Observer, dentist and family perceptions of shared decision-making consultations about compromised first permanent molars

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Submitted in accordance with the requirement for the degree of Professional Doctorate of Paediatric Dentistry

The University of Leeds

School of Dentistry

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

Dedication

This is dedicated to my beloved husband, daughter, and family.

Acknowledgements

First, I would like to express my sincere gratitude to my wonderful supervisors for their continuous guidance and support throughout the Doctoral program years. Professor Richard Balmer for his continued mentorship and advice throughout the research and clinical program. I am profoundly grateful that he believed in my potential in this research and allowed me to grow. I am also very thankful for Dr. Sophy Barber, who continually challenged me to think outside the box and constantly drove me to work hard to reach my full potential. I am very grateful for her continuous support and mentorship. Even on the days when I felt that it was so difficult for me to proceed, both of my supervisors constantly reassured me that I could do it.

I would like to thank the orthodontic and paediatric dentistry teams in Leeds and Wakefield, who have been extremely helpful with recruiting patients for my research. Also, the dentists who have participated in the research and consultants who facilitated data collection during consultations.

I would like to thank all of the young people and parents who have been involved in the research, especially for taking the time to answer the questionnaires. I would like to thank my sponsor for providing me a scholarship to support me in completing my doctoral degree, with financial and training support.

Finally, I am extremely thankful to my beloved husband Abdulrahaim, who sacrificed a lot of time, money, and his career to support my study in the UK for always being there for me and never doubting my ability to flourish. I would have never completed this degree without the constant support and understanding of my wonderful and inspiring husband. I would also like to thank my beautiful daughter, Mariam, for always believing in me and encouraging me to grow. A big thanks to my parents, brothers and sisters for always encouraging me to keep going and inspiring me to finish. I would like to thank my friends, especially Alaa, for always being there to listen to me and support me throughout this journey.

“I acknowledge the use of Grammarly (Grammarly Inc, https://www.grammarly.com/) to proofread my final draft.”

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Abstract

Treating compromised first permanent molars (cFPM) is complex and requires consideration of multiple factors to identify the different treatment options for each individual. Shared decision-making (SDM) is important to ensure dentists and patients work together to deliberate these options and reach a decision about which treatment right for the individual at the time.

Aim: To explore observer raters who are the researchers, dentist, and families' perception of shared decision-making consultations for compromised first permanent molars.

Design: Cross-sectional observational study.

Population and setting: Young people (aged 7-11 years), their families and dentists involved in making decisions about cFPM in consultations in the paediatric dentistry clinic, orthodontic clinic and joint orthodontic-paediatric clinic in two NHS hospitals in Yorkshire, England.

Methods: Clinical consultations were observed and audio-recorded to allow three observers to independently score the consultation using a bespoke 14-item SDM measure then reach a consensus score. The family and dentist also scored the consultation using the same items. The scores for each of the 14 items were described from the three different perspectives (observer, family and dentist). Trends in scores across items, individuals and rater groups were described to identify areas of good practice and potential improvement. Inter-rater and intra-rater reliability tests were performed for the observer scores.

Results: In total, 12 consultations were observed. Consultations were scored poorly by observers in key elements of SDM, such as identifying roles in decision-making, assessing understanding, and citing the source of information. Paediatric dentists were scored higher than orthodontists in explaining the clinical issue, treatment options, risks and benefits. Consultations showed similar trends in SDM ratings. Families rated the consultations the highest, while dentists fell in between observers and families in scoring.

Conclusion: Key elements of SDM were missing in consultations about cFPM with evident difference in perceptions of families, dentists, and observers in SDM.

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Abbreviations

cFPM	Compromised First Permanent Molars
COM-B model	Capability, Opportunity, Motivation – Behaviour model
EAPD	European Academy of Paediatric Dentistry
FPM	First Permanent Molars
FPM	First Permanent Molar
HCRW	Health and Care Research Wales
HRA	Health Research Authority
IDM	Informed Decision Making
IRAS	Integrated Research Application System
LDI	Leeds Dental Institute
MIH	Molar Incisor Hypomineralisation
NHS	National Health Service
PDA	Patient Decision Aids
PGH	Pinderfields General Hospital
RCS	Royal College of Surgeons
SDCEP	Scottish Dental Clinical Effectiveness Programme
SDM	Shared Decision Making
SPM	Second Permanent Molar
TPM	Third Permanent Molar

Chapter 1 Introduction

1.1 The research problem

Treating compromised first permanent molars (cFPM) is complex and requires consideration of the child's age, compliance, general health, stage of dental development, dental health, occlusion, and the young person's wishes. The current guidelines state that if a child presents with a cFPM with an uncertain long-term prognosis, elective extraction of cFPM could be considered within the context of the individual and their underlying occlusion (Noar et al., 2023). The ideal outcome of interceptive extraction of the cFPM is to allow the eruption of the second permanent molar (SPM) into the first permanent molar (FPM) space and ideally third permanent molars (TPM) eruption to complete the molar dentition (Noar et al., 2023). A challenge arises in the decision when the young person presents beyond the ideal age of extraction, making the discussion of benefit versus risk or uncertainty in outcome more complicated.

Shared decision-making (SDM) is a collaborative process that involves the young person, family members and their healthcare provider working together to reach a joint decision about their care, which is cFPM in this study (NICE, 2021). According to the NICE guideline published in 2021, SDM is the standard of care to reach a joint decision about non-emergency care and should be practised by everybody who delivers healthcare services (NICE, 2021). The healthcare worker requires skills and willingness to provide the appropriate evidence-based treatment options to the patient. On the contrary, the patient should be willing to share information during the consultations to provide his/her preferences, values and beliefs (NHS England and NHS Improvement, 2019).

Electronic searches were carried out in MEDLINE and Google Scholar. The search strategy involved the topic (shared decision making OR problem solving OR decision making), the setting (health OR dentist OR dentistry OR teeth OR tooth OR permanent). The search was complemented by cross-referencing, hand searches, screening through available reviews, building on existing knowledge, and webpages of conferences and government policies. The literature search did not identify any studies evaluating SDM in consultations in the paediatric dental department. In paediatric dental consultations, the dentist makes decisions with two people, the

guardian and the child, making the process of SDM even more complex. A recent study assessed whether SDM was demonstrated in consultations for hypodontia (Barber et al., 2019). It demonstrated that multiple challenges and barriers were present; hence SDM was not promoted in such consultations (Barber et al., 2019). A scoping review in 2018 found that no studies assessed the extent how which patients and dentists engage in the implant decision treatment planning (Alzahrani and Gibson, 2018). A cross-sectional study found that full SDM was not promoted in the implant consultations (Alzahrani, 2016).

1.2 Purpose of the research

This research aimed to explore observers' perceptions of SDM in consultations about managing cFPM and compare this to dentists' and families' perceptions. The observer raters were the research team involved in this study (SA, RB, and SB). This was crucial to understanding whether paediatric and orthodontic dental practitioners consider all the elements of SDM in consultations regarding cFPM. Assessing the observers' perspective was useful in providing an objective consideration of whether important suggested components of SDM have been demonstrated in the consultations. This knowledge has the potential for improvement in practice, training and encourages future research in this area.

Chapter 2 Literature Review

2.1 Compromised first permanent molars

2.1.1 First permanent molar development

The FPMs are derived from the dental lamina (Cobourne et al., 2014). The first evidence of calcification in maxillary and mandibular FPM is at birth (Berkovitz et al., 2018). Crown development of FPM is completed at 2-3.5 years, and eruption occurs at approximately 6 years old (Berkovitz et al., 2018).

2.1.2 Aetiology

If the FPM are subjected to unfavourable circumstances, they become compromised and may have a limited prognosis (Noar et al., 2023). The main causes of cFPM are caries and developmental defects.

2.1.2.1 Dental disease

The most vulnerable permanent teeth to decay in childhood and adolescence are the FPM (SDCEP, 2018). FPMs are susceptible to large carious lesions due to their early eruption into the oral cavity and predisposition to dental anomalies (Cameron and Widmer, 2021).

The FPMs are the first permanent teeth to erupt in the oral cavity (Gürcan and Bayram, 2021). Dental enamel undergoes post-eruptive maturation, which resists calcification. Newly erupted teeth lack the highly calcified layer, which protects the tooth. FPMs also have deep pits and fissures, predisposing them to further decay (Gürcan and Bayram, 2021).

