

## **Dental preventative advice and preparation of children and young people with cardiac disease by children's cardiac nurses in the UK: An online survey**

### **Abstract (150 words)**

Background: Optimum oral health care and dental education is vital for children with congenital heart disease due to infective endocarditis risk.

Aim: To ascertain the dental care information provided by children's cardiac nurses for children with cardiac disease and their families.

Methods: A cross-sectional online survey of children's cardiac nurses, during Nov 2021-March2022; Oct 2022-Nov 2022.

Findings: Participants (n=27) from seven English cardiac networks gave dental advice (89%, 24/27); were moderately or highly confident providing advice (78% 21/27); but were unaware of national congenital heart disease dental standards (54%, 14/26). Three themes emerged: educational needs, resources availability and empowerment.

Conclusions:

Despite the low response rate, inconsistencies in the implementation of cardiac standards amongst different networks was evident. Recommendations include: improved access to dental services, improved collaborations between dental and cardiac teams, dental education for children's cardiac nurses, and correct caregiver advice to promote optimum dental health for this high-risk group.

## **Background**

Children with congenital heart disease (CHD) are at high risk of developing infective endocarditis (IE), a bacterial infection typically caused by staphylococcus or streptococcus species, with 10-11% developing IE during their life (Hughes et al, 2019). These children have structural heart changes (congenital or post operatively), creating turbulent blood flow that can disrupt the endocardium making the heart vulnerable. Haemostasis and scar formation can occur during the post-operative healing process and pathogens can settle in these scarred areas, suture lines or along the rings of implanted heart valves, infecting the endocardium. Altered blood supply to these areas can increase susceptibility to vegetation, abscess formation and hard to treat infections (Leonard et al 2017).

There are numerous IE risk factors for children and young people with CHD, such as being under 3 years of age (Rushani et al 2013), home environment, age, animal exposure and lifestyle recreational risks (tattoos and piercings) in adolescents (Sable et al 2011). Furthermore, the highest IE risk has been identified in children with cyanotic CHD (tetralogy of Fallot, truncus arteriosus, tricuspid valve anomalies, pulmonary atresia and hypoplastic left heart syndrome) possibly due to the number of surgical procedures in the more complex cases (Rushani et al, 2013; Elder & Baltimore, 2015).

Poor oral care is also a risk factor in children with CHD and oral bacteria are implicated in 15-40% of cases (Tong et al, 2015), with viridians streptococci identified in a large percentage of patients undergoing dental extraction (Farbod et al 2009). These children often have poorer oral health compared to healthy children and can be complex to manage due to dental anxiety and impaired access to dental care (Hughes et al 2019). A case control study comparing the dental health of children with CHD with healthy matched controls found that children with CHD had poorer dental health (dental decay) compared to the healthy controls (Stecksén-Blicks et al 2004). This was despite the children with CHD having intensive dental preventative advice and interventions. The conclusion was that closer cooperation was needed between dental

and cardiology teams. A more recent systematic review looked at articles published between 2000 and 2019 on dental decay in children with CHD. The quality of the nine studies varied widely; however, dental decay was significantly higher in children with CHD when compared with healthy children in three of the nine articles (Karikoski et al 2021).

Attitudes of parents (n=105) of children with CHD to oral health care, living in Bengaluru, Southern India, were studied by Suvarna et al (2011). Whilst parents and children were aware of the importance of oral health care and its relevance to the rest of the body, the author's deemed attitudes were unsatisfactory and needed to be improved.

Children's nurses have a vital role to play in dental education for all children as tooth decay is one of the most common and most preventable diseases affecting children and young people (CYP) in England (Public Health England 2018); and is the most common reason for hospital admission in 5 to 9 year-olds with the number of tooth extractions rising to 16,959 in 2021-22 compared to 9,429 in 2020-21 (National Health Service (NHS) Digital 2022). Furthermore, due to the increased risk of IE, optimum oral health care and dental education is vital for these CYP with cardiac disease and their parents. This is reflected in the CHD standards for England, which indicate that CYP and adults with CHD should receive oral health care from both cardiology and dental healthcare professionals; and children's cardiac nurses play a paramount role in providing patient care and education (NHS England 2016).

As these standards have been in place for over six years, the research question asked:

*“Are children and young people with acquired, inherited or congenital heart disease and their families, being adequately prepared regarding preventative dental care by children's cardiac nurses in England?”*

**Aim:** To ascertain the appropriateness, consistency and confidence of information provided in relation to preventative dental care for CYP with acquired, inherited or congenital heart disease and their families from children's cardiac nurses in England.

