Clinicians' Perspectives On Challenges In Complying With The National Cardiac Standards On Dental Care Of Children With Congenital Heart Disease: A Two Part Study

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Abstract

Background: Children with congenital heart disease are often at increased risk of infective endocarditis and its associated mortalities. Meticulous dental care and prevention in this cohort of children is of extreme importance.

Aim: To explore compliance of children in Yorkshire with congenital heart disease, born subsequent to the implementation of the Congenital Heart Disease Standards and Specifications (CHDS) 2016.

Design: This two-part study looked at the proportion of children appropriately referred for specialist paediatric dental screening at the age of two years within Yorkshire and the Humber. Semi-structured interviews were subsequently conducted using the theoretical domains framework to identify and describe current behaviours and barriers amongst cardiology consultants, nurses and paediatric dental specialists and consultants.

Results: One patient of the 49 had been referred for dental screening as per the standards. Five core themes were identified during interviews. Clarification of standards was raised by the dentists, for example who should screen the patient and follow them up. In general, clinical priority was given to the referrals received from cardiology. Challenges associated with the current referral process included a lack of delegation amongst staff. Organisation barriers were predominantly based on the lack of specialist dentists in the region and the lack of nursing staff to do the referrals. The value of communication between cardiology and paediatric dentistry was also highlighted.

Conclusions: The standards are not well implemented at present, with low numbers being referred. Barriers need to be discussed within the region to help overcome them.

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Abbreviation Key

BSPD- British Society of Paediatric Dentistry

CC- Cardiac consultant

CDHS- Child Dental Health Survey

CDS- Community dental service

CHD- Congenital heart disease

CHDSS- Congenital Heart Disease Standards and Specifications

CN- Cardiac nurse specialist

DC- Dental consultant

dmft- Decayed, missing or filled primary teeth

DMFT- Decayed, missing or filled permanent teeth

DREC- Dental Research Ethics Committee

DS- Dental specialist

GDP- General dental practitioner

IE- Infective endocarditis

LTHT- Leeds Teaching Hospital Trust

LPSD- Local Paediatric Specialist Dentist

MCDAS- Modified Children's Dental Anxiety Score

NHS- National Health Service

NICE- The National Institute for Health and Care Excellence

SDCEP- Scottish Dental Clinical Effectiveness Programme

1. Introduction

1.1 Congenital heart disease

Congenital Heart Disease (CHD) refers to structural or functional heart disease that is present at birth, regardless of whether this diagnosis is made at later life (1). The current survival rate into adulthood is around 85% (2). CHD is thought to present between 8 to 12 cases per 1,000 live births, with 40% diagnosed within the first year of life (3). Many congenital lesions are diagnosed during routine ultrasound of the foetus at 20 weeks (4). In addition, another 10 to 12 children will have non-stenotic bicuspid aortic valves. This rarely causes problems in infancy, but later account for many adults requiring treatment for late-onset aortic stenosis or regurgitation (5). These figures are, however, thought to be an underrepresentation due to numerous factors. Firstly, lesions with subtle defects (such as atrial or ventricular septal defects, or pulmonary stenosis), may not be detected until adulthood. It is estimated that only 40-50% of cases are diagnosed within the first week and 50-60% diagnosed within the first month (1). Secondly, severe defects may prove fatal in some neonates before a diagnosis is made. Prior to good echocardiography, diagnoses that were unclear after clinical examination would require confirmation with cardiac catheterization. If these lesions were minor, cardiologists could be reluctant to catheterize due to the associated risks. Nowadays, clinical and echocardiographic diagnosis are highly accurate, reducing the risk of lesions going undiagnosed (6). Echocardiograms on neonates suggest that approximately five percent have small muscular ventricular septal defects, most of which heal spontaneously by their first birthday. A larger portion have atrial septal defects, which also behave similarly with spontaneous closure (5).

There has long been a clinical view that most children with CHD occur as isolated cases. With recent studies of recurrence risks (prevalence within the same generation, e.g. siblings) and transmission risks (prevalence between consecutive generations, e.g. children), it is now thought to be of multi-factorial aetiology, with genetic, environmental and stochastic components (3). The recurrence risk for future siblings is two to six percent, whereas for parent-to-child can vary between one and ten percent (1). Risk factors include maternal diabetes (associated with a 30% risk of structural CHD), as well as maternal drug and alcohol use (4).

During foetal development, the lungs are bypassed to allow oxygenated blood from the placenta to the rest of the body. Blood may pass from the right to left via the patent foramen

ovale, or may flow from the pulmonary artery to the aorta through the ductus arteriosus. On the first breath of air after birth, the lungs expand and the pressure changes within the system. An increased blood pressure and reduced pulmonary pressure reduces the blood flow through the ductus arteriosus, promoting closure. This subsequently results in an increased pressure in the left atrium, thus causing closure of the foramen ovale. These pathways typically close during the first two weeks of birth (4). At this stage, it is usual for neonates with undiagnosed CHD to present with signs of shock, cyanosis and/or congestive heart failure. Those with left-sided obstructive lesions will present with insufficient systemic perfusion and shock, whereas those with right-sided obstructive lesions, will have an increased level of deoxygenated blood in the capillaries and display signs of cyanosis.

Cyanotic heart defects include truncus arteriosus, transposition of the great arteries, tricuspid atresia, tetralogy of Fallot and total anomalous pulmonary venous return. Some common non-cyanotic congenital heart defects include atrial septal defects, patent ductus arteriosus, coarctation of the aorta and aortic or pulmonary stenosis (4). Isolated ventricular septal defects are the most common form of CHD, with it making up 30 to 40% of all children with CHD (1).

1.2 Dental health

Oral health involves the care of an individual's teeth, gums and soft tissues. The Decayed, Missing or Filled Teeth Index (DMFT) is a well-established key to measure dental decay. It is calculated as the number of teeth that have untreated decay, have been extracted due to decay, or have fillings due to caries. In the permanent dentition this is recorded as 'DMFT', where-as the primary dentition is noted as 'dmft'. Teeth excluded from these indices include unerupted and congenitally missing teeth, supernumeries, or teeth extracted for reasons other than decay (such as periodontal disease or orthodontic purposes).

The Child Dental Health Survey specifically looks at DMFT scores into dentine (D3MFT/d3mft scores) and defines it as any teeth or restorations that are cavitated or have visual dentine caries, teeth filled due to decay or teeth extracted due to decay. It excludes teeth with enamel caries present. (7) The latest CDHS conducted in 2019 by the British Association for the Study of Community Dentistry looked at the dental experiences of 5-year-old school children. Using solely visual assessment, without radiographical or trans-illumination aid (thus potentially underrepresenting true caries), 23.4% of 5-year-old children had caries experience (i.e. d3mft score>0). The mean score amongst these children was 3.4 (CI 3.36-3.44). Variations presented

amongst different geographic locations, socioeconomic background and ethnicity. This ranged from an average of 1.6 dmft (CI 1.23-1.92) in Rushcliffe, Nottinghamshire to 5.4 (CI 4.36-6.49) in Norwich, Norfolk. Children presenting in more deprived areas of the country had higher levels of decay than those in less deprived areas (34.3% compared to 13.7%). Ethnic groups with the highest decay rate included 'Other Ethnic Group' (44.3%) and 'Asian/Asian British' (36.9%) (8).

An analysis of the CDHS in 2013 explored the relationship between the caries experience and sugar consumption. After taking into consideration the adjustments for factors such as age, gender, socio-economic status and oral health behaviour, results suggested that frequent consumption of sugary drinks (drinks with added sugar, excluding juices) correlated with higher caries experience (IRR 1.3 for 1-3 sugary drinks and IRR 1.4 for more than 3 sugary drinks). Similarly, having foods with added sugar more than the recommended 4 times a day was associated with higher DMFT (IRR 1.3). Caries experience was also higher for older children, those from low socio-economic backgrounds, children who brush less than the recommended amount, attend the dentist irregularly (i.e. when having problems) or drink water less than once daily (9).

1.1 The link between congenital heart disease and dental health

Children with congenital heart disease often present with higher rate of dental decay compared to their healthy counterparts. Table 1 presents a summary of key papers comparing the dental health of children with CHD. The majority of papers show a significantly higher rate of caries in children with cardiac disease, although the oral hygiene differences varied between studies. There was also a higher care index in the cardiac population, meaning that more children received previous care for dental caries.

Table 1: Literature exploring caries rate in children with CHD

Paper	Study Design	Cohort	Data Collection	Results
Pollard 1992 (10)	Case controlled prospective study	100 children with congenital heart disease, attending their cardiac appointment were matched with 100 healthy children of similar age, sex, ethnicity and socio-economic status, attending school	Children were clinically assessed either in the classroom or in the cardiac consultation room. Lighting, but no additional equipment was required, which was likely to result in under diagnosis of early lesions. dmft and DMFT scores were recorded, along with gingival, plaque and calculus scores. Saliva samples were taken with a spatula to measure Streptococcus mutans levels.	There was a statistically higher rate of caries in the study group compared to control group in the 5-9 year age group only (4.32 compared to 2.77). The similarity between study and control groups in lower decayed and missing teeth at 10-16 years could be due to the changeover to sound permanent dentition. There was no statistically significant difference between the mean number of segments free of gingivitis/plaque/calculus. Although this would indicate similar oral hygiene levels between the two groups, during data collection, there was no randomisation of segments selected for the gingival, plaque and calculus scores. Significant correlation was revealed between decayed primary and permanent teeth and Strep mutans levels in the 5-9 year olds and between missing permanent teeth and Strep mutans levels in the 10-16 year olds.
Stecksen-Blicks 2004 (11)	Case controlled retrospective study	41 children with grade II and grade III CHD and 41 healthy children	Medical and dental clinical records and radiographs were used to measure caries experience, level of prevention and medical history.	The mean age of cardiac children was 6.9 years and 6.5 years for the control group, showing good matching for age. However, socioeconomic variables were not controlled which could have masked the effect of CHD on dental health. The cardiac group had a higher caries experience in the primary dentition (dmft 5.2 vs 2.1) but not in the permanent dentition (DMFT 0.9 vs 0.5). However, cardiac children had more preventative treatment, with 52% having been prescribed fluoride tablets compared to 17%. On average, a cardiac child had 3.8 fluoride varnish applications compared to 1.8 in the control group. It would have been expected that these children with high preventative regimes would have lower dmft scores, so it could suggest that the preventative treatment was only commenced once decay developed and not as true prevention.