FPMs usually start erupting at the age of 6 years (Warrilow and McDonald, 2021). At this age, brushing can be compromised by the limited dexterity of the child and often requires supervision or support from an adult (Warrilow and McDonald, 2021). Moreover, according to the Public Health England Nutrition Survey, 4- to 10-year-old children in the UK eat double the recommended amount of sugar per day, indicating a cariogenic diet (Public Health England, 2019). A cariogenic diet and brushing limitations at this age may contribute to the high caries risk in the FPMs (Warrilow and McDonald, 2021).

Extensive caries may result in pulpal involvement, leading to symptomatic manifestation of reversible or irreversible pulpitis and radiographic involvement of the pulpal and peri-radicular area. Clinical and radiographic factors should be considered in decision-making and listing all valid treatment options to the patient (SDCEP, 2018).

2.1.2.2 Developmental defects

FPMs are also vulnerable to developmental anomalies. Calcification is also affected by changes in diet and nourishment, such as deficiencies and malnutrition (Warrilow and McDonald, 2021). If calcification is affected, the tooth is susceptible to hypomineralisation, in which ameloblast function is disturbed, and deposited enamel is not as durable (Warrilow and McDonald, 2021). Hypomineralised FPMs are more vulnerable to caries as the enamel is affected (Noar et al., 2023).

The most common developmental defect in FPMs is Molar Incisor Hypomineralisation (MIH). MIH was defined by Weerheijim (2003) as a qualitative enamel defect affecting at least one FPM and can also be associated with permanent incisors. It is highly prevalent and affects 1 in 6 children worldwide (Hubbard, 2018). The exact aetiology of MIH is not fully understood. The European Academy of Paediatric Dentistry (EAPD) 2010 policy document states *"It is likely that MIH is not caused by one specific factor. Several harmful agents/conditions may act together and increase the risk of MIH occurring additively or even synergistically"* (Schwendicke et al., 2018; Lygidakis et al., 2022). However, it is suggested that MIH follows a multifactorial model with genetic, systemic and medical aetiological factors (Lygidakis et al., 2022). Systemic medical factors, such as perinatal hypoxia, prematurity, and caesarean section, appear to multiply the risk of MIH (Garot et al., 2022). Childhood and infant diseases are linked to MIH, as are fever and antibiotic use, which are considered consequences of illness (Garot et al., 2022). Studies have identified specific gene variants, such as those associated with enamel formation and immune response, that may increase susceptibility to MIH (Bussaneli et al., 2018; Pang et al., 2020). Additionally, epigenetic mechanisms demonstrate how environmental factors interact with genetic predispositions to influence enamel development (Lygidakis et al., 2022).

This evidence supports the multifactorial nature of MIH, where genetic and environmental factors collectively contribute to its occurrence and variability in clinical presentation (Lygidakis et al., 2022).

2.1.3 Severity

The prognosis of FPM may be influenced by the severity of hypomineralisation and the presence of post-eruptive breakdown and caries (Lygidakis et al., 2022). The EAPD guideline ‘Best clinical practice' emphasised the importance of documenting the severity of cFPM in MIH to formulate an appropriate treatment plan and discuss prognosis (Lygidakis et al., 2022). The guideline classifies FPM as mild or severe. Mild describes demarcated enamel opacities without breakdown, and sensitivity is induced by a stimulus. Severe describes enamel opacities with breakdown, caries, and spontaneous persistent sensitivity.

2.1.4 Prevalence

In the UK, the prevalence of caries in FPMs has been shown to increase with age from 5% in 8-year-old children to 25% in 15-year-olds (NHS England, 2013). There has been a trend of reducing caries prevalence and disease severity among 12-year-old children for the past 26 years (Rooney et al., 2010). On the other hand, MIH has reported a prevalence of 14.2% in the UK and a global prevalence ranging from 0.5% to 40.2% (Kusku et al., 2008; Balmer et al., 2012).

2.1.5 Quality of life and dental health

Compromised FPM can have detrimental effects on the child’s and parents’ quality of life. One of the most commonly reported symptoms is pain, which affects the child’s ability to eat, sleep, attend school, and perform daily activities (Taylor et al., 2019). Parents can be affected through loss of sleep and days off work because of their child’s symptoms (Taylor et al., 2018). A systematic review highlights that MIH predominantly impacts the domains of “Oral Symptoms” and “Functional limitation”, with severe cases demonstrating a greater negative influence on these aspects as reported by children and caregivers (Jälevik et al., 2022). The condition is associated with hypersensitivity, pain, and challenges in maintaining oral hygiene, which collectively impair daily functioning and emotional well-being (Jälevik et al., 2022). Evidence suggests that appropriate treatment of MIH-affected teeth can mitigate hypersensitivity and improve oral health related quality of life, underscoring the critical need for effective management strategies to enhance the overall well-being of affected individuals (Fütterer et al., 2020).

2.1.6 Treatment options and delivery

The treatment options for managing cFPM are dependent on patient, dental and clinical factors (Table 2.1). Assessing a young person with cFPM requires consideration of these factors.

One of the key aspects to consider is the young person's dental age because this will determine whether they are suitable for interceptive extraction. Chronological age is the individual's actual age in years, while dental age reflects the stage of tooth development (Bakhsh et al., 2024). While chronological age provides a general guideline, dental age, assessed through tooth development and eruption patterns, is a more precise indicator of when interceptive extraction will be most effective (AAPD, 2024). Interceptive orthodontic treatment refers to the early management of occlusal disturbances to eliminate or simplify their future treatment, typically during the mixed dentition phase (Wong, 2009). The current Royal College of Surgeons (RCS) guidance recommends interceptive extractions for cFPM when the second permanent molars are developing, which is approximately 8-10 years of age (Noar et al., 2023). Challenges may also arise when a young person presents before or after this ideal developmental stage.

Patient factors affecting the treatment options for young people with cFPM include the person's age, their ability to cope with dental treatment, their general health, and whether they can access different healthcare services. For example, if a young person lives in an area where general anaesthesia is not available or requires significant travel to attend an appointment, this may influence their decision about having treatment under general anaesthesia. Individual preferences are also important. In some cases, the parents or young person may prefer to maintain a cFPM and restore the tooth, while others may prefer extracting the cFPM to avoid the need for regular restorative maintenance and restoration repair or replacement (Taylor et al., 2025).

There are several dental factors that affect the treatment options of cFPMs. These include the dental age of the young person. This is important to assess eligibility for interceptive extraction of cFPM. The severity and number of cFPMs can also affect treatment. If a cFPM is severely affected, this can impact tooth restorability, making extraction more likely. The presence of additional dental anomalies, such as hypodontia or ectopic teeth, may shift the discussion more towards restoring the

cFPM. The presence of a third permanent molar (TPM) is crucial in planning for interceptive extractions of cFPMs. However, although TPMs are typically visible radiographically by age 8 this is not always the case. In cases where the TPM is not visible, treatment planning becomes more complex (Ashley and Noar, 2019).

Young people presenting with cFPM may have features of malocclusion, such as class II and class III inter-arch relationships. These cases require specialist orthodontic opinion about whether there is benefit in maintaining cFPMs to aid future orthodontic treatment. Caries risk is a dental factor that influences treatment options for cFPM. If a young person has a high risk of caries with multiple deep lesions, a more aggressive treatment approach is necessary.

The clinical factors that influence treatment options for cFPM include the dentist's expertise in treatment planning and management, the availability of various treatment modalities in the area, and the accessibility of multidisciplinary teams, which include orthodontists and paediatric dentists within the region. Multidisciplinary clinics involve specialists and specialist trainees from various departments, ensuring a comprehensive, holistic approach in treatment planning (Alkadhimi et al., 2021). In these clinics, dentists address early interventions, treatment options and special considerations. Early diagnosis and management are important to prevent further complications and the need for more intensive treatment later. The treatment plan takes into consideration the severity of the tooth’s condition, the child’s age and cooperation, and the potential impacts on the developing dentition (Alkadhimi et al., 2021).