The objectives were to ascertain:

- whether preventative dental advice, dental techniques and risks are discussed with CYP and their families and how confident nurses feel giving this advice
- Levels of awareness of the national CHD dental standards
- What sources of dental information are provided to CYP and their families
- How referrals are made to dental services
- How well the CHD service specifications are being implemented across England.

**Materials and methods:**

*Design:* This study used a cross sectional survey design, collecting both quantitative and qualitative data.

*Population:* Nurses working with children and young people with acquired, inherited or congenital heart disease in the United Kingdom. Inclusion was children's cardiac nurses working in one of the children's cardiac networks and exclusion was nurses working outside of the UK.

*Sampling strategy:*

Reaching the target population was challenging due to the national reach of the project, therefore, a snowball sampling strategy was used. Snowball sampling is an established and feasible method of recruiting participants not easily accessible or known to the researcher (Leighton et al 2021, Marcus et al 2017, Naderifar Goli & Ghaljaie 2017, Reagan et al 2019, Wohl et al 2017). Furthermore, snowball sampling is familiar to qualitative researchers, where those known to the researcher are contacted first and these individuals connect them to other research participants (Leighton et al 2021, Marcus et al 2017, Parker, Scott & Geddes 2019).

Snowball nonprobability convenience sampling was used by first sending an invitation email to Lead Nurses for the CHD networks and members of the Congenital Cardiac Nurses

Association (CCNA) (currently approximately 150 members) via the membership secretary as gatekeeper. Secondly, details of the study were included in the quarterly CCNA newsletter, which is often disseminated on noticeboards in clinical areas and on the CCNA website [www.ccn-a.co.uk](http://www.ccn-a.co.uk) . The research team also connected with professionals via twitter @CongentialCNA and these posts were reshared by CHD networks and individual personal social media sites (Facebook, Twitter, LinkedIn). It was therefore impossible to know how many people the posts reached.

The survey was initially opened 3<sup>rd</sup> November 2021 until 3<sup>rd</sup> December 2021. However, despite snowballing the response rate remained low (n=10), therefore, to reach more nurses the survey was extended until 31<sup>st</sup> March 2022, by which point another eleven nurses had responded. The research team met in June 2022 to discuss additional recruitment strategies; the survey was reopened from 1<sup>st</sup> October until 11<sup>th</sup> November 2022, to coincide with the annual national CCNA conference in November 2022. An invitation email was sent to all children's cardiac nurses registered for the CCNA national conference (n=52) via the conference organisers (CFS events) as gatekeepers and details of the survey were circulated via posts on social media (Twitter). During this time the researchers attempted to keep the snowball 'rolling' through reminder emails and regular retweets and reposting the survey link via social media. An additional six nurses responded.

*Ethics:* Ethical approval was gained from the College of Health, Life and Environmental Sciences Research Ethics Panel, University of Worcester. To fulfil requirements of this approval, participants completed a mandatory online consent question before proceeding to questions.

*Data collection instrument:* The questionnaire was designed to collect quantitative and qualitative data ascertaining demographic information (the congenital heart network they work in, their role, and Agenda for Change (AfC) band (NHS Employers 2022)). Five quantitative

and nine qualitative questions were included. A Likert scale was used to measure confidence in delivering preventative dental advice. The qualitative component aimed to gain insights from participants about the educational support they have received, the advice they give, how advice is given, how referrals are made, knowledge of the CHD standards (NHSE 2016) and whether these have been implemented in their CHD network. The questionnaire was piloted by children's cardiac nurses (n=2) and minor amendments made to some questions prior to dissemination of the final version.

*Data collection procedure:* For speed, flexibility, and accessibility the questionnaire was made available online, accessed via JISC online survey software (JISC.ac.uk). The url link to the survey was included in invitation emails and in posts on social media. The first page of the survey included the participant information, inclusion/exclusion criteria and mandatory questions about consenting to participate. Completed surveys were stored in JISC and then downloaded as an Excel 2007 file for data analysis.

*Data analysis:* Data were analysed using descriptive statistical analysis and thematic analysis (Braun & Clarke 2006). Thematic analysis proceeded as follows: familiarization of data (AD, MV, KG, NB), generation of codes (AD, MV), combining codes into themes (AD, MV), reviewing themes (AD, MV, KG), determine significance of themes (AD, MV, KG), reporting of findings (AD, MV, KG).

## **Results:**

Overall, twenty-seven (n=27) nurses responded (18% response rate based on CCNA membership N=150). From across the seven congenital heart networks in England (table 1), there was a range of job roles and AfC banding with n=16 (59%) clinical nurse specialists and n=13 (48%) at band 7.