Talebi 2007 (12)	Cross sectional study	100 cardiac patients were compared to 50 healthy patients of similar ages.	Patients were clinically assessed for dmft, DMFT and simplified debris index (DI-S).	There was no significant difference between the cardiac group and control group. However, there was considerably higher levels of debris recorded in the cardiac children, with DI-S score of 0.42 compared to 0.23. When this was explored with questionnaires, a statistically higher portion of patients did not brush their teeth at least once a day in the cardiac group (38%) compared to the control group (10%), possibly due to lower priority compared to medical care.
Tasioula 2008 (13)	Case controlled prospective study	86 children with CHD diagnosed before first birthday, with no other medial issues and at risk of infective endocarditis were compared to 60 control children who attended the cardiac clinic with murmurs or were under follow up for family history of cardiac condition. There were no significant differences between mean age, sex, race or SES	Children were all assessed during their outpatient cardiac visit	There was no statistically significant difference in dmft/DMFT scores between the two groups and between the levels of untreated decay. The exclusion of children with other medical conditions and syndromes could result in diagnostic purity bias as cardiac conditions often occur alongside other medical conditions, which could hinder oral care. A significant difference was noted between the care index of the cardiac patients (10%) and control patients (3%).
Balmer 2010 (14)	Case controlled prospective study	28 children who were very high risk of infective endocarditis (prosthetic heart valve and/or diagnosed with an episode of infective endocarditis), compared with control group of cardiac patients without any structural heart defects.	Patients were clinically assessed for dmft and DMFT scores. Patient questionnaires were sent to explore dental health.	No statistically significant differences between caries rate in primary and permanent teeth between the study and control groups. A statistically significant increase in fissure sealants was noted in the cardiac group. This could be due to the cases having an exceptionally high risk of infective endocarditis (compared to the average cardiac patient) and therefore received more diligent dental care. There was also a statistically significant higher percentage of care index (i.e. restored teeth) in the primary dentition of the healthy cohort group (50% vs 11.9%).

Cantekin 2012 (15)	Case controlled prospective study	165 children with CHD and 165 healthy children, excluding those undergoing endodontic treatment or with systemic disease.	Clinical examination, radiographs, intraoral pictures to assess for caries. Orthopantomography to assess dental ages. Simplified oral hygiene index to measure oral hygiene.	No difference in oral hygiene between the two groups. There was statistically significant differences in dmft scores, with CHD mean of 2.8 and control mean of 1.4. There was also a significant difference in the DMFT score, with CHD mean of 2.0 and control mean of 1.1. The biological dental age of children with CHD was 8.8 years compared to 9.6 years, showing statistically significant delayed development. There was no difference between acquired heart disease and healthy children. No power calculation was conducted for this study, and multiple hypotheses were tested, potentially resulting in data dredging.
Ali 2017 (16)	Cross sectional study	111 children with CHD selected from cardiac clinic and 182 healthy children selected from local schools and kindergartens were matched with age and sex.	Patients were assessed for dmft/DMFT and gingival health, including plaque scores.	The cohort of children from the control group came from a variety of rural and urban areas but were not matched for socioeconomic status with the cases. Almost all the children in both groups presented with plaque but there was no statistically significant difference between the two. The presence of caries was significantly higher in the control group (66.7% vs 46.7%), as was the presence of gingivitis (82.0% vs 64.8%).

The differences between the higher levels of untreated dental disease within the paediatric cardiac population can be as a result of a multiple factors.

Firstly, the quality of the enamel in these children is more likely to be poorer. Children with cardiac conditions often present with enamel defects. These defects may be chronological, corresponding to the period of poorer health. A case-controlled study in Brisbane compared children attending their cardiology appointments with their healthy siblings for enamel hypoplasia. By comparing children from the cardiology clinic, this ensured a good range of cardiac diagnoses and caries risks. Effort was made to reduce confounding factors by matching as much as possible with age and gender, although logistically it was not possible to get perfect matches. Comparing children with their siblings meant that home lifestyle could be matched as much as possible to reduce bias. There was no statistically significant difference between the groups in terms of frequency of sugar exposure, fluoride use and frequency of brushing, however cardiac children were more likely to receive parental support in brushing. Results showed no statistically significant difference between the groups when looking at enamel defect in the permanent dentition. However, when looking at the primary dentition, a statistically significant higher proportion of children in the cardiac group had at least one developmental enamel defect (52% vs 21%). Taking into consideration the calcification dates of primary and secondary teeth, these defects will have occurred in utero, as opposed to the first few years of life, possibly due to cardiac defects having been repaired by this stage (17).

With multiple invasive procedures and frequent medical appointments, it is not uncommon for children to develop a fear surrounding medical and dental visits. Dental anxiety in children can be measured using the Modified Children's Dental Anxiety Scale (MCDAS). This is a questionnaire using a Likert scale out of five, to assess anxiety in response to eight questions relating to dental health. The total score is then used to classify the level of the child's anxiety. In a 2015 study, children were recruited into the study group from outpatient cardiology clinics, and the control group was filled using healthy children attending new patient orthodontic clinics. This method of selection could potentially be flawed in introducing bias, as children on the orthodontic clinic would most likely be of low caries risk and not a good representative of the general population. The results revealed a significantly higher level of dental anxiety (MCDAS score 21.96) compared to the control group (MCDAS score 18.48). It was noted, as expected, that the cardiac group had a statistically significant rate of overnight hospital admissions. Once this was adjusted, there was no longer a statistically significant difference in the anxiety scores. Conversely, the difference in anxiety scores remained

significant once the number of general anaesthetics was accounted for (18). This supports the theory of invasive medical interventions impacting medical and dental anxieties. A second study in 2003 concluded that children with frequent exposure to invasive medical treatment and those with experience of operative dental care, particularly extractions, are more likely to display apprehension dentally (19).

Children with CHD are more likely to be on multiple medications. Xerostomia is a well-known side effect of polypharmacy. Saliva has an important role in flushing away food debris and acting as a buffer to reduced pH following sugar consumption, thus xerostomia increases the risk of dental caries. In addition to this, despite a push for sugar-free medications, many still contain sugar to mask unpleasant tastes for children (20), such as digoxin syrup, which contains 30% sucrose. These medications increase the frequency of sugar intake per day, to above the recommended four sugar attacks a day. When comparing the rate of caries amongst cardiology patients, only 11.2% of those that took long-term medications were caries free, compared to 38.1% of those who did not take regular medication (17).

Furthermore, children with CHD often have difficulties surrounding feeding and nutrition, which includes frequent vomiting. As a result, their diet requires frequent feeds, including throughout the night. These nutritional supplements are often high in sugar, thus jeopardising oral health even more (13).

Due to the complex medical care required by this cohort of children, dental care often becomes lower priority when looking at the child's general health (21) (15). These children are also more likely to be burdened with other associated comorbidities. Over half of children with severe CHD and a quarter of those with milder CHD have moderate to severe neurodevelopmental disabilities (5). Children with Trisomy-21, are often at increased risk of CHD, with between 23 and 56% reported in the literature to have some cardiac defect (1).

1.2 Infective endocarditis

Due to the increased risk of severe medical complications from untreated oral infections, children with cardiac disease should be classified as high risk of developing dental decay, in order to receive high quality preventative treatment. This could help defer extensive treatment requiring general anaesthesia, which poses a risk of life with some children (22). Thus, children should receive intervention as per the 'giving concern' category of the 'Delivering Better Oral Health' Toolkit (23). A three-month recall is recommended, to ensure

oral care is being received (24).

Children with structural congenital heart disease are at an increased risk of infective endocarditis (IE), with the exceptions being isolated ASDs, fully repaired VSDs or PDAs and fully endothelialised closure devices. Children with a previous history of IE are considered more likely to develop IE and those with prosthetic heart valves are more likely to suffer from severe consequences following IE. As a result, these two categories are considered very high risk (25).

Endocarditis has a mortality of 20% at one month and the disease itself is on the increase due to the increased number of children with CHD surviving into adulthood. When analysing the age of onset of IE, this follows a bimodal distribution with a first peak at around 10 years and a second in adulthood, at approximately 28 years (2). The most common presenting symptom is fever, with vague systemic symptoms. The recently updated 2023 Duke criteria is the most recommended diagnostic criteria (41). Definite endocarditis can either be diagnosed via pathologic criteria or by clinical criteria. Pathological criteria require either a) microorganisms identified in the context of clinical signs of active endocarditis in a vegetation on specific cardiac structures or b) active endocarditis identified in or on a vegetation from cardiac tissue from specific cardiac structures. Clinical criteria is defined as the presence of at least a) two major criteria, b) one major and three minor criteria or c) 5 minor criteria.