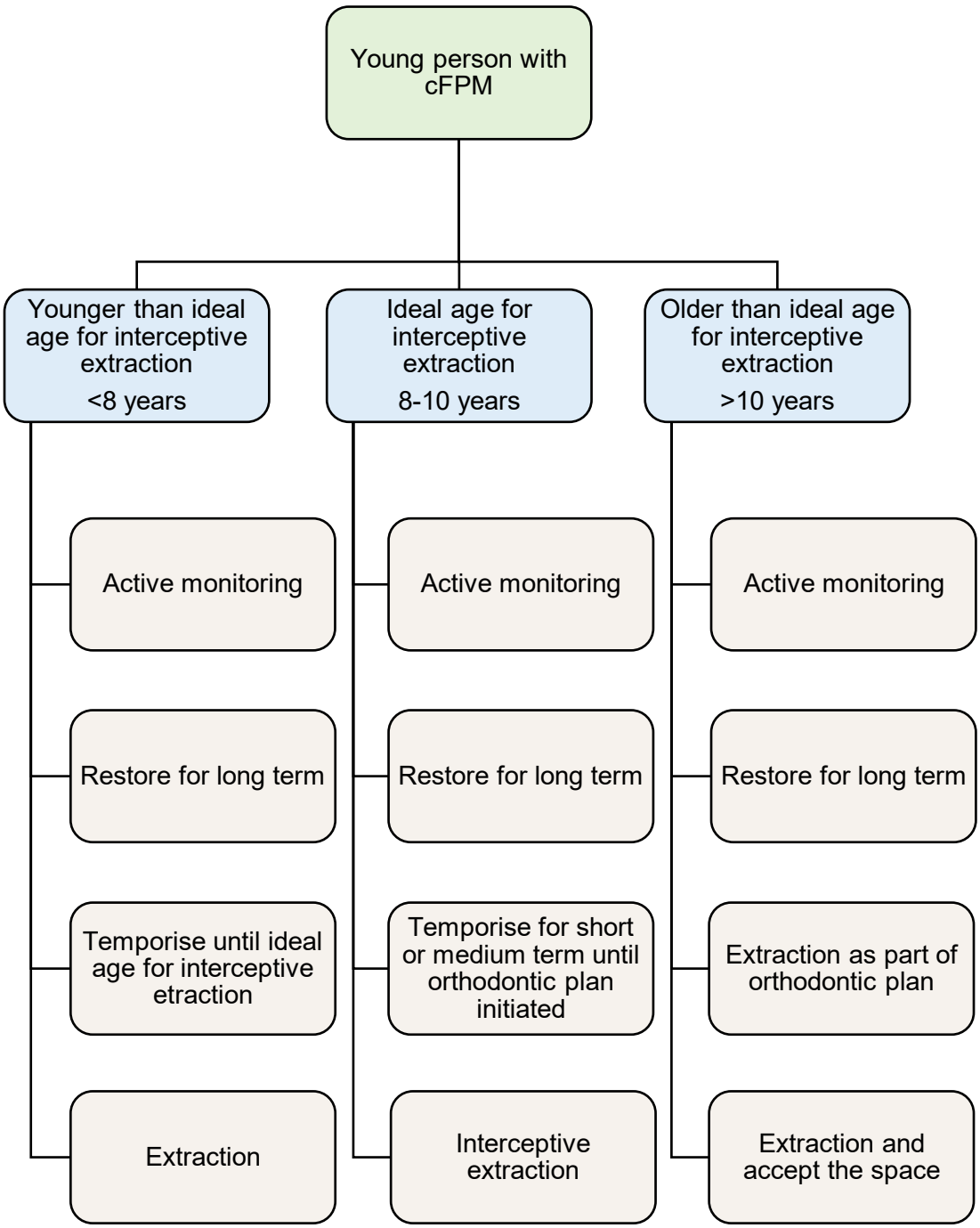
Table 2.1: Factors affecting the treatment options for young people with compromised FPM.

Patient factors	Dental factors	Clinical factors
- Chronological age - Parent and patient's attitudes - Ability to cope with dental treatment. - General health - Accessibility to health care	- Dental age - Severity of cFPM - Number of cFPM - Presence of other dental anomalies: Hypodontia, enamel defects, ectopic teeth - Presence of TPM - Occlusal relationship - Crowding - Caries risk	- Dental expertise - The availability of multidisciplinary opinions - General anaesthesia and conscious sedation availability

Table 2.1 is adapted from (Lygidakis et al., 2022)

The dental age at presentation determines the treatment options of cFPMs. Figure 2.1 summarises the possible treatment options in young people presenting with cFPM depending on the age of presentation. The treatment options include active monitoring, temporary treatment to support short- or medium-term maintenance of the tooth, definitive restoration and long-term maintenance, forced extraction, interceptive extraction, and balancing and compensating extractions. There is no single approach that fits all cases, as multiple factors must be considered for each individual situation, considering the dental, patient and clinical factors (Lygidakis et al., 2022; Noar et al., 2023).

Figure 2.1: Possible treatment options for cFPM depending on the age of presentation



2.1.6.1 Active monitoring

Active monitoring involves regular check-ups to track the progression of the carious lesion or post-eruptive breakdown in a cFPM (Taylor and Bulmer, 2025). Enhanced prevention is also recommended through toothbrushing, dietary advice, and professionally delivered interventions such as fluoride and fissure sealants (SDCEP, 2018).

Active monitoring, rather than intervention, could be considered in the absence of acute symptoms such as pain, swelling, or infection (Taylor and Bulmer, 2025) or if the young person is very anxious and unable to accept dental treatment. The risk of dental pain and infection is dependent on the severity of the cFPM and can be high in severely cFPM. Choosing to monitor requires a thorough discussion of these risks with the young person and parent (Taylor et al., 2018; Somani et al., 2022). Another risk of active monitoring is that there may be caries progression and further post-eruptive breakdown, which would then potentially require more difficult and extensive treatment with an uncertain outcome (Taylor and Bulmer, 2025).

2.1.6.2 Temporisation to maintain FPM as a space maintainer for the short- or medium-term

Restoring a compromised FPM with a temporary restoration provides the young person with time for planning an extraction later. This may be either to time the interceptive extraction to match the ideal age for spontaneous space closure, or to delay the extraction until orthodontic treatment is initiated to allow the space to be used for orthodontic correction. If a young person presents with one or more cFPMs, an orthodontic assessment should be undertaken to assess any malocclusion or crowding. If space in the arch may be required for future orthodontic treatment, an option to maintain the cFPM for the short or medium term may be considered. One of the indications for maintaining one or more FPMs is a young person presenting with dental crowding or a large overjet. The FPM could then be extracted as part of an orthodontic treatment plan, and the space used to relieve the crowding or to retract the anterior teeth to correct the overjet.

Commonly used temporary restorations for cFPM include glass ionomer cements, such as conventional resin-modified glass ionomer cements (Fayle, 2003). Due to their poor wear resistance, regular reviews to detect deficiencies are advised. Their poor wear resistance precludes their use in cFPM as a definitive restoration; however,

they can be useful for short- and medium-term temporisation of cFPM (Fayle, 2003; SDCEP, 2018; Lygidakis et al., 2022).

If the young person presents with acute symptoms such as dental pain, abscess or infection, temporisation is not indicated and managing the acute symptoms is necessary.

2.1.6.3 Definitive restoration

There are several reasons to consider restoring cFPM, including mild cFPM defects, hypodontia of other teeth, absence of third molars, and the patient's ability to undergo dental treatment. In addition, advances in restorative materials and advanced techniques have made restorations more successful (Alkhalaf et al., 2025). Parents and young people might choose to restore the cFPM rather than undergo tooth extraction, thus emphasising the importance of the person’s preferences (Noar et al., 2023; Taylor and Bulmer, 2025).

The decision to restore a cFPM should carefully consider the long-term prognosis of the tooth. This initially depends on assessing whether the tooth has caries, with or without pulpal involvement, or presents with a significant enamel defect. If the cFPM has caries only, long-term restorations may be possible, including direct or indirect restorations, depending on the extent of the lesion. Bonding of composites is not affected in sound enamel once caries has been removed from the margins. Several factors contribute to the longevity of composite restorations including operator experience, restoration size, and tooth position (SDCEP, 2018; Lygidakis et al., 2022; AAPD, 2024b). The benefits and risks of restoring a cFPM are summarised in Table 2.2.