Table 1 participant demographics

Demographic, confidence, dental advice given (N=27)	n (%)
Congenital cardiac network: <ul style="list-style-type: none"> <li>• East Midlands</li> <li>• Northwest, North Wales, Isle of Mann</li> <li>• South Wales and Southwest</li> <li>• Yorkshire and Humber</li> <li>• Northeast and North Cumbria</li> <li>• One Heart GOSH/BARTS</li> <li>• The Guy's and St Thomas' - Evelina London</li> <li>• Not known</li> </ul>	3 (11.1) 1 (3.7) 2 (7.4) 4 (14.8) 1 (3.7) 4 (14.8) 3 (11.1) 9 (33.3)
Role <ul style="list-style-type: none"> <li>• Ward nurse</li> <li>• Outpatient's department</li> <li>• Clinical nurse specialist</li> <li>• Advanced practitioner</li> <li>• other</li> </ul>	5 (18.5) 1 (3.7) 16 (59.3) 1 (3.7) 4 (14.8)
AfC Band <ul style="list-style-type: none"> <li>• 5</li> <li>• 6</li> <li>• 7</li> <li>• 8</li> </ul>	5 (18.5) 5 (18.5) 13 (48.1) 4 (14.8)

Although 89% (24/27) agreed that they give dental advice to CYP and their families (table 3), the content of this advice varied considerably (table 2). 78% (21/27) of participants were either moderately confident or highly confident in providing dental advice (table 3). 52% (14/27) of respondents use and distribute dental leaflets and 89% (24/27) liaised with their patient's local dentist or signposted patients to dentists if they believed the CYP required dental treatment. Interestingly, over half of the participants, 54% (14/26), were not aware of the dental standards in the CHD service specifications and standards (NHSE 2016) and over half, 59% (16/27), did not know if the dental standards were fully implemented within their cardiac network (table 3).

Table 2 Dental advice given to CYP and families

Advice	n	%
Brush two times a day for two minutes	26	96.3
Use fluoridated toothpaste	11	40.7
Not rinse (with water or mouthwash) after brushing	9	33.3
See a dentist for regular check-ups,	26	96.3
Using a fluoride mouthwash (children over 8 years),	6	22.2
Impact of sugary foods/drinks	23	85.2
Type of toothbrush	3	11.1
Not to share a toothbrush	6	28.6
How often to change the toothbrush	4	14.8

Table 3 Confidence and awareness of CHD dental standards (NHSE 2016)

Do you provide dental advice?	
<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Other</li> </ul>	24 (88.9) 1 (3.7) 2 (7.4)
Confidence giving advice:	
<ul style="list-style-type: none"> <li>• Slight confidence</li> <li>• Moderately confident</li> <li>• High confidence</li> </ul>	6 (22.2) 14 (51.9) 7 (25.9)
Awareness of CHD standards for dental care?	
<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	12 (44.4) 14 (51.9)
Are these fully implemented in your network?	
<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know</li> </ul>	4 (14.8) 7 (25.9) 16 (59.3)



The three main themes drawn from the qualitative data were: education needs, availability of resources, and empowering the multi-disciplinary team. The themes closely overlapped, and some of the comments could be linked to all three themes, and the quantitative data. To maintain anonymity we have opted not to identify the location of individual respondents in the quotes below; instead, quotes are labelled with the participants number e.g., P1).

### Education Needs

Participants were asked if they had received education regarding dental care for CYP with cardiac conditions. 22% (6/27) had not received any formal training. When asked in the open-ended questions what teaching they had received, responses included: *“Minimal”* (P23), *“Very little to none”* (P18), *“Advice from consultant cardiologists”* (P5), *“Links with Dental Hospital and specialist dentists”* (P16), *“No formal education, just learnt from other colleagues and consultants and dental staff within the team”* (P13)

Although 78% of the respondents had reported they had received some form of education on dental care, the qualitative analysis was able to highlight variations in the type of dental education they received. One respondent reported that their experience of teaching was as follows:

*“Teaching sessions are with the trust’s dental team on what to look for, tips on examining mouths/teeth, being present when dental examinations are being made and what advice the dental team give, clinical exam qualification”* (P22)

The overriding finding was the need for more support, informal and formal training days, as demonstrated below:

*“More education to the nursing staff when starting the job”* (P7)

*“Educational information provided by dental teams” [is needed]* (P8)

*“Teaching on what advice to give to make sure it’s the right advice, a leaflet to give to parents to make sure they definitely have the information and have understood”* (P20)

In addition, awareness of Section M in the cardiac standards (NHSE 2016) varied amongst the participants, one quoted:

[There is a need for] “*guidelines*” (P3)

Availability of resources:

One participant in the study commented on the need for children to have toothbrushes while in hospital and the difficulty in getting supplies:

*“All children coming into hospital should bring a toothbrush and use it - few nurses check this and it is almost impossible to get ward supplies of toothbrushes suitable for children” (P2)*

Limited access to local and specialist dental services was reported as a challenge and also a potential burden to the hospital dental services.