Table 2: Updated Duke Criteria (41)

Criteria	
Major Criteria	Microbiologic: positive blood cultures or positive laboratory tests
	Imaging: echocardiography and cardiac computed tomography or positron emission computed tomography
	Surgical: direct inspection shows evidence of IE during heart surgery
Minor Criteria	Predisposing heart condition or intravenous drug user
	Fever with temperature >38 degrees Celsius
	Vascular phenomena: arterial emboli, septic pulmonary infarcts cerebral or splenic abscess, mycotic aneurysm, intracranial haemorrhage, conjunctival haemorrhage, Janeway lesions, purulent purpura
	Immunological phenomena: glomerulonephritis, Osler nodes, Roth spots, rheumatoid factor
	Microbiological evidence: positive blood culture but does not meet major criteria or serological evidence of active infection with organism

	consistent with infective endocarditis
	Imaging: abnormal metabolic activity detected by PET or CT scan within 3 months of prosthesis placement
	Physical: new valvular regurgitation on auscultation, worsening of pre-existing murmur

Management of endocarditis is complex and relies on a multidisciplinary team response, including cardiologists, cardiothoracic surgeons, infectious disease specialist, radiologists and neurologists. Treatment often requires combination therapy with a prolonged duration (depending on the location of vegetation and whether the valve is prosthetic or natural). Right-sided endocarditis usually involves a lower density of bacteria and therefore often requires less aggressive treatment (26).

The most common route of bacterial entry for children are dental causes, such as suboptimal oral hygiene, followed by ear, nose and throat entry points (sinusitis, angina, and otitis), as well as through the skin. The most frequent bacteria involved is Streptococcus (2). A paper looking at the dental causes of bacteraemia involved obtaining blood samples from anaesthetised children immediately after a range of dental procedures (27). Whilst all procedures produced bacteraemia, an intra-ligamental injection did so 96.6% of the time, highlighting the risk of this type of local anaesthetic delivery method. Other significant procedures included scaling (40.0%) and polishing teeth (24.5%), rubber dam (29.4%) and matrix band placement (32.1%), single (38.7%) or multiple extractions (50.9%) and raising a mucoperiosteal flap (39.2%). Toothbrushing caused bacteraemia in over a third of the cases. This is significant when making decisions about the relative risk of dental procedures, as seen by the changes in guidance.

The National Institute for Health and Care Excellence (NICE) guidelines had, from 2008, recommended that 'Antibiotic prophylaxis against infective endocarditis is not recommended for people undergoing dental procedures.' Justification for this included the prevalence of bacteraemia from simple, daily activities such as toothbrushing, poor association between IE and prior interventional procedures, and the lack of efficacy of antibiotic prophylaxis. However, since the drop in prophylactic antibiotic prescriptions, cases of IE started to rise (28). This global increase was not well understood but prompted a review of the guidelines. The revised NICE guidelines which followed in 2016 were different in that antibiotic prophylaxis was not 'routinely recommended', resulting in the need for case-by-case risk assessment and discussion between dental and cardiology teams (29).

The Scottish Dental Clinical Effectiveness Programme provided implementation advice in 2018. In this document, they introduced a 'Special considerations' sub-category amongst those at increased risk of infective endocarditis. This subcategory included patients with any cyanotic CHD, patients who have had a prosthetic CHD repair in the last 6 months, or any CHD patients with residual shunt or valvular regurgitation. For these children, it is recommended that the cardiology consultant, surgeon or local cardiology centre should be consulted (25).

1.3 Dental access

Access to dental care may also be difficult for children with CHD. The literature repeatedly shows lower numbers of children with CHD having access to a GDP, compared to their healthy counterparts (30) (31). Whilst it is important for health care professionals to reinforce early prevention and promote the importance of good oral hygiene in this cohort of children, parents play a fundamental role as their primary care providers. It is therefore important to consider parental knowledge and attitude and its influence of the child's oral health and behaviour. A study in Leicester that assessed parental knowledge of children with CHD through a series of questionnaires surprisingly revealed no difference in the dental health of those registered with a GDP and those who weren't, although a significant improvement in knowledge was reported if the child was registered with a dentist, emphasising the importance of early access to care. 37% of the parents were unaware of the crucial link between dental and cardiovascular health, namely infective endocarditis (32). An American paper explored potential reasons for parents not registering their child and reported the most common reason was that parents felt that their child wasn't old enough to have dental needs. Other reasons were fear due to their child's heart condition, and dentists refusing to see the child (30).

General dental practitioners (GDPs) were sent questionnaires to explore their confidence in treating children with medical conditions. GDPs were generally very willing to provide preventative advice for all medical conditions, ranging from 88% in patients with haemophilia, to 95% in children with epilepsy. When looking at CHD, 94% were willing to provide preventative advice, 83% restorations under local anaesthesia and 62% extractions under local anaesthesia. It should be noted that the willingness did not necessarily reflect on confidence, with only 37% feeling 'very confident'. In fact, most dentists (80%), expressed a desire for further training, either in the form of seminars, courses or guidelines (33).

As a result, this can present as barriers in the child not only getting tailored preventative advice, but can result in potentially avoidable referrals to specialist services for simple restorative or exodontia treatment. With the current lack of specialised dental facilities, this can lead to unnecessary delay to treatment. The British Society of Paediatric Dentistry (BSPD) estimates the need for one specialist in paediatric dentistry per 20 000 children, but at present the ratio is 1 per 250,000 (33) (34). Furthermore, barriers can arise from these children not being registered with a regular dentist, or a lack of coordination among different community health care professionals (21). A retrospective study, conducted using data from Glaswegian children attending the Royal Hospital for Sick Children between 2002 and 2003, looked into their oral care habits and dental experiences. 73% of these patients were registered with a General Dental Practitioner or were being seen in Community Dental Services, 5% were being seen by a specialist and 21% were not under anyone's care for regular check-ups (35).

To help overcome this barrier to dental care, standards have been formulated to promote and enable easy access to secondary and tertiary care.

1.4 Current standards

The Congenital Heart Disease Standards and Specifications (CHDSS) was introduced in May 2016 with immediate effect. This document contains recommendations for CHD services in the UK. It was collaborated by NHS England using input from clinicians and patients from units across the nation. Of importance to dental care professionals is 'Section M- Dental', which outlines standards for dental care, as reproduced in Table 2 (36). These standards help provide a streamlined service for children with CHD to optimize their dental care and covers prevention as well as dental screening for these children. Emphasis is placed on liaison between the cardiology and dental teams to ensure that children can access the appropriate dental care, whether for screening or for treatment.

Table 3: Dental standards released by CHDSS

Evidence based preventative dental advice must be given to patients and their parents/carers at the time of diagnosis by the cardiologist or nurse.
Cardiology centres must ensure dental treatment is addressed prior to referral to the interventional or surgical team. Any pending treatment should be highlighted and included in the referral.
Patients with increased risk of infective endocarditis should be referred to a paediatric dental specialist at the age of two and have a specialist- led paediatric follow-up.
Congenital Heart Networks are required to have a clear pathway to refer patients for urgent dental care should they present with infective endocarditis, pain, acute infection or trauma.
Any child admitted and diagnosed with infective endocarditis must receive dental assessment within 72 hours.
Cardiology centres must provide access to theatre facilities for the specialist dental team, along with the relevant anaesthetic support OR refer the patients to a Specialist Children's Surgical Centre.
Should local dental services not be able to provide care, cardiology centres must refer these children onto hospital dental services

2. Study Aims

2.1 Aims

- To explore compliance of children in Yorkshire with congenital heart disease, born subsequent to the implementation of the Congenital Heart Disease Standards and Specifications (CHDS) 2016.

2.2 Objectives

- To explore compliance in referring children at increased risk of infective endocarditis for specialist dental screening at the age of two years
- To explore the barriers to care as perceived by specialist dentists and the cardiology team

2.3 Outcomes

Primary outcome: to measure compliance with the CHDSS:

"Patients with increased risk of infective endocarditis should be referred to a paediatric dental specialist at the age of two and have a specialist- led paediatric follow-up."

Secondary outcome: to explore barriers, as perceived by paediatric dentists and cardiologists, preventing full compliance with CHDSS.

3. Permissions and approvals

The study was divided into qualitative and quantitative aspects.

In order to access cardiology and dental notes for quantitative data collection, Trust approval was obtained from the Leeds Teaching Hospital Trust (LTHT). Furthermore, a Caldicott Letter was granted from the LTHT Deputy Caldicott Guardian to allow information to be collected, processed and used externally (Appendix 1).

Access was provided to patients' dental notes across Yorkshire and The Humber dental services. This included Leeds, Rotherham, Harrogate and District, Hull and East Riding, Mid Yorkshire, Bradford and Sheffield Community Dental Services, Leeds Teaching Hospital Trust, and Sheffield Children's Foundation Trust. Services were thus contacted to register the project locally, as per the trusts' requirements. Data were anonymised using participant numbers and transferred using a secure NHS.net email, to maintain security and confidentiality.

Permission was provided by the School of Dentistry's Dental Research Ethics Committee (DREC) to contact consultant and specialist paediatric dentists, cardiologists, and cardiac nurse specialists for virtual interviews (Appendix 2).

This research project took place during the Covid-19 pandemic. Unfortunately, the pandemic had led to the backlog of research projects waiting for an NHS ethical approval. As NHS ethical approval was required for parental interviews, we unfortunately had to omit this from the project and proceed with DREC approval to interview the dental and cardiology team.

4. Methodology

In order to investigate the dental health experience of children with congenital heart disease, born subsequent to the implementation of the standards, quantitative data were collected regarding their dental journey. In addition, to understand the perceived barriers to the standards being achieved, qualitative interviews were conducted to explore both the cardiac and dental teams' views.

4.1 Quantitative data

4.1.1 Sample

Patients were selected retrospectively from the Leeds Cardiology database, containing a list of all children registered with congenital heart disease. The standards, which were introduced in 2016 are applicable to children from the age of two years, therefore the sample includes children born after 2014. Data were collected until a sample of 50 subjects meeting the inclusion criteria was achieved. Electronic medical records were used to identify whether the patient met the inclusion and exclusion criteria below.

4.1.2 Inclusion criteria

- Aged 2-7 years
- Registered with Leeds Cardiology Team
- At risk of infective endocarditis (any structural congenital heart defect, excluding isolated atrial septal defect, fully repaired ventricular septal defect or patent ductus arteriosus)

4.1.3 Exclusion criteria

- Live out of Yorkshire and Humber area

4.1.4 Data collection

All cardiology notes and clinical letters were accessed through electronic medical records, including the specific cardiology records, which contained all clinical notes, letters and

operations. Data collected included the patient's postcode, age at registration, cardiac diagnosis, and whether clinical notes mentioned that a dental referral was made (Appendix 3).

