q10 Do you have any further comments?

_____

End of Block: Survey Questions

Appendix 2.9: Study 2 -Consent and Questionnaire- Parents/Carers (downloaded from online platform Qualtrics)

qualtrics XM

Toothbrushing Video Survey- Parent/Caregivers

Start of Block: **Participant Information**

You have been invited to take part in this anonymous online survey as your child attends the Dental Department in CHI Tallaght. As part of your child's care, you would received access to our Dental Health Video education tool. The following survey asks you for your feedback on this education tool.

As the survey is entirely anonymous, we ask that you do not identify yourself, your child or any staff member in your answers.

The goal of this research is to improve the access and quality of the educational tools we use here in the Dental Department and we appreciate your input into helping us reach that goal.

Prior to completing the survey questions, please read the accompanying participant information leaflet and ensure to complete the following consent section.

End of Block: Participant Information

Start of Block: **Consent**

Prior to proceeding, your consent is required. Please read the following and tick the check boxes if you agree with the following statements.

I have read and understand the study Participant Information Leaflet (PIL).

○ Yes

I understand that this survey is intended to be anonymous and should not identify any particular individual

○ Yes

Page 1 of 6

qualtrics XM

I understand that should I provide my name or other identifiable information, my responses may be linked to me.

- ○ Yes

I understand that if I include any identifiable information, this will be anonymised by the researchers.

- ○ Yes

I understand that on completion of this survey I am providing consent for the use of this data.

- ○ Yes

I understand that on completion of this survey, as everything is anonymised it will not be possible to have my specific responses removed from the pooled data.

- ○ Yes

End of Block: Consent

Start of Block: **Survey Questions**

qualtrics XM

Q1 Did you like or dislike the video?

- Strongly dislike
- Dislike
- No opinion
- Like
- Strongly Like

Q2 How much effort did it take to access and watch the video?

- No effort at all
- A little effort
- No opinion
- A lot of effort
- Huge effort

Q3 How suitable is this method of toothbrushing for your child?

- Very unsuitable
- Unsuitable
- No opinion
- Suitable
- Very suitable

qualtrics XM

Q4 The video improved my knowledge around toothbrushing.

- Strongly disagree
- Disagree
- No opinion
- Agree
- Strongly agree

Q5 It is clear to me how the video will help me manage toothbrushing at home.

- Strongly disagree
- Disagree
- No opinion
- Agree
- Strongly agree

Q6 How confident do you feel about toothbrushing having watched the video?

- Very unconfident
- Unconfident
- No opinion
- Confident
- Very confident

qualtrics XM

Q7 Watching the video interfered with my other priorities.

- Strongly agree
- Agree
- No opinion
- Disagree
- Strongly disagree

Q8 Overall how acceptable was the video to you? (given your answers to the previous questions)

- Completely unacceptable
- Unacceptable
- No opinion
- Acceptable
- Completely acceptable

Q9 Would you prefer to receive dental health education material in a different format (such as handouts)?

- Yes
- No

If yes what format would you prefer? _____

Q10 Do you have any further comments?

_____

End of Block: Survey Questions