Young people presenting with a cFPM due to hypomineralisation pose another layer of complexities to treatment. MIH creates qualitative demarcated enamel opacities that may break down and lead to atypical cavity formation, restoration bonding issues, increased sensitivity, and difficulty anaesthetising the tooth (Lygidakis et al., 2022). A decrease in the mineral content and an increase in protein and carbon content with alterations of the microstructure of the lesions will result in decreased bond strength and higher failure rates of restorations compared to sound teeth (Elhennawy et al., 2017). Some studies have investigated pre-treatment with 5% sodium hypochlorite to deproteinise the hypomineralised enamel in MIH teeth; however, results show that

this technique does not improve the success of composite resin restorations substantially (Sönmez and Saat, 2017).

If the cFPM had pulpal involvement, more complex restorative treatment, such as vital pulp therapies, can be used (Taylor et al., 2020; Lygidakis et al., 2022). Vital pulp therapy in cFPMs in young people has an overall success rate of 91.3% for partial pulpotomies and 90.5% for coronal pulpotomies (Taylor et al., 2020). Success requires a young person to be able to accept treatment to have a good outcome (Taylor et al., 2020). If the young person is very anxious, lengthy, complex procedures are often not possible using local anaesthesia only, increasing the complexity of management.

Teeth that are restored enter the “restorative cycle” early in childhood (Taylor et al., 2019). Restorations have a finite lifespan so any restoration would eventually require replacement until the point where the tooth will be unrestorable (Taylor and Bulmer, 2025).

Table 2.2: Benefits and risks of restoring compromised first permanent molars

Benefits	Risks
• Maintaining the FPM, especially if other permanent teeth are not present.	• Enter the restorative cycle • Require maintenance of the restoration • Require good cooperation • Might not last long term

2.1.6.4 Interceptive extraction

Interceptive extraction of the cFPM aims to eliminate the teeth with poor prognosis and encourage mesial migration of the second permanent molar (SPM) to replace the cFPM. To ensure the successful eruption of the SPM into the FPM space, interceptive extraction is advised at a specific dental development stage, which is when the SPM is mesially angulated and the TPM is present (Patel et al., 2017; Noar et al., 2023). This usually corresponds to a chronological age of 8-10 years. However, the dental developmental stage is what predicts success. The ideal outcome of interceptive extraction of a cFPM is that the SPM erupts into the FPM space with no residual spacing or crowding in the area, and without tipping of adjacent teeth or overeruption of opposing teeth (Noar et al., 2023).

Although the UK guidelines support the interceptive extraction of cFPM, this recommendation is of low-quality evidence, and complete gap closure is not guaranteed (Eichenberger et al., 2015; Taylor et al., 2019; Noar et al., 2023). One study found that good gap closure was observed in 72% of maxillary molars extracted at the ideal time but in comparison, only 48% of extracted mandibular molars achieved a good or perfect gap closure (Eichenberger et al., 2015). It is also known that extracting cFPM early or late compared to the ideal developmental stage will increase the chances of poor outcomes (Teo et al., 2013). The extraction timing of the FPM in the mandibular arch is more critical than the maxillary arch for space closure and eruption of the second permanent molar (Noar et al., 2023).

2.1.6.5 Forced extraction

An extraction may be required regardless of the young person's age. The term forced extraction may be used to describe the removal of a cFPM that presents with acute symptoms such as pain, swelling, and infection and is either unrestorable at a non-ideal dental developmental stage for removal or the patient/parent might choose to have the tooth extracted before the ideal age to prevent any risk of future pain. The extraction will mean the child becomes symptom-free, but it may result in a remaining gap in the cFPM area. Additionally, tilting of adjacent teeth with occlusal disruptions may occur. The options following forced extraction are to accept the space, to replace the tooth with a prosthesis or attempt to close the space orthodontically (Warrilow and McDonald, 2021). The resulting space depends on the SPM position and any existing buccal segment crowding (Warrilow and McDonald, 2021). An orthodontist specialist’s opinion is beneficial to consider the child’s occlusion and whether the space can be utilised for future orthodontic treatment (Warrilow and McDonald, 2021).

2.1.6.6 Balancing and compensating extractions

A balancing extraction is the removal of the contralateral FPM from the opposite side of the same dental arch. A compensating extraction is the removal of the FPM from the opposing arch. The aim of compensating and balancing extractions is to preserve arch symmetry and occlusal relationships in the developing dentition (Noar et al., 2023). Compensating and balancing extractions are only considered in conjunction with interceptive extractions because outside the ideal timing for spontaneous space closure there would be no benefit (Noar et al., 2023).

Different factors influence the decision for compensating or balancing extractions. These include whether the cFPM that requires enforced extraction is in the maxillary or mandibular arch, the condition and long-term prognosis of the remaining FPMs, the development of the remaining dentition and if there is an underlying malocclusion (Noar et al., 2023).

The current Royal College of Surgeons (RCS) guidance 'A Guideline for the Extraction of First Permanent Molars in Children' recommends that *"When the enforced extraction of the lower FPM is required, the compensating extraction of the upper FPM should not be routinely carried out unless there is a clear occlusal requirement or likelihood of the upper FPM being unopposed for a significant period of time"* (Noar et al., 2023). However, the guideline does not specify the time period that is important. Moreover, there is little evidence that over-eruption of an upper FPM occurs because of a lower FPM extraction. The evidence available is based on retrospective studies with small sample sizes (Mejàre et al., 2005; Jälevik and Möller, 2007). This poses challenges to dentists when performing interceptive extractions of lower FPM for a young person under general anaesthesia because they have to judge the risk of over-eruption of the maxillary FPM.

The RCS guideline recommendation regarding balancing extractions states that *"Routine balancing extractions of a sound FPM to preserve a dental centreline is not recommended unless part of a comprehensive orthodontic treatment plan"* (Noar et al., 2023). Current evidence suggests that it is unlikely that the centrelines will be affected after extraction of a cFPM in either the maxillary or mandibular arches (Mejàre et al., 2005; Jälevik and Möller, 2007).

2.2 Decision making

Consultations regarding cFPM in young people are complex, usually requiring input from specialist dentists to plan for the best clinical outcome. A general dentist could also manage a treatment plan for cFPMs, however, the child is often referred to a specialist due to dental or behavioural challenges at a young age group. The consultation involves a three-way conversation between the dentist, young person with a cFPM, and their carer. The discussion about the treatment plan starts by understanding the values of each party, treatment options, and associated risks and benefits (Noar et al., 2023).

A good clinical decision in the context of cFPM means selecting the most appropriate treatment option for each individual young person at that specific point in time. The decision may not necessarily be the one leading to the optimal clinical outcome based on the best available evidence (Jacobs et al., 2023). Even children presenting with similar diagnosis and prognosis of their cFPMs will have different values and preferences. Therefore, a treatment plan considered ideal for one child might not be suitable for another. The optimal course of action is determined by a combination of factors: the individual's specific clinical presentation, the best available evidence, the clinician's experience, and, importantly, the young person's and family's preferences (Noar et al., 2023). These factors can differ significantly between individuals, so there is no best approach for managing cFPMs. SDM is paramount in these situations, as the chosen treatment should align with what matters most to the patient and their family. This approach empowers families to actively participate in the decision-making process, leading to increased satisfaction and improved adherence to the chosen treatment plan (Noar et al., 2023).

2.2.1 Shared decision making

2.2.1.1 Definition

Shared decision-making is defined by the National Institute for Health and Care Excellence (NICE) as *"A collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care."* (NICE, 2021). The National Health Service (NHS) advocates SDM for all non-urgent treatment decisions, and it is considered the standard of care to reach a joint decision, so it should be practised by everybody who delivers healthcare services (NHS

England and NHS Improvement, 2019). SDM is mainly a conversation between the healthcare worker and the patient (NHS England and NHS Improvement, 2019). The healthcare worker requires skills and willingness to provide the appropriate evidence-based treatment options to the patient. In contrast, the patient and family should be willing to share information about their preferences, values, and beliefs during the consultations (NHS England and NHS Improvement, 2019).

SDM requires that the patient is informed about the diagnosis, the different treatment options, the risks and benefits, and any consequences related to any treatment option (NHS England and NHS Improvement, 2019). The clinician then supports the patient and their parent/carer to deliberate to reach a decision based on their personal preferences (NHS England and NHS Improvement, 2019).

SDM is advocated whenever more than one treatment option is to be discussed, including the option of no treatment. It is particularly useful when there is uncertain evidence regarding outcomes or when the options have varying risks and benefits for health and quality of life (NHS England and NHS Improvement, 2019).

