# Oral Health Beliefs and Behaviours among Adults with Sickle Cell Diseases in Ireland

A thesis submitted to fulfil partially the prerequisites for achieving the degree of Clinical Doctorate in Dental Surgery (D.Ch.Dent.) in Special Care Dentistry

**2023**


**Hussain IbnAhmad**

**Supervisors**

Professor Alison Dougall

Professor Blánaid Daly

Dr Caoimhín Mac Giolla Phádraig

Dublin Dental University Hospital

Trinity College Dublin, The University of Dublin

# DECLARATION

I affirm that this thesis has not been presented as an exercise for a degree at this institution or any other, and it is solely the result of my own effort. I consent to the inclusion of this thesis in the university's open-access institutional repository or grant the library permission to do so on my behalf, in compliance with Irish Copyright Legislation and Trinity College Library's terms of use and acknowledgement requirements.

Hussain IbnAhmad

# ABSTRACT

**TITLE:** Oral health beliefs and behaviours among adults with Sickle Cell Diseases in Ireland

**STUDENT:** Hussain IbnAhmad(HI)

**CO-SUPERVISORS:** Professor Alison Dougall, Professor Blánaid Daly,
Dr Caoimhín Mac Giolla Phádraig

**Background:** The number of Adults Living with Sickle Cell Disease (ASkCD) in Ireland has risen, driven by recent immigration. A new multi-disciplinary national adult sickle service centre has been introduced to meet their medical and psychosocial needs. To date, the oral health needs, oral health beliefs and behaviours of this group are unknown. Anecdotal evidence suggests there is considerable ambivalence around oral health.

**Aim:** To explore the oral health beliefs and behaviours of ASkCD, who attend Ireland's national adult sickle cell service centre. Additionally, this work seeks to gather information on barriers to oral care in this group and examine potential predictors of dental service utilization, aiming to shape future oral healthcare pathways to minimize the occurrence of dental crises.

**Methods:** A cross-sectional survey among ASkCD who attend Ireland's national adult sickle cell service centre, adopting total population sampling. Participants self-completed a questionnaire while undergoing transfusion therapy. Oral health beliefs and behaviours were assessed using standardised measures (Xiang et al. 2020). A logistic regression was adopted to identify predictors of reported dental attendance among a range of health beliefs.

**Results:** Out of the 230 registered service users at Ireland's national adult sickle cell service centre, invitations were extended to 216 individuals who were currently attending appointments with the sickle cell service. Remarkably, a substantial majority of 214 participants (99.07%) exhibited keen enthusiasm and accepted the invitation, constituting an impressive 93.04% of the entire service user population**.**

Among these participants, 58.6% (n=125) identified as female, with 88.2% (n=188) describing their ethnicity as Black or Black Irish/African, and 7.0% (n=15) identifying as of Asian origin. The mean age of the participants was 30.2 years (SD 10.3), with ages ranging from 16 to 63 years. Over half of the respondents reported employment, 52.3%(n=110), while approximately a quarter reported their status as students 26.1% (n=55). Notably, a high level of educational attainment was evident, with 73.6% (n=154) reporting possessing a bachelor's degree or higher.

Regarding their self-assessed health, the majority rated their general health positively, with 82.7% (n=177) describing it as excellent, very good, or good. Similarly, over three-quarters of respondents, 77.1% (n=162), perceived dental health as excellent, very good, or good. Only a limited number of participants, 20.9%(n=43) believed that their SkCD had an adverse impact on their oral health.

All surveyed individuals reported possessing essential oral hygiene items, namely toothbrushes and toothpaste. The majority, 62.8% (n=130) said they brushed their teeth at least twice daily, whereas 29.5% (n=61) admitted consuming sugary drinks six or more times per week.

Intriguingly, a large proportion, 82.8% (n=173) reported that their mouth was not routinely examined as part of their annual health screening by the SkCD healthcare team. The participants' beliefs and perceptions were assessed following the framework outlined by Xiang et al. in 2020. It was observed that less than half of the respondents, 43.5% (n=91) agreed or strongly agreed that they were susceptible to caries, while only 26.3% (n=55) felt at risk of periodontal disease. Conversely, participants had a marked positive perception of the benefits of regular brushing and flossing.

Frequent dental attendance was not a common practice, with only a third of respondents reporting attendance every six months 13.0%(n=27) or at least once per year 20.2% (n=42), while 44.4% (n=92) indicated visiting the dentist solely in the event of oral issues. Twenty-one participants had never seen a dentist, with over a third (n=66) attributing cost as a considerable barrier to regular dental attendance. Only 16 individuals (8.1%) acknowledged a fear of dental treatment as a hindrance to dental visits. While there was a positive attitude towards overcoming barriers to dental attendance, there was a considerable absence of external cues or reminders for oral health practices among the participants.

The likelihood of being an irregular (*symptomatic or never*) attender compared to being a regular attender was 0.44 times more likely per unit rise in the Barrier scale score (OR= 0.439, 95% CI = 0.24-0.79, $p < 0.007$). This indicated that increasing the perception of barriers reduced the likelihood of regular dental attendance. No other variable was found to significantly predict attendance in the model.

The study also uncovered individuals' experience of sickle crises due to infections within the past two years, as reported by two individuals. Three

participants also recounted instances of dental treatment refusal owing to their condition. A major proportion, 53.3% (n=113) expressed the intention to visit the dentist solely when experiencing oral problems, with 39.4% (n=78) believing routine dental visits were unnecessary. Additionally, 24.2% (n=48) admitted to either forgetting or being unable to schedule dental appointments, while a further 10.1% (n=20) cited a lack of time as a hindrance to dental attendance.

**Conclusions:** In summary, this study sheds light on the oral health beliefs and behaviours among ASkCD in Ireland, a group whose oral health beliefs and behaviours have remained largely unexplored until now. The findings indicate that a significant proportion of ASkCD in Ireland perceive their general and oral health positively, with a majority reporting excellent, very good, or good oral health. However, a notable portion of the participants did not perceive SkCD as impacting their oral health, and oral health checks were not routinely included in their annual health screenings by the SkCD team.

While participants showed a strong positive attitude towards the benefits of regular oral hygiene practices, such as brushing and flossing, there were gaps in their perceived susceptibility to oral issues, particularly periodontal disease. Interestingly, participants demonstrated a generally positive attitude towards overcoming barriers to dental attendance, even though external cues and reminders for oral health practices were lacking. The study also identified a potential link between cues to action and dental attendance frequency. Despite most participants having access to toothbrushes and toothpaste and engaging in regular toothbrushing, frequent dental attendance was not commonly reported. Barriers to dental attendance included cost, forgetfulness, lack of time, and a belief that dental visits were

unnecessary. Some participants also reported experiences of sickle crises due to oral infections and refusals of dental treatment due to their condition.

In light of these findings, it is evident that there is a need for a more holistic and patient-centred oral healthcare model for ASkCD in Ireland, considering their unique beliefs, behaviour, and barriers to dental attendance. Further research and targeted interventions are essential to address these specific challenges and promote better oral health outcomes for this population. This study provides a valuable foundation for designing such interventions and improving the oral health and overall well-being of ASkCD in Ireland.

# SUMMARY

**Aim & Objectives**: The study aims to analyse the oral health beliefs and behaviours of ASkCD attending Ireland's national adult sickle cell service centre while also identifying barriers to oral care. This information will be used to design improved oral healthcare pathways to prevent dental crises and investigate factors influencing dental service utilization.

**Method and Material**: After obtaining ethical approval, a comprehensive cross-sectional survey was conducted amongst the entire population of ASkCD attending this service centre, employing a total population sampling approach. Participants autonomously completed a meticulously standardized and pilot-tested anonymous questionnaire during their transfusion therapy sessions. Oral health beliefs and behaviours were assessed using well-established measures (as outlined by Xiang et al. 2020). Furthermore, the survey thoroughly investigated sociodemographic factors, self-reported health and oral health status, oral health behaviours, and dental attendance patterns. The preliminary data analysis plan incorporates elementary descriptive statistics, with subsequent adoption of logistic regression to discern predictors of reported dental attendance drawn from a spectrum of health beliefs.

**Results:** This study surveyed 214 participants (93.04% response rate) attending a national sickle cell service centre in Dublin, Ireland. Most participants were female (58.6%) and of Black or Black Irish/African ethnicity (88.2%), with a mean age of 30.2 years. The majority rated their general health (82.7%) and dental health (77.1%) positively. Few believed SkCD impacted their oral health (20.9%). The mouth was not routinely checked during annual health screenings (82.8%). Beliefs showed lower perceived

susceptibility to caries (43.5%) and periodontal disease (26.3%). Positive attitudes toward oral health practices were prevalent, but cues to action were lacking. Dental attendance was infrequent, with cost and ambivalence as barriers. The likelihood of regular attendance increased with higher cue-to-action scores. Few participants reported sickle crises due to dental infections (n=2), though a minority reported dental treatment refusals (n=3). Many intended to visit the dentist only when experiencing trouble (53.3%), while some believed routine visits were unnecessary (39.4%), citing forgetfulness (24.2%) or lack of time (10.1%).

**Conclusion**: This study reveals that (ASkCD) in Ireland generally perceive their oral health positively, yet there are gaps in their awareness of oral issues related to their condition. Despite a positive attitude toward oral hygiene practices, barriers such as cost and misconceptions about dental visits limit frequent dental attendance. Thus, a patient-centred oral healthcare model addressing these unique needs and beliefs is crucial for this population.

The study's findings have broader implications for informing policy, enhancing practices, and advancing oral health promotion efforts. Further research and tailored interventions are necessary to improve their oral health outcomes.

# ACKNOWLEDGEMENTS

In the name of ALLAH, The Most Gracious, The Most Merciful

I express my deepest gratitude to the government of the Kingdom of Saudi Arabia for affording me the invaluable opportunity to advance my skills and knowledge in dentistry, enabling me to extend my services to those in need.

My heartfelt thanks extend to my principal supervisor and SCD program director, Professor Alison Dougall. Her insightful guidance, unwavering support, and immense patience were instrumental throughout this thesis journey. Without her exceptional wisdom and steadfast belief in my doctorate, this thesis would not have come to fruition.

I extend immense appreciation to my co-supervisor, Dr.Caoimhín Mac Giolla Phádraig, for his valuable advice and encouragement, continuously inspiring me to evolve as a proficient clinician and researcher.

I acknowledge with gratitude the constructive input and feedback provided by Professor Blánaid Daly and Professor Colman McGrath on this thesis.

Being mentored by Dr.Siobhan Stapleton to become a Specialist in Special Care Dentistry was a privilege.

My appreciation also goes to Dr.Mary Clarke, Dr.Danielle McGeown, Dr.Michael O'Sullivan, Dr.Osama Omer, and Dr.Ioannis Polyzois for their valuable clinical knowledge and guidance.

I extend my thanks to Mr. Nowell Noel Ngwenya and Ms. Ciara Sheehan, whose support and guidance were pivotal in shaping this thesis.

Special gratitude is extended to all who contributed to my positive postgraduate journey - my parents, siblings, close friends, and family in Saudi

Arabia & Kuwait, who ensured the well-being of my wife and children while I pursued my studies.

Thanks are due to Ms. Amy Fisher , Salman BuAbbas and Ahmad Budairi for facilitating my seamless transition into Dublin, my fellow postgraduates, especially Kim, Jessica, Ivana, Riikka, and Ayisha; my friends Isabel and Coon, Othman W. , A. Ashkanani, S. Muwail, I. Demestani and all my other wonderful friends from Kuwait who supported me all the way during my studies, as well as the staff at DDUH, particularly the Division 1 ladies, Susan, Anne, Grace, ladies of West Clinic, Erin, Eleanor, Elaine B, Catherine, Sviatlana, Audrey, Healy, Tamara, Louise, Carol, Sinead, Mary Joy, Emma, and Liz from Clinic 2; and Laura from St. James Hospital. Your prayers, support, and encouragement have been invaluable throughout my course.

Finally, to my beloved wife, Fatimah, I am profoundly indebted for her unwavering support, understanding, and sacrifices, which made this dream of mine a reality.

To my daughter, Dana, and my sons, Ali, Mohammad, and Suliman, may this achievement serve as a perpetual inspiration in your pursuit of dreams.

---

# Table of Contents

# List of Figures

# List of Tables

# 1.Introduction and Literature Review

Chapter one shows the case for the current study based on demographics and the need for evidence-based health service planning. This section opens with an introduction to Sickle Cell Disease (SkCD), its genetic basis and pathophysiology. Epidemiology is then explored, focusing on the increasing prevalence in Europe, particularly in Ireland, and the challenges such trends present. The morbidity and mortality of SkCD are reported alongside corresponding healthcare strategies aimed at improving life expectancy and quality of life for those affected. Evidence regarding the oral health of ASkCD is next presented, reflecting the critical need for tailored oral health services.

Before understanding how to design better oral healthcare services for ASkCD, the literature on oral health service utilisation is briefly introduced, with a particular focus on the impact of beliefs on health behaviour. As such, the Health Belief Model (HBM) is presented in some detail to explain its use in this study to understand the oral health beliefs specific to ASkCD. This section concludes with a rationale for the study by illustrating the research gap that this thesis aims to address.

## 1.1 Sickle Cell Disease

SkCD is one of the world's most common and frequently critical hereditary single-gene diseases (Walker et al. 2021). SkCD is an autosomal recessive hereditary disorder that disturbs haemoglobin, a protein transported by the red blood cells that distribute oxygen all over the body (Abed et al. 2019; Global Blood Therapeutics 2020). Haemoglobin is a globular protein particle consisting of two pairs of polypeptide chains, each of which is surrounded by a heme molecule. The formation of a normal haemoglobin molecule (HbA)

involves two α-chains and two β-chains, which could be triggered by a genomic alteration that progresses with the existence of an obvious distortion in the β chains (Abed et al. 2019; Global Blood Therapeutics 2020).

SkCD is a clinical syndrome that occurs when haemoglobin S (HbS) is present as a single gene deformity. HbS leads to what is called a sickle cell trait that causes the formation of improperly produced haemoglobin that leads red blood cells to transform shape from round to sickle or crescent shape (Williams et al. 2018; Global Blood Therapeutics 2020; Walker et al. 2021).

The homozygous form (HbSS) is mostly identified as sickle cell anemia (SCA) and results once there are two faulty β chains. It is the common reason (65–70%) for SkCD (Williams et al. 2018; Global Blood Therapeutics 2020).

The sickling process promotes premature red blood cell breakdown, resulting in haemolytic anemia, as well as preventing red blood cells from flowing through the tiny blood arteries, obstructing the oxygen supply. This subsequently causes a vaso-occlusive crisis and ischemia (Walker et al. 2021).

### 1.2 Historical Epidemiology

Although known in Africa for generations, SCA made its debut in Western literature in November 1910. This recognition occurred when Herrick documented a case of anemia in a dental student from Grenada (Chakravorty et al. 2015; Williams et al. 2018).

#### 1.2.1 Global Impact

The World Health Organization designated SkCD as a worldwide public health issue. This decision followed the emergence of epidemiological evidence indicating that around 300,000 new-borns globally are born with SkCD each year, a number projected to exceed 400,000 by 2050 (McMahon et al. 2001;

Gibbons et al. 2015; Abed et al. 2019). Initially concentrated in India, Sub-Saharan Africa, the Middle East and the Mediterranean region, then SkCD has witnessed a significant shift in its global distribution and has evolved into a worldwide health challenge due to human migration, particularly over the past 10-15 years (Gibbons et al. 2015), with a substantial number of cases now occurring even in higher-income countries like European countries and United States (Chakravorty et al. 2015).

### 1.2.2 Sickle Cell Disease in Europe

SkCD is on the rise in Europe despite being classified as one of the region's most prevalent rare diseases. In 2019, the European Medicines Agency (EMA) reported that approximately 1 in 10,000 individuals in the EU/European Economic Area had SkCD, totalling around 52,000 affected individuals (Global Blood Therapeutics, 2020). Orphanet, a rare disease information source, estimated a slightly higher prevalence, indicating that in 2020, there were ten cases per 100,000 individuals affected by SkCD (Global Blood Therapeutics, 2020). It's important to note that the actual prevalence of SkCD and other haemoglobin disorders might be underestimated due to reasons such as limited access to healthcare and diagnostic facilities and the absence of national registries (Global Blood Therapeutics, 2020).

### 1.2.3 Sickle Cell Disease in Ireland

In the early 2000s, Ireland experienced a significant shift in its demographic makeup due to increased immigration. This influx of people from various parts of the world laid the foundation for a noteworthy transformation in the landscape of SkCD within the country. At that time, SkCD prevalence within the Irish population was very low, with only twenty children known to be affected in 2000. However, this would change over the next two decades.

Between 2000 and 2020, the number of people presenting as patients with SkCD in Ireland surged dramatically, soaring from a mere 20 to over 500. This transformation is meticulously documented in studies by Fogarty et al. 2022.

In 2015, Gibson and their team delved deeper into the change in Irish trends. Their study examined 109 children referred to the haemoglobinopathy(Hb) services provided by either St. James Hospital, Dublin or Our Lady's Children's Hospital, Dublin, between January 2009 and December 2012. Within this group, 78 children were native-born Irish, indicating a noteworthy increase in the trend of SkCD within the Irish population. In response, the Hb service expanded significantly, serving 396 children by 2011. This expansion highlighted the growing challenges posed by SkCD within the healthcare system in Ireland.

The 2011 national census in Ireland painted a stark picture; it revealed that 19,423 children under the age of fifteen were now at risk of developing SkCD due to their ethnic backgrounds (Central Statistics Office 2011).

In summary, the narrative of SkCD in Ireland unfolds as a sequence of findings, highlighting the effects of immigration, the steady rise in SkCD cases, and the diverse population affected by this condition. These findings underscore the need for ongoing research and targeted interventions to address the evolving landscape of SkCD in Ireland's healthcare system.