*“Due to the lack of local dentists, children often present without dental assessment for surgery/catheter. Therefore, adding to the waiting list of in-house dental team. Referral at an earlier stage is required” (P11)*

*“Not all patients before the age of 2 are seen by a specialist dentist. Access to dentistry in the network is difficult” (P6)*

*“Easy in Lead Centre but immensely difficult in local areas as sparsity of NHS dentists and areas inundated with a backlog of children needing extractions and conservative dentistry” (P2)*

Another respondent perceived that the pandemic had influenced access to dental care:

*“Seeing increase in lack of dental care post covid pandemic (patients not attending dentist)” (P1)*

The need for educational resources was highlighted, for example

*“Webinars dedicated to this topic” (P17) and “More health promotion materials and free toothbrushes” (P6) and “Webinars, patient/parents’ experiences, nurse-led clinics to boost autonomy” (p27)*

Some CHD networks are creating their own educational resources for parents, demonstrating a recognition of the importance of dental care:

*Currently working on age-appropriate animated video to promote oral hygiene that will be shown in cardiac OPD and available on the network website. Funded by local charity partner (P10)*

*“Am working with specialist dentist on a parent/carer book and a child’s book looking at the importance of dental hygiene and cardiac issues” (P15)*

#### Empowerment (staff and parents):

The theme empowerment related to giving both nursing staff and parents confidence to action the appropriate dental advice for these CYP. This was closely linked to educational needs and the availability of resources. Several respondents highlighted the importance of clear communication pathways with local dental teams, with one respondent stating:

*“Poor engagement from dental team” (P5)*

To help reduce disparities in communication and allow for stream-lined communication, some participants perceived that an effective referral pathway should be in place for CYP to access dental services within the local area or their CHD service. One respondent reported:

*“More structured referral to specialist dentist at 1 yr of age” (P12)*

However, respondents also highlighted that due to the availability of local dentists being a challenge, signposting to local dentists for their patients’ dental needs was difficult. One respondent’s comment about improving preventative dental care was:

*“Improving access to NHS dentists would help” (P6)*

The qualitative comments indicate an awareness that parents could be empowered to improve their child’s dental care through education about IE, structured information pathways and knowing who to contact for advice:

*“Endocarditis is more common in young people with CHD and is entirely preventable by good dental care, regular checkups and daily dental hygiene, good diet, and avoidance of sugary food/drinks. Endocarditis is life-threatening and every year children die from it” (2)*

*Structured information pathway[s], to advise patients/families what to do if they suspect dental problems (P9)*

Another participant’s comment about how care could be improved related to empowering parents through the development of CHD resources in their network:

*“Patient education about dental care - project currently underway to review current literature.*

*Will share with network when completed” (P1)*

## **Discussion:**

The aim of this study was to ascertain the appropriateness, consistency and confidence of information provided in relation to preventative dental care for children and young people (CYP) with acquired, inherited or congenital heart disease and their families from children’s cardiac nurses. We found that most participants already provided education for parents and CYP and with further appropriate support, preventative dental education could be more accessible to this high-risk group.

## **Education:**

Our first main finding was the need for further education to help increase knowledge, understanding and confidence in the delivery of condition specific dental advice, particularly around IE for newly qualified nurses or those new to the CHD speciality. Parental education by cardiac nurses is particularly important for CYP and their families due to the higher risk of dental decay (Karikoski et al 2021).

Similarly, Cianetti et al (2020) revealed a gap in nurses' knowledge, willingness, and consideration of oral health status of patients with CHD through a survey of nursing staff (n=44) working in semi-intensive heart failure units. However, whilst this survey was conducted with adult CHD nurses rather than CYP nurses, the findings indicate that further education and research is needed in this area, focusing on both adult and CYP CHD services as the CHD standards apply to both areas (NHSE 2016).

Dental education for nurses needs to ensure they have a greater awareness of the specific advice within the cardiac dental care standards (Section M, NHSE 2016). Furthermore, in developing educational programmes educators need to consider offering both online and in-person programmes to increase flexibility, accessibility and satisfaction for learners and staff, recognising the individual preferences and learning styles (Bastable 2008). Some preferring face-to-face lectures and others preferring the greater flexibility and accessibility to learning using virtual means, including webinars and e-learning resources (Ismail et al 2021, Cook 2008 a, b; Cook 2009).