Patients were divided by postcode to their closest dental service. A secure NHS.net email was sent with patient name, National Health Service (NHS) number and date of birth to dental representatives from each of the dental services to conduct data collection. Dental notes were accessed by the internal data collector to check whether the child was registered and seen by a specialist in paediatric dentistry (Appendix 4).

All patients were allocated a participant number so that populated data collection forms could be emailed back anonymously. The reason for referral was also explored to ensure the child was referred specifically for a dental screen, as per the standards and specifications, and not for other reasons (e.g., specialist treatment or pre-cardiac surgery assessment). All patient identifiable information was stored with password protection against unauthorised access and processing.

4.2 Qualitative data

4.2.1 Sample

In Yorkshire and The Humber, specialists and consultants in paediatric dentistry attend a Local Paediatric Specialist Dental (LPSD) forum. An email was sent from the secretary of the LPSD forum to recruit specialists and consultants for interviews. Cardiologists and cardiac nurse specialists were recruited through an email from the cardiology clinical lead to recruit volunteers.

Participant Information sheets were sent out along with the emails (Appendix 5). Subjects would then email directly if they were interested in participating in the interviews and were given an opportunity to ask questions before signing a consent form (Appendix 6) for participation, up to the point of data transcription and analysis, which was outlined in the Participant Information Sheet.

4.2.2 Inclusion criteria

- Specialists and consultants in Paediatric Dentistry, Cardiac nurse specialists, Cardiologist consultants

- Working in Yorkshire and Humber area

4.2.3 Data collection

Subjects would email directly if they were interested in participating in the interviews and were given an opportunity to ask questions before signing a consent form for participation and audio recording. Researchers were responsive to withdrawn consent throughout the interview, up to the point of data transcription and analysis, which was outlined in the Participant Information Sheet.

Semi- structured interviews were conducted using the theoretical domains framework to identify and describe current behaviours and barriers. All interviews were undertaken with the help of topic guides (Appendix 7) on Microsoft Teams, at a mutual convenient time. At the start of each interview, participants had the opportunity to ask any questions, and consent was reconfirmed. Interviews lasted between 15 and 30 minutes and were all recorded with consent.

4.2.4 Analysis

All interviews were transcribed verbatim and anonymised by the chief investigator. This was followed by data familiarisation with the transcripts. N-vivo coding software was used to code all transcripts. Thematic coding was conducted independently by the chief investigator (YY). Ten percent of transcripts were then coded by the second investigator (JO) and any discrepancies were discussed until resolution. A phenomenological approach was used to analyse the data to formulate an in-depth description, or essence of the experiences of the clinicians.

A combined inductive-deductive semantic approach was used to analyse the qualitative data. Themes were discussed and refined with the research team.

5. Results

5.1 Quantitative Results

122 patients were analysed by the cardiology database until 50 patients were selected who were at increased risk of infective endocarditis (Appendix 8). These patients were divided, based on their geographical area, into the following dental service catchment area (Table 3).

Table 4: Distribution of children amongst different CDS

Area	**Number of patients (%)**
Leeds	14 (28)
Rotherham	8 (16)
Harrogate and District	10 (20)
Hull and East Riding	4 (8)
Mid Yorkshire	4 (8)
Bradford	6 (12)
Sheffield	3 (6)
Dewsbury and Halifax	1 (2)

The children's ages ranged from four years and ten months to seven years nine months. The mean age was six years and zero months.

Medical notes stated that four of these patients were planned for referral to a specialist for dental assessment: two in Leeds, one in Bradford and one in Hull. Dental notes for these patients revealed that of these, only three were actually seen by a specialist dentist (Table 4). None of these were seen for a two-year screening.

Table 5: Patients referred by cardiology and seen by specialist dentist

Area	Age	Referred by	Reason for referral	Grade of dentist	Time taken to be seen	Outcome
Leeds	3 years	Cardiac	Pre cardiac surgery	Consultant	5 weeks	Discharged
Bradford	2 years	Cardiac	Caries in teeth	Specialist	4 weeks	XGA
Hull	5 years	Cardiac	Pre cardiac surgery	Consultant	3 weeks	Leeds XGA

Unfortunately, permission was not granted for access to dental notes in Dewsbury and Halifax, reducing our sample to 49. Of the remaining 46 children, five were registered with a specialist dentist (Table 5).

Table 6: Patients seen by specialist dentist

Area	Age	Referred by	Reason for referral	Grade of dentist	Time taken to be seen	Outcome
Leeds	4 years	Cardiac	Pre cardiac surgery	Consultant supervision	0 weeks	Discharge to GDP
Hull	4 years	Cardiac	Pre cardiac surgery	Consultant	1 week	Discharge to GDP
Doncaster	5 years	Cardiac	Pre cardiac surgery	Specialist	6 weeks	Leeds XGA
Bradford	5 years	Key worker	Dental caries	Dental officer	4 weeks	Leeds XGA
Bradford	2 years	Cardiologist	Dental assessment	Specialist	0 weeks	Review

From the 49 patients audited, only one patient (2.04%) was referred for a dental assessment at the age of two years old. The assessment was arranged in the same week as the cardiologist consultant's referral. They were dentally fit at the time of dental assessment, and the patient was kept under specialist review.

5.2 Qualitative Results

In total, three consultants in cardiology, three cardiac nurse specialists, four paediatric dental specialists and nine paediatric dental consultants were interviewed from across Yorkshire. Five core themes appeared to describe the experience of the children, as perceived by the cardiologist and dentists:

- Clarification of current standards
- Clinical priority for referrals
- Challenges with the current referral process
- Organisational barriers' impact on referrals
- Value of communication

Quotes are either from a dental consultant (DC), dental specialist (DS), cardiac nurse (CN) or cardiac consultant (CC).

5.2.1 Clarification of current standards

In general, the clinicians were aware of current guidelines, however there were mixed opinions on whether they were appropriate. For example, some of the dental clinicians agreed with the standard that the children should be referred to specialists and consultants for a dental screening.

> *"We obviously recognise that this is a standard and the importance of it… I think it's important to get those preventative messages across, especially because a lot of these families have quite a lot going on with lots of appointments and maybe children are sometimes over indulged."* (DC1)

> *"If you can get that prevention side up and running from an early stage, you're going to make them more stable into the future. Perhaps compared to a GDP, we have a bit more time and we see these patients more frequently, so perhaps we can get that message across a bit better".* (DS2)

However, an area of uncertainty was whether it should be specialists and consultants in paediatric dentistry that should screen the child, as it was deemed that other members of staff could provide this service. Some participants questioned the wording used around 'specialist-led paediatric follow up'. They were unclear as to whether specialist and consultants in

paediatric dentistry were required to routinely follow up the patient and if this was best practice.

> *"I think that certainly all the preventative doesn't need to be given by a specialist in paediatric dentistry and I also don't think you need to be specialist or consultant in paediatric dentistry to examine and diagnose caries…I'm not convinced by that, but maybe that's the only way to ensure it happens."* (DC1)

> *"I don't even know what we do with them afterwards. If they were dentally fit at that stage, would I then move them onto a flexible commissioning practice, or would I send them back to the family practice and write to them? Maybe [flexible commissioning practices] should see all those children and then refer them in if needed, because where do they go after they've seen us? Do we keep them on?"* (DS3)

> *"I don't see the benefit of seeing them every three months as a specialist. I wouldn't want to keep them within the service. Unless there was another reason, like they had autism or something like that*." (DS2)

A point argued by two of the dentists, was the significance of the age of two. They felt that it didn't align with existing published dental guidance and could be simplified.

> *"I think it's quite a specific age group that doesn't necessarily relate to anything. So, I guess it's maybe meant to relate to the fact that their primary dentition would be almost complete, but it doesn't really make sense in terms of the 'Dental Check by One', which is aimed at all children. So, are we saying that all children should be seen by age one? But children at risk of infective endocarditis should only be seen by a specialist at age two? I think it would have made more sense to me to tie those things together and say, you know, all children should have a dental check by one, but children with these specific medical conditions should have a dental check by one with a specialist or consultant or level 2 dentists."* (DC9)

From the cardiology team's point of view, there was a general agreement that the standards were important in preventing issues down the line, particularly in relation to the pre-surgical assessment aspect of the standards. However, not all the cardiologists felt this was their duty and felt that the onus should be on the dental team to arrange this.

> *"You see the results when it comes to us listing them for surgery and it's a sort of mad rush to try and get them assessed and of course if they were already seen and sorted that wouldn't happen anymore."* (CC2)

"From a personal point of view, I think that making it the responsibility of the cardiologist when this is a non-cardiac aspect of care, puts too much onus on the cardiologist. I think it should be on the wider team…" (CC1)

5.2.2 Clinical priority for referrals

When discussing the triaging of referrals, there was agreement amongst the dental professionals that they were willing to accept these patients once they have been referred by the cardiology team. Most clinicians agreed that they should get a high priority. This was reflected in the results as reported by the nursing team, who were impressed with the rapid turnover.

"I put any medical patient as urgent. I'd say every single medical patient is seen within a few weeks." (DC3)

"I know the pandemic has caused them to prioritise our patients even more." (CN1)

"The response to the referral seems to be really quick. It's fantastic. Sometimes you might ring somebody at 9am in the morning and they don't answer, so you leave a voicemail saying you'll call them back. You think 'I'll just get on and do my referrals'. By the time you ring them back again in the afternoon the mum's like 'oh yeah. I had a dentist ring me!'. Like, it can literally be a matter of hours. And they're usually seen within, like a couple of days. So, the response is usually really, really, quick." (CN3)

However, it was acknowledged by the dental team that this would have a knock-on effect on other patients on the waiting list, which was a cause for concern. Dentists expressed that it would make them more confident, and they would find it easier triaging the patients as high priority if more information as provided in the referral that would justify the patient having outstanding dental treatment needs. Two consultants felt that as a result of this, they would not be happy to give these children high priority if they were thought to be free of dental disease. Priority instead should be given to those needing a surgical pre-assessment.