### 1.3 Morbidity and Mortality

Repeated sickling causes chronic organ damage, contributing to early mortality and significant lifelong morbidities (Ware et al. 2017). These challenges include anemia-related symptoms such as shortness of breath, fatigue, and developmental delays in children, along with risks of acute chest

syndrome, stroke, blindness, and bone damage. Pain crises, a hallmark symptom of SkCD, vary in frequency among individuals (Global Blood Therapeutics, 2020). Additionally, as ASkCD age, they become increasingly susceptible to end-organ damage, further elevating mortality and morbidity risks (Maitra et al. 2017). The health effects outlined above significantly affect the quality of life, resulting in decreased productivity at school and work due to both acute and chronic injuries. This situation leads to an escalation in the utilization of both outpatient and inpatient healthcare facilities (Lubeck et al. 2019).

Given the above, it is perhaps unsurprising that SkCD has such a major impact on life expectancy that screening programmes are now well-established in many Western countries. As a result of such screening programs, infant mortality has been reduced from 8% to 1%, with a significant reduction in mortality among those under-five years of age (Gibbons et al. 2015). This can be attributed to the early commencement of neonatal screening, vaccinations, prophylactic antibiotics to prevent infection, as well as the introduction of hydroxyurea (Lubeck et al. 2019). This indicates a need for improved care as ASkCD enters adulthood and beyond.

### 1.4 Pathophysiology

Pathologically, SkCD is characterized by a high degree of adhesion between erythrocytes, leukocytes, and endothelial cells, resulting in a slowed blood flow (Hsu et al. 2020). In this case, erythrocytes then aggregate into foci as the haemoglobin molecules are defective. Extended exposure to low oxygen levels may trigger the sickling process. The red blood cells in the body normally circulate for fifteen seconds, but if they sickle, they become rigid and irregular. This causes the blood viscosity to increase, causing infarction

(Abed et al. 2019). Acute pain, dehydration, acidosis, fever, infection, and stress can contribute to the sickling process. To prevent sickling, the exacerbating factors should be reduced. Patients with classic-type (homozygous) SkCD can experience a variety of crises, including painful crises, aplastic crises, megaloblastic crises, and splenic sequestration crises (Abed et al. 2019).

### 1.5.Oral Health for Adults Living with Sickle Disease

ASkCD often experiences compromised oral health due to a combination of factors related to their condition and its treatment (Mulimani et al. 2019). SkCD can affect blood flow and oxygen delivery to various body parts, including oral tissues (Acharya et al. 2015). This diminished blood flow can lead to issues such as delayed wound healing, making it challenging for the oral tissues to recover from injuries or infections (Brandão et al. 2018). Additionally, ASkCD may require frequent blood transfusions or medications, which can impact oral health by increasing the risk of iron overload and subsequent complications such as staining or damage to the teeth (Coates et al. 2017). Furthermore, the condition may cause chronic fatigue, making it difficult for individuals to maintain a consistent oral hygiene routine, further exacerbating the risk of oral problems (Ralstrom et al. 2014).

A recent study by (da Costa et al. 2023) achieved a systematic review and meta-analysis to determine the occurrence of orofacial changes in SkCD and compare it to the general population. The study reviewed 770 records, selecting 28 relevant studies. In ASkCD, the study found a prevalence of 57% for decreased bone density, 30% for a mandible stepladder pattern, 20% for delayed tooth eruption, and 66% for malocclusion. Additionally, patients

with SkCD showed varying prevalence of tooth necrosis, periodontal disease, and neuropathies.

### 1.6 Oral Health Services Should Support Utilisation, Treatment and Prevention

While regular dental check-ups, specialized care, and diligent oral hygiene are obvious recommendations to protect the oral health of ASkCD (Mulimani et al. 2019), however, a nuanced approach to understanding the service needs is required. Researchers recognise the need for a comprehensive and multifaceted approach to oral healthcare delivery for ASkCD that is tailored and holistic. As a basic first step, ensuring accessibility and affordability of dental services is vital (Vujicic et al. 2016). Specialized oral healthcare clinics or units within healthcare facilities that understand the unique needs of ASkCD can provide tailored oral care. This includes regular dental check-ups, oral health education, cleanings, and early intervention for any oral issues. Recommendations have been made to integrate oral health services into the overall care plan for ASkCD, emphasizing the interconnectedness of oral health with their general health (Javed et al. 2013).

Another recommendation for service design includes utilizing telehealth and digital platforms that can facilitate ongoing consultations and monitoring (Daniel et al. 2019). This is particularly beneficial for ASkCD, who may face challenges in travelling or maintaining regular in-person appointments (Maqsood et al. 2021). Providing guidance on oral hygiene practices and self-care at home can further empower individuals to maintain better oral health.

Lastly, the need for nuance in design means addressing the health beliefs of ASkCD about the specific oral health challenges associated with the condition (Holderle et al. 2021). Modifying their beliefs about the increased risks of oral

complications, such as delayed wound healing and susceptibility to infections, is crucial to influencing their regular dental check-ups and preventive measures (Sams et al. 1990).

### 1.6.1 Factors Influencing Behaviours Around Oral Health

Understanding the behaviour of ASkCD concerning oral health is crucial for devising effective strategies to support positive health behaviours, including dental service utilization. From a dental service utilization perspective for ASkCD, their behaviour is influenced by a variety of factors, such as:

Pain and discomfort management: Chronic pain is a significant aspect of SkCD (Childerhose et al. 2023). Fear of triggering pain during dental procedures may cause individuals to avoid or delay dental visits.

Previous negative experiences: Negative past experiences with oral care, such as pain, insensitivity, or lack of understanding from healthcare providers, can lead to dental anxiety and reluctance to seek further dental treatment (Cohen et al. 2000).

Perceived severity: Awareness regarding the potential severity of oral issues related to SkCD can vary. Individuals might not entirely recognise the impact of their condition on oral health or may not prioritize it compared to other health concerns (Maggirias et al. 2002).

Socioeconomic factors and access to care: Limited financial resources, lack of insurance, or living in areas with inadequate access to dental services can significantly affect their capability to look for regular oral care (Limo et al. 2023).

Psychological factors: Mental health challenges like anxiety or depression, often associated with dealing with a chronic illness like SkCD, can affect an

individual's willingness to engage in oral care (Jenerette et al. 2005; Tiwari et al. 2022).

Trust and communication with healthcare providers: Trust and effective communication with healthcare providers, including dentists, are crucial. A good relationship with the healthcare team can encourage individuals to seek oral care and follow recommendations (Röing et al. 2014).

Cultural beliefs and practices: Cultural beliefs and practices related to health and illness, including oral health, can strongly influence their behaviour towards seeking oral care (Butani et al. 2008). Addressing these beliefs and providing culturally sensitive care is essential.

Peer and family influence: Family members and peers can significantly impact health-seeking behaviour. Encouragement and understanding from loved ones can motivate individuals to prioritize their oral health and seek oral care (Duijster et al. 2017).

Understanding and addressing these behavioural factors through targeted education, improving access to oral care, fostering trust through positive experiences, and integrating oral health within their overall healthcare management may significantly enhance dental service utilization and improve oral health outcomes for ASkCD.

### 1.7 Health Belief Model

Given the wide range of beliefs that are understood to influence oral healthcare utilisation among ASkCD, this section introduces a model of health behaviour that provides a structured and theoretically robust means of exploring such beliefs and their influence on oral healthcare utilisation in detail. This study adopted the Health Belief Model (HBM) as the theoretical

basis for understanding the health service use of ASkCD. It was felt that this model was suitable because it allows for a comprehensive examination of individual perceptions, motivations, and barriers related to oral health within the context of SkCD. The HBM's constructs, including perceived susceptibility, severity, benefits, barriers, and cues to action(Figure 1), provided a solid framework to elucidate the intricate dynamics influencing oral healthcare behaviour in this specific population. By applying the HBM, we aimed to derive actionable insights that can inform targeted interventions promoting improved oral health practices and better healthcare services utilization among ASkCD.

### 1.7.1 Health Beliefs Model Principles

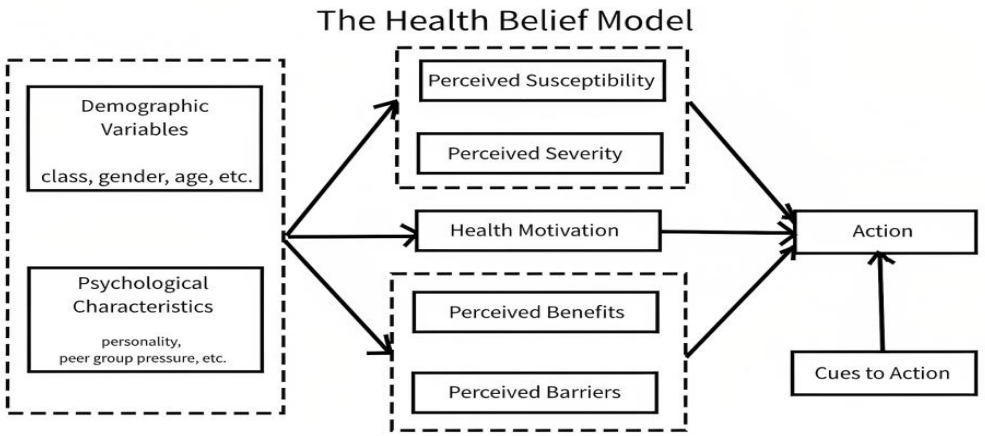
Historically, HBM was first proposed by Hockbaum in the 1950s and adopted by the United States Public Health Service in the 1970s. It was one of the first attempts to view health in the context of society at large (Hollister et al. 2004). In order to get the optimal results from health communication campaigns, Rosenstock in 1966 re-formulated the HBM to focus on individual beliefs and perceptions regarding health conditions and health-promoting behaviours (Rosenstock et al. 1974). According to this model, when individuals perceive a negative health outcome to be severe, perceive themselves as susceptible to it, believe that adopting behaviours to mitigate this outcome holds significant benefits, and view the barriers to adopting these behaviours as low. They will likely engage in such behaviour (Carpenter et al. 2010).

The key principle of HBM is that health-related decisions are better when individuals have better information. When one is ready to accept new concepts, self-understanding will be enhanced. People will be able to make

intelligent, independent, mature decisions if they have a better understanding of how and why they make choices. Every step in the HBM depends on the previous decision or belief to determine the next step in the process (Hall, 2011). In this theory, individuals should believe that a condition is serious, that a successful treatment intervention exists, and that they can overcome all barriers to using the treatment (Hollister et al. 2004).

HBM is one of the most broadly used behavioural science models, and multiple reports support the positive influence that educational programs underpinned by HBM theory have on children, teenagers, and adults regarding oral health beliefs (Hosseini et al. 2014; Rahmati et al. 2016).

**Figure 1 Health Belief Model**(Adapted from Rosenstock et al. 1988)




### 1.7.2 Adherence

Adherence is the degree to which people adhere to or follow prescribed guidelines, suggestions, instructions, or treatment plans. It includes following a prescribed regimen consistently and accurately, such as taking medications as directed, following a particular diet or oral hygiene programme, engaging in regular exercise, attending doctor appointments, or making suggested lifestyle modifications. Adherence is essential to the success of medical

interventions, therapies, and treatments since failing to follow instructions can influence results and general health (Hegedüs et al. 2014; Fogarty et al. 2022).

An individual's adherence to positive oral health behaviours, including regular dental check-ups, is influenced by their perception of oral health threats and their expectations regarding the effectiveness of dental visits in mitigating these threats. For instance, when considering encouraging individuals to schedule and attend dental appointments regularly, three critical factors come into play; perceived susceptibility, people need to believe that they are susceptible to oral health diseases such as periodontal disease or cavities. Perceived severity, individuals should be concerned about the seriousness of oral health problems. Understanding that untreated oral issues can lead to pain, discomfort, and even more severe health complications can motivate them to take oral care seriously. Also, perceived benefits and motivation play a significant role in dental attendance. People are more likely to prioritize their oral health when they are genuinely motivated to do so. This motivation may arise from a desire to maintain a healthy smile, prevent dental pain, or avoid more extensive and costly treatments in the future.

Moreover, the HBM indicates that individuals are more likely to attend dental appointments when they receive "cues to action." These cues can be internal and external, such as experiencing dental pain, discomfort, or noticing changes in oral health (e.g., bleeding gums), or they come from their social environment or healthcare providers. For example, external cues include friends, family members, or dentists recommending regular check-ups.

Encouraging positive oral health practices and better dental attendance patterns involves fostering a belief in one's susceptibility to oral issues, raising awareness of the severity of these problems, and motivating individuals to prioritize their oral health. Additionally, providing internal and external cues can prompt individuals to take proactive steps to maintain their oral well-being. This approach aligns with the principles of the HBM and can contribute to improved dental attendance patterns within the general population (Ramseier et al. 2011).

### 1.8 SkCD and HBM Together to Identify Gaps in Understanding Oral Health Beliefs and Behaviours in Patients with SkCD

From the preceding review, it is clear that health beliefs are likely to influence the oral health practices and oral healthcare service utilisation of ASkCD. This is extremely important in Ireland now because of changing demographics. The HBM offers a robust lens through which to observe facilitators and barriers to accessing oral care. Data are needed to ensure that those who design and deliver services can relate to the nuances of patents' beliefs and behaviours so that holistic, appropriate services can be delivered to ASkCD in Ireland.

To address the gap in understanding the ASkCD, this study was conducted to systematically comprehend the beliefs and behaviours related to oral health care service use in ASkCD. This approach involved a comprehensive strategy. Initially, a structured survey was created to explore their perceptions of oral health, dental care, and past experiences, aiming to gain valuable insights from the perspective of an ASkCD. The questions focused on their perceived susceptibility to oral issues, potential problems' severity, and perceived benefits and barriers to seeking oral care. Also, the survey was planned to

gather information about people's knowledge of oral health and their understanding of the connection between SkCD and oral health, recognizing the vital importance of this data**.** This information could be helpful in designing targeted educational campaigns and interventions tailored to address their specific beliefs and concerns, emphasizing the significance of regular oral care in order to effectively motivate behavioural changes that align with optimal oral health practices within this population. Maintaining a culturally sensitive and empathetic approach was crucial to fostering trust and understanding throughout this process.

---

# 2.Methods

## 2.1 Study Design

A cross-sectional survey among all ASkCD who attended the Adult Sickle Cell and Thalassemia Service Centre (SCTSC) at St James's Hospital (SJH), Dublin, Ireland. The study was reviewed and approved in Jan 2022 by the Local Hospital Research Ethics Committee (LREC) St James's Hospital/Tallaght University Hospital Joint Research Ethics Committee(Project ID:0438). See Appendix 1 for a copy of the approval letter.

## 2.2 Setting

The study was conducted in SCTSC at St James' Hospital from 22 January 2022 to 23 January 23. The centre provides a service to all adult patients with SkCD and/or thalassaemia who are referred there by their general practitioner/consultant or through a transition clinic from the national children's hospital in Ireland. SCTSC offers a range of diagnostic, treatment, and support services for adults. As a medical speciality centre, the primary responsibility of the SCTSC lies in providing specialised medical treatment and providing support and advice to patients relating to their physical and social well-being. In contrast to the children's SkCD service, no dentist is assigned to the SCTSC. The SCTSC maintains a national database listing all people using SkCD services living in Ireland.

## 2.3 Population and Sampling

The population of interest included all adult people (n=230) who registered at the SCTSC to manage SkCD. All potential participants had been diagnosed with SkCD prior to this study. Full eligibility criteria are listed in Table 1 below. From 22 January 2022 to 23 January 2023, all patients who were regularly

attending their yearly clinical reviews (n=216) at the SCTSC were approached in a sequential manner and invited all patients to participate in the study.

**Table 1: Eligibility criteria**

| Inclusion criteria | Exclusion criteria |
|---|---|
| ● Women and men aged 16 and over<br>● Currently registered at SCTSC in SJH<br>● Have a diagnosis of SkCD<br>● Can read, understand English | ● Women and men aged under 16<br>● Patients with any other Hemoglobin disorders, including Thalassemia<br>● Can not read, understand English |

## 2.4 Recruitment

On the day of their scheduled annual review in the out-patient department, patients were approached and identified as meeting inclusion criteria by a member of the ward team against eligibility criteria and invited to participate in the research. They were supplied with a copy of the Patient Information Leaflet (PIL) and given at least 30 minutes to consider participating in the study. See Appendix 2 for a copy of the PIL. The PIL was given to each participant and clearly stated that:

-Participation in the study was entirely voluntary.

-Participants were free to decline or accept without having to provide a reason.

-Should the participant choose not to enter the study or withdraw from the study at any time, they were assured that this in no way affected their care.

-Participants were assured their responses were fully anonymised.

-The ward team were on hand to support participants with literacy problems or answer specific participation questions.

**2.5 Informed Consent**

Consent posed an ethical consideration within the research, particularly concerning various aspects of the study, such as pressure to participate and participants' fears that refusal might compromise or result in withdrawal of care. The researcher(HI) took steps to ensure that participants fully understood these aspects by presenting a comprehensive PIL that elucidated all these points and concerns. The PIL was drafted a number of times and pilot-tested on 25 individuals for clarity and understanding. Ample time was allocated for participants to seek clarification or pose questions regarding any apprehensions they might have had. A member of the ward team, rather than the treating clinician, was chosen as a point of contact to reduce anxiety about the possible impact of refusal to participate on receipt of medical care. Additionally, it was emphasized to participants that the purpose of the questionnaire was not to assess their knowledge but to collect information about their opinions and personal experiences. Participants were also explicitly informed about the confidentiality of their involvement, their voluntary choice to participate, and their entitlement to withdraw from the study at any point. The nature of the study was a self-complete anonymous questionnaire; submission of the completed questionnaire implied consent. It was confirmed that participants in this study, being over 16, were able to provide their own informed consent. Once all these matters were thoroughly addressed, the research proceeded. This study did not involve financial incentives or other rewards.

## 2.6 Data Collection

The ward team distributed the PIL to patients who met the selection criteria. When participants indicated they were happy to proceed, they were supplied with an anonymous questionnaire, and they self-completed the questionnaire while having their transfusion (approximately three hours). The questionnaire usually took no more than 10-15 minutes. Participants were asked to place the completed fully anonymized questionnaires into the box in the ward marked 'Completed Forms'.