2.2.2 Steps in shared decision making

There are many different models of SDM, but most have common steps, which can include:

1. Stating the decision to be made

The healthcare worker and the individual involved in the decision discuss and understand the medical or dental issue that needs to be addressed (Coulter, 1997; Elwyn et al., 2001; Coulter, 2003; Makoul, Gregory and Clayman, Marla L., 2006; Elwyn et al., 2010; Elwyn, Glyn et al., 2012; Elwyn et al., 2013).

2. Explanation of roles

The healthcare worker and the individual involved in the decision clarify the desired level of responsibilities and involvement in the decision-making process, ensuring that both parties understand their respective roles. The patient's role includes expressing their preferences, values, concerns, and expectations regarding the issue. However, the healthcare provider's role involves offering their medical expertise, discussing options with the risks and benefits of each, and providing evidence-based recommendations (Makoul, G. and Clayman, M. L., 2006; Elwyn, Glyn et al., 2012).

3. Information exchange

The healthcare worker provides the patient with evidence-based information, listing the risks and benefits of each treatment option in non-medical terms. This includes using non-jargonised language, considering the health literacy of the patients and families involved. The patient explains what they already know and understand. This ensures that both parties are well-informed, crucial for making collaborative decisions (Charles et al., 1999; Makoul, G. and Clayman, M. L., 2006; Elwyn, Glyn et al., 2012).

4. Clarifying values and preferences

The patient's values reflect what they consider important in their life and health, including quality of life and personal beliefs. Their preferences involve identifying what the patient desires regarding treatment options and their willingness to undergo specific procedures or make lifestyle changes. By clarifying these, the healthcare provider can tailor the information and recommendations to align with the patient's values and preferences. This leads to choices that are more likely to be accepted and adhered to (Charles et al., 1999; Makoul, G. and Clayman, M. L., 2006; Coulter and Collins, 2011; Elwyn, Glyn et al., 2012).

5. Discussing feasibility

This process involves evaluating whether the treatment options discussed are practical and achievable for the patient. It includes assessing whether the patient can realistically follow the treatment plan, understanding their self-efficacy in carrying out the necessary actions, and identifying any obstacles that may hinder their ability to adhere to the plan (Makoul, G. and Clayman, M. L., 2006).

6. Deliberating together to reach a decision

The final and essential stage of the SDM process is bringing all this information together to deliberate about the options for that patient to reach a decision together (Makoul, G. and Clayman, M. L., 2006).

2.2.3 Reported benefits of SDM

The literature documents several benefits of SDM, which include:

1. Increased patient engagement and satisfaction

SDM and increased patient involvement in treatment choices have been reported to have beneficial effects. Patients feel more involved in their healthcare decisions, leading to higher satisfaction levels (Bot et al., 2014). According to a systematic review, greater patient involvement in clinical practice resulted in a better quality of care, increased patient and healthcare worker satisfaction, and improved patient self-esteem (Crawford et al., 2002).

2. Improved health outcomes

SDM can lead to better health outcomes. This occurs by aligning treatment with the patient's preferences and values (Durand et al., 2014). SDM is shown to reduce overdiagnosis and overtreatment because often patients usually choose more conservative options when fully informed about the risks and benefits (Dwamena et al., 2012).

3. Enhanced patient knowledge and understanding

Patients gain a better understanding of their condition and treatment options, leading to more informed decisions (Durand et al., 2014).

4. Better clinician-patient relationship

SDM fosters trust and collaboration between patients and healthcare workers, improving the overall quality of care. SDM involves open communication and mutual respect, which helps build confidence in the relationship. Patients feel respected when their preferences and values are considered (Hamann et al., 2016; Waddell et al., 2021).

5. Potential reduction in healthcare utilisation

Research in the medical field has shown that shared decisions result in patients with fewer complaints, fewer missed appointments and overall improvement in health outcomes (NHS England and NHS Improvement, 2019). This is because patients make decisions according to their preferences with good information from their physicians, resulting in better outcomes (NHS England and NHS Improvement, 2019). Shared decision-making is shown to increase the patients' confidence, decrease their anxiety levels and decrease overtreatment (Alzahrani and Gibson, 2018).

Most of the evidence of the effectiveness of SDM comes from research on patient decision aids (PDAs) used in consultations for shared decision-making. PDAs have been shown to increase patient knowledge and risk perception and improve the patient-clinician communication (Hoffmann et al., 2014; Stacey et al., 2024). Moreover, PDAs decreases decisional conflict, the feeling of the patient being uninformed, and decreases passivity in decision-making (Hoffmann et al., 2014; Stacey et al., 2024).

2.2.4 Challenges of SDM

Shared decision-making is influenced by the patient personal preferences, experiences, relationships, as well as structural constraints such as education, ethnicity, and culture (Edwards and Elwyn, 2009). Patients' experiences will vary over time, and patients may value the process of SDM more as they become more experienced with the process during consultations, but before implementing SDM, patients are likely to require physicians who listen and give understandable information in routine consultations (Longo et al., 2006). This suggests that the implementation of SDM cannot be advocated unless the previously mentioned communication skills are part of a routine consultation (Longo et al., 2006).

Two consecutive systematic reviews highlighted the main barriers to implementing SDM in clinical practice, which included insufficient time to engage in SDM compared to usual consultations, a lack of acceptability of shared decision-making to the population in practice due to patient characteristics and patient outcomes, a lack of knowledge in terms of awareness, familiarity, or inadvertently omitting the SDM implementation (Gravel et al., 2006; Légaré et al., 2008). The attitudes of the professionals play a role in the implementation as well, such as the lack of agreement in specific elements of SDM interpretation of evidence, the lack of agreement with particular components of SDM, and the perception that there will be an increased cost if SDM is implemented. Clinicians might also perceive that SDM will not improve the patient's outcome, will not lead to an improved healthcare process, will provoke difficult feelings, or might even lack self-efficacy and motivation (Gravel et al., 2006; Légaré et al., 2008; Waddell et al., 2021).

Several factors that pose challenges to implementing SDM are the lack of compatibility, lack of observability, and lack of flexibility. It is perceived as a complex process. Barriers associated with environmental factors include time pressure,

insufficient materials, lack of staff to put SDM into action, organisational constraints, and lack of access to services (Légaré et al., 2008; Boland et al., 2019).

2.2.5 Challenges and facilitators to shared decision-making in the paediatric population

Decision-making in paediatric consultations is different from that in adults. A systematic review published in 2019 captured the main barriers and facilitators in paediatric shared decision-making. The barriers were reported at different levels from different perspectives, including healthcare practitioners, parents, children, and observers. From the healthcare practitioners' view, the most cited barrier was insufficient time, hence the lack of feasibility in paediatric consultations (Boland et al., 2019). Additionally, SDM has been advocated to increase treatment adherence and build decision-making capacity in children (Boland et al., 2019).

An important barrier to consider in SDM is the patient and child's emotional state, as being overwhelmed or anxious can hinder the SDM process (Boland et al., 2019). In many settings, healthcare professionals lack SDM skills, such as knowing the right time and way to incorporate family preferences and values in the process (Fiks and Jimenez, 2010). This lack of skill for SDM was the most frequently cited barrier reported by observers. However, the desire for, and agreement with, SDM was the most commonly reported facilitator (Boland et al., 2019). Parents, healthcare practitioners, and observers thought that parent and child involvement is important and that it will improve patient outcomes and satisfaction (Boland et al., 2019).

2.2.6 COM-B model for behaviour change

The COM-B (Capability, Opportunity, Motivation – Behaviour) model offers a robust framework for understanding and influencing behaviour change (Michie et al., 2011) This model explains that for any behaviour to occur, an individual must possess the necessary Capability, be presented with the Opportunity, and have the Motivation to do so (Michie et al., 2011).

Shared decision-making can be viewed as a complex set of behaviours engaged in by both healthcare professionals and patients/families. Applying the COM-B model allows for a structured analysis of the factors that facilitate or hinder active participation in SDM (Michie et al., 2011). For instance, a dentist's capability in SDM

might relate to their communication skills, while their opportunity could be influenced by consultation time, and their motivation by a belief in patient autonomy. Similarly, a family's capability may involve health literacy, their opportunity might depend on a clear and supportive clinical environment, and their motivation could be driven by a desire for involvement in treatment decisions. This model therefore offers a theoretical framework for understanding how various factors influence the involvement of all parties in shared decision-making, thereby facilitating targeted efforts to change behaviour (Michie et al., 2011).