Whilst our study did not aim to explore parent's knowledge or educational needs, there is extant evidence that parent's education needs continue (Public Health England 2018; NHS Digital 2022). Koerdt et al (2018) survey for parents of children with CHD (n=150) found that the knowledge regarding preventative dental advice and indication for medications such as possible antibiotic prophylaxis was low. An increase in communication between cardiology and dental teams was highlighted as necessary to help coordinate dental advice for this patient

group at a young age. Education at a young age is vital to help instil positive dental attitude and prevention of dental disease; therefore, improving dental education for children's cardiac nurses will assist in improving the knowledge of CYP and their families.

### **Availability of resources**

The availability of physical, educational, and operational resources could empower nurses to deliver dental education and signpost CYP and their families to appropriate dental care. We found that educational resources (patient friendly leaflets) were being used by about half of the participants, however, there was evidence of new dental educational resources and leaflets being developed and disseminated in some CHD networks, which was encouraging. Patient information leaflets are considered essential in providing good health tips for CYP and their families and encouraging them to take responsibility in their own health choices (Protheroe et al, 2015). We also found evidence of multi-disciplinary contribution towards patient information leaflet formation, involving dentists, specialist nurses, medical teams, charities, and CHD support groups, ensuring that appropriate information is being shared.

A key finding of our study related to access to NHS dentists, which was deemed challenging for parents of CYP with cardiac disease. Several factors have influenced this accessibility in recent years and, therefore, the findings were not particularly surprising given that the study was conducted shortly after the third lockdown for the Coronavirus (COVID-19) pandemic. The COVID-19 pandemic resulted in a halt of routine dental care for the population and more than two thirds of children in England did not see an NHS dentist in 2020 (The Royal College of Surgeons of England 2021). Additionally, the shortage of NHS dentists in the UK, the decrease in availability of NHS dentistry, and long waiting lists (Charlwood 2022), has potentially further exacerbated issues for children with CHD accessing dental care at a local level.

Children are advised to visit a dental professional at least once a year, to reinforce preventative dental measures and identification of any dental disease at an early stage (NICE

2004). However, untreated dental disease in this group of CYP with cardiac disease is more likely given the accessibility challenges, increasing their risk of dental infections and IE (Hughes et al, 2019). Therefore, dental education about optimum oral health care is essential to prevent IE. Research is needed to ascertain the full impact of the availability of dentistry during COVID-19, the shortage of NHS dentists in the UK and any changes in the incidence of IE for this group of CYP.

### **Empowerment:**

Empowering professionals to engage in multi-disciplinary collaboration is paramount to providing effective patient care; ensuring that dental care for CYP with cardiac conditions is personalised, individualised, and enables CYP and parents to have more autonomy over their [dental] health and wellbeing (NHSE 2019). Our study found variations in cardiac dental knowledge, education, and multi-disciplinary working across seven of the ten CHD networks in England.

Closer co-operation between dental and cardiology teams was recommended nearly 20 years ago (Stecksén-Blicks et al 2004). However, despite the CHD standards and service specifications (NHSE 2016) including dental standards, which outline what oral health care patients should receive from both cardiology and dental healthcare professionals, *with immediate effect* (Hughes et al 2019), our study found that there were variations in practice across the CHD networks in England. Further work is required within and across CHD networks in the UK to expand upon the CHD standards (NHSE 2016) to create an effective and consistent dental care pathway, which increases collaboration between the dental, nursing and cardiology teams.

### **Strengths and limitations:**

The benefits of online surveys are the ability to reach a wider population, by recruiting via social media platforms such as Twitter and email. Online surveys allow participants flexibility

and time to respond, reducing anxiety and respecting respondents' anonymity. It is also a cost-effective technique and data can be collated over a shorter period (Ball, 2019).

However, despite these benefits the main limitation of our study was the small sample size and low response rate (18% response rate based on CCNA membership N=150, however we have no way of knowing exactly how many nurses saw the invitation). An average response rate of 35% (range 27-35%) has been identified for online surveys by Cunningham et al (2015) and a recent meta-analysis of online surveys found that the average online survey response rate is 44.1% (Wu et al 2022). There could be several reasons for this, such as emails could have been missed or deleted by participants (Mudavath & Narayan, 2019), lack of time can also be a burden to online survey participation (Cunningham et al 2015).

For snowball sampling to work effectively each researcher needs to commit to reposting, retweeting, and sharing their own and others' posts on a planned bi or tri weekly basis over the recruitment phase of the study (Leighton et al 2021). This could have been improved had all researchers been active on social media. Furthermore, the researchers could also have tracked dates of social media data (postings, views, shares, reactions, comments) and Twitter data (tweets, impressions, engagements, retweets, replies, likes, URL clicks, and detail expands) to further clarify the snowballing method (Leighton et al 2021).