"We've got a very long waiting list at the moment and these children would obviously be prioritised and we do that… But that's at the detriment of the P4s that get pushed down the waiting list." (DC1)

"I think the emphasis is really on the pre-surgical patients. I think that any children

coming to us who are at risk of infective endocarditis and already have a dental treatment need are prioritised as urgent. I think a screening probably wouldn't be prioritised as urgent because there is no identified treatment need there… at the moment it means they would be waiting 6 months plus." (DC2)

Despite, this, one of the consultants raised concerns regarding numbers if the standards were to be implemented more robustly and there was an influx of referrals.

"I think we would actually really struggle. For one, I don't know how many patients that would involve." (DC9)

The cardiology team on the other hand gave the referrals lower urgency as arranging dental access wasn't considered a medical priority during the appointments. This was also echoed by one of the dental consultants who also felt that this was the perception. But this didn't reflect the importance of dental care as a whole, as deemed by the cardiac team. Many of the consultants and nurses stressed how they would spend time emphasising the link between infective endocarditis and dental health at all appointments.

"I just think there are too many other things on… we don't have time to really address anything that isn't obviously a real issue in that moment. It's sad but it's true." (CC2)

"Other medical specialities don't always see dental as priority but when you do get that one case where dentistry has been missed, the implications of that are huge." (DC4)

"Dental hygiene and endocarditis: every single clinic I go through it… and you can see some of them glaze over with utter boredom 'off he goes again'. I've seen an eight- year-old die from that, and it just frightens the living daylights out of me. And if we can stop somebody going through that, I think that's brilliant." (CN1)

5.2.3 Challenges with the current referral process

Amongst the dentist and the cardiac nursing team, there was a general consensus that the referrals were not being completed and this was reflected in the low numbers being seen by the specialist and consultants on clinic. Only one consultant said they were routinely getting these, and this was considered as a result of an allocated paediatrician working in the area. The importance of a specified individual to do the referrals was echoed within the cardiology team, who felt the low referral rate may have been due to a lack of clear delegation. There was no set guidance on who should be expected to do a referral between the cardiologists and the

cardiac nurse specialist.

"I'd say the majority of [referrals] would be dental preassessments prior to surgery, but I have started to see a few more where the child doesn't have a dentist and needs dental input. But I don't think we're receiving every single child that's at increased risk of infective endocarditis. I haven't specifically noticed that there's been lots of two- year-olds referred." (DS2)

"I think we've got quite a bit of set up in [our area] and the paediatrician with a cardiac special interest is very good at having on her checklist 'dental'. We're getting a good number in either coming from the paediatrician with special interest or from the specialist cardiac nurses. And they're not just the ones that need surgery. It's the ones that also just need a dental review." (DC4)

"I think it's a team responsibility because we don't always have the cardiac specialist nurses with us." (CC2)

The nursing staff were confident in how to do the referral and found the use of a standardised form (Appendix 9) very useful in ensuring quick and easy referrals. However, the cardiologists weren't confident in knowing how the referral process works. The dentists in general also appreciated the use of the same proforma. However, one of the specialists found the layout of the form difficult to read.

"I'm not really sure [how the referral works], to be honest with you." (CC2)

"We've just within the last kind of six months had the standardized referral form. So that all the specialist dentists accept the same form. From my perspective they're really quick and easy for us to fill in and actually they don't ask us for that much information." (CN3)

"I do a lot of referrals… if someone hasn't seen a specialist dentist or definitely isn't you know kind of seeing any dentist I would always refer them in…I think I don't mind [doing referrals]. We're happy to do it. And I do feel like as part of our role when we're in the clinics, we kind of pick up the referrals and do the referrals…I feel like it's our responsibility. Because it's spread between the team, it doesn't seem like such a big undertaking." (CN2)

"I think if you're looking at the same proforma every time, it makes it quicker and easier to pick out the information, how urgent it needs to be." (DC4)

"I don't like the new form if I am honest. I think it's really difficult to extract information on it. Visually for me, the new one is incredibly busy and it's not always clear." (DS3)

A difficulty that was echoed amongst the cardiac nursing team was knowing which dental service to refer to, especially when children are on the border between two areas. Nurses appreciated being directed to the appropriate service, rather than having referrals bounced back.

"So the problem my colleagues have had is knowing who to refer to. Some of the referral places would just bounce them back and say that they've been sent to the wrong place… It's sometimes quite difficult to just simply find out where to send them and the referrals can bounce around quite a bit trying to find the right places. It's really frustrating. In other places, they'll forward it on to the right place and that's really helpful." (CN1)

On the other hand, the major barrier for the cardiac consultants doing the referrals was considered to be insufficient time. This was quoted by both the consultants and the nurses, who appreciated this difficulty.

"I have to see 20 patients in a day, if not more. So that gives you a maximum of 20-minute slots in which you have to see how they are, listen to parents' worries, do the scan and then give them advise. So, I have one minute at most to talk about the teeth, which I will. But then after that it's a lot of extra work to do the referrals. So, if it was something like more automatic like I could press the button and then the referral is made, I would do that." (CC2)

"I'm not sure the consultants would get around to them very quickly, because it's got to be on specific forms rather than it just being a letter that goes that you could copy." (CN2)

5.2.4 Organisational barriers' impact on referrals

It was generally acknowledged that amongst the cardiac team, the consultants relied heavily on the nurses to do the referrals. The cardiologists tend to liaise with the clinic's allocated nurse to arrange the referrals to the specialist paediatric dentists. The major issue with this was thought to be the lack of nursing staff on clinic, especially at the main site. This meant there were concerns as to whether there was someone to contact for the outstanding referrals. The team explained that this barrier could be overcome by remote availability of the

nurses.

> *"It happens with our cardiac specialist nurses rather than us. They're very, very diligent at referring every patient at around the age of two to the dentist…There are lots of clinics where we don't actually have support"* (CC2)

> *"It's usually the cardiologist asking if we can refer the patient. It's just one of those jobs that you get a list of names that you've got to refer on to. They just come and give it to us… they wouldn't do the referral; they would just pass it to us to do. We do get some consultants who will maybe drop us an email saying, 'Can you refer so and so to a dentist?', but they're quite few and far between and I'm quite sure they see a lot more children than what they do email through."* (CN3)

Another significant barrier that was discussed was the difficulties in accessing dental care. This was a problem that the cardiologists picked up on, where some children were unable to get routine care with their general dentist. Following on from the lack of dentists in the region, a large portion of the paediatric dentists voiced concerns over the distance that parents had to travel to obtain specialist services. This was thought to increase the already existing burden of care, and many wished for a more streamlined service where visits could be more local and if the patient required travelling to the dental hospital, could be conducted on the same day as other medical appointments.

> *"I have patients where I say they need to see a dentist and then they come in a year and say that their dentist refused to see them or something. It really varies what happens to them depending on their postcode."* (CC2)

> *"But of course, there's such a limited number of specialists in the country, we don't want to throw the baby out with the bathwater by making these children wait longer just because they need to be seen by a specialist…I still don't think there are enough specialists and I think its ridiculously difficult for people to get into specialty training. And I think it's a lot of pressure as a specialist myself, a lot of my spare time goes into doing my job… They need to address the workforce issues*." (DS3)

> *"To be honest, coming to [dental appointment] is a real challenge for our patients. Parking, just the ease of coming here. We've had conversations with patients from outside of the area who have said they can't afford to come because it's too expensive."* (DC3)

"So that does hinder their ability to come to appointments when they should. The other issue is location for some of these parents, there could be pockets of areas where there isn't a paediatric dentist specialist that can see them. Because our cardiologists are dotted all along Yorkshire in district generals. So, I feel that unless they can get to a specialist in the area, to come all the way here for an appointment is difficult. I think that it would be a good idea to have the appointments on the day, so if they see cardiac in the morning, that they see us in the afternoon." (DC8)

Expanding on the lack of specialists in the region and their scepticism regarding the standard's need for a specialist to screen these patients, dentists felt that the wider dental team could be utilised. Furthermore, the specialists recommended oral health educators, including hygienists and nurses, to provide the preventative advice to help ease pressure off the dentists.

"I think it's about maximising skill mix, and I think that certainly all the preventative advice and everything doesn't need to be given by a specialist or consultant in paediatric dentistry. It's probably better given by oral health educators. And I don't think you need to be a specialist and consultant to examine and diagnose caries… We've got Level 2s and I think the Level 2s are perfect to see the kids because they're under the supervision of a specialist anyway." (DC1)

"I'd be really confident actually that any of the Level 2 dentists that have become accredited via that programme have had the necessary information and teaching that's required so that they would be able to do a robust assessment…If the focus is on getting preventative advice at age two, then it could be done by a dental therapist, a dental hygienist and a dental nurse who has done their oral health educator qualification." (DC9)

5.2.5 Value of communication

Unsurprisingly, a lot of emphasis was placed on the communication within the process. In general, the cardiac nurses were grateful for the responsiveness of the dental team when queries were raised and felt that the existing link between the two departments contributed to this. This was confirmed by the dental consultants, whereby they were happy to be approached for any queries.

"The number of times I've got in touch [with the dental team] just to say I'm struggling with this or that, they're just brilliant. I can just send [the dentist] an email and I just know it's going to get sorted... It's a really nice system in that if you're concerned about

somebody and you're not sure what to do, they would just help you. That's good." (CN1)

"Obviously, there's consultant to consultant communication, so in a situation where there's a worry about a patient, we'll be happy to receive an email." (DC3)

Where there was not a robust link between the two services, this was highlighted by the dental consultant, who felt it would be beneficial to the whole process. Not only was it felt that this would improve the rate of referrals, but also to help plan their dental care.