2.2.7 SDM impact on children's involvement in decisions

SDM can promote children's involvement in healthcare decisions by encouraging children to express their preferences and values, making them active participants in the decision (Boland et al., 2019). Healthcare workers also provide the child with information tailored to their developmental stage, helping them understand their condition and the treatment options in meaningful ways and leading to informed decisions. When children are included in the decision-making process, it can reduce their anxiety and fear about treatment, making them feel more involved and informed (Kelly et al., 2017).

A qualitative study by Barber et al (2019) explored young people's perceptions of SDM by interviewing them and their parents. The interviews indicated that children often relied on parental advocacy and perceived the SDM process to be led by the dental team. Young people did not appear to recognise their role in determining their level of involvement in SDM. Another qualitative study demonstrated that young people want to express their autonomy in decision-making (Taylor et al., 2025).

2.3 Evaluation of decision-making in dental clinical consultations

Evaluating decision-making in dental clinical consultations, particularly those involving cFPMs, presents several challenges. Shared decision-making is inherently complex, encompassing multiple facets that are difficult to measure in isolation. Decision-making could be evaluated in terms of the SDM process itself, the specific treatment decision reached, the resulting health outcomes, or the satisfaction levels of both the young person and their carer with the process, decision, or outcome.

Measuring the SDM process may be the evaluation of one or more elements, such as information exchange, exploring values and preferences, or the deliberation process (Ryan and Cunningham, 2014). Alternatively, measurement could focus on the outcome from the specific choice, such as treatment adherence or changes in oral health status (NICE, 2021). Evaluating patient and carer satisfaction, based on their experience with the decision-making process, is crucial. However, the subjectivity of experience and perspectives make it challenging to reach a universal agreement on what constitutes "good" shared decision-making (Davidson et al., 2017).

To measure SDM, direct observation of consultations is often considered a reliable method. This can involve using structured observation tools such as observer checklists and questionnaires for patients, family members or the healthcare professional, or detailed observation protocols. Direct observations can have limitations. It can be resource-intensive, and observers may introduce bias (Boyko, 2013).

Checklists, like the OPTION scale, provide a structured method to ensure that all essential steps in the SDM process are addressed (Elwyn et al., 2013). For instance, a checklist can confirm that the dentist discussed the clinical issue, outlined treatment options, and considered the patient's preferences. Trained observers use these checklists to evaluate the extent of collaboration between healthcare workers and patients in making decisions. The advantages of this method include increased objectivity, direct assessment of healthcare workers' behaviour, and reduced recall bias since data is collected in real time. On the other hand, the disadvantages of using observer checklists include observer bias, the time-consuming and costly nature of training observers, and the potential failure to capture the patient experience.

Questionnaires, such as the COMRADE instrument, provide insights into the patient, family, or healthcare professional’s experiences and perceptions of the consultation (Edwards et al., 2003). Participant questionnaires provide valuable insights into the patient’s experience, satisfaction, and perceptions of the involvement in the decision-making process. They are also relatively easy to administer and less expensive than observational methods. However, they are subjected to recall bias, may not accurately reflect the actual behaviours during the consultation, and have a potential for response bias.

There is scarce literature regarding shared decision-making in dentistry. In the dental literature, a significant body of research on shared decision-making has focused on evaluating the influence of patient decision aids (PDA) on improving health outcomes. In endodontics, a study has examined patients' knowledge about the treatment options of endodontic treatment or extraction, satisfaction and anxiety levels (Johnson et al., 2006). It was a randomised control trial studying a PDA in endodontics by comparing the use of the PDA with regular practice. Park et al. (2012) developed a tool/patient decision aid to help support SDM about restorative fillings, which was shown to be successful (Park et al., 2012). A study looking at preferences for restorative materials choice found that dentists tend to prefer fillings with higher longevity, however, young patients prefer tooth-coloured restorations with better aesthetics and less focus on how long the filling will stay in the mouth (Espelid et al., 2006). This emphasises how the preferences of patients should be integrated into decision-making.

Two studies have assessed a PDA for supporting decisions about fixed appliance treatment (Marshman et al., 2016; Parker et al., 2017) with conflicting results. Marshman et al. (2016) demonstrated a statistically significant decrease in the decisional conflict between the dentist, parent and adolescent with increased knowledge of the treatment course, while Parker et al. 2017 found no difference. The study designs differ, with one using a pre-post-test design and the other using a randomised controlled trial (Marshman et al., 2016; Parker et al., 2017). The presence of a control group allows for stronger conclusions about the effectiveness of the PDA compared to the pre-post-test- design (Marshman et al., 2016; Parker et al., 2017).

One observational study examining decision-making processes in hypodontia consultations found multiple challenges and barriers were present and overall, SDM was not fully performed (Barber et al., 2019). The research paper by Barber et al (2019) investigated whether the existing care pathway for the management of hypodontia supports SDM. The findings indicated that the current hypodontia pathway did not facilitate SDM adequately, especially in areas of managing patient preferences and values and communicating complex information. A scoping review in 2018 found that no studies assessed the extent how which patients and dentists engage in the implant decision treatment planning (Alzahrani and Gibson, 2018).

A cross-sectional ethnographic study by Alzahrani found that full SDM was not promoted in implant consultations in Saudi Arabia (Alzahrani, 2016). The study involved observations of dental consultations followed up by interviews of dentists and patients. It was found that no implant consultation involved a SDM approach (Alzahrani, 2016).

A recent qualitative study by Taylor et al (2025) explored young people's and adults views and experiences of decision making in consultations for managing cFPM. It was evident that young people want to be involved in SDM and express their autonomy. However, this study included young people aged 12 to 16 years old. Literature searches did not identify any studies that evaluated SDM in consultations in the paediatric dental department in a younger age range with more complexities in cFPM, such as the need for interceptive extractions or planned temporisation. No studies explored if SDM is being practised in the paediatric department and what elements of SDM require improvement.

2.4 The research question

This study purpose was to answer the following questions:

- Do paediatric and orthodontic dental practitioners, including postgraduates, speciality trainees, and consultants, consider all the elements of SDM in consultations regarding cFPM?
- Do families of children with cFPMs think that SDM is practised in child consultation?

2.4.1 Aim

To explore observer, dentist, and families' perception of shared decision-making in consultations for cFPMs.

2.4.2 Objectives

- To assess if all items of SDM are practised in consultations regarding cFPMs.
- To explore any trends in items of SDM from the perspectives of an observer, dentist and family in the consultation.
- To explore any trends in different items of SDM in different consultations.

Chapter 3 Overview of research methods

This chapter provides an overview of the methods and the research governance.

3.1 The rationale for the choice of measure

Using an SDM measure to assess the consultation was chosen for this study to add structure and objectivity to the assessment and provide a framework by which to assess SDM. It also has the additional benefit of allowing the three different perspectives (observer/dentist/family) to be compared, which would not be possible in a purely qualitative analysis. A tool was used to score the consultations, but the results were descriptive rather than quantitative due to the small sample. Describing the scoring patterns both within and across the cases, as well as comparing the scoring patterns for each of the different perspectives (observer/dentist/family), provided richer data than purely reporting aggregate scores.

3.2 Design

The research was a cross-sectional observational study conducted in two stages. The stages are summarised as below.

3.2.1 Phase 1: Pilot study (Chapter 4)

Phase 1 included the development of the preliminary SDM measure and then a pilot study to test the tool and planned methods.

To develop the preliminary SDM measure, a review of the validated SDM tools from a review paper was completed, and a summary of key components of the SDM measures was produced. The existing tools were discussed to identify the most appropriate tool to use. One tool, the Informed Decision Making (IDM) SDM measure, was felt to include the main SDM elements involved in a consultation (Braddock et al., 1997; Braddock et al., 1999). However, it was not judged to be completely comprehensive, so elements from different validated tools were added to ensure all important components of SDM were captured. This created the preliminary Observer-SDM measure. From this, a dentist and family versions of the measure were created.

For the pilot study, four simulated consultations with actors were video recorded. The preliminary Dentist-SDM measure was given after the consultation to the dentist actor

to gain feedback on the tool. The video recordings were then used by the research team to independently score the consultations using the preliminary Observer-SDM measure. This allowed the assessment of inter-rater reliability and provided training and calibration for the research team in applying the tool. The family tool was tested by friends and family, who were all adults. No children were involved in the development of the study, acknowledging this as a limitation, but it was challenging to involve children at this stage. The tools were finalised to create the Observer-SDM, Family-SDM, and Dentist-SDM measures.