## 2.7 Data Management

The data for the present study were gathered from 22 January 2022 to 23 January 2023. The anonymised forms were collected by the researcher(HI) from the ward on a regular basis and transported in sealed self-addressed envelopes to the Dublin Dental University Hospital(DDUH) for data input and analysis. Data storage and management were guided by the general data protection regulation (GDPR) of the European Union (EU) 2018.

Datasheets at the DDUH were collected, coded, and inputted by the researcher (HI) into a password-protected computer and saved as a password-protected file. The responses from the self-report questionnaire were first entered by the researcher (HI), then the data were merged into one Excel spreadsheet and then cleaned and checked again for any anomalies. Every 10th entry was checked for entry accuracy. Each record took approximately 25 minutes to input. The paper files will be destroyed as confidential medical record waste at the DDUH.

## 2.8 Data Collection Instrument

The self-report questionnaire was in two sections. The questionnaire was piloted initially by ten dental staff and postgraduate students. Then, a second pilot took place with twenty-five potential participants. Feedback was positive, and questionnaire completion took approximately 15 minutes. There were minimal changes needed to the questionnaire after piloting. All individuals who participated in the pilot reported that they understood the questions without difficulty.

The first section, using validated questions from previous population studies, recorded sociodemographic data (CSO, 2017), self-report of health (Ware et al. 1992), self-report of oral health (White et al. 2012), oral health behaviours and dental attendance patterns (O'Sullivan et al. 2011).

In the second section of the questionnaire, the study used a validated 35-item instrument called the "Oral Health Behaviour Questionnaire for Adolescents based on the Health Belief Model (OHBQAHBM)" This instrument assessed six key factors related to the health belief model: perceived susceptibility, perceived benefits, perceived severity, perceived barriers, cues to action, and self-efficacy. Permission to use this questionnaire in the study was obtained from the original authors (Xiang et al. 2020). A brief validation exercise was undertaken with the principal author(Professor Colman McGrath) to ensure the meanings of questions used in the original survey were maintained in the Irish study. This applied to one question where the original question was poorly phrased in English and was rephrased for use in the Irish setting. See Appendix 3 for a copy of the questionnaire.

## 2.9 Sample Size

The study team decided on the sample size based on discussions with the SCTSC team. Conversations with the SCTSC team indicated that it was feasible to approach the entire population of adults over 16 years with SkCD attending SCTSC for the study. The study protocol, including statistical advice and sample size calculation, was prepared prior to the study.

## 2.10 Analysis

Analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 27.0 (SPSS Inc. Chicago, IL, USA, 2021) in two phases: Firstly, descriptive statistics were reported in frequencies and percentages for categorical data, and numerical variables by means and standard deviation. These analyses summarise the sample, participants' service use and reported barriers, perceived susceptibility, perceived benefits, perceived severity, perceived barriers, cues to action, and self-efficacy.

Secondly, logistic regression analyses were applied to assess the relationship between service use and health beliefs to assess the likelihood of being an irregular (symptomatic or never) attender compared to being a regular attender, based on differences in health belief scores. A 95% confidence level (CI) and a significance level (P-value) of 0.05 were adopted.

# 3.Results

## 3.1 Participant Flow

The research was conducted from January 22, 2022, to January 23, 2023. Out of a potential pool of 216 participants, a total of 214 individuals took part in the study. This sample size of 214 participants was drawn from the larger population of 230 individuals who are currently registered with the SCTSC, St. James Hospital and expected to attend during the calendar year, resulting in a response rate of 93.04%.

## 3.2 Demographics

As per Table 2, the sample gender distribution consisted of 125 females (58.6%) and eighty-eight males (41.3%). The ages of participants ranged from 16 to 63 years. The mean age for all participants was 30.2 years (SD 10.3).

Most respondents, 88.2%(n=188), described themselves as Black or Black Irish, with 7.0% describing themselves as Asian.

Over half of the respondents, 52.3%(n=110) described their status as employed or working for profit. More than a quarter of the participants, 26.1%(n=55) were students; the remainder were either unemployed or looking for a job.

The respondents showed high educational achievement, with 73.6% (n=154) reporting a bachelor's degree or higher. More than a quarter of the participants have described themselves as having secondary education or lower, 26.3%(n=55).

**Table 2 Sociodemographic characteristics of the sample of patients with SkCD**

| Sociodemographic characteristics* | | N (valid%) |
|---|---|---|
| **Gender** (n=213) | **Female** | 125 (58.6%) |
| | **Male** | 88 (41.3%) |
| **Age Group** (n=208) | **15-24** | 82 (39.4%) |
| | **25-44** | 99 (47.5%) |
| | **45-64** | 27 (12.9%) |
| **Nationality** (n=212) | **Irish** | 136 (64.1%) |
| | **Other** | 76 (35.8%) |
| **Ethnicity** (n=213) | **Black/Black Irish** | 188 (88.2%) |
| | **Asian** | 15 (7.0%) |
| | **White** | 6 (2.8%) |
| | **Others** | 4 (1.8%) |
| **Education Levels** (n=209) | **Bachelor's Degree or Higher** | 154 (73.6%) |
| | **Secondary or Lower or No Education** | 55 (26.3%) |
| **Employment Status** (n=210) | **Working** | 110 (52.3%) |
| | **Students** | 55 (26.1%) |
| | **Unemployed/other** | 45 (21.4%) |

*All characteristics do not add up to 214, as all participants did not report some characteristics

### 3.3 Self-Rating of General Health, Oral Health and Self-Report of The Impact of Sickle Cell Disease on Oral Health

As per Table 3, most participants 82.7% (n=177) rated their general health as “excellent” or “very good” and “good”. This compares to 77.1% (n=162) who rated their oral health as “excellent” or “very good” or “good”.

When asked about the impact of SkCD on their oral health, 48.7% (n=100) either strongly disagreed or disagreed, and 30.2% (n=62) were neutral or unsure whether there was an impact. Only 20.9% (n=43) agreed that SkCD impacted their oral health.

**Table 3 Distribution of response of the general health self-rating and oral health self-rating amongst patients with SkCD**

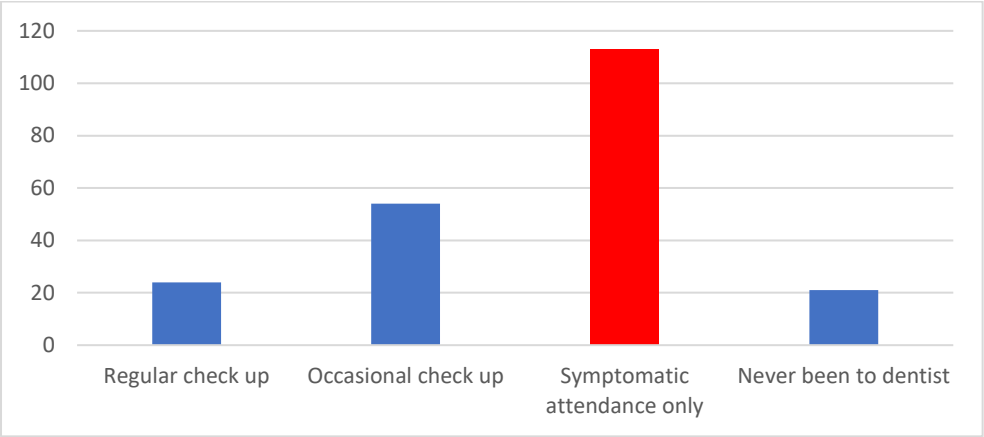
| Self-Rating | Excellent or Very good or Good | Fair or Poor |
|---|---|---|
| **General Health Self Rate***(n=214)* | 177 (82.7%) | 37 (17.2%) |
| **Dental Health Self Rate***(n=210)* | 162 (77.1%) | 48 (22.8%) |

### 3.4 Oral Health Service Use

#### 3.4.1 Regularity of Attendance

As per Figure 2, 11.3% (n=24) reported that they went regularly for a check-up. Most participants, 53.3% (n=113) reported symptomatic attendance only, while 9.9% (n=21) reported never attending a dentist.

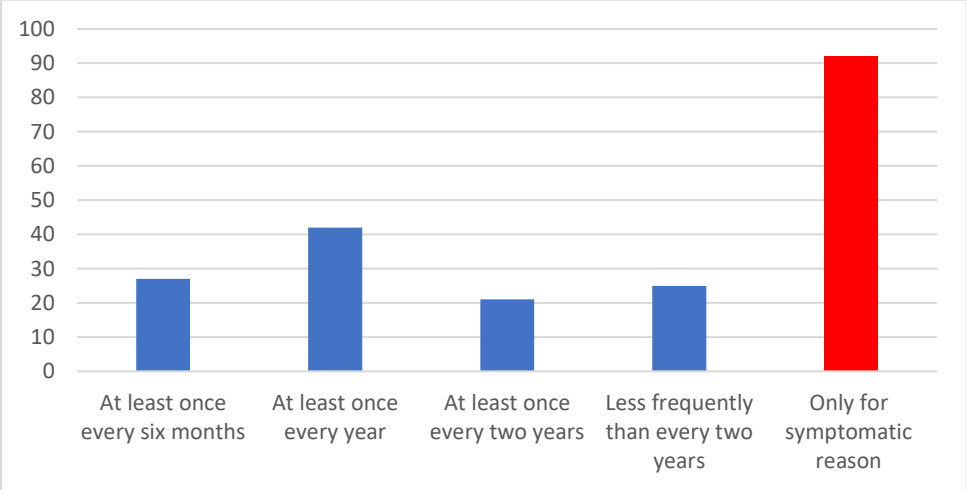
**Figure 2 Distribution of responses about the regularity of dental attendance amongst patients with SkCD** (n=212)




### 3.4.2 Reported Frequency of Dental Service Use

When participants were asked about the frequency of attendance, 13.0% (n=27) reported attending at least once every six months, while 44.4% (n=92) only reported visiting a dentist when having trouble with their teeth. Further details are illustrated in Figure 3.

**Figure 3 Distribution of reported frequency of dental service use**(n=207)



### 3.4.3 Reasons for Not Attending Dentist in The Last Two Years

Table 4 and Figure 4 illustrate the reasons reported for not attending the dentist in the last two years. The lack of perceived need was 39.4% (n=78); Cost of care 33.3% (n=66) emerged as the most commonly reported barrier to accessing oral care.

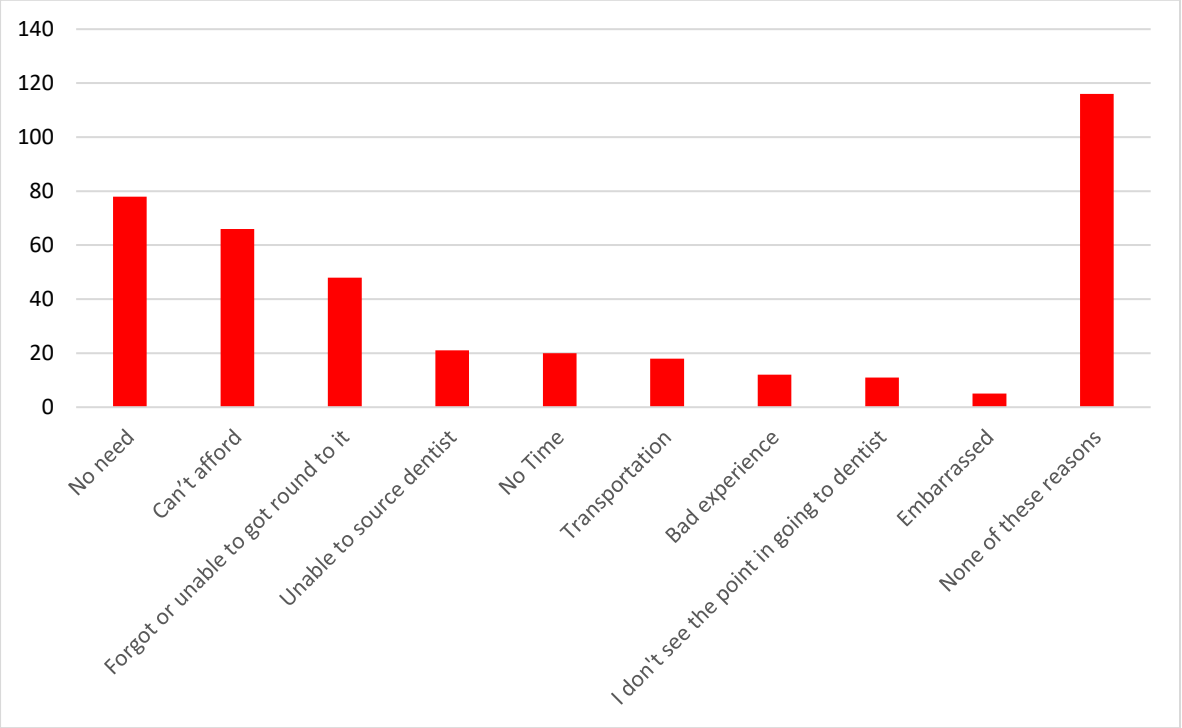
In general, among all the participants in the survey, there was a consensus of disagreement or strong disagreement regarding the notion of being denied dental treatment due to their SkCD; in other words, most participants did not believe that having SkCD had resulted in them being refused oral care.

**Table 4 Distribution of reasons for not attending the dentist in the last two years**

| Reasons for not attending dentist in last two years* | N (valid%) |
|---|---|
| **No need**(n=198) | 78 (39.4%) |
| **Can't afford**(n=198) | 66 (33.3%) |
| **Forgot or unable to got round to it**(n=198) | 48 (24.2%) |
| **Unable to source a dentist**(n=198) | 21 (10.6%) |
| **No Time**(n=198) | 20 (10.1%) |
| **Transportation**(n=195) | 18 (9.2%) |
| **Bad experience**(n=195) | 12 (6.2%) |
| **I don't see the point in going to dentist**(n=195) | 11 (5.6%) |
| **Embarrassed**(n=195) | 5 (2.6%) |
| **None of these reasons**(n=195) | 116 (59.5%) |

* This item allowed for multiple responses from each participant. All boxes not ticked were considered as a "No" response relating to the item, leading to the creation of a "No" dummy response option.

**Figure 4 Distribution of responses about reasons for not attending the dentist in the last two years.**




### 3.4.4 Oral Screening Within the Sickle Cell Services Centre

Participants were asked if an examination of the mouth was part of the medical routine assessment within the SkCD services pathway they experienced, with 82.8% (n= 173) reporting it had not. Further details are illustrated in Table 5.

**Table 5 Distribution of self-report of no oral examination within SkCD pathway services**(n=209)

| Self-report of no oral examination within SkCD pathway services | N (valid%) |
|---|---|
| **Tongue** | 159 (76.1%) |
| **Mouth** | 173 (82.8%) |
| **Teeth** | 201 (96.2%) |

### 3.5 Oral Care Behaviours

#### 3.5.1 Teeth Cleaning

Respondents were questioned regarding their oral hygiene practices, including tooth brushing and interdental cleaning routines. The majority, constituting 62.8% (n=130) of individuals, stated that they brushed their teeth twice daily, while the remaining participants reported cleaning once daily, Table 6.

Every participant surveyed confirmed having a toothbrush and toothpaste. The majority, 97.6%(n=209) stated using supplementary oral hygiene tools, including mouthwash 75.5%(n=157), dental floss 44.0%(n=92), interdental picks 29.2%(n=61), interspace brush 5.3%(n=11), electric toothbrush 28.7%(n=60), and sugar-free chewing gum 15.8%(n=33). Different toothpaste brands, including Oral B, Sensodyne, and Colgate, were utilised.

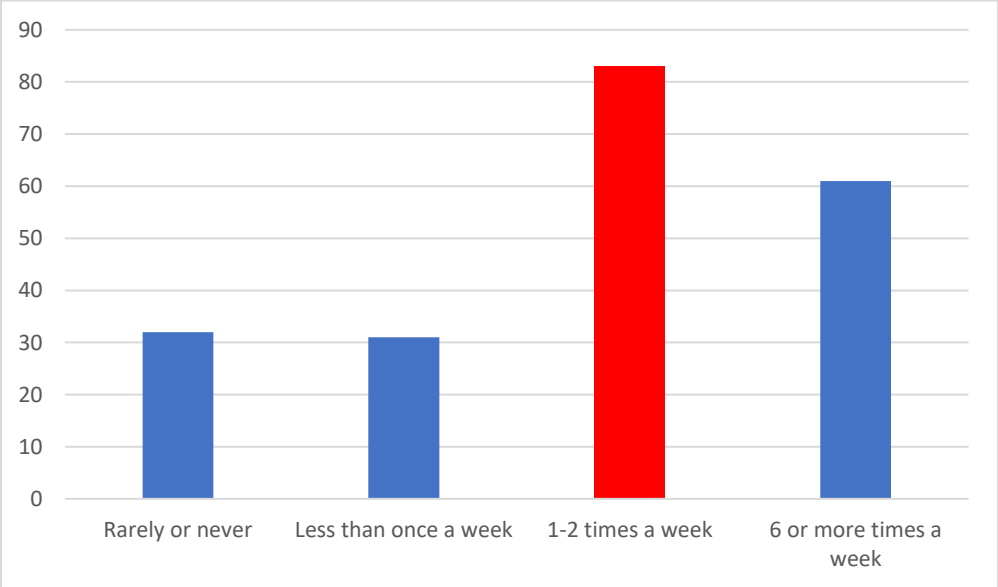
**Table 6 Distribution of self-report of teeth cleaning**(n=207)

| Teeth Brushing | N(valid %) |
|---|---|
| **Less than once a day or Never** | 0 |
| **Once a day** | 77 (37.1%) |
| **Twice or more** | 130 (62.8%) |

### 3.5.2 Consumption of Sugary Drinks

In Figure 5, the data presents the frequency of consuming sugary drinks among the participants in the sample. Approximately 15.5% (n=32) of respondents mentioned consuming fizzy drinks, fruit juice, or soft drinks (excluding sugar-free options) rarely or not at all. On the other hand, 40.1% (n=83) stated that they have sugary drinks 1-2 times a week.