"So, I think it is up to us specialist services in the hospitals to ensure that we've got a cardiac service set up in liaison with the cardiac teams. I would just add that for me as a clinician, probably the most difficult thing is the communication with the information that we have for patients… when you start prepping [the children] for theatre, that's when more information comes out and trying to find out who to contact and who can answer questions can be tricky. So, for me at a clinician point level, the communication is probably the difficult thing and trying to get timely answers." (DC4)

"I think communication is the main one. Letting us know that there is a patient to be seen. I think that is the issue. And that is probably one of the reasons, I would say, it would be a good idea for when the GP knows, we know. And we can make the appropriate arrangement to see them. Or arrange for someone to see them if they are unable to travel in." (DC8)

6. Discussion

6.1 Findings

6.1.1 Quantitative Findings

The aim of this study was to explore the dental health experiences of children with congenital heart disease in Yorkshire. This study revealed that children at risk of infective endocarditis were not routinely being referred at the age of two for assessment with a paediatric dental specialist, despite the release of the CHDSS. The majority of children (97.96%) were not referred.

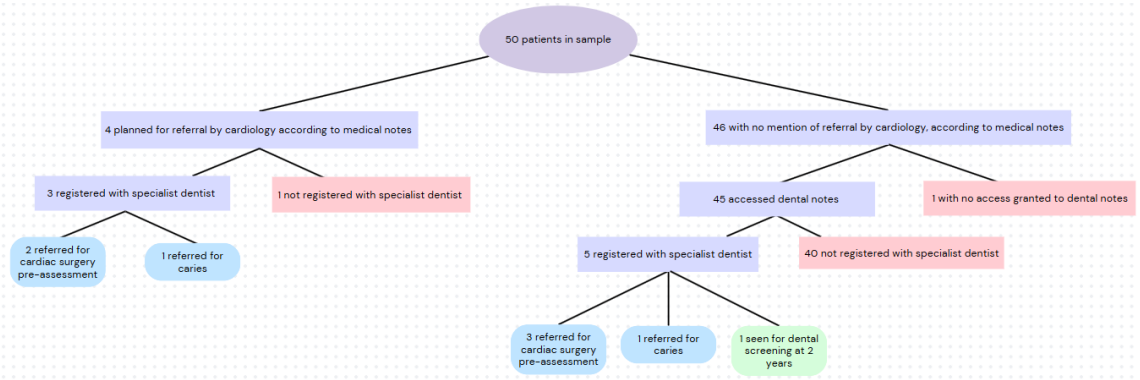
When accessing medical notes, only four of the fifty patients were planned for dental referrals. In reality, only three were seen by a specialist. Of these, two (aged three years and five years) were referred for a cardiac preassessment, which showed promising collaboration for this cohort of patients as per the standards (22). The remaining child (aged two years) was referred for existing dental caries that was noted at the cardiology assessment. This emphasises the important role the cardiology team, as a routine point of contact, plays in reiterating dental health. Ideally this child should have had access to a dentist to have picked up the dental caries in a timely manner. For a child to have presented with obvious dental caries during a cardiac assessment would usually indicate that the caries is extensive, and again stresses the importance of the standards in ensuring that these children are screened dentally and given timely preventative advice.

Dental notes revealed that five further patients from a sample of 49 were referred to a specialist in paediatric dentistry. The lack of documentation in the medical notes may make it more difficult for referrals to be followed up, thus affecting the urgency of outcome. Of these patients, one was referred by the child's key worker. This uncommon pathway most likely indicated that they were not registered with a dentist. If the child was being seen regularly by their cardiologist, it would be expected that they would be asked about dental access and dental problems as part of their cardiac appointment and hence this would provide an opportunity for a dental referral. This same child was then seen by a dental officer. Whilst the standards specifically request that a specialist screens children at the age of two and before cardiac surgery, there is no clarity as to who is required to provide dental assessment and treatment for a routine caries management in a child at increased risk of infective endocarditis. Three of the patients (one aged five years and two aged four years) were, again, referred for pre-cardiac surgery assessment, which was reassuring for reasons discussed

above. Only one was referred for a dental assessment at the age of two, in line with the study aims. However, it should be noted that the referral was done by a cardiologist consultant with a special interest in the topic.

All eight children were seen within 6 weeks of referral, alluding to high clinical priority given to cardiac patients.

Figure 1: Flow diagram of referral pathway of patients in sample



6.1.2 Qualitative Findings

A combined inductive-deductive semantic approach was used to analyse data from the interviews. The use of a framework during interviews resulted in an initial deductive approach, but additional data during the interviews generated an inductive method, in addition. The core themes reflect the barriers to referrals being made and can help explain why so few children were screened by a specialist dentist within the Yorkshire and Humber area.

Participants felt that some clarification of the current standards was required. A systematic meta-review by Francke et al revealed that the complexity of a set of guidelines was the predominant barrier in its implementation (37). Although there was good knowledge of the cardiac standards, there was some confusion as to whether the standards required consultant and specialist continuation of care. Some participants mentioned the standards didn't align with current guidance, such as the Dental Check by One (38), which is a BSPD driven campaign that encourages collaboration with health care and educational organisations to improve dental access for all children by their first birthday. With a current drive to get children registered with a GDP, it may be beneficial to reconsider the age of referral to a specialist dentist, or to encourage GDPs to get involved with the standards. The latter point was also recommended by one of the cardiologists, who felt the duty lay with GDPs and not cardiologists. However, at present, the level of registration in England is very low with 2019

results showing 11.7% attendance rate in children under the age of two years (39). It may therefore be more feasible if the referrals were made by the cardiology team, who are likely to be the health care professional seeing the child the most routinely and therefore best placed.

Some participants discussed the high clinical priority of the referrals. This was supported by the quick turnaround from referral to new patient assessment of the ten children that were seen by the dental teams in the region, although this looked at all cardiology referrals, not specific to two-year-old screenings. The knock-on effect on other children on the dental waiting lists was a cause for concern, and clinicians felt more confident giving the cardiac cohort higher priority if they knew they had active disease. As a result, the referral process may benefit from the cardiology team checking inside the mouth for obvious active disease before referral. A study in Catalonia exploring the knowledge and attitude of paediatricians towards dentistry revealed a promising 86.82% of clinicians conducted an oral examination in a routine visit, whereas 4.65% would only do so if the patient reported pain (40). This compliments the Mini Mouth Care Matters initiative, approved by BSPD, that encourages health care professionals working in hospital to 'lift the lip' to assess intraoral tissues for any sign of disease (42).

Some of the challenges with the referral process included the lack of time and pressure to do the referrals during the consultations. In Francke's meta-review (37), the need for additional resources was another aspect assessing the complexity of a set of guidelines. Whilst time was clearly a significant obstacle for the cardiology paediatricians, the physical process of form-filling was deemed simple and streamlined by the cardiac nurses.

A lack of delegation meant that there was no clarity as to who was expected to do the referrals. Accountability has been shown to be an important factor when implementing guidelines (43). The nurses were happy to do the referrals, but it was not widely known and accepted that this was the expected pathway. An issue with this was the lack of nurses available on clinics to do the referrals, which was repeatedly brought up by participants. Although not explored within this study, potential reasons for a lack of nurse availability could be recruitment, funding and retention. A systematic review of 48 studies worldwide explored recruitment and retention of nursing staff. Multifactorial challenges have been shown to be responsible, with work related stress and low job satisfaction a major contributor due to high demands and pressures on the job (44). This has undoubtedly heightened since the COVID-19 pandemic. However, in our study, the nurses showed enthusiasm for the referral process and were willing to pick up the work remotely, if contacted via email.

Although it was discussed previously that the specialists and consultants in paediatric dentistry were willing to accept the patients referred in, the existing lack of specialists (33) (34) meant that there was immense pressure on the specialists, increased waiting times, and increased distance patients had to travel. Common recommendations included Level 2 dentists doing screenings. Level 2 dentists are qualified dentists, that are further trained in a 24-month programme in Yorkshire and The Humber, to manage children with dental anxiety, and provide enhanced care for complex dental and medical conditions and trauma (45). Utilising their advanced skill set within the region could reduce workload and waiting times for specialists and consultants. These dentists will, however, need to be well supported by more experienced colleagues, should they need to escalate complex cases.

6.2 Strengths and Weaknesses

Children aged between two and seven years were included as these patients would have turned two years old since the release of the 2016 standards. Patients were selected retrospectively from 2016 to ensure maximum time for any referrals to be actioned at the dental services. Collecting data immediately after publishing the standards may mean that there was insufficient time to implement these standards.

Unfortunately, not all patient dental records were accessed. Permission was not granted in one of the services, and therefore one patient from our sample could not have their records accessed. This cohort may have shown better relations between cardiology and dental, although given the trend, this seemed unlikely. Additionally, patients' dental notes were accessed by contacting their nearest community dental service depending on their postcode. However, patients may have changed postcode meaning they would have been referred to a different service, or, they may have had reasons to opt to be seen by a different service. A more thorough method would have been to search for the sampled patients amongst all the dental services in Yorkshire and the Humber.

The perceived barriers were explored through interviews with paediatric dental specialists and consultants, as well as cardiology consultants and nurse specialists. Purposive sampling was used to ensure that interviewees could provide information rich interviews for good depth of understanding. Participants consisted of a mix of roles, who had a range of experience, and covered a wide geographic range across Yorkshire, representing both community services as well as hospital base. An open invitation amongst this group ensured equal opportunity to participate, thus eliminating the risk of researcher bias in selecting individuals. However, this

may have introduced nonresponse bias whereby only interviewees with a special interest in the topic may have been more inclined to volunteer their time for the research.