A further limitation is that there was no existing validated tool to explore the phenomenon of interest (Latour and Tume, 2021), therefore this was developed by the study team.

### *Implications for clinical practice*

Training, education, and service delivery implications for nursing staff and parents regarding provision and receipt of consistent specialist information and advice were identified. Recommendations include the provision of continuing professional development to all nursing staff about optimum oral health care and the risk of infective endocarditis in children with congenital heart disease, as well as inclusion in pre-registration children's nursing and preceptorship programmes. There are educational opportunities through the CCNA annual



conference and website [www.ccn-a.co.uk](http://www.ccn-a.co.uk) and an e-learning resource should be developed to improve accessibility of education. The impact of a national educational programme should be evaluated. The national picture around accessibility to specialist dental services and the incidence of infective endocarditis in children and young people with congenital heart disease since the COVID-19 pandemic, should be ascertained through further research.

### **Conclusion:**

As the sample size was small in this study, the results were analysed accordingly, however the information ascertained has drawn some valuable observations. Some disparities exist regarding access to dental services requiring improved collaborations between dental and cardiac teams and further research in this area. Whilst over 75% of participants indicated they were confident in providing specific dental education to children and parents, they perceived that improved education was required for children's cardiac nurses. Quality assured educational programmes as well as provision of resources could empower nurses to provide the correct advice to carers to ensure optimum dental care for their children.

(4274 words including tables, 4025 without tables)

## **Key points**

- Tooth decay is one of the most common and most preventable diseases affecting children and young people
- Poor oral care is a risk factor for infective endocarditis in children with congenital heart disease
- Optimum oral health care and dental education is vital for children with congenital heart disease and their families to reduce the risk of infective endocarditis.
- Dental standards for children with congenital heart disease were included in the national standards and service specifications (NHSE 2016), however there is a lack of awareness and inconsistency in implementation of these standards amongst different networks
- Children's cardiac nurses need to be educated about optimum oral health care and the risk of infective endocarditis in children with congenital heart disease
- Better collaboration between dental, nursing, and medical teams are needed to ensure dental care pathways are in place for children with congenital heart disease

## **Reflective questions**

1. Critically explore the risk of infective endocarditis for children and young people with congenital heart disease and the association with dental health
2. Review section M of the congenital heart disease standards and service specifications (NHSE 2016) and consider how the dental standards have been implemented in your congenital heart disease network.
3. What educational opportunities are available to children's cardiac nurses in your congenital heart disease network? How could this be improved?
4. What advice is currently given to children, young people and their parents about optimal oral health and the risk of infective endocarditis in your congenital heart disease network? What improvements could be made?

## References:

Ball HL (2019) Conducting Online Surveys. *Journal of Human Lactation*, 35(3):413-417. doi:10.1177/0890334419848734

Bastable SB (2008) *Nurse as Educator: Principles of Teaching and Learning for Nursing Practice, third edition*. Massachusetts. Jones and Bartlett.

Braun V & Clarke V (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3:2, 77-101, DOI: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)

Charlwood, S. (2022). *NHS dentistry: Have we reached the point of no return?* Available at: <https://bda.org/news-centre/blog/Pages/NHS-dentistry-have-we-reached-the-point-of-no-return.aspx> [Accessed 10<sup>th</sup> April 2023]

Cianetti S, Anderini P, Pagano S, Eusebi P, Orso M, Salvato R, Lombardo G. (2020) Oral Health Knowledge Level of Nursing Staff Working in Semi-Intensive Heart Failure Units. *Journal of Multidisciplinary Healthcare*, 13:165-173. doi: 10.2147/JMDH.S224453.

Cook KL (2008a) Learning on the go, *Nursing Standard*, vol 23, no 12, p. 61

Cook KL (2008b) Your flexible friend: e-learning, *Nursing Standard*, vol. 22, no 39, p.62-3

Cook KL (2009) Networked Learning, *Nursing Standard*, vol 23, no 19, p. 61

Cunningham CT, Quan H, Hemmelgarn B *et al.* (2015) Exploring physician specialist response rates to web-based surveys. *BMC Med Res Methodol*, **15**, 32, available at: <https://doi.org/10.1186/s12874-015-0016-z> [Accessed 10<sup>th</sup> April 2023]

Elder RW & Baltimore RS (2015) The changing epidemiology of pediatric endocarditis. *Infectious Disease Clinics*, 29(3), 513-524.