3.2.2 Phase 2: Cross-sectional observation of clinical consultations (Chapter 5)

Phase 2 included observing and audio-recording 12 clinical consultations and scoring them from the observer, dentist, and family perspectives using the finalised SDM measures. The consultations included paediatric dentistry, orthodontics, and joint orthodontic-paediatric dentistry (JOP) at Leeds Dental Institute (LDI) and Pinderfields General Hospital, Wakefield (PGH).

3.3 Research governance

3.3.1 Ethical considerations

This study was sponsored by the University of Leeds and conducted following the ethical principles outlined in the 1964-2013 Declaration of Helsinki (World Medical Association, 2007). Before the commencement of the study, the University of Leeds provided a course about ethics in research, which included training in child-centred research, data management, and consent in the United Kingdom. The Good Clinical Practice (GCP) training was also completed (National Institute for Health and Care Research NIHR, 2024).

3.3.2 Children as research participants

Children involved in this study were within the age range of 7-11 years, so specific considerations were given to their ethical involvement. Recruitment was planned to ensure there were opportunities for the children to decide whether they wanted to participate. Participant information sheets were written and sent to the family in two forms: a parent or adult form and a young person's form. The young person's form was designed in a language that is age-appropriate and jargon-free. The study procedure, aim, confidentiality, anonymity, and the opportunity to withdraw with guides on who to talk to were described in child-friendly terms.

The young person and parent information sheets were sent via mail at least one week before recruitment, which allowed the family to discuss any concerns or issues, and also gave the family and the child some time to think if they did not wish to participate.

The children involved in this study are under 16 years old. Thus, the principle of Gillick competence can be applied. A child or young person has the right to consent if they can understand, retrieve, and convey information about the research. Even if the child can consent, obtaining consent from the parents or legal guardians is good practice (Health Research Authority). Consent forms were created for the legal guardians, and assent forms for the young person. If the parents gave consent for their child to participate, but the young person objected, their decision was respected, and they were not recruited. The researcher's contact information was listed in the information sheets to allow a chance for withdrawal from the research if the family wishes to.

There were some potential harms to the young people, families and dentists participating in the study, which included distress from the research, distress relating to the consultation regarding cFPMs or the dental treatment itself, and potential identification of poor practice or safeguarding issues. Research distress was managed by providing contact information on the information sheets and support from the research team. The opportunity to ask questions was given at the recruitment stage and at the end of the consultations. The research team's email addresses were provided if any questions arose after data collection. To manage any potential distress relating to the consultation, the lead researcher (SA) was a passive observer, sitting in a corner of the clinic and not engaging in the consultations. If there were any concerns that the observer was affecting the consultation or causing distress, the observer would leave the consultation, and the participant would be removed from the study.

If there was evidence of poor practice or safeguarding issues, the dentist was informed, and if necessary, the matter was escalated through the hospital trust's policy of whistleblowing and safeguarding. This was determined by the lead researcher, SA, and this was required as part of direct observations of clinical consultations in NHS hospitals.

3.3.3 Data confidentiality and management

Data was collected and managed to comply with the University of Leeds' research data policy (University of Leeds, 2017). Personal data, including names and signatures, were collected on the consent form and stored in a locked cabinet in the researcher's office at the School of Dentistry, University of Leeds. The young persons' personal data was kept in an Excel spreadsheet on a password-protected drive

accessible only to the lead researcher. All the research data were anonymised so that participants could not be identified.

Audio recordings from the consultations were made using an external recorder (Olympus WS-853). The recordings were transferred to the university's encrypted drive and then deleted from the recording device. The audio recordings were sent to a transcription company provided by the University of Leeds, Transcription City. The transcription company complies with the University of Leeds data protection policy and has a current Data Processing Agreement with the University.

The audio recordings were kept for 1 year after data collection to allow study write-up, thesis submission, and degree completion. The anonymised transcriptions will be kept for 3 years for further qualitative analysis beyond the contents of this thesis and publication.

Personal data, including the young persons' name and hospital identification number, consent forms, and hard copies of the answered SDM measures and notes, will be kept until the completion of the degree and thesis submission in case of academic challenge.

3.3.3.1 Withdrawal from the study

The information sheets, consent, and assent forms included a right to withdraw section that included the researcher's email address. The right to withdraw was up to the point of data analysis, for which a 2-month time frame was given. The family was informed that they could request the observer to stop the audio recording at any time during the consultation, and all data would be deleted immediately.

3.3.4 Ethical approval

Before commencing the study, ethical approval was sought from the Wales Research Ethics Committee (REC reference: 23/WA/0034). Health Research Authority (HRA) approval was granted for this study (IRAS project ID 321063) (Appendix 1). NHS site permissions were given by Leeds Teaching Hospital NHS Trust and Mid Yorkshire Teaching Hospitals NHS Trust. The process of ethical approval with site permissions approval is summarised in Table 3.1.

Table 3.1: Research ethics committees and site permission approvals

Ethics body	Approval	Study stage approval
HRA and Health and Care Research Wales (HCRW)	31 January 2023 IRAS 321063	Observation of clinical consultations at Leeds Dental Institute
NHS site permission capacity and capability LTHT	12 July 2023 Delays in obtaining access to the electronic system EDGE, access was granted on 03 October 2023	Site permission to commence the study at LTHT
HRA and Health and Care Research Wales (HCRW)	01 August 2023 Amendment one	- Transcription of audio recordings for further qualitative analysis - Amendment of all information sheets, consent and assent forms to add information about transcription and storage
HRA and Health and Care Research Wales (HCRW)	25 September 2023 Amendment two	Additional NHS site recruitment
NHS site permission capacity and capability Mid Yorkshire Teaching Trust	11 April 2024	Recruitment permission at Pinderfields Hospital, Wakefield

Chapter 4 Phase 1: Pilot study

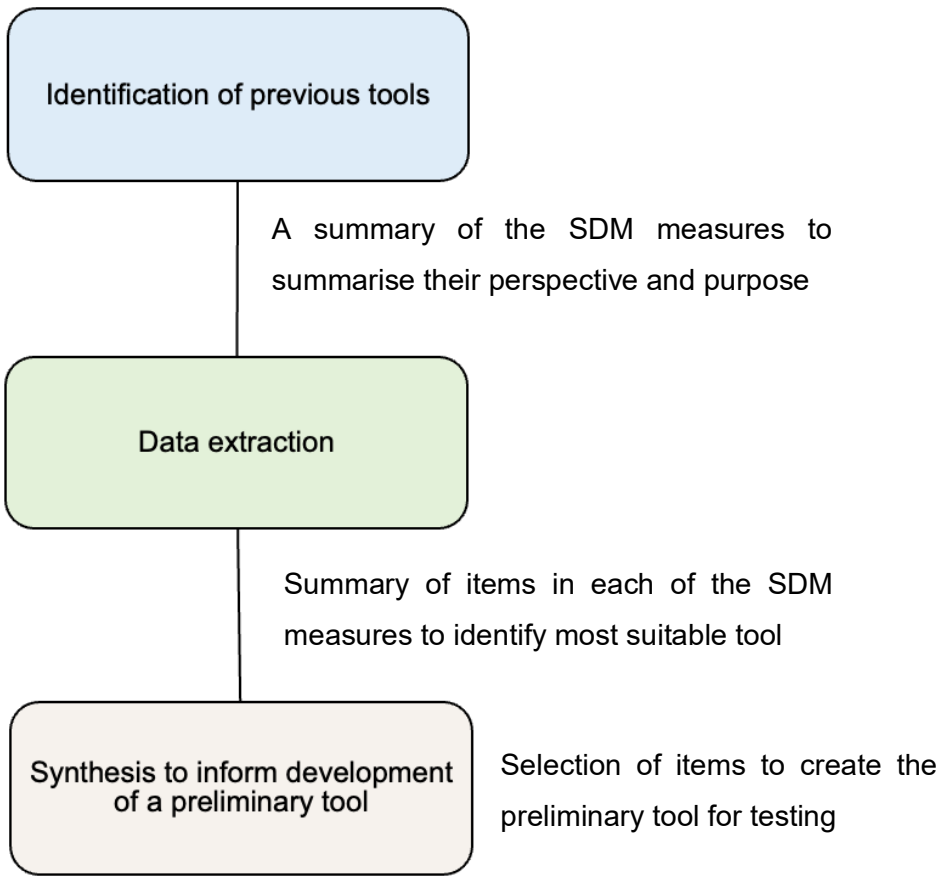
The objectives for this phase are:

- To develop an SDM measure that is structured, easy to read and apply.
- To ensure the researcher can collect data, including field notes, without impacting the consultation.
- To train and calibrate the observer raters.