Individual interviews were conducted rather than focus groups, to give the interviewee the freedom to speak honestly, which may have been an issue if colleagues were in the same room. In addition, it was anticipated that individual interviews may give participants the confidence to express their opinions freely, which may have been an issue if they were in a room with more vocal or senior interviewees.

In terms of reflexivity, interviewees were aware that the interviewer (YY) was a paediatric dentist, so this may have influenced answers, such as the importance of dental care in cardiology. The interviewees also were aware of the purpose of the interview from the recruitment information leaflets and therefore may have influenced their answers on the understanding and importance of the guidelines. Furthermore, when coding, the chief investigator may have been more inclined to generate specific codes based on their own interpretation and experience of the guidelines.

Occasionally, individuals expressed opinions and experience that altered from the majority and contradicted the emerging themes. This was taken into consideration and discussed in the results.

A strength of this study was that we explored the views of both the dental and cardiac teams to ensure we covered the viewpoints of both the referring team and the dental team. However, this study does not explore the parental views of children at increased risk of infective endocarditis. These results could be valuable in exploring whether there are some patient or parent factors that might have influenced the low number of referrals. This is particularly important as one of the reoccurring concerns raised by both teams was the long-distance patients had to travel for the appointments, and the burden of care with the numerous medical appointments.

7. Conclusion

The standards were released with immediate effect in 2016. At the time of data collection and interviews, six years had passed, providing sufficient time for them to have been achieved. Fischer et al concluded that the act of publication and dissemination of guidelines does not automatically result in its use (46). This was evident by the results of our study. A structured implementation is required, by firstly exploring barriers which we have done in this study. Following this, the standards need to be adapted to the workplace, whilst taking into consideration the barriers. In general, there was a lack of delegation, collaboration and protocol that was echoed amongst the three different roles. The results of this study can therefore inform the development of the local referral pathway using the perceived barriers to help achieve the goals.

This study concluded that there was a low access (2.04%) to specialist dental care in children with congenital heart disease, at risk of infective endocarditis. Barriers to care as perceived by specialist dentists and the cardiology team revealed a lack of implementation of the standards. This can be addressed locally or on a national scale.

Locally within Yorkshire and Humber, access can be improved by introducing a Standard Operating Procedure to outline the pathway for referral from cardiology to dental. Delegation during the referral process needs to be agreed locally, with cardiology nurses likely to be the most appropriate team member to complete referrals. For children to be seen on time at the age of two years by a paediatric dental specialist, referrals need to be done in a timely manner. The two specialties should decide whether referrals are made as the child approaches the age of two, which could put pressure on the dental teams to give the child high priority at the expense of routine referrals, or if advanced notice is required. For example, when a diagnosis of congenital heart disease is made, the local paediatric dental team could be notified by being copied into the general medical practitioner letter, giving advanced notice for the dental team to organize their two-year dental screening. It may also be beneficial to standardize the level of priority a child should get for their dental screening. This could be improved by cardiologists checking the mouth for obvious active disease to help determine the triaging dental clinician as to the level of urgency.

Nationally, the CHDSS could also benefit from revision. One area is whether it is solely specialists that can provide the two-year screening or if well supported dental colleagues, such as Level Two dentists, can provide this. The standards also mention ‘specialist-led follow up’

for this cohort of children who are at increased risk of infective endocarditis. To help support dentists in decision making when it comes to their follow up, it would be beneficial if the standards could clarify what this means. If this requires specialists to provide all dental follow up, a decision may need to be made as to whether this is appropriate, given the backlog of children waiting to see specialists and consultants within the country.

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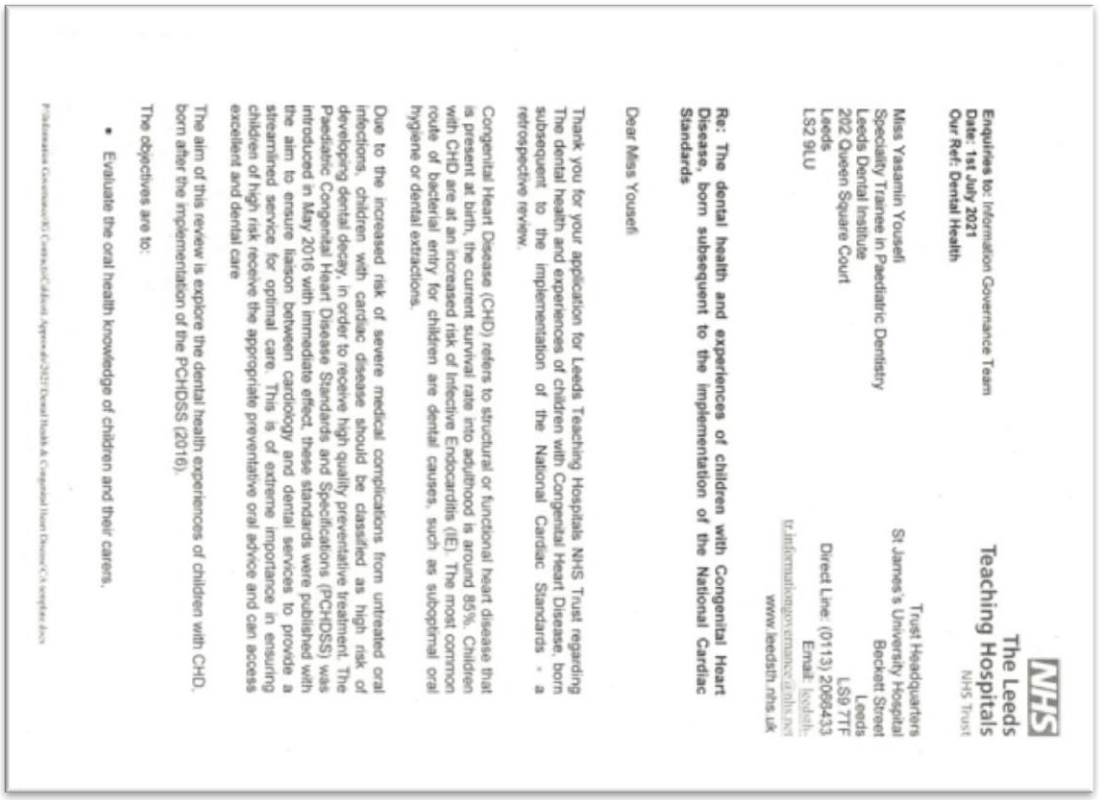
9. Appendices

Appendix 1: Caldicott Letter



NHS
The Leeds Teaching Hospitals
NHS Trust

Enquiries to: Information Governance Team
Date: 1st July 2021
Our Ref: Dental Health

Miss Yasamin Yousefi
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Re: The dental health and experiences of children with Congenital Heart Disease, born subsequent to the implementation of the National Cardiac Standards

Dear Miss Yousefi

Thank you for your application for Leeds Teaching Hospitals NHS Trust regarding The dental health and experiences of children with Congenital Heart Disease, born subsequent to the implementation of the National Cardiac Standards - a retrospective review.

Congenital Heart Disease (CHD) refers to structural or functional heart disease that is present at birth. the current survival rate into adulthood is around 85%. Children with CHD are at an increased risk of Infective Endocarditis (IE). The most common route of bacterial entry for children are dental causes, such as suboptimal oral hygiene or dental extractions.

Due to the increased risk of severe medical complications from untreated oral infections, children with cardiac disease should be classified as high risk of developing dental decay, in order to receive high quality preventative treatment. The Paediatric Congenital Heart Disease Standards and Specifications (PCHDSS) was introduced in May 2016 with immediate effect, these standards were published with the aim to ensure liaison between cardiology and dental services to provide a streamlined service for optimal care. This is of extreme importance in ensuring children of high risk receive the appropriate preventative oral advice and can access excellent and dental care

The aim of this review is explore the dental health experiences of children with CHD, born after the implementation of the PCHDSS (2016).

The objectives are to:

- Evaluate the oral health knowledge of children and their carers.
- explore the oral health experience of these children, including access to specialist care.
- explore barriers to care as perceived by paediatric specialist dentists.

Data will be collected from eligible patient records where there is a diagnosis of CHD, aged 2 and above, who were born after the 2016 PCHDSS. this will done via a retrospective records review and data collected by member of the direct care team. All data will be securely stored on the Trust network and only accessible by staff involved in this project. In addition to this, data will also be collected via questionnaires; these will be de-identified and fully informed consent sought from the eligible parent/guardian of the patient.

As no new or additional data is being collected, patient consent will not be required for the retrospective records review.

Results from this project will be shared with paediatric and cardiology teams across the Yorkshire region to help inform and improve future treatment pathways and care.

Miss Yousefi has demonstrated a clear understanding of the Data Protection legislation and Caldicott guidelines, understanding her duties to comply fully with the legislation during the collection and processing of Trust data/other organisations data.

I am happy to express my support for The dental health and experiences of children with Congenital Heart Disease, born subsequent to the implementation of the National Cardiac Standards project and wish Miss Yousefi well with her project.

Yours sincerely

Dr John McElwaine
Deputy Caldicott Guardian
Leeds Teaching Hospitals NHS

Appendix 2: DREC approval

Dear Yasamin

DREC ref: 110322/YY/347
Study title: Exploring the dental health and experiences of children with Congenital Heart Disease, born subsequent to the implementation of the National Cardiac Standards

Thank you for submitting the amended documents for the above study. The documents have been reviewed and I am pleased to inform you that the application has been approved by the Dental Research Ethics Committee (DREC).