**Figure 5 Distribution of reporting of consumption of sugary drinks**(n=207)



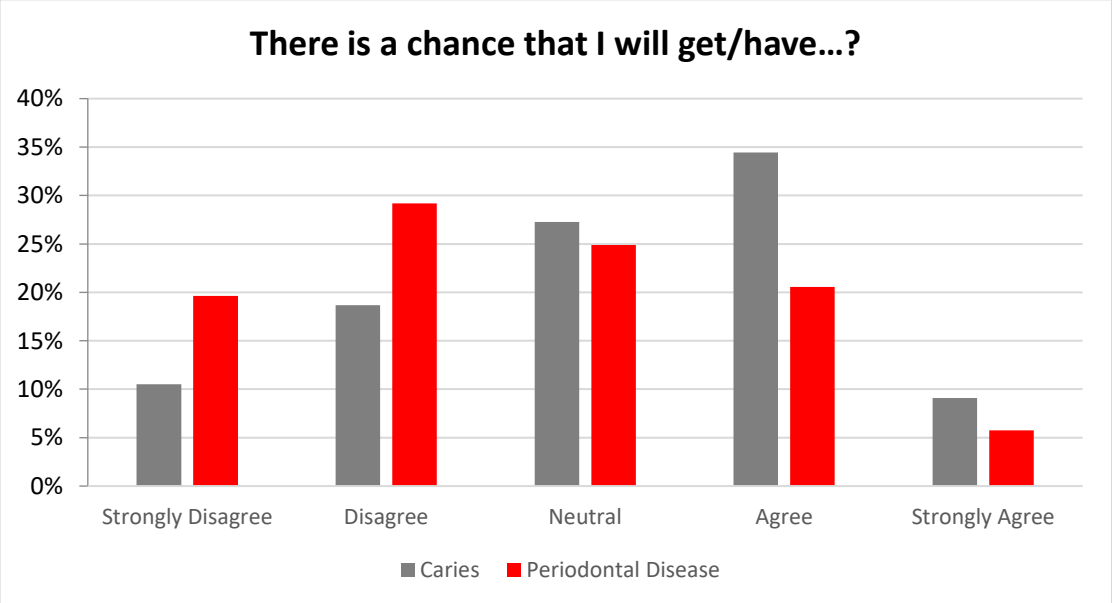
### 3.6 Oral Health Beliefs

This section summarises adolescents' responses to the OHBQAHBM. In later sections, the performance of the scale will be discussed, and mean scores will be presented for subscales as used in further analyses.

#### 3.6.1 Susceptibility to Caries and Periodontal Disease

Relating to the two items under the susceptibility subscale, the following was found: 43.5% (n=91) respondents agreed or strongly agreed that they were susceptible to caries, whereas 26.3% (n=55) respondents reported (agreed/strongly agreed) as being at risk of periodontal disease. See Figure 6 for further details.

**Figure 6 Distribution of responses about susceptibility to caries and periodontal disease**(n=210)

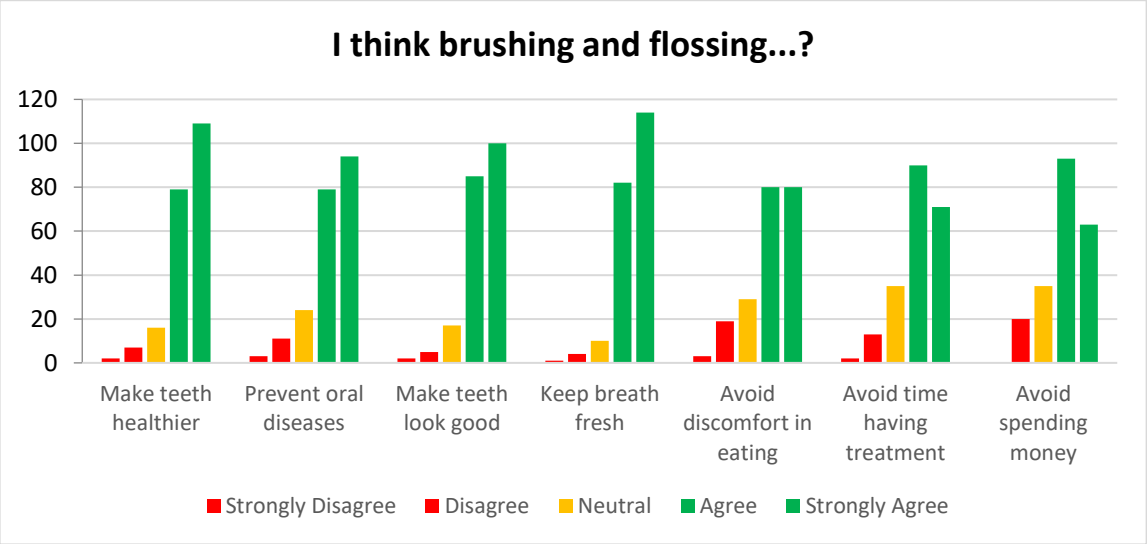


### 3.6.2 Benefits of Brushing and Flossing Teeth

Relating to the seven items under the subscale of the benefit of brushing and flossing teeth, agreement or strong agreement was reached for 50% of respondents or higher for all items (Range=37-54%). These findings were as follows: 88.3% (n=188) believed that brushing or flossing made teeth healthier; 81.9% (n=173) agreed or strongly agreed that they thought brushing and flossing could prevent oral diseases; 88.1% (n=184) agreed or strongly agreed that brushing or flossing made teeth look good; 92.9% (n=196) agreed or strongly agreed that brushing or flossing kept breath fresh; 75.8% (n=160) agreed or strongly agreed that brushing or flossing helped avoid discomfort in eating; 76.3% (n=161) agreed or strongly agreed that brushing or flossing helped avoid spending more time on dental treatment in the future; 74% (n=156) of respondents agreed or strongly agreed that they thought brushing and flossing can help them avoid spending money on dental treatment in the future.

These findings highlight a strong positive perception among participants regarding the benefits associated with regular brushing and flossing, emphasizing the importance of these practices for oral health. Further details are illustrated in Figure 7.

**Figure 7 Distribution of responses about benefits of brushing and flossing teeth**(n=211)

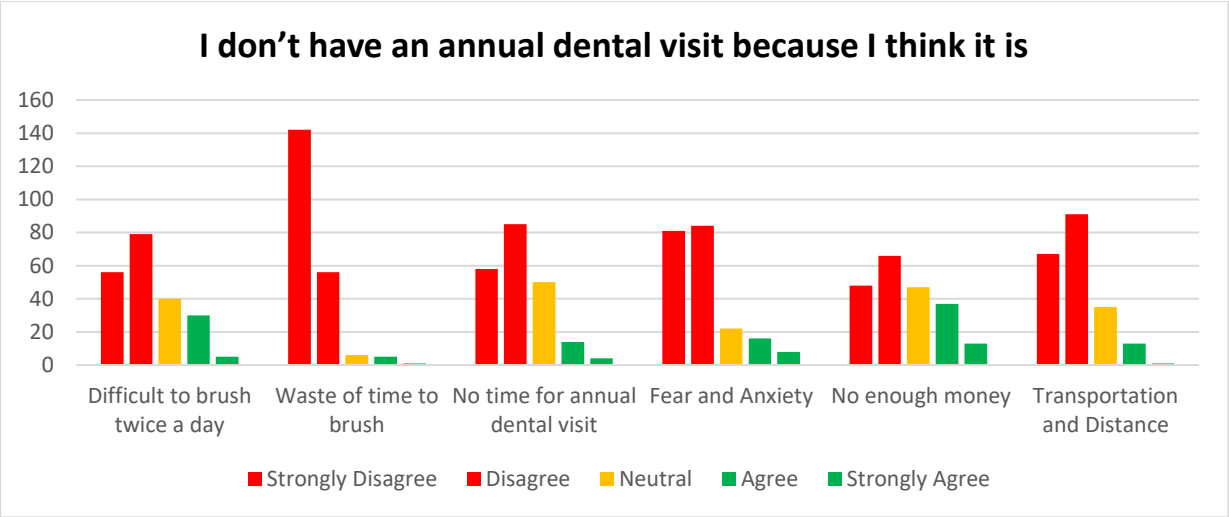



### 3.6.3 Beliefs About Barriers to Dental Attendance

As per Figure 8, the six items under the barrier's subscale, disagreement, or strong disagreement, reached up to 90% of respondents for all items (Range=50-94%). These findings were as follows: 94.2% (n=198) of respondents disagreed or strongly disagreed with the idea that they skipped annual dental visits because they considered it a waste of time to brush or floss; 78.1% (n=165) disagreed or strongly disagreed with the notion that fear and anxiety prevented them from having an annual dental visit; 76.2% (n=158) disagreed or strongly disagreed with the idea that transportation and distance deterred them from having an annual dental visit; 67.6% (n=143) disagreed or strongly disagreed with the belief that they lacked enough time for an annual dental visit; 64.2% (n=135) disagreed or strongly disagreed with the perception that it was difficult to brush twice a day, leading to the avoidance of annual dental visits; 53.9% (n=114) disagreed or strongly disagreed with the notion that they lacked enough money at home to afford

an annual dental visit. These findings underscore a substantial disagreement among participants regarding various barriers to annual dental visits, indicating a positive attitude towards overcoming these obstacles. Further details are in Figure 8.

**Figure 8 Distribution of responses about barriers to dental attendance**(n=212)

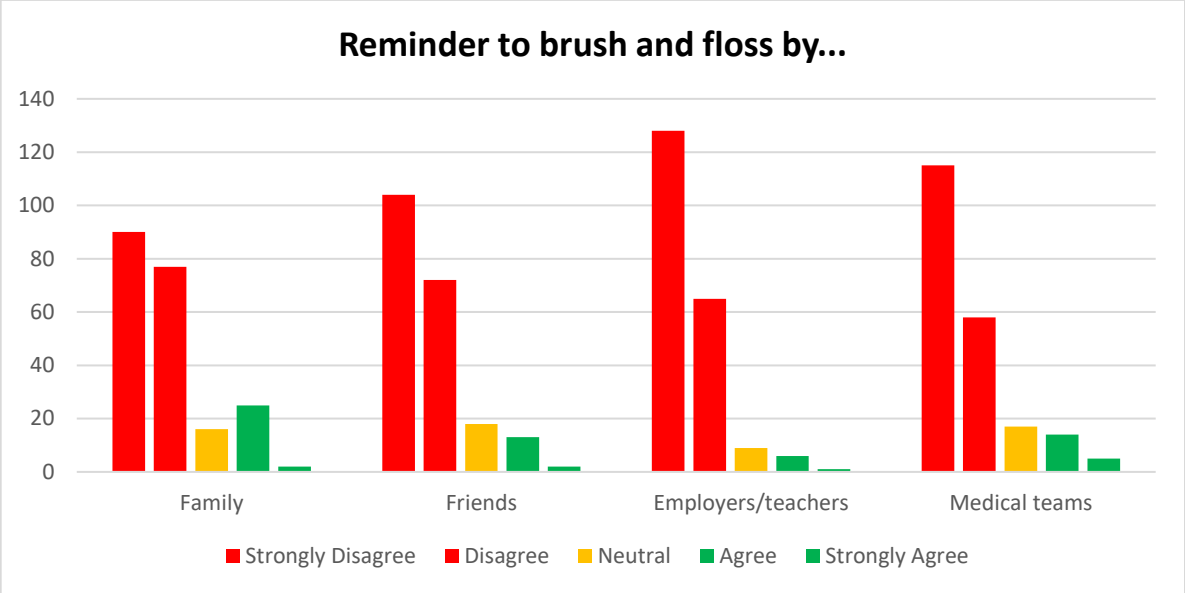



### 3.6.4 Cue to Action

Relating to the four items under the cue to actions subscale, disagreement or strong disagreement reached up to 80% of respondents for all items (Range=30-60%). Specifically, 82.7% (n=173) of participants disagreed or strongly disagreed when asked if they had received reminders from 'Doctors/nurses/medical teams' to brush and floss; 92.3% (n=193) disagreed or strongly disagreed when it came to receiving reminders from Employers/teachers; 84.1% (n=176) disagreed or strongly disagreed regarding reminders from Friends; 79.4% (n=167) disagreed or strongly disagreed concerning reminders from Family. These findings highlight the substantial lack of external cues or reminders for oral health practices among

the participants, indicating a significant area of concern. Further details are provided in Figure 9.

**Figure 9 Distribution of responses about cues to action**(n=211)

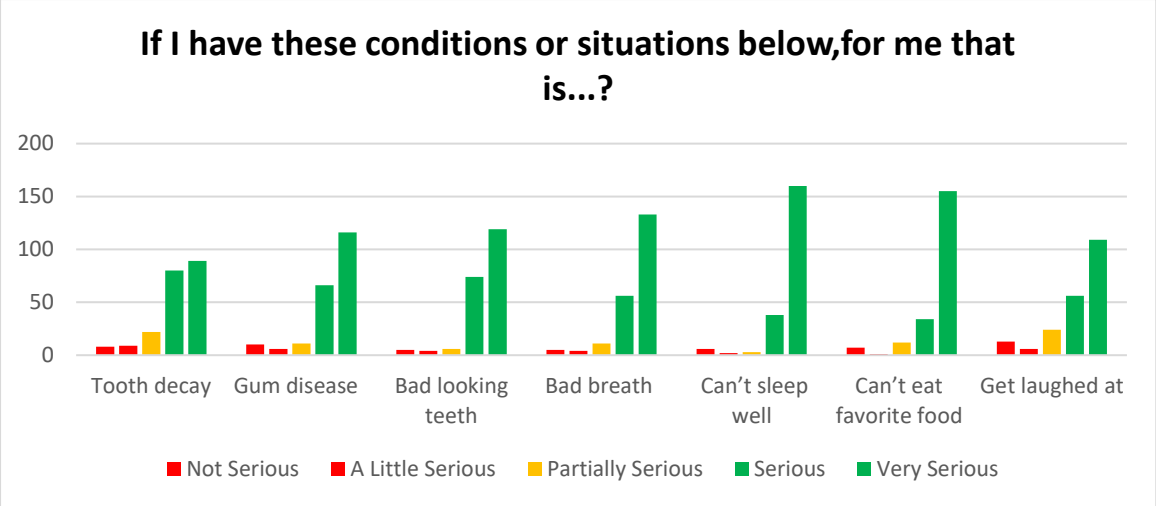



### 3.6.5 Severity of Consequences of Oral Disease

Relating to the seven items under the severity subscale, over 75% of respondents scored conditions as serious or very serious for all items (Range=16-76%). These notable findings were as follows: 94.6% (n=198) of participants regarded the inability to sleep due to oral disease as either serious or very serious; 92.7% (n=193) reported that having bad-looking teeth due to oral disease was perceived as a serious or very serious concern; 90.3% (n=189) considered the inability to eat their favourite foods due to oral disease to be a serious or very serious issue; 90.3% (n=189) viewed having bad breath due to oral disease as a serious or very serious problem; 87% (n=182) deemed periodontal disease to be a matter of seriousness; 81.1% (n=169) of participants regarded tooth decay as a serious or very serious

condition. For 79.3% (n=165) of participants, the prospect of being laughed at by classmates because of oral diseases was considered a serious or very serious concern. These findings emphasize the significant impact of various oral health conditions on participants, highlighting their perception of the severity of these issues. Further details are in Figure 10

**Figure 10 Distribution of responses about the severity of oral disease**(n=210)

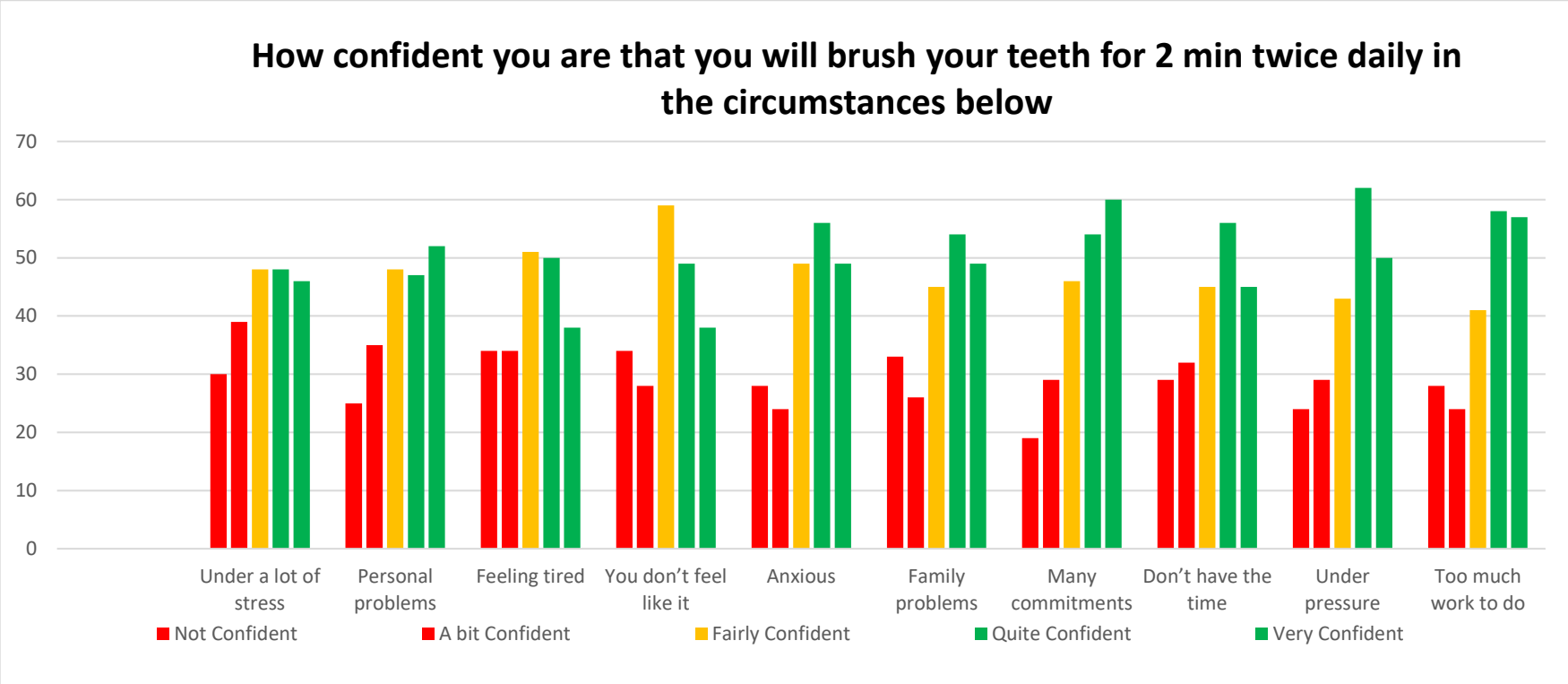



### 3.6.6 Self Efficacy

Relating to the ten items under the subscale of self-efficacy, quite confident or very confident was reached for over 25% of respondents or higher for all items (Range= 18-29%). Specifically, the following notable percentages of participants demonstrated confidence in brushing their teeth for two minutes daily despite facing different challenges; 55.2% (n=115) felt confident even when they had 'Too much work to do at home'; 54.7% (n=114) displayed confidence even when they had 'Other commitments'; 53.8% (n=112) exhibited confidence even when they were 'Feeling under pressure'; 50.8% (n=105) maintained confidence even when they were 'Anxious'; 49.6% (n=103) retained confidence even when they were 'Experiencing family

problems'; 48.7% (n=101) remained confident even when they felt 'Don't have the time'; 47.8% (n=99) sustained confidence even when they were 'Experiencing personal problems'; 44.5% (n=94) maintained confidence even when they were 'Under a lot of stress'; 42.4% (n=88) expressed confidence even when they were 'Feeling tired'; 41.7% (n=87) showed confidence even when they 'Didn't feel like it'. These findings underscore the resilience and determination of the participants in maintaining their commitment to daily tooth brushing, even in challenging circumstances. Further details are in figure 11 below.