Farbod F, Kanaan H, Farbod J (2009) Infective endocarditis and antibiotic prophylaxis prior to dental/oral procedures: latest revision to the guidelines by the American Heart Association

published April 2007, *International Journal of Oral and Maxillofacial Surgery*, 38 (6) 626-631, ISSN 0901-5027, <https://doi.org/10.1016/j.ijom.2009.03.717>.

Hughes S, Balmer R, Moffat M et al. (2019) The dental management of children with congenital heart disease following the publication of Paediatric Congenital Heart Disease Standards and Specifications. *British Dentistry Journal*, 226(6):447-452.

Ismail II, Abdelkarim A, Al-Hashel JY (2021) Physicians' attitude towards webinars and online education amid COVID-19 pandemic: When less is more. *PLOS ONE* 16(4), available at: <https://doi.org/10.1371/journal.pone.0250241> [Accessed 10<sup>th</sup> April 2023]

Karikoski E, Sarkola T, Blomqvist M (2021) Dental caries prevalence in children with congenital heart disease - a systematic review. *Acta Odontologica Scandinavica*, 79(3):232-240. doi: 10.1080/00016357.2020.1849792. Epub 2021 Jan 8. PMID: 33415995.

Koerdt S, Hartz J, Hollatz S, Frohwitter G, Kesting MR, Ewert P, Oberhoffer R, Deppe H. (2018) Dental prevention and disease awareness in children with congenital heart disease. *Clinical Oral Investigations*, 22(3):1487-1493. doi: 10.1007/s00784-017-2256-2.

Koerdt S, Hartz J, Hollatz S *et al.* (2022) Prevalence of dental caries in children with congenital heart disease. *BMC Pediatr* 22, 711, available at: <https://doi.org/10.1186/s12887-022-03769-2> [Accessed 10<sup>th</sup> April 2023]

Kwiatkowska J, Meyer-Szary J, Mazurek-Kula A, Zuk M, Migdal A, Kusa J, Skiba E, Zygielo K, Przetocka K, Kordon Z, Banaszak P, Michalczyk A, Rzeznik-Bieniaszewska A, Surmacz R, Bobkowski W, Wojcicka-Urbanska B, Werner B, Pluzanska J, Ostrowska K, Bazgier M, Kopec G. (2021) The Impact of COVID-19 Pandemic on Children with Pulmonary Arterial Hypertension. Parental Anxiety and Attitudes. Follow-Up Data from the Polish Registry of Pulmonary Hypertension (BNP-PL). *Journal of Clinical Medicine*, 10(8):1640. <https://doi.org/10.3390/jcm10081640> [Accessed 10<sup>th</sup> April 2023]

Latour J. and Tume LN. (2021) How to do and report survey studies robustly: A helpful mnemonic SURVEY. *Nursing in Critical Care*. 26:313–314. DOI: 10.1111/nicc.12669

Leighton K, Kardong-Edgren S, Schneidereith T, & Foisy-Doll C (2021, Month). Using Social Media and Snowball Sampling as an Alternative Recruitment Strategy for Research. *Clinical Simulation in Nursing*, 55, 37-42. <https://doi.org/10.1016/j.ecns.2021.03.006>.

Leonard EJ, Kuebler BE, Zenni MM, Scuderi CB. A review of infective endocarditis associated with congenital heart disease. *Consultant*. 2017;57(11):363-641, available at: <https://www.consultant360.com/articles/review-infective-endocarditis-associated-congenital-heart-disease> [Accessed 17th August 2023]

Marcus B, Weigelt O, Hergert J, Gurt J & Gelléri P (2017) The use of snowball sampling for multi source organizational research: Some cause for concern. *Personnel Psychology*, 70(3), 635-673. <https://doi.org/10.1111/peps.12169>.

Mudavath N & Narayan KA (2019). Strengths and Weakness of Online Surveys. *Journal of humanities and social sciences*. 24(5). Pp 31-38. DOI: 10.9790/0837-2405053138. Retrieved from: [https://www.researchgate.net/publication/333207786\\_Strengths\\_and\\_Weakness\\_of\\_Online\\_Surveys](https://www.researchgate.net/publication/333207786_Strengths_and_Weakness_of_Online_Surveys) [Accessed 10<sup>th</sup> April 2023]

Naderifar M, Goli H & Ghaljaie F (2017) Snowball sampling: A purposeful method of sampling in qualitative research. *Strides in Development of Medical Education*, 14(3), Article 367670. <https://doi.org/10.5812/sdme.67670>.

NHS Digital (2022) Hospital Admitted Patient Care Activity, 2021-22, available at: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity/2021-22> [Accessed 17/8/23]

NHS England (2016) Congenital Heart Disease Standards and Specifications. Online information available at: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-specstandards-2016.pdf> [Accessed 17th August 2023].