Documents reviewed

Document name	Version number/date
Ethics application form	Dated 30.05.2022
Protocol	Version 1
Information sheet – Cardiologists	Version 1 09.03.2022
Information sheet – Paediatric Dentists	Version 1 09.03.2022
Consent form	Version 1 09.03.2022
Topic guide – Cardiologists	Version 1
Topic guide – Paediatric Dentists	Version 1

With best wishes for the success of your project.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, signed consent forms, participant information sheets and all other documents relating to the study, including risk assessments. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks' notice.
It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

For and on behalf of
Professor David Wood
DREC Chair

Appendix 3: Data collection tool for patient demographics, diagnosis and referral status

	A	B	C	D	E	F	G
1	Participant Number	Initial	Postcode	Age at registration (months)	Diagnosis	Medical notes mentioned?	Referred?
2							
3							
4							
5							
6							
7							
8							
9							
10							
11							

Appendix 4: Data collection tool for children who were referred to CDS

Participant number:

Postcode					
Age at diagnosis	months				
Diagnosis					
Dental advice given at diagnosis	Yes	No			
If yes, by:	Cardiologist	CNS	Unknown	Other:	
Registered with dentist	Yes	No			
If yes, with:	GDP	CDS	HDS	Unknown	
Last check up	0-3m	3-6m	6-12m	12m+	Unknown
Referred to specialist at 2y	Yes	No			
If yes, by:	Cardiologist	CNS	Unknown	Other:	
Date referred		Age when referred		months	
Date seen		Age when seen		months	
Time taken to be seen	weeks				
Dental review	Reason for referral: Diagnosis: Seen by (grade): Treatment: Outcome:				

UNIVERSITY OF LEEDS

Exploring the Dental Health and Experiences of Children with Congenital Heart Disease

INFORMATION SHEET

We would like to invite you to take part in an interview regarding the treatment of children with congenital heart disease.

Why ~~we are~~ carrying out these interviews?

We would like to hear your experience on treating children at risk of infective endocarditis. As specialists in paediatric dentistry, we would like to discuss what you think currently works well within your services, and what could be potential barriers to the children being referred for assessment and prevention. The interview would be in the format of a conversation. Anything you share with us is important and will help us to understand the way dental services could be delivered and organised to support the oral health care needs of children with congenital heart disease.

Why am I being asked to take part?

We are looking at the dental experiences of children at risk of infective endocarditis. With your help, we are hoping to improve the pathway from cardiac diagnosis to dental assessment, in line with the National Cardiac Standards.

What will happen to me if I take part?

If you agree to take part, you will be ~~contacted~~ and a convenient time will be arranged for the interview to take place remotely. We do need to ask you to sign a consent form if you are happy to take part, and you will be given a copy and this information sheet to keep in case you want to talk to us about the project at any time. Please note that you are not expected to participate during your working NHS hours.

The conversations we have will be confidential. With your permission, we would like to audio record the discussion, although this is not compulsory. Audio information gives a better understanding of conversations, and this will help us to reflect accurately what we discussed that day. The audio recording will be deleted after use. All of the information shared by the group will be securely stored at the University of Leeds and only the people directly involved in the research will have access to it.

Do I have to take part?

It is up to you to decide whether or not to take part; you can withdraw from the study at any time up until your interview has been written-up from the recording. When we do this all of the information that might identify you personally will be removed from the written record and your tape recording will be destroyed. If you agree to take part but during the interview you feel uneasy in any way or worried, you can leave at any time – you don't have to give any explanation – simply that you do not wish to go on. Even if you decide after the interview has taken place you can still opt out until it has been converted from recording to writing.

Email Contact: dnyhy@leeds.ac.uk

What will happen to the information collected at the group?

If you consent to take part, everything that you say will be kept confidential and the information collected about you will be handled strictly in accordance with the consent that you have given and also the 1998 Data Protection Act and 2016 General Data Protection Regulation. Your full name will only be included on your consent form that will be stored at the University of Leeds.

What will happen to the findings of this study?

Once the study has been completed, a report will be written based on the findings. You may, if you wish, have a copy of this report to read for yourself. We will publish our findings in professional and academic journals. You will not be personally identified in any report or publication.

Who is organising and funding the research?

The interviews are being organised and completed by staff at the Paediatric Dental and Cardiology departments.

Who has reviewed the study?

The study has been reviewed by the University of Leeds Dental Research Ethics Committee to protect your safety, rights and dignity. The groups are supported by funds from the University of Leeds Health Sciences Innovation Hub.

What do I do if I have concerns?

If you have any concerns, please feel free to contact us on the details below.

How to contact us for further information?

Thank you for reading this information. If you decide to take part you will be given a copy of this information sheet and your signed consent form to keep.

If you want further information about the discussion groups, please contact:

Ms Yasamin Yousefi
Paediatric Dental Department
Worsley Building
University of Leeds
Email: dnyhy@leeds.ac.uk

Thank you for taking the time to read this and if you do decide to take part, we very much appreciate your involvement.

Appendix 6: Consent form for interviews

Participant ID Number:_____

Exploring The Dental Health and Experiences Of Children With Congenital Heart Disease

CONSENT FORM FOR INTERVIEWS

	Please initial each box
1. I understand the information sheet for the above study and have had the opportunity to ask questions.	☐
2. I understand this interview is voluntary and that I am free to leave/stop taking part at any time during or even after its taken place, I can have my part taken out at a later date.	☐
3. I am aware that after the interview I will have the opportunity to review what was said.	☐
4. I agree to a copy of this Consent Form being kept at the University of Leeds.	☐
5. I agree to take part in the study.	☐

The following point is OPTIONAL. Even if you agree to take part in this study, you do not have to agree to this section.

	Please initial Yes	No
6. I give permission to be audio recorded.	☐	☐

Participant:

Signature.....

Name (block capitals).....

Date.....

Investigator:

I have explained the study to the above named participant and he/she has indicated his/her willingness to participate.

Signature.....

Name (block capitals).....

Date.....

Topic Guide:
Interviews with Dentists

Before the focus group / interview starts:

- Specify how long the session will take.
- Bring extra copies of information sheets and consent forms.
- Make sure all consent forms are signed.
- Inform about procedure if disconnects

Introduction and Welcome:

- Thank you for taking the time to attend this discussion and sharing with us your views and experiences regarding the management of children with congenital heard disease, who are at risk of developing infective endocarditis.
- The purpose of this group discussion/ interview is to gather your thoughts and opinions on the National Cardiac Standards 2016.
- There are no right or wrong views and opinions. It is important that you understand that anything mentioned in the group discussion / interview is completely confidential, will only be used for the purposes of this research, and all responses will be anonymised before being used in any type of report. In this way, we hope you feel comfortable in providing honest and open views.

- Let's start by introducing ourselves.
  - E.g. Name, where we work, what our role is?

Focus on general practice of contacts with children and families

We would like to start the discussion by learning about your current practice when seeing children and their parents.

Current practice- knowledge

- Are you aware of the Cardiac Standards and Specifications released in 2016?
- What is your understanding of the new standards?

Current practice- patient base

- Do you routinely see 2-year-old cardiology patients for dental screening (**excluding surgical pre-assessment**)?
- What advice do you give?
- How much time do you spend on oral health and care advice?
- How do families usually respond to your advice on oral health and care?
- Do you have any resources you give out specifically to these patients?

Focus on pathway

Potentials

- In an ideal world, how would this referral pathway work/look like?
- Who should be in charge of receiving these referrals?
- What resources would be used?
- Why would these resources be used?

Barriers/ challenges

- What prevents this ideal intervention from being delivered currently?
- Have these barriers occurred recently or are they long-term challenges?
- Can you suggest any potential ways of improving this pathway?

Appendix 8: Cardiac diagnoses of children in sample

Cyanotic Defects		**Acyanotic defects**	
Ebstein's anomaly	1	Septal defects	10
Transposition of the great arteries	7	Patent ductus arteriosus	2
Tetralogy of Fallot	6	Pulmonary/aortic valve stenosis	14
Truncus arteriosus	1	Dilated cardiomyopathy	2
Single ventricle pathology	6	Pulmonary/ mitral regurgitation	5
		Coarctation of aorta	1
		Aortic dilation	1
		Right aortic arch	1
		Right atrial isomerism	1

Appendix : Referral Proforma from cardiology to dental

Yorkshire and Humber Congenital Heart Disease Operational Delivery Network	leeds children's hospital Department of Paediatric Cardiology Leeds Children's Hospital Great George Street Leeds LS1 3EX Cardiac Clinical Nurse Specialists: 0113 392 5467 ccns.lgi@nhs.net
Date of decision to list for surgery/intervention:	

Routine Oral Health Assessment

Dear Specialist/Consultant in Paediatric Dentistry based at:

Barnsley CDS		Rotherham CDS		Doncaster CDS		Charles Clifford Dental Hospital	
Sheffield CDS		Derbyshire CDS		Wakefield CDS		Leeds Dental Institute	
Bradford CDS		Harrogate/York CDS		Hull CDS		North Lincolnshire	

Patient's name:	
Patient's address:	
Patient's DoB:	
NHS number:	
Medical history:	
Medication:	
At increased risk of infective endocarditis:	
Interpreter required: Language required:	
Social Care involvement: Contact details:	
Parent/legal guardian contact details Name: Telephone Number:	
Cardiology Consultant/Paediatrician with Expertise in Cardiology	
Cardiac Clinical Nurse Specialist:	

I would be grateful if you could arrange to see the above child and provide a dental assessment and completion of any dental treatment required. This child has:

Evidence of dental decay	Potentially – drinks bottles of milk overnight
History of pain and/or infection	No

Any child with evidence of dental trauma, dental decay or a history of pain or infection should be given 'URGENT' priority if at risk of infective endocarditis.
Once the assessment and dental treatment (if indicated) has been completed please could you return the form (Appendix 3) for our records by email to ccns.lgi@nhs.net

Dental General Anaesthetic:	

X If this is required it can be provided within a District General Hospital

X If this is required it may be carried out within a District General Hospital pending advice from your anaesthetic team

✓ If this is required it must be provided at the Leeds Children's Hospital

Thank you for your help.
Yours sincerely,

Consultant Paediatric Cardiologist/ Paediatrician with Expertise in Cardiology/ Cardiac Clinical Nurse Specialist