**Figure 11 Distribution of responses about the self-efficacy**(n=210)



### 3.7 Prediction of Oral Health Service Use by Health Beliefs

#### 3.7.1 Mean of (OHBQAHBM) Subscale Scores.

Mean subscale scores were derived as per source for the OHBQAHBM. All subscales were tested for normality before analysis. Shapiro-Wilk's test and a visual inspection of their histogram, normal Q-plots and box plots showed that the subscale scores were normally distributed. These results indicated that parametric analysis was valid to undertake.

Table 7 illustrates subscale means and standard deviations of Cronbach's alpha score for each health belief subscale. Summative subscales' mean scores ranged from 1.72 to 4.38, with a range in SD from 0.63 to 1.16. Five out of six subscales were found to possess Cronbach's alpha coefficient approximating 0.70 thresholds or above and were summed as per source accordingly. However, one subscale scored significantly below this threshold (Benefits Subscale, seven items, initial alpha= 0.459). Further analyses of alpha *(if items were removed)* indicated sufficient consistency (alpha=0.82) for use as a scale with the removal of two items (Q37 and Q40). Following their removal, the final five-item benefits subscale was applied for final analysis.

**Table 7 OHBQAHBM scale: subscale means, standard deviations, Cronbach's alpha score for each health belief subscale.**

| Scale | No. of items | Cronbach's alpha | Mean | Standard Deviation |
|---|---|---|---|---|
| **Susceptibility** | 2 | 0.78 | 2.89 | 1.05 |
| **Benefits**(modified scale) | 5 | 0.82 | 4.1 | 0.74 |
| **Barriers** | 6 | 0.66 | 2.06 | 0.63 |
| **Cues of Action** | 4 | 0.86 | 1.72 | 0.78 |
| **Severity** | 7 | 0.91 | 4.38 | 0.78 |
| **Self-efficacy** | 10 | 0.96 | 3.30 | 1.16 |

The results of the regression model are shown in Table 8; 214 participants were included in the model once missing data was accounted for. According to Cox & Snell R2 and Nagelkerke statistics, only between 7.4% and 10.1% of the variance in data were explained by the model.

The likelihood of being an irregular (*symptomatic or never*) attender compared to being a regular attender was 0.44 times more likely per unit rise in Barrier scale score (OR= 0.439; 95% CI = (0.24-0.79), $p < 0.007$). This indicated that increasing the perception of barriers reduced the likelihood of regular dental attendance. No other variable was found to significantly predict attendance in the model.

**Table 8 HBM factors for predicting dental attendance reasons.**

| Items | Only for symptomatic attendance or never | Regular check-ups or Occasional attendance | Odd Ratio | 95% C.I. | *P*-Value |
|---|---|---|---|---|---|
| **Gender**(n=211/valid%) | Male (n=55/ 26.0%)<br>Female (n=78/ 36.9%) | Male (n=33/ 15.6%)<br>Female (n=45/ 21.3%) | 1.11 | (0.60-2.03) | 0.734 |
| **Age**(Mean) | 29.5 | 30.2 | 1.015 | (0.98-1.04) | 0.363 |
| **Mean of Susceptibility Scale** | Mean: 2.92(SD=1.06) | Mean:2.82(SD=1.06) | 0.956 | (0.71-1.28) | 0.766 |
| **Mean of Benefit Scale**(Modified) | Mean:4.10(SD=0.70) | Mean:4.29(SD=0.79) | 0.973 | (0.80-1.18) | 0.784 |
| **Mean of Barriers Scale** | Mean:2.15(SD=0.61) | Mean:1.89(SD=0.61) | 0.409 | (0.22-0.74) | 0.003 |
| **Mean of Cues to Action Scale** | Mean:1.69(SD=0.76) | Mean:1.77(SD=0.80) | 1.494 | (0.97-2.30) | 0.068 |
| **Mean of Severity Scale** | Mean:4.36(SD=0.80) | Mean:4.44(SD=0.74) | 1.061 | (0.69-1.62) | 0.785 |
| **Mean of Self-Efficacy Scale** | Mean:3.26(SD=1.18) | Mean:3.39(SD=1.17) | 0.947 | (0.70-1.26) | 0.715 |

# 4.Discussion

This study had two aims. Firstly, it was aimed to describe the oral health beliefs, behaviours, and perceived barriers to oral healthcare utilisation among individuals in Ireland who have SkCD. Secondly, to determine whether oral health beliefs predicted dental service use.

## 4.1 Summary of Key Findings

### Aim 1 Oral Health Beliefs, Behaviours and Dental Attendance

The study participants expressed a general belief in their susceptibility to oral problems, particularly caries and periodontal disease. They strongly endorsed the effectiveness of regular brushing and flossing in promoting oral health, appearance, disease prevention, and fresh breath. Furthermore, participants largely disagreed with commonly perceived barriers to annual dental visits, such as fear, lack of time and difficulty in maintaining daily oral hygiene. This indicates a positive attitude toward regular oral care and a willingness to overcome potential obstacles.

Most individuals reported brushing their teeth twice daily, with a range of additional oral hygiene tools reported. However, moderate to high frequency of consumption of sugary drinks was noted.

In terms of dental attendance, many participants reported having recently seen the dentist, but a high number went to a longer time gap between check-ups, possibly forgoing preventive care. The majority depended on symptomatic attendance or infrequent visits to the dentist, with just a tiny number reporting regular check-ups. Only a few had never visited a dentist

at all. The variation in dental attendance points to the necessity for focused measures to encourage this population's proactive use of dental services.

Most participants visited the dentist when they had oral problems, indicating a reactive approach to oral care when the frequency of dental service use was examined. The absence of oral care in the previous two years was due to various factors, the most prevalent of which were perceived needlessness and cost considerations. Few people reported dental anxiety as barrier.

In the absence of regular oral health check-ups, it was relevant to explore the possibility of oral health assessment by the medical team. However, oral screening by the medical team was rarely reported.

**Aim 2 Predictors of Attendance**

This study explored the impact of oral health beliefs on dental attendance based on the constructs outlined in the health belief model. As may be expected, the model's ability to explain variance was not very strong, indicating that the factors that influence dental attendance are more remarkable than simple health beliefs.

Among the range of health beliefs constructs under scrutiny, only one exhibited statistically significant predictive power concerning regular dental attendance as (*perceived barriers)* to accessing oral healthcare. When individuals held a perception of heightened obstacles in obtaining oral healthcare services, it was found to be inversely related to their likelihood of reporting a pattern of regular dental attendance.

While the association did not attain statistical significance, as evidenced by a p-value of 0.068, the association between cues to action and reporting regular dental attendance is worth noting. However, given the uncertainty

observed, one cannot conclude that "cues to action" serve as predictors of consistent dental attendance.

### 4.2 Comparing the Findings with Existing Literature

This study's results are best considered compared to prior research on comparable groups. Insufficient data exists to directly compare this study's data regarding dental attendance patterns among ASkCD. Consequently, this study represents a pioneering and vital contribution towards advancing knowledge and promoting enhanced oral healthcare outcomes for ASkCD and may have application for settings other than Ireland. In the absence of a direct comparison group with SkCD, useful comparisons can be made with the general population. To compare with national anticipated oral health service utilization among the broader Irish adult population, comparisons can be made to Whelton et al.'s study in 2007. Other studies will also be considered. Comparisons, detailed below, indicate that ASkCD were less likely to report a lack of perceived need as a reason for not using dental services, were less likely to report dental anxiety and were more likely to report financial constraints as barriers to oral care.

#### Attendance Patterns

Firstly, analysing the attendance patterns reveals a noteworthy disparity. The proportion of ASkCD who engage in regular dental attendance stands at 11.3%, significantly lower than the varied attendance rates observed in the general Irish adult population, with 42.4% in the 35-44 age group. This discrepancy implies a potential barrier to regular oral care for those with SkCD and underlines the necessity for targeted efforts to improve oral health accessibility in this demographic. However, the findings from this population study relate to an older group (35-44) and from a time when access to oral

care was marginally more accessible. It is recognised in population studies that the age 16-24 studies are less likely to attend the dentist regularly and, indeed, sometimes consider themselves less vulnerable to oral disease (White et al. 2009).

The differences above hold when compared to other research. For example, compared to the Healthy Ireland Survey 2022, significant differences in oral healthcare services utilization among adults are evident. The survey reported a notably higher percentage (49%) of adults visiting the dentist in the past year compared to the current study's findings, which indicated 11.3% as regular attendees and 25.4% as occasional attendees. Moreover, the Healthy Ireland Survey highlighted a larger proportion (63%) of visits for routine check-ups and cleaning, in contrast to the present study, where a majority (53.3%) sought oral care only when experiencing symptoms. The low percentage (11.3%) of regular dental check-up attendees within the population with SkCD suggests potential barriers, including cost and lack of awareness, which might deter individuals from seeking routine oral care.

**Potential Barriers**

**1.Perceived Need**

ASkCD possess a range of perceptions of their need for oral healthcare. Only 39.4% of participants reported no need to visit the dentist as a reason for non-attendance, in contrast to 67% of the general Irish adult population (Whelton et al. 2007). This ambivalence is interesting given that children's SkCD services include a dental service, while the adult SkCD service in Ireland does not. As children and adolescents transition from the children's centres, it is important that they are encouraged to find a 'dental home' and ensure regular oral care is part of their health routines.

The fact that 48.7% of individuals disagree or strongly disagree that their SkCD influenced their oral health indicates that different participants have different views on how SkCD and oral health are related and currently have inaccurate information about their risk of oral disease and potential impact on their SkCD (Fiorillo et al. 2019). Delay in seeking oral care or acting on symptoms, as reported by the majority of participants (53.3%), can raise the risk of oral health problems, and necessitate higher treatment needs.

**2.Dental Anxiety**

Studies have demonstrated that dental anxiety is associated with reduced dental visit frequency and longer intervals between dental appointments, indicating its significant impact on individual oral health service utilization(Badran et al. 2023; Burgette et al. 2016). Dental anxiety prevalence was notably lower at 8.1% in the current study, compared to the general Irish adult population, at 27.6% (Whelton et al. 2007). This finding is at odds with the findings that ASkCD has high levels of health-related anxiety (Ibrahim et al. 2017). This suggests that, on average, dental anxiety might not be a significant impediment to dental visits for ASkCD. Despite the low frequency, it is important to note that many anxious people need support. The decreased prevalence of dental anxiety in ASkCD may be linked to their comfort with medical environments due to their health condition. It is vital to comprehend the precise anxiety triggers within this group to craft effective anxiety-focused oral care interventions. Customizing oral care to include structured communication and integrating coping techniques emerge as crucial approaches to mitigating dental anxiety for ASkCD as well as the broader population. However, a note of caution is required as studies assessed reported dental anxiety in different ways. Nevertheless,

understanding these variations in dental anxiety across different populations is imperative to tailor appropriate support and interventions, albeit if it affects less than 10% of the SkCD population in Ireland.

**3.Financial Barriers**

Financial barriers to oral care emerged as a significant factor in the present study for fewer people than expected. Financial constraints serve as a reason for not attending dental visits for a notable portion of the SkCD population (33.3%), a higher percentage compared to the general Irish adult population (17.0%) (Whelton et al. 2007). In the UK, this figure sits at 26% of the population (Hill et al. 2013). This highlights the critical need to address affordability in oral care for ASkCD. Financial restrictions and socioeconomic position can greatly impact oral health behaviour. The price of dental services and limitations on dental insurance may hamper access to routine oral care. People with little financial resources could put off or skip dentist appointments, which could result in problems with their oral health. Additionally, the frequency of dental visits may change depending on where inexpensive oral care is offered (Locker et al. 2005; Akifusa et al. 2005).

Previous research has not delved into the utilization of dental services for ASkCD. However, Whiteman et al. 2016 conducted a study wherein free basic oral care was offered to ASkCD. The objective was to investigate whether this provision led to a reduction in overall healthcare usage. Their findings revealed a notable decrease in the number of days that ASkCD spent in hospitals when they had access to basic dental evaluation and treatment (Laurence et al. 2013; Whiteman et al. 2016).

**4.Access-Related Barriers**

Oral health practices and beliefs can also be influenced by the standard of dental treatment delivered and the relationship between patients and healthcare professionals. (Hooper et al. 2019). The current study showed that 21(10.6%) participants complained of being unable to source a dentist, and 18(9.2%) indicated that transportation is an issue in having regular dental treatment. So, while people may desire to attend, inaccessibility factors are still a deterrent.

**5.Social and Cultural Barriers**

This study's sample predominantly comprised individuals of black African ethnicity who were employed and educated. Many were likely from immigrant families. These demographic features have noteworthy implications worth exploring in greater detail. Acknowledging the impact of personal and social factors on service design in SkCD groups (Geber et al. 2018), this section expands on the current study findings.

Beliefs and customs from different cultures can significantly impact how people act and think about their oral health. Different cultural origins could have different ideas about oral care and oral health. Many individuals may retain beliefs about oral care and access attributed to the setting from which their family might have migrated. For example, some societies might prioritize preventive oral care, while others lean towards traditional dental remedies. This holds particular importance because the study focused on a demographic of Black and African individuals with lower dentist attendance rates.

Additionally, migrant communities face challenges in accessing oral health services due to language barriers and unfamiliarity with the system. This highlights the necessity of addressing the inclination to avoid seeking care and the need for diverse language support. Additionally, cultural norms governing eating patterns and oral hygiene routines may have an effect on the incidence of dental illnesses in the populace.(Silveira et al. 2018).

Social influences on oral health behaviour include peer pressure, social support, and family impact. Peers and family members can affect how people feel about oral health and how they practice oral care(El Tantawi et al. 2017; Khoshnevisan et al. 2019). Positive role models that place a high priority on oral health can inspire others to follow their example. On the other hand, individuals may be deterred from obtaining oral care by social stigma or embarrassment associated with oral health concerns. In this study data, although not of statistical significance, the roles of 'cues to action' such as family or professional support could have a role to play in supporting optimal oral health behaviours.

### 4.3 Strengths and Weaknesses of the Study

It is important to note that this is the first study of those with SkCD in Ireland; the study's demographic representation also emphasizes the ethnic variety of Ireland's adult population with SkCD, with 88.2% of participants identifying as Black or Black Irish and 7.0% as Asian. This population's diversity may lead to distinctive cultural viewpoints on oral health practices and beliefs. It is almost a total population sample, so it is possible that this study's findings are generalizable to all ASkCD in Ireland.

### 4.3.1 Data Collection Methods

The study's reliance on survey-based self-reported data could introduce social desirability and response biases (Krumpal et al. 2013). Participants may provide responses they perceive as socially acceptable or may underestimate specific behaviours. This raises a significant concern regarding the accuracy of reported service utilization, manifesting as recall bias (forgetting) or misattribution bias (incorrect categorization of usage) among individuals.

Although the study's quantitative analysis offered insightful information, it may not have fully reflected the complexity of different people's activities and opinions. The quantitative results may be supplemented with qualitative research methods, offering a deeper understanding of participants' viewpoints and experiences.

### 4.3.2 Limited Consideration of Factors Affecting Services Use

Perhaps the major limitation of this study is the restricted theoretical framework for understanding oral health services use. Current concepts of access to health care and oral health care recognize the range of barriers and facilitators that influence health services use. The source of these barriers arises from political, social, and environmental factors, just as much as they do from patients.

A decision to look only at patient-oriented factors is limited to one model of health behaviour due to the complexity of the study and the need to maintain a specific focus. Future research should expand the theoretical framework to encompass a broader spectrum of influencing factors, including structural, economic, and policy-related elements. A comprehensive examination of systemic barriers, such as healthcare policies, socioeconomic disparities, and

geographic accessibility, could offer a more nuanced understanding of the intricate dynamics affecting oral health service utilization among ASkCD.

### 4.3.3 Theoretical Perspective

In selecting HBM, it should be recognised that other complementary and competing theories may also be considered. For example, the Theory of Planned Behaviour emphasizes the role of attitudes, subjective norms, and perceived behavioural control in predicting and understanding behaviour(Amin et al. 2019; Shi et al. 2021); Social Cognitive Theory highlights the interplay between personal, behavioural, and environmental factors in shaping behaviour (Bandura et al. 1999); the Transtheoretical Model describes stages individuals go through when adopting new behaviours(Astroth et al. 2002) and Health Promotion Model that considers individual characteristics and experiences, behaviour-specific cognitions and affect, and behavioural outcomes (Pender et al. 2011). Finally, the Behavioural Model of Health Services(Baker et al. 2009) focuses on factors influencing health services utilization. It considers predisposing factors (e.g., beliefs, knowledge), enabling factors (e.g. access, resources), and need factors (e.g. perceived need for care). Depending on the specific model adopted, it is possible to conceive the influencers of service use differently, offering healthcare professionals and policymakers a vista from which to plan.