NHS England (2019) The NHS Long Term Plan, available at: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/> [Accessed 17/8/23]

NICE (2004) Dental checks: intervals between oral health reviews, Clinical Guidance CG19, available at: <https://www.nice.org.uk/guidance/cg19/ifp/chapter/how-often-should-i-come-back-for-a-check-up> [Accessed 17/8/23]

Parker C, Scott S, & Geddes A (2019) Snowball sampling. Sage research methods foundations. London, UK: Sage Publications. <https://doi.org/10.4135/9781526421036831710>.

Protheroe J, Estacio EV, Saidy-Khan S (2015) Patient information materials in general practices and promotion of health literacy: an observational study of their effectiveness. *British Journal of General Practice*, 65 (632): e192-e197. DOI: 10.3399/bjgp15X684013

Public Health England (2018) National Dental Epidemiology Programme for England: oral health survey of five-year-old children 2017 A report on the inequalities found in prevalence and severity of dental decay, available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/768368/NDEP\\_for\\_England\\_OH\\_Survey\\_5yr\\_2017\\_Report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/768368/NDEP_for_England_OH_Survey_5yr_2017_Report.pdf) [Accessed 17/8/23]

Public Health England (2020) *Congenital heart disease: information for parents*. Online information available at: <https://www.gov.uk/government/publications/congenital-heart-disease-description-in-brief/congenital-heart-disease-information-for-parents-html> [Accessed 10<sup>th</sup> April 2023]

Reagan L, Nowlin SY, Birdsall SB, Gabbay J, Vorderstrasse A, Johnson C & Melkus GD'E (2019). Integrative review of recruitment of research participants through Facebook. *Nursing Research*, 68(6), 423-432. <https://doi.org/10.1097/NNR.0000000000000385>.

Royal College of Surgeons of England (2021). *Two thirds of children did not see an NHS dentist last year*. Available at: <https://www.rcseng.ac.uk/news-and-events/media-centre/press-releases/children-dental-attendance-2020/> [Accessed 10<sup>th</sup> April 2023]

Rushani D, Kaufman JS, Ionescu-Iltu R, Mackie AS, Pilote L, Therrien J, Marelli AJ. (2013) Infective endocarditis in children with congenital heart disease: cumulative incidence and predictors. *Circulation*, 128(13):1412-9. doi: 10.1161/CIRCULATIONAHA.113.001827. PMID: 24060942, available at: <https://pubmed.ncbi.nlm.nih.gov/24060942/> [Accessed 17<sup>th</sup> August 2023]

Shaymaa Abdulreda Ali, Walid El Ansari (2022) Is tele-diagnosis of dental conditions reliable during COVID-19 pandemic? Agreement between tentative diagnosis via synchronous audioconferencing and definitive clinical diagnosis. *Journal of Dentistry*. Volume 122, 104-144. ISSN 0300-5712. <https://doi.org/10.1016/j.jdent.2022.104144>. Available at: <https://www.sciencedirect.com/science/article/pii/S0300571222002007> [Accessed 10<sup>th</sup> April 2023]

Stecksén-Blicks C, Rydberg A, Nyman L, Asplund S, Svanberg C (2004) Dental caries experience in children with congenital heart disease: a case-control study. *International Journal of Paediatric Dentistry*, 14(2):94-100. doi: 10.1111/j.1365-263x.2004.00531.x. PMID: 15005697.

Suvarna R, Rai K, Hegde AM (2011) Knowledge and Oral Health Attitudes among Parents of Children with Congenital Heart Disease. *International Journal Clinical Pediatric Dentistry*, 4(1):25-8. doi: 10.5005/jjp-journals-10005-1076. Epub 2011 Apr 15. PMID: 27616854; PMCID: PMC4999633.

Tong SY, Davis JS, Eichenberger E et al. (2015) Staphylococcus aureus infections: epidemiology, pathophysiology, clinical manifestations, and management. *Clinical Microbiology Reviews*, 28(3):603-661.

Wohl AR, Ludwig-Barron N, Dierst-Davies R, Kulkarni S, Bendetson J, Jordan W, & Perez M (2017) Project engage: Snowball sampling and direct recruitment to identify and link hard-to-reach HIV-infected persons who are out of care. *Journal of Acquired Immune Deficiency Syndromes*, 75(2), 190-197. <https://doi.org/10.1097/QAI0000000000000312>.

Wu MJ, Zhao K, Fils-Aime F (2022) Response rates of online surveys in published research: A meta-analysis, *Computers in Human Behavior Reports* (7), 2022, 100206, ISSN 2451-9588, <https://doi.org/10.1016/j.chbr.2022.100206>.