**4.3.4 Novel Study:** The high response rate (93.04%) among persons with SkCD who participated in the survey demonstrates a great interest and involvement in sharing their opinions and experiences related to oral health beliefs and behaviours. This is one of the study's novel or unique findings.

This high response rate may be viewed as a strength of the study because it shows that ASkCD is open to participating in oral health.

### 4.5 Recommendations

#### 4.5.1 Practice

**The Need to Integrate Oral Healthcare into Sickle Cell Diseases Care**

This study highlights the need to incorporate both oral health messaging and oral health screening into the regular health screenings offered by specialised Sickle Cell Services. The current study's findings suggest that this aligns quite closely with existing practice. However, to deliver this tweak to oral health screening and messaging, a number of steps are needed. These include agreeing protocols and meeting training needs with SkCD staff, so as they can screen and signpost effectively. Engaging stakeholders in this integration process is crucial, and this study offers a solid basis for such endeavours. Evaluation, of course, will be needed, including effectiveness and cost-effectiveness analyses.

Considering the possible impact of oral health on the general health and well-being of ASkCD, this will assist in identifying and managing oral health issues early on.

**Collaborative Healthcare Approach**

A collaborative approach to healthcare is essential, including cooperation between specialists in oral care and those who treat SkCD. This collaboration may result from comprehensive treatment plans that cover dental and medical health needs.

**Addressing Barriers to Dental Attendance**

Barriers to dental attendance should be addressed by targeted initiatives that make it easier to get oral care. Additionally, more frequent dental visits can be encouraged by easing dental fear through patient-centred communication and comforting dental settings.

**Culturally Sensitive Interventions**

Designing culturally responsive interventions that address the distinctive beliefs, behaviours, and challenges towards oral healthcare in various ethnic groups is crucial, given the ethnic diversity within the sample. Interventions' acceptability and efficacy can be increased by making them specifically relevant to a given cultural environment.

### 4.5.2 Oral Health Promotion

The overall participants' responses to the questionnaire based on the health belief model (OHBQAHBM) underline the need for an efficient oral health promotion strategy in Ireland that is geared towards ASkCD. Most participants had favourable opinions of their general and oral health, suggesting that treatments should promote these attitudes and encourage people to continue visiting the dentist and practising good oral hygiene. Based on the findings, several strategies can be proposed to promote oral health among ASkCD in Ireland:

- Increase the knowledge of ASkCD regarding to the value of routine oral exams and preventative care by highlighting the connection between oral health and overall well-being.
- Develop clear oral healthcare messages for ASkCD regarding financial constraints and difficulty accessing oral care, as discussed in the study

by Watt et al. 2012. For example, while not measured in this study, many participants are likely to have medical card.

- Medical card holders may avail certain oral healthcare services at no cost. Medical card holders benefit from a complimentary annual dental check-up and necessary extractions. Moreover, they are eligible for an initial endodontic treatment each year for anterior teeth. Furthermore, the medical card allows for two fillings without charge annually, as outlined in the latest information from (CitizensInformation.ie 2023). Therefore, ASkCD could benefit from having the SkCD team explore the dental services entitlements for their patients. This can be achieved through direct communication with patients by the medical staff or through reminders, whether written or verbal, by the SkCD administrative team, regarding the dental benefits linked to the medical card.
- Implement educational programmes to encourage people to drink less sugary drinks and promote healthier options.
- Provide individualized oral health information and assistance, taking into account ethnic and cultural characteristics that may have an impact on oral health behaviours.
- Add oral health screening to the SkCD pathway services to better spot and handle oral health problems(Watt et al. 2005).
- Encourage interprofessional cooperation between healthcare professionals and oral health specialists to create thorough treatment programmes and attend to the unique needs of ASkCD.
- Enhance oral health knowledge and attitudes, it is crucial to raise public awareness of the value of routine oral exams, preventive oral health practices, and the adverse effects of skipping appointments.

- Educational initiatives should also target ASkCD, healthcare professionals, and dental staff.

### 4.5.3 Policy

The SkCD centres could incorporate oral care as an integral component of their holistic approach to healthcare such as following the Irish national oral health policy, Smile agus Sláinte, that was established in 2019 with the aim of enhancing oral healthcare for all individuals. This initiative promotes the delivery of comprehensive care, delivered by qualified healthcare professionals, in the most appropriate environments. Embracing a 'primary care approach' it prioritizes prevention, local accessibility, and person-cantered care (Kavanagh et al. 2019). Advocacy is needed to prioritise the oral healthcare access for ASkCD within national oral health policy, in view of the issues raised by this study, for this highly targetable and beneficial population.

Moreover, policymakers could proactively explore and implement financial support programs aimed at reducing the financial burden associated with dental treatment for this vulnerable population. These support programs should encompass subsidies, insurance coverage enhancements, or partnerships with oral care providers to ensure equitable access to quality oral healthcare for ASkCD. By taking these specific steps, we can effectively address the unique oral health challenges this disadvantaged group faces and improve their overall well-being.

Economic analysis is needed to focus on how such a study can assess the cost-effectiveness of initiatives and programs that aim to encourage people to regularly visit the dentist for check-ups and adopt preventive oral health practices. In other words, health economic analysis helps decision-makers

understand whether these programs are a wise investment by weighing the costs associated with their implementation against the expected benefits in terms of improved oral health outcomes and potential cost savings in treating oral issues in the long run. This information can guide policymakers and healthcare professionals in making informed decisions about allocating resources and developing effective strategies to promote oral health.

**4.5.4 Research:**

Examining additional variables that affect dental visit patterns and oral health behaviours in ASkCD will require more investigation. The long-term effects of oral health on this population's general health outcomes should be better understood through longitudinal studies.

Enhanced health surveillance is critical to capture the true extent of the impact of oral care avoidance in ASkCD. Analysing hospitalization data in depth, considering the reasons for hospitalization related to oral health issues, will provide valuable insights into the implications of neglecting dental services for prevention and treatment. Establishing a systematic data collection and surveillance system dedicated to oral health outcomes among ASkCD is fundamental. This system should encompass data on sickle crisis incidents attributed to oral disease, as well as dental attendance patterns. Such a surveillance system will aid in tracking the effectiveness of therapies, identify improvement areas, and ensure that oral health is a significant component of their overall healthcare management.

Finally, a thorough comparative investigation should be undertaken between ASkCD and a control group comprising black Irish individuals without SkCD in Ireland. This research should focus on identifying disparities and factors that could explain these distinctions. Recognizing these differences is vital for

customizing interventions and strategies to improve oral health outcomes within both population groups living in the same country. This research could contribute to advancing knowledge in the field of oral health disparities within specific populations, particularly those with SkCD. This can stimulate further research and promote a deeper understanding of the complexities involved.

---

# 5.Conclusion

The study aimed to describe oral health beliefs, behaviours, and barriers to oral healthcare services utilization among ASkCD in Ireland. Additionally, it sought to determine whether oral health beliefs predicted dental service use. This study found that participants demonstrated a positive belief towards regular oral care and were willing to overcome barriers. Dental attendance was often symptomatic or infrequent, highlighting the need for proactive measures. Perceived barriers, rather than overall health beliefs, significantly predicted regular dental attendance.

Comparisons with existing literature highlighted disparities in dental attendance patterns and barriers specific to the ASkCD population. Financial constraints and cultural influences were notable factors affecting oral health behaviours.

The research findings have substantial implications for healthcare providers and policymakers. The study's findings have already influenced the medical team to incorporate oral health information into health coaching. The unexpected barriers to dental attendance, primarily financial concerns and a lack of perceived value, underscore the importance of societal and personal efforts in overcoming these obstacles.

Nudging and motivation can encourage regular dentist visits. The study underscores the importance of considering oral health screening and messaging in the care of this group for better outcomes. Strategies like cues, reminders, and addressing financial barriers can enhance dental attendance and overall oral health.

Incorporating oral health into routine assessments are likely to prevent crises, reducing healthcare costs, and ultimately improving overall health.

The study acknowledges limitations, including the reliance on self-reported data and the restricted theoretical framework. The study focused on patient-oriented factors and may benefit from considering broader systemic factors influencing healthcare access and oral health service utilization.

Future research should explore additional variables affecting dental visit patterns and oral health behaviours in ASkCD. Longitudinal studies examining the long-term effects of oral health on general health outcomes are warranted. Comparative investigations between ASkCD and a control group can provide valuable insights into oral health disparities.

The study's high response rate demonstrated a genuine interest in sharing opinions and experiences related to oral health behaviours and attitudes.

This study, being the first of its kind in Ireland, contributes valuable insights into the oral health beliefs, behaviours, and barriers among ASkCD. It serves as a foundational study for future research and interventions aimed at improving oral healthcare outcomes in this demographic.

In conclusion, this study provides crucial insights into the attitudes and practices related to oral health among ASkCD in Ireland. It emphasizes the necessity of encouraging routine dental check-ups, removing barriers to dental visits, and integrating oral health assessment and messaging into healthcare programs. Targeted interventions can be designed to address this population's unique oral health needs, thereby improving oral health service use, outcomes and overall well-being among ASkCD in Ireland.

On a personal note, conducting this research has been a gratifying and educational experience. Witnessing the impact of oral health awareness on a vulnerable population has reinforced my dedication to healthcare

inclusivity. This experience has fuelled my passion to continue advocating for equitable access to oral healthcare and contribute to meaningful improvements in oral health outcomes for all.

This pioneering study delved into the oral health beliefs, behaviours, and barriers faced by ASkCD in Ireland. The findings revealed a positive attitude towards regular oral care, yet financial constraints and perceived barriers remained significant obstacles. Bridging this gap requires targeted interventions, integration of oral health in healthcare, and culturally sensitive approaches. By addressing these challenges, we can enhance oral healthcare accessibility and overall well-being for the population with SkCD.

---

## References


1. Abed, H., Sharma, S. P., Balkhoyor, A., Aljohani, K., & Dickinson, C. (2019). Special care dentistry for patients diagnosed with sickle cell disease: an update for dentists. *General Dentistry*, *67*(6), 40-44.
2. Acharya S. (2015). Oral and Dental Considerations in Management of Sickle Cell Anemia. *International journal of clinical pediatric dentistry*, *8*(2), 141–144.
3. Akifusa, S., Soh, I., Ansai, T., Hamasaki, T., Takata, Y., Yohida, A., ... & Takehara, T. (2005). Relationship of number of remaining teeth to health-related quality of life in community-dwelling elderly. *Gerodontology*, *22*(2), 91-97.
4. Al Khamis, S., Asimakopoulou, K., Newton, T., & Daly, B. (2017). The effect of dental health education on pregnant women's adherence with toothbrushing and flossing - A randomized control trial. Community Dentistry and Oral Epidemiology.
5. Amin, M., Elyasi, M., Bohlouli, B., & ElSalhy, M. (2019). Application of the Theory of Planned Behavior to Predict Dental Attendance and Caries Experience among Children of Newcomers. *International journal of environmental research and public health*, *16*(19), 3661.
6. Asimakopoulou, K., & Daly, B. (2009). Adherence in dental settings. *Dental update*, *36*(10), 626–630.
7. Asimakopoulou, K., & Newton, J. T. (2015). The contributions of behaviour change science towards dental public health practice: a new paradigm. *Community dentistry and oral epidemiology*, *43*(1), 2-8.
8. Astroth, D. B., Cross-Poline, G. N., Stach, D. J., Tilliss, T. S., & Annan, S. D. (2002). The transtheoretical model: an approach to behavioral change. *Journal of dental hygiene*, *76*(4).
9. Badran, A., Keraa, K., & Farghaly, M. M. (2023). The impact of oral health literacy on dental anxiety and utilization of oral health services among dental patients: a cross sectional study. *BMC Oral Health*, *23*(1), 146.
10. Badri, P., Saltaji, H., Flores-Mir, C., & Amin, M. (2014). Factors affecting children's adherence to regular dental attendance: a systematic review. *The Journal of the American Dental Association*, *145*(8), 817-828.
11. Baker, S. R. (2009). Applying Andersen's behavioural model to oral health: what are the contextual factors shaping perceived oral health outcomes?. *Community Dentistry and Oral Epidemiology*, *37*(6), 485-494.
12. Bandura, A., Freeman, W. H., & Lightsey, R. (1999). Self-efficacy: The exercise of control.

13. Brandão, C. F., Oliveira, V. M. B., Santos, A. R. R. M., da Silva, T. M. M., Vilella, V. Q. C., Simas, G. G. P. P., ... & Ladeia, A. M. T. (2018). Association between sickle cell disease and the oral health condition of children and adolescents. *BMC oral health*, *18*(1), 1-9.
14. Broadbent, J. M., Zeng, J., Foster Page, L. A., Baker, S. R., Ramrakha, S., & Thomson, W. M. (2016). Oral Health–related Beliefs, Behaviors, and Outcomes through the Life Course. *Journal of Dental Research*, *95*(7), 808–813.
15. Buglar, M. E., White, K. M., & Robinson, N. G. (2010). The role of self-efficacy in dental patients' brushing and flossing: testing an extended Health Belief Model. *Patient education and counseling*, *78*(2), 269-272.
16. Burgette, J. M., Lee, J. Y., Baker, A. D., & Vann Jr, W. F. (2016). Is dental utilization associated with oral health literacy?. *Journal of dental research*, *95*(2), 160-166.
17. Butani, Y., Weintraub, J. A., & Barker, J. C. (2008). Oral health-related cultural beliefs for four racial/ethnic groups: Assessment of the literature. *BMC oral health*, *8*, 1-13.
18. Carpenter C. J. (2010). A meta-analysis of the effectiveness of health belief model variables in predicting behavior. *Health communication*, *25*(8), 661–669.
19. Central Statistics Office. Data from 2011 national census.
20. Chakravorty, S., & Williams, T. N. (2015). Sickle cell disease: a neglected chronic disease of increasing global health importance. *Archives of disease in childhood*, *100*(1), 48-53.
21. Childerhose, J. E., Cronin, R. M., Klatt, M. D., & Schamess, A. (2023). Treating Chronic Pain in Sickle Cell Disease—The Need for a Biopsychosocial Model. *New England Journal of Medicine*, *388*(15), 1349-1351.
22. Citizensinformation.ie. (2023). Dental Services. https://www.citizensinformation.ie
23. Coates, T. D., & Wood, J. C. (2017). How we manage iron overload in sickle cell patients. *British journal of haematology*, *177*(5), 703–716.
24. Cohen, S. M., Fiske, J., & Newton, J. T. (2000). The impact of dental anxiety on daily living. *British dental journal*, *189*(7), 385-390.
25. Conner, M., & Norman, P. (2015). *EBOOK: Predicting and Changing Health Behaviour: Research and Practice with Social Cognition Models*. McGraw-Hill Education (UK).
26. CSO. (2017, October 19). *2016 Census Forms - CSO - Central Statistics Office*.
27. da Costa, T. M. P., Narchini, M. D. C. N., Peralta-Mamani, M., Rubira-Bullen, I. R. F., Junqueira, J. L. C., & Soares, M. Q. S. (2022). Prevalence of orofacial alterations in patients with sickle-cell disease: Systematic review and meta-analysis. *Oral Surgery, Oral Medicine, Oral Pathology and Oral Radiology*.

28. Daniel, S. J., & Kumar, S. (2014). Teledentistry: a key component in access to care. *Journal of evidence based dental practice*, *14*, 201-208.

29. Department of Health. Smile agus Sláinte: National Oral Health Policy. Dublin: Department of Health; 2019. https://health.gov.ie/wp-content/uploads/2019/04/NOHP-Main-FINAL.pdf.
30. Donaldson, A. N., Everitt, B., Newton, T., Steele, J., Sherriff, M., & Bower, E. (2008). The effects of social class and dental attendance on oral health. *Journal of dental research*, *87*(1), 60-64.
31. Duijster, D., & van Loveren, C. (2017). De invloed van het gezin op de mondgezondheid van kinderen. Een kijkje achter de voordeur [The family's influence on the oral health of children. A peek behind the front door]. *Nederlands tijdschrift voor tandheelkunde*, *124*(4), 180–186.
32. El Tantawi, M., Bakhurji, E., Al-Ansari, A., Al-Khalifa, K. S., & AlSubaie, A. (2017). Influences of parents, close friends and classmates on four co-existing oral health practices in Saudi male teenagers. *Acta Odontologica Scandinavica*, *75*(2), 137-143.
33. Fiorillo, L. (2019). Oral health: the first step to well-being. *Medicina*, *55*(10), 676.
34. Fogarty, H., Gaul, A., Syed, S., Aleksejenko, N., Geoghegan, R., Conroy, H., ... & McMahon, C. (2022). Adherence to hydroxyurea, health-related quality of life domains and attitudes towards a smartphone app among Irish adolescents and young adults with sickle cell disease. *Irish Journal of Medical Science (1971-)*, 1-8.
35. Gambhir, R. S., Brar, P., Singh, G., Sofat, A., & Kakar, H. (2013). Utilization of dental care: An Indian outlook. *Journal of natural science, biology, and medicine*, *4*(2), 292.
36. Geber, J., & Murphy, E. (2018). Dental markers of poverty: Biocultural deliberations on oral health of the poor in mid-nineteenth-century Ireland. *American Journal of Physical Anthropology*, *167*(4), 840–855.
37. George, D., & Mallery, P. (2019). *IBM SPSS statistics 26 step by step: A simple guide and reference*. Routledge.
38. Gibbons, C., Geoghegan, R., Conroy, H., Lippacott, S., O'Brien, D., Lynam, P., ... & McMahon, C. (2015). Sickle cell disease: time for a targeted neonatal screening programme.
39. Gibson, B., Gulliford, M., & Morgan, M. (2003). Access to dental services. *Access to health care*, *174*, 188.
40. Glick, M., Williams, D. M., Kleinman, D. V., Vujicic, M., Watt, R. G., & Weyant, R. J. (2016). A new definition for oral health developed by the FDI World Dental Federation

opens the door to a universal definition of oral health. *British dental journal*, *221*(12), 792-793.

41. Global Blood Therapeutics. (2020). *Overview of the sickle cell disease environment in select european countries*.
42. Guiney, H., Woods, N., Whelton, H. P., & Morgan, K. (2011). Predictors of utilisation of dental care services in a nationally representative sample of adults.
43. Hall, K. S. (2011). The Health Belief Model Can Guide Modern Contraceptive Behavior Research and Practice. *Journal of Midwifery & Women's Health*, *57*(1), 74–81.
44. Hamasha, A. A.-H., Alshehri, A., Alshubaiki, A., Alssafi, F., Alamam, H., & Alshunaiber, R. (2018). Gender-specific oral health beliefs and behaviors among adult patients attending King Abdulaziz Medical City in Riyadh. *The Saudi Dental Journal*, *30*(3), 226–231.
45. Hegedüs, A., & Kozel, B. (2014). Does adherence therapy improve medication adherence among patients with schizophrenia? A systematic review. *International Journal of Mental Health Nursing*, *23*(6), 490–497.
46. Hill, K. B., Chadwick, B., Freeman, R., O'sullivan, I., & Murray, J. J. (2013). Adult Dental Health Survey 2009: relationships between dental attendance patterns, oral health behaviour and the current barriers to dental care. *British dental journal*, *214*(1), 25-32.
47. Holderle, K., Sheth, M., Arany, S., Schiff, L., & Planerova, A. (2021). Orofacial manifestation and dental management of sickle cell disease: A scoping review. *Anemia*, *2021*.
48. Hollister, M. C., & Anema, M. G. (2004). Health behavior models and oral health: a review. *Journal of dental hygiene : JDH*, *78*(3), 6.
49. Hosseini, M., Bekry, G., Mozaffari, H. R., Sadeghi, R., Yousefifard, M., Rostambeigi, M., & Shojaeezadeh, D. (2014). Effect of educational intervention on Oral health behaviour based on health belief model in female secondary school students of Paveh in 2011.
50. Hsu, L. L., & Fan-Hsu, J. (2020). Evidence-based dental management in the new era of sickle cell disease: a scoping review. *The Journal of the American Dental Association*, *151*(9), 668-677.
51. Hung, H.-C., Joshipura, K.J., Colditz, G., Manson, J.E., Rimm, E.B., Speizer, F.E. and Willett, W.C. (2007). The Association Between Tooth Loss and Coronary Heart Disease in Men and Women. *Journal of Public Health Dentistry*, 64(4), pp.209–215.
52. IBM Corporation. IBM SPSS Text Analytics for Surveys Information Center. 2011.

53. Ibrahim, H., Lyons, K., Armfield, J., & Thomson, W. (2017). Performance of the Index of Dental Anxiety and Fear in a population-based sample of adults. *Australian Dental Journal*, *62*(4), 478–484.
54. Ireland, H. (2021). Healthy Ireland Survey 2021 Summary Report. *publications G, editor. Dublin2021*.
55. Javed, F., Correa, F. O., Nooh, N., Almas, K., Romanos, G. E., & Al-Hezaimi, K. (2013). Orofacial manifestations in patients with sickle cell disease. *The American journal of the medical sciences*, *345*(3), 234–237.
56. Jenerette, C., Funk, M., & Murdaugh, C. (2005). Sickle cell disease: a stigmatizing condition that may lead to depression. *Issues in Mental Health Nursing*, *26*(10), 1081-1101.
57. Kasl, S. V., & Cobb, S. (1966). Health behavior, illness behavior and sick role behavior: I. Health and illness behavior. *Archives of Environmental Health: An International Journal*, *12*(2), 246-266.
58. Kavanagh, D., O'Mullane, D., O'Connell, B., Barry, M., Dougal, A., Madden, D., ... & McLoughlin, J. (2019). Smile agus Sláinte–National Oral Health Policy.
59. Khoshnevisan, M. H., Shariatpanahi, S. P., Roudsari, M. S., Namdari, M., Malek-Mohamadi, M., & Foroughmand, M. H. (2019). The role of peer influence on oral health knowledge and behaviors among adolescents.
60. Krumpal, I. (2013). Determinants of social desirability bias in sensitive surveys: a literature review. *Quality & quantity*, *47*(4), 2025-2047.
61. Laurence, B., Haywood Jr, C., & Lanzkron, S. (2013). Dental infections increase the likelihood of hospital admissions among adult patients with sickle cell disease. *Community dental health*, *30*(3), 168.
62. Limo, L. (2023). The Impact of Access to Oral Health Care on Inadequate Oral Health and Multimorbidity.
63. Locker, D., & Gibson, B. (2005). Discrepancies between self-ratings of and satisfaction with oral health in two older adult populations. *Community dentistry and oral epidemiology*, *33*(4), 280-288.
64. Lubeck, D., Agodoa, I., Bhakta, N., Danese, M., Pappu, K., Howard, R., ... & Lanzkron, S. (2019). Estimated life expectancy and income of patients with sickle cell disease compared with those without sickle cell disease. *JAMA Network Open*, *2*(11), e1915374-e1915374.

65. Maggirias, J., & Locker, D. (2002). Psychological factors and perceptions of pain associated with dental treatment. *Community dentistry and oral epidemiology*, *30*(2), 151-159.
66. Maitra, P., Caughey, M., Robinson, L., Desai, P. C., Jones, S., Nouraie, M., ... & Ataga, K. I. (2017). Risk factors for mortality in adult patients with sickle cell disease: a meta-analysis of studies in North America and Europe. *haematologica*, *102*(4), 626.
67. Maqsood, A., Sadiq, M. S. K., Mirza, D., Ahmed, N., Lal, A., Alam, M. K., & Halim, M. S. B. (2021). The teledentistry, impact, current trends, and application in dentistry: a global study. *BioMed research international*, *2021*.
68. Mayo-Gamble, T. L. (2014). A Review of the Literature: Use of the Health Belief Model in Sickle Cell Research. *Online Submission*, *31*(1), 37-41.
69. McMahon, C., Callaghan, C. O., O'Brien, D., & Smith, O. P. (2001). The increasing prevalence of childhood sickle-cell disease in Ireland. *Irish journal of medical science*, *170*, 183-185.
70. Michie, S. (2014). Implementation science: understanding behaviour change and maintenance. *BMC Health Services Research*, *14*(S2).
71. Michie, S., Rumsey, N., Fussell, A., Hardeman, W., Johnston, M., Newman, S., & Yardley, L. (2008). Improving health: changing behaviour. NHS health trainer handbook. *London: Department of Health and British Psychological Society*.
72. Misra, S., Daly, B., Dunne, S., Millar, B., Packer, M., & Asimakopoulou, K. (2013). Dentist–patient communication: what do patients and dentists remember following a consultation? Implications for patient compliance. *Patient preference and adherence*, *7*, 543.
73. Mulimani, P., Ballas, S. K., Abas, A. B., & Karanth, L. (2019). Treatment of dental complications in sickle cell disease. *The Cochrane database of systematic reviews*, *12*(12), CD011633.
74. Munro, S., Lewin, S., Swart, T., & Volmink, J. (2007). A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*, *7*(1).
75. Nagasawa, T., Shirai, K., Kono, M., Kato, S., Mori, M. and Yasushi Furuichi (2016). Relationship between periodontitis and cardiovascular diseases via the immune responses against phospholipids. *Journal of the Japanese Association of Periodontology*, 58(3), pp.98–106.

76. Naseem, M. (2017). Oral health knowledge and attitude among caregivers of special needs patients at a Comprehensive Rehabilitation Centre: An Analytical Study. *Annali Di Stomatologia*, *8*(3), 110.
77. Newton, J. T., & Asimakopoulou, K. (2018). Behavioral models for periodontal health and disease. *Periodontology 2000*, *78*(1), 201-211.
78. NHS Information Centre for Health and Social Care. Adult Dental Health Survey 2009. London: Health and Social Care Information Centre; 2011.
79. O'Sullivan, V. and O'Connell, B.C. (2014). Water fluoridation, dentition status and bone health of older people in Ireland. *Community Dentistry and Oral Epidemiology*, 43(1), pp.58–67.
80. O'Sullivan, I., Lader, D., Beavan-Seymour, C., Chenery, V., Fuller, E., & Sadler, K. (2011). Foundation report: Adult Dental Health Survey 2009 (Technical report). *London: The Information Centre for Health and Social Care*.
81. Painter, J. E., Borba, C. P., Hynes, M., Mays, D., & Glanz, K. (2008). The use of theory in health behavior research from 2000 to 2005: a systematic review. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*, *35*(3), 358–362.
82. Pender, N. J. (2011). Health promotion model manual.
83. Peres, M. A., Macpherson, L., Weyant, R. J., Daly, B., Venturelli, R., Mathur, M. R., Listl, S., Celeste, R. K., Guarnizo-Herreño, C. C., Kearns, C., Benzian, H., Allison, P., & Watt, R. G. (2019). Oral diseases: a global public health challenge. *Lancet (London, England)*, *394*(10194), 249–260.
84. Poul Erik Petersen, Bourgeois, D., Ogawa, H., Saskia Estupiñán-Day and Charlotte Faty Ndiaye (2005). The global burden of oral diseases and risks to oral health. *PubMed*, 83(9), pp.661–9.
85. Rahmati-Najarkolaei F, Rahnama P, Fesharaki MG, Behnood V. Predictors of oral health behaviors in female students: an application of the health belief model. Iran Red Crescent Med J. 2016;18(11):e24747.
86. Ralstrom, E., da Fonseca, M. A., Rhodes, M., & Amini, H. (2014). The impact of sickle cell disease on oral health-related quality of life. *Pediatric dentistry*, *36*(1), 24-28.
87. Ramseier, C., & Suvan, J. E. (Eds.). (2011). *Health behavior change in the dental practice*. John Wiley & Sons.
88. Röing, M., & Holmström, I. K. (2014). Involving patients in treatment decisions - a delicate balancing act for Swedish dentists. *Health expectations : an international journal of public participation in health care and health policy*, *17*(4), 500–510.

89. Rosenstock, I. M. (1974). The health belief model and preventive health behavior. *Health education monographs*, *2*(4), 354-386.
90. Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health education quarterly*, *15*(2), 175-183.
91. Sabbah, W., Tsakos, G., Chandola, T., Sheiham, A., & Watt, R. G. (2007). Social gradients in oral and general health. *Journal of dental research*, *86*(10), 992-996.
92. Sams, D. R., Thornton, J. B., & Amamoo, P. A. (1990). Managing the dental patient with sickle cell anemia: a review of the literature. *Pediatr Dent*, *12*(5), 316-20.
93. Sanders, A. E., Spencer, A. J., & Slade, G. D. (2006). Evaluating the role of dental behaviour in oral health inequalities. *Community Dentistry and Oral Epidemiology*, *34*(1), 71–79.
94. Santos, P. R. B., Machado, P. D. C., Passos, C. P., Aguiar, M. C., Nascimento, R. J. M., & Campos, M. I. G. (2013). Prevalence of orofacial alterations in sickle cell disease: a review of literature. *Brazilian Journal of Oral Sciences*, *12*, 153-157.
95. Shi, H., Wang, J., Huang, R., Zhao, J., Zhang, Y., Jiang, N., Tanimoto, T., Ozaki, A., Shao, C., Wang, J., He, X., & Xu, X. (2021). Application of the extended theory of planned behavior to understand Chinese students' intention to improve their oral health behaviors: a cross-sectional study. *BMC public health*, *21*(1), 2303.
96. Shiue, M. S., Chen, Y. C., & Hsu, C. C. (2019). Associations between oral health knowledge and attitudes among pregnant females in Taiwan. BMC Oral Health, 19(1), 162.
97. Silveira, M. L., Dye, B. A., Iafolla, T. J., Adesanya, M. R., Boroumand, S., Youngblood, M. E., Salazar, C. R., Finlayson, T. L., Khambaty, T., Beaver, S. M., & Garcia, A. I. (2018). Cultural factors and oral health-related quality of life among dentate adults: Hispanic community health study/study of Latinos. *Ethnicity & Health*, *25*(3), 420–435.
98. Solhi, M., Zadeh, D. S., Seraj, B., & Zadeh, S. F. (2010). The application of the health belief model in oral health education. *Iranian journal of public health*, *39*(4), 114–119.
99. Tâncu, A. M. C., Purcărea, V. L., Pantea, M., & Imre, M. (2019). Key factors correlations in selecting dental services. *Journal of Medicine and Life*, *12*(1), 83.
100. Thomson, W. M., Williams, S. M., Broadbent, J. M., Poulton, R., & Locker, D. (2010). Long-term dental visiting patterns and adult oral health. *Journal of dental research*, *89*(3), 307-311.

101. Tiwari, T., Kelly, A., Randall, C. L., Tranby, E., & Franstve-Hawley, J. (2022). Association Between Mental Health and Oral Health Status and Care Utilization. *Frontiers in oral health*, *2*, 732882.

102. Vujicic, M., Buchmueller, T., & Klein, R. (2016). Dental care presents the highest level of financial barriers, compared to other types of health care services. *Health affairs*, *35*(12), 2176-2182.

103. Walker, I., Trompeter, S., Howard, J., Williams, A., Bell, R., Bingham, R., ... & Elton, C. (2021). Guideline on the peri-operative management of patients with sickle cell disease: Guideline from the Association of Anaesthetists. *Anaesthesia*, *76*(6), 805-817.

104. Ward, L. M., Cooper, S. A., McSkimming, P., Greenlaw, N., Pacitti, C., Gibson, J., ... & Kinnear, D. (2020). Dental attendance, restoration and extractions in adults with intellectual disabilities compared with the general population: a record linkage study. *Journal of Intellectual Disability Research*, *64*(12), 980-986.

105. Ware Jr, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical care*, 473-483.

106. Ware, R. E., de Montalembert, M., Tshilolo, L., & Abboud, M. R. (2017). Sickle cell disease. *The Lancet*, *390*(10091), 311-323.

107. Watt, R. (2005). *Strategies and approaches in oral disease prevention and health promotion. 83*(9), 711–718.

108. Watt, R. G., & Petersen, P. E. (2012). Periodontal health through public health - the case for oral health promotion. *Periodontology 2000*, *60*(1), 147–155.

109. Webb Hooper, M., Mitchell, C., Marshall, V. J., Cheatham, C., Austin, K., Sanders, K., Krishnamurthi, S., & Grafton, L. L. (2019). Understanding Multilevel Factors Related to Urban Community Trust in Healthcare and Research. *International Journal of Environmental Research and Public Health*, *16*(18), 3280.

110. Werner, H., Hakeberg, M., Dahlström, L., Eriksson, M., Sjögren, P., Strandell, A., Svanberg, T., Svensson, L., & Wide Boman, U. (2016). Psychological Interventions for Poor Oral Health. *Journal of Dental Research*, *95*(5), 506–514.

111. Whelton H, Crowley E, O'Mullane D, Woods N, McGrath C, Kelleher V, Guiney H, Byrtek M. Oral Health of Irish Adults 2000-2002. 2007; Department of Health, Dublin.

112. White, D. A., Tsakos, G., Pitts, N. B., Fuller, E., Douglas, G. V. A., Murray, J. J., & Steele, J. G. (2012). Adult Dental Health Survey 2009: common oral health conditions and their impact on the population. *British dental journal*, *213*(11), 567-572.

113. Whiteman, L. N., Haywood Jr, C., Lanzkron, S., Strouse, J. J., Batchelor, A. H., Schwartz, A., & Stewart, R. W. (2016). Effect of free dental services on individuals with sickle cell disease. *Southern medical journal*, *109*(9), 576.

114. Williams, T. N., & Thein, S. L. (2018). Sickle cell anemia and its phenotypes. *Annual review of genomics and human genetics*, *19*, 113-147.

115. Xiang, B., Wong, H. M., Cao, W., Perfecto, A. P., & McGrath, C. P. (2020). Development and validation of the Oral health behavior questionnaire for adolescents based on the health belief model (OHBQAHBM). *BMC Public Health*, *20*, 1-11.

116. Zheng, S., Zhao, L., Ju, N., Hua, T., Zhang, S., & Liao, S. (2021). Relationship between oral health-related knowledge, attitudes, practice, self-rated oral health and oral health-related quality of life among Chinese college students: a structural equation modeling approach. *BMC Oral Health*, *21*(1).

# Appendices

## Appendix 1: Ethical approval Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin (Reference No 0438 )

Tallaght University Hospital | Ospidéal Ollscoile Thamhlachta

An Academic Partner of Trinity College Dublin

Ospidéal San Séamas – Seirbhís Dé agus A Phobail

Research Office

Project ID: 0438

Dear Mr Hussain IbnAhmad,

Dr. Alison Dougall, St James's Hospital

Approval Date: 31 January 2022

Submission Number: 666

Submission Title: Oral health and sickle cell diseases in Ireland
Submission Date: 24.Jan.2022 12:36

Dear Postgraduate student IbnAhmad,

On behalf of the Chair and members of the SJH/TUH Joint Research Ethics Committee I wish to inform you that your study has received **FULL APPROVAL.** Your study can now proceed.

The following documents were reviewed and approved:

| Document Type | File Name | Date | Version |
|---|---|---|---|
| Default | R&I Office at SJH | 20.Oct.2021 | 1 |
| Principle Investigator C.V. | Dr.Dogaull CV | 20.Oct.2021 | 1 |
| Survey/Questionnaire | 20.10.2021 Baseline Questionnaire Oral health & Sickle cell disease Version 1 | 20.Oct.2021 | 1 |
| Participant Information Leaflet | 22.01.2022 Participant Information Leaflet version 2 | 22.Jan.2022 | 2 |
| Survey/Questionnaire | 22.01.2022 questionnaire version 2 | 22.Jan.2022 | 2 |

*Please note that ethical approval for this study is only active under the following conditions:*

1. *Applicants must submit an annual report for ongoing projects.*
2. *Applicants must submit an end of study declaration/end of study report upon completion of the study.*
3. *All adverse events must be reported to the JREC.*

Page 1 of 2

4. *All changes (minor and substantial) to documentation/study must be submitted to the JREC using the amendment request form and the changes must be tracked/highlighted clearly. Approval from the JREC is required before implementation of the changes.*

*It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018.*

Yours sincerely,

**Dr Sadhbh O'Neill**

**Research Ethics & Clinical Trials Manager,**

**SJH/TUH Joint Research Ethics Committee**

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

## Appendix 2 Participant information leaflet

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

***Patient Information Leaflet***

Title of the study:

### *Oral health beliefs, behaviours & attitudes toward dentistry among young adults with sickle cell diseases in Ireland*

**Introduction:**

You are being invited to take part in a research study. It is a local study that will involve patients at the Adult Sickle Cell and Thalassemia Centre at St James Hospital, Dublin. Before you decide whether you wish to be involved, it is important for you to understand why the research is being done and what it will involve. Please, take time to read the following information carefully and discuss it with people that are important to you and with your GP if you wish so. Ask us if there is anything that is not clear or if you would like to get more information. Take time, whether or not you wish to take part. Thank you for taking the time to read this.

**What is the purpose of the study?**

Some people with sickle cell disease (SCD) do not have good dental health. In this study we want to find out what people with SCD know about keeping their teeth healthy. To do this we need to ask some questions about dental health, looking after teeth and going to the dentist. We would like to find out about these things in order to design dental health information that is useful and focused on people living with SCD.

**Why have I been chosen?**

You have a personal diagnosis of having sickle cell disease. By involving you in the study we hope to get a better understanding of how people keep their teeth healthy and what the barriers are to keeping their teeth healthy.

**Procedures:**

If you kindly agree to participate in the study, we will ask you to fill out a paper questionnaire. It will ask you about your dental health, about going to the dentist and how often you go, and finally about what you think about dental health and the things you can do to prevent getting dental diseases. We will also ask a few questions about yourself. You do not need to give your name on the questionnaire, and no one will be able to link your answers to you. If you need any help with the questions, please ask the clinical nurse manager: Ms. Ciara Sheehan, *cisheehan@stjames.ie* or the clinical nurse specialist: Mr. Nowell Noel Ngwenya, *nngwenya@stjames.ie*

After you complete the questionnaire, please hand the-paper questionnaire to the receptionist

**What are the possible benefits of taking part?**

In this study we hope to get a better understanding of what people with SCD believe and know about dental health. You would not directly benefit from this study, but we will use what we learn from the study to design a dental education program focusing on young people living with SCD.

Please note patients will not receive a dental examination or check up as part of the study. However, should a dental health problem be raised by a participant, they will be advised to contact their general dental practitioner for a dental checkup.

**What are the possible disadvantages and risks of taking part?**

Entering this study will not affect your normal treatment at the Sickle Cell & Thalassemia unit in any way. There are no risks to taking part, but it will take up to 15 minutes of your time.

**Alternative treatment:**

If you do not wish to take part in this study, you will continue under the care of your treating physician and / or surgeon, and your routine clinical care will remain unchanged.

**Confidentiality:**

All information that is collected about you during the course of the research will be kept strictly confidential. You will be allocated an individual study number. No one will be able to identify you on the questionnaire and you will not be identifiable in any reports we write.

**Compensation:**

Nothing in this document restricts or curtails your rights. The research team will not alter your treatment in any way during their conduct of the study; we do not anticipate you experiencing any harm from taking part. However, if taking part in this research projects harms you, there are no special compensation arrangements.

**Voluntary Participation:**

Your participation in the study is entirely voluntary. You are free to decline to enter or withdraw from the study until the point you submit the questionnaire without having to give a reason. If you choose not to enter the study, or withdraw from the study, this will in no way affect your future medical care. If you decide to take part, you will be given this information sheet to keep.

**Stopping the study:**

When the study comes to an end, the data will be analyzed by the Research team and by an experienced Medical Statistician. Anonymized, aggregated data will be published to inform the wider community of doctors and dentists treating patients with sickle cell disease. All data will be anonymized and you will not be identifiable.

**Permission:** The study has been reviewed and approved by the Local Hospital Research Ethics Committee (LREC) St James's Hospital/Tallaght University Hospital Joint Research Ethics Committee

**Further Information:** If you have any queries, you can contact: Dr. Alison Dougall, National Coagulation Centre, St. James's Hospital. Telephone: **016127303**, Email: **alison.dougall@tcd.ie**

## Appendix 3 Questionnaire version 2

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

Title of Study:

***Oral health beliefs, behaviours & attitudes toward dentistry among young adults with sickle cell diseases in Ireland***

You are invited to participate in a short questionnaire to answer some questions about your dental health, and your experience of going to the dentist.

Your responses are important, and we are interested in your views. There are no right or wrong answers to these questions.

Ask us if there is anything that is not clear or if you would like to get more information. Please ask the clinical nurse manager: Ms. Ciara Sheehan, *cisheehan@stjames.ie* or the clinical nurse specialist: Mr. Nowell Noel Ngwenya, *nngwenya@stjames.ie* , who are happy to help you on the ward.

Please complete the questionnaire on the following pages. The questionnaire should take no longer than 15 minutes to complete.

Hand this paper questionnaire to the receptionist when you have completed the questionnaire. All responses will be treated confidentially. Thank you for taking the time to take part.

**If you have any queries, you can contact: Dr. Alison Dougall. Telephone: 016127303, Email: alison.dougall@tcd.ie**

**For office use only: Participant code** ☐☐☐

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

| Part I | General Information: |
|---|---|

| 1. Gender | ☐ Male ☐ Female |
|---|---|

| 2. What is the year of your birth? | Click or tap to enter a date. |
|---|---|

| 3. Have you lived outside the Republic of Ireland for a continuous period of one year or more? |
|---|
| ☐ No |
| ☐ Yes |
| If 'Yes', please write the YEAR of last taking up residence in Ireland: ……<br><br>AND the COUNTRY of last previous residence: …… |

| 4. What is your nationality? | |
|---|---|
| ☐ Irish | ☐ Other nationality, please write in: ……..... |

| 5. What is your ethnic or cultural background? | |
|---|---|
| **White:**<br>☐ Irish<br>☐ Irish Traveler<br>☐ Any other White background | **Black or Black Irish:**<br>☐ African<br>☐ Any other Black background |
| **Asian or Irish Asian:**<br>☐ Chinese<br>☐ Any other Asian background | **Mixed background**<br>☐ Mixed<br>☐ Other, please give details: |

| 6. Do you speak a language other than English at home? | |
|---|---|
| ☐ No | ☐ Yes<br>What is this language?..... |

| 7. How well do you speak English? | |
|---|---|
| ☐ Very well | ☐ Well |
| ☐ Not well | ☐ Not at all |

| 8. Do you have any of the following long-lasting conditions or difficulties? |
|---|
| ☐ Blindness or a serious vision impairment |
| ☐ Deafness or a serious hearing impairment |
| ☐ A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying |
| ☐ An intellectual disability |
| ☐ A difficulty with learning remembering or concentrating |
| ☐ A psychological or emotional condition |
| ☐ A difficulty with pain, breathing, or any other chronic illness or condition, for example Sickle cell or Thalassemia |

| 9. Have you finished your full-time education | |
|---|---|
| ☐ No | ☐ Yes<br>If 'Yes', write in the AGE at which it finished: …… |

| 10. What is the highest level of education/training (full-time or part-time) which you have completed to date? |
|---|
| ☐ No formal education/training |
| ☐ Primary education |
| ☐ Lower Secondary/ Upper Secondary |
| ☐ Technical or Vocational |
| ☐ Advanced Certificate/Completed |
| ☐ Higher Certificate |
| ☐ Ordinary bachelor's degree or National Diploma |

| 11. How would you describe your current principal status? |
|---|
| ☐ Working for payment or profit |
| ☐ Looking for first regular job |
| ☐ Unemployed |
| ☐ Student or pupil |
| ☐ Looking after home/family |
| ☐ Unable to work due to permanent sickness or disability |
| ☐Other, please write in: …… |

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

| Part II | We would like to ask you about how you rate your health and dental health (Please tick one response only): |
|---|---|

| # | | Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|---|---|
| 12. | In general, how would you describe your **General Health**? | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13. | In general, how would you describe **Dental Health**? | ☐ | ☐ | ☐ | ☐ | ☐ |

| Part III | The next questions are about going to the dentist and how often you go (Please tick one response only to each question below): |
|---|---|

| 14. In general, do you go to the dentist for... |
|---|
| ☐ A regular check up |
| ☐ An occasional check up |
| ☐ Only when you're having trouble with your teeth |
| ☐ Never been to the dentist |

| 15. How often do you go to the dentist? |
|---|
| ☐ At least once every six months |
| ☐ At least once every year |
| ☐ At least once every two years |
| ☐ Less frequently than every two years |
| ☐ Only when having trouble with your teeth |

| **16. About how long ago was your last visit to the dentist?** |
|---|
| ☐ Within the last 6 months |
| ☐ Within the last 7-12 months |
| ☐ More than 2 years, but less than 3 years ago |
| ☐ More than 3 years, but less than 5 years ago |
| ☐ More than 5 years, but less than 10 years ago |
| ☐ More than 10 years ago |

| **17. Would you say that nowadays you go to the dentist more often, about the same, or less often than you did 5 years ago** |
|---|
| ☐ More often |
| ☐ About the same |
| ☐ Less often |

| **18. How many times have you been to the dentist in the last five years purely for a checkup?** |
|---|
| Please write the number of times: |

| **19. How many times have you been to the dentist in the last five years because you have had trouble with your teeth?** |
|---|
| Please write the number of times: |

| **20. Which of these, if any, are the reasons why you have not been to the dentist in the last two years?**<br>(You may tick all the reasons that apply to you) |
|---|
| ☐ No need to go to the dentist / nothing wrong with my teeth |
| ☐ I can't find a dentist / or my dentist changed to private |
| ☐ I can't afford the dentist charges |
| ☐ I haven't got the time to go |
| ☐ I am afraid of going to the dentists |
| ☐ Keep forgetting / Haven't got round to it |

| **21. Also, which of these, if any, are also reasons why you have not been to the dentist in the last two years?**<br>(You may tick all the reasons that apply to you) |
|---|
| ☐ It's difficult to get to / from the dentist |
| ☐ I've had a bad experience with a dentist |
| ☐ I'm too embarrassed to go to the dentist |
| ☐ I don't see the point in going to the dentist |
| ☐ None of these reasons |
| ☐ Other reason (please specify) |

| Part VI | **We are interested in what you think about dental health and the things you feel that you can do to prevent getting dental diseases**<br>**(Please tick only one answer that best reflects what you think for each statement)** |
|---|---|

| # | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| **22.** | There is a chance that I will get caries (dental decay or cavities). | ☐ | ☐ | ☐ | ☐ | ☐ |
| **23.** | There is a chance that I will have periodontal disease (gum disease) | ☐ | ☐ | ☐ | ☐ | ☐ |
| **24.** | I think brushing and flossing can make teeth healthier. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **25.** | I think brushing and flossing can prevent oral diseases from happening | ☐ | ☐ | ☐ | ☐ | ☐ |
| **26.** | I think brushing and flossing can make teeth look good | ☐ | ☐ | ☐ | ☐ | ☐ |
| **27.** | I think brushing and flossing can keep breath fresh | ☐ | ☐ | ☐ | ☐ | ☐ |
| **28.** | I think brushing and flossing can prevent dental problems that make it uncomfortable for me to eat. | ☐ | ☐ | ☐ | ☐ | ☐ |

| # | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| **29.** | I think brushing and flossing can help me avoid spending more time having dental treatment in the future. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **30.** | I think brushing and flossing can help me avoid spending money on dental treatment in the future. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **31.** | I think it is difficult for me to brush twice a day. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **32.** | I think it's a waste of time to brush and floss. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **33.** | I think I do not have enough time to have an annual dental visit. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **34.** | I am afraid of having dental treatment, so I don't have dental visits annually. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **35.** | I think there isn't enough money at home for me to go to the dentist once a year, so I don't have an annual dental visit. | ☐ | ☐ | ☐ | ☐ | ☐ |

| # | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| **36.** | I think the dental clinic/surgery is far from my home, so I don't have an annual dental visit. | ☐ | ☐ | ☐ | ☐ | ☐ |

**Next , we are going to ask you about your teeth brushing :**

**(Please tick only one answer that best reflects what you think for each statement)**

| # | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| **37.** | My family often reminds me to brush and floss. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **38.** | Friends/People who are important to me often remind me to brush and floss. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **39.** | My employers /tutors/ teachers often remind me to brush and floss. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **40.** | My doctors /nurses /medical teams often remind me to brush and floss. | ☐ | ☐ | ☐ | ☐ | ☐ |

**We are now would like to ask you about your views on dental/oral health?**

**(Please tick only one answer that best reflects what you think for each statement)**

| # | | Not serious | A little serious | Partially serious | Serious | Very serious |
|---|---|---|---|---|---|---|
| **41.** | If I have tooth decay, for me that is … | ☐ | ☐ | ☐ | ☐ | ☐ |
| **42.** | If I have gum disease, for me that is … | ☐ | ☐ | ☐ | ☐ | ☐ |
| **43.** | If my teeth do not look good because of oral diseases, for me that is … | ☐ | ☐ | ☐ | ☐ | ☐ |
| **44.** | If I have bad breath because of oral diseases, for me that is … | ☐ | ☐ | ☐ | ☐ | ☐ |
| **45.** | If I can't sleep well because of oral diseases or dental problems, for me that is … | ☐ | ☐ | ☐ | ☐ | ☐ |
| **46.** | If I can't eat my favorite food because of oral diseases, for me that is … | ☐ | ☐ | ☐ | ☐ | ☐ |
| **47.** | If I get laughed at by classmates because of oral diseases, for me that is… | ☐ | ☐ | ☐ | ☐ | ☐ |

| How confident you are that you will brush your teeth for 2 min twice daily in the circumstances below: | | | | | | |
|---|---|---|---|---|---|---|
| **#** | | **Not confident** | **A bit confident** | **Fairly confident** | **Quite confident** | **Very confident** |
| **48.** | When you are under a lot of stress | ☐ | ☐ | ☐ | ☐ | ☐ |
| **49.** | During or after experiencing personal problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| **50.** | When you are feeling tired | ☐ | ☐ | ☐ | ☐ | ☐ |
| **51.** | When you don't feel like it | ☐ | ☐ | ☐ | ☐ | ☐ |
| **52.** | When you are anxious | ☐ | ☐ | ☐ | ☐ | ☐ |
| **53.** | After experiencing family problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| **54.** | When you have other commitments | ☐ | ☐ | ☐ | ☐ | ☐ |
| **55.** | When you feel you don't have the time | ☐ | ☐ | ☐ | ☐ | ☐ |
| **56.** | When you are feeling under pressure from school/college, work/job | ☐ | ☐ | ☐ | ☐ | ☐ |
| **57.** | When you have too much work to do at home | ☐ | ☐ | ☐ | ☐ | ☐ |

**The next questions are about your personal oral care and diet (Please tick one response only for each question):**

| **58. How often do you clean your teeth nowadays?**<br>(Question refers to brushing only) |
|---|
| ☐ More than twice a day |
| ☐ Twice a day |
| ☐ Once a day |
| ☐ I don't see the point in going to the dentist |
| ☐ Less than once a day |
| ☐ Never |

| # | | Yes | No |
|---|---|---|---|
| **59.** | Do you have a toothbrush | ☐ | ☐ |
| **60.** | Do you have toothpaste? | ☐ | ☐ |
| **61.** | Do you use anything other than an ordinary (manual) toothbrush and toothpaste for dental hygiene purposes? (Electronic toothbrush, chewing gum) | ☐ | ☐ |

| **63. What do you use anything other than an ordinary (manual) toothbrush and toothpaste for dental hygiene purposes?** |
|---|
| ☐ Mouthwash |
| ☐ Interdental toothpicks/wood sticks |
| ☐ Dental floss |
| ☐ Interspace brush |
| ☐ Electric toothbrush |
| ☐ Sugar-free chewing gum |
| ☐ Something else (please mention it: …… |

| **64. Which brand of toothpaste do you currently use (most often)?** |
|---|
| |

| **65. How often, on average do you have fizzy drinks, fruit juice, or soft drinks like squash, excluding diet or sugar-free drinks?** |
|---|
| ☐ 6 or more times a week |
| ☐ 1-2 times a week |
| ☐ Less than once a week |
| ☐ Rarely or never |

| **66. Do you usually have sugar in hot drinks like tea and coffee?** |
|---|
| ☐ Yes |
| ☐ No |
| ☐ Does not drink hot drinks |

| **67. Have you ever been refused dental treatment because you have sickle cell disease?** |
|---|
| ☐ Yes |
| ☐ No |
| **If you answered Yes, could you write briefly why you were refused and what happened next? (Optional question).**<br><br>……<br>……<br>…… |

| # | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| **68.** | I think my sickle cell disease has affect in my teeth/oral health? | ☐ | ☐ | ☐ | ☐ | ☐ |

**If you agree/strongly agree, please explain why you think sickle cell disease might affect your teeth/oral health? (Optional question).**

……
……
……

| # | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| **69.** | I think my sickle cell disease has affect in my teeth/oral health? | ☐ | ☐ | ☐ | ☐ | ☐ |

**If you agree/strongly agree, please explain why you think sickle cell disease might affect your teeth/oral health? (Optional question).**

……
……
……

| **70. Which parts of your body that you usually checked by your medical team of the sickle cell center? (You may tick all that apply to you)** |
|---|
| ☐ Eye |
| ☐ Skin/face/hand color |
| ☐ Liver function tests |
| ☐ Lungs |
| ☐ Spleen/Liver palpation |
| ☐ Fingers/Toes |
| ☐ Heart rate/Blood pressure |
| ☐ Tongue |
| ☐ Mouth |
| ☐ Teeth |

**Thank you for your participation**