4.1 Development of the preliminary SDM measure

The SDM development is summarised in Figure 4.1
The final three versions of the measure are listed in the appendices (Appendix 10, Appendix 11, and Appendix 12).

Figure 4.1: The steps followed in SDM measure development



4.1.1 Identification of previous tools

Tools available for measuring SDM from different perspectives were identified from a previous review paper (Gärtner et al., 2018). The review paper was the most recent review paper identified during the literature search. It was chosen as it included a a comprehensive list of validated tools used in previous studies. Tools were then obtained and examined.

The eligibility criteria for selecting potential tools to use in this study were:

1. The SDM measure should be validated to be used by the assigned perspective, which is the observer in this study. This is crucial because validation ensures that the tool measures the concept accurately and consistently. A validated measure provides confidence in the results obtained and allows for meaningful comparisons across different studies and populations (Elwyn, G. et al., 2012).
2. The SDM measure should be available. Access to the specific items included in the SDM measure is essential for a thorough understanding of its content and scope. This will allow for the application of the measure in the context of the study.
3. The SDM measure should be available in English. In alignment with the study's setting within English-speaking healthcare environments, the selected SDM measurement instrument had to be available in English to ensure direct applicability and to prevent potential distortions in meaning that might arise from linguistic translations, which are known to introduce biases (Xiao et al., 2024).
4. The SDM measure should be designed for use in any clinical consultation, rather than being specific to a particular medical concern. The selection criteria prioritised SDM measurement tools applicable across diverse clinical consultations to ensure versatility and relevance, independent of the specific medical condition being addressed.
5. The tool should have the most comprehensive set of items measuring SDM, based on the current guidance (NICE, 2021). Selecting an SDM measure with items based on NICE guidance ensures that the tool aligns with established best practices and recommendations for SDM (NICE, 2021).

Initially, tools measuring SDM from different perspectives were examined but a decision was then made to focus on the tools measuring SDM from an observer perspective because this was the focus of this study, Table 4.1.

The suitability of tools was judged based on their version, language and purpose. The reasons for excluding some SDM tools were mostly due to the availability of newer versions and non-English language versions. Some tools were excluded because they were designed for a specific condition, such as oncology, psychiatry, and palliative care. One of the SDM measures, Detail of Essential Elements and Participants in Shared Decision-Making (DEEP-SDM) was excluded because it was not possible to find the actual measure.

4.1.2 Data extraction

Five tools were identified as potentially suitable for this research, so data were extracted for them. Table 4.2 summarises the items of each of the included SDM measures. The lead researcher (SA) highlighted item similarities by colour-coded schemes. The study by Braddock et al (1999) was the reference study in Table 4.2 as it was found to be most comprehensive. Other tools were found interesting to add by the research team (SA, SB, RA) and were shaded in light blue.

Table 4.1: Summary of existing SDM measures from an observer perspective

Instrument	Measurement aims	Eligibility
IDM Elements of Informed Decision Making (Braddock et al., 2008)	Characterize the completeness of informed decision-making during consultations as a function of the complexity of the decision	Included
DSAT Decision Support Analysis Tool (Guimond et al., 2003)	Providers' use of decision support and related communication skills during clinical encounters	Excluded - newer review version is available (below)
DSAT-10 Brief Decision Support Analysis Tool (Stacey et al., 2008)	Decision support skills	Included
OPTION Observing Patient Involvement scale (Elwyn et al., 2003)	Extent to which providers involve patient in the decision-making process during a consultation	Excluded - newer review version is available (Observer OPTION5)
OPTION (revised) (Elwyn et al., 2005)	Extent to which clinicians involve patients in decision making process	Excluded - newer review version is available (Observer OPTION5)
OTION (Italian) (Goss et al., 2007)	Extent to which clinicians involve patients in decision	Excluded - translated version in Italian
OPTION (revised) (German) (Hirsch et al., 2012)	Extent to which clinicians involve patients in decision	Excluded - translated version in German
OPTION (revised and modified) (German) (Keller et al., 2013)	Extent to which clinicians involve patients in decision and active involvement of patients	Excluded - translated version in German and is modified
OPTION12 (Dutch) (Stubenrouch et al., 2016)	Extend to which healthcare providers involve patients in decision-making	Excluded - translated version in Dutch
Observer OPTION5item (Elwyn et al., 2013)	Essential requirements of SDM when providers make an effort to involve patients in decisions	Included
OPTION5 (Dutch) (Stubenrouch et al., 2016)	Extend to which healthcare providers involve patients in decision-making	Excluded - translated version in Dutch

RPAD Rochester Participatory Decision-Making Scale (Shields et al., 2005)	Provider behaviours that encourage participatory decision making	Included
DAS-O Decision Analysis System for Oncology (Brown et al., 2011)	Quality of key aspects of SDM during oncology consultations in which treatment options, including clinical trials are discussed	Excluded - targets specific for oncology/cancer patients
SDM scale shared Decision-Making Scale (Singh et al., 2010)	SDM behaviours used by cancer specialists in their consultations	Excluded - targets specific for oncology/cancer patients
PES Parental Engagement Scale (Kearney and Byrne, 2011)	Parental engagement in decision making and planning for seriously ill children during paediatric palliative care consultations	Excluded - targets specific for paediatric palliative care
DEEP-SDM Detail of Essential Elements and Participants in Shared Decision-Making (Clayman et al., 2012)	Essential elements of SDM	Excluded - actual measure could not be found
Shared decision-making rating (Salyers et al., 2012)	Level of SDM in psychiatric visits	Excluded - targets specific for psychiatry patients
Mappin'SDM (Norge) (Kienlin et al., 2017)	Patient involvement	Excluded - translated version in Norwegian
Mixed instruments measuring SDM from patient, provider perspective		
Dyadic OPTION (including two questionnaires Dyadic OPTIONpatient and Dyadic OPTIONclinician (Melbourne et al., 2010)	Extent to which patients have been involved in (shared) decision making	Excluded – did not include an observer perspective.
Mixed instruments measuring SDM from patient, provider, and observer perspective		
MAPPIN'SDM Inventory (including a patient questionnaire, a doctor questionnaire, and a coding scheme) (Kasper et al., 2012)	Interactions of SDM indicators administered from different perspectives (doctor, patient, observer); (For the SDM mass: Integrative compound measure of SDM)	Included

Table 4.2: The included SDM measures with their items (blue shading indicates the item was judged to be relevant)

Items	IDM Elements of Informed Decision Making (Braddock et al., 1999)	DSAT-10 Brief Decision Support Analysis (Stacey et al., 2008)	Observer Option 5 items (Elwyn et al., 2013)	RPAD Rochester Participatory Decision-Making Scale (Shields et al., 2005)	MAPPIN'SDM (Kasper et al., 2012)
1	Discussion of the **patient's role** in decision making	Identify **uncertainty** about making a decision	For the health issue being discussed, the clinician draws attention to or confirms that **alternate treatment or management options** exist or that the need for a decision exists. If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need deliberation.	Explain the **clinical issue or nature** of the decision	Clinician and patient agree on a **concrete problem** as one that requires a decision-making process.
2	Discussion of the **clinical issues or nature** of the decision	timing for when decision needs to be made is discussed/acknowledged	The clinician reassures the patient or re-affirms that the clinician will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained information prior to the encounter, the clinician supports such a deliberation process.	Discussion of the **uncertainties** associated with the situation	Clinician and patient discuss that there is more than one way to deal with the concrete problem (‘*equipoise*’).

3	Discussion of **alternatives**	Stage of decision making assessed or self-evident	The clinician gives information or **checks understanding about the options** that are considered reasonable (this can include taking no action), to support the patient in comparing alternatives. If the patient requests clarification, the clinician supports the process.	Clarification of agreement	Clinician and patient choose an approach to exchanging information (*e.g. in which setting, with which media, which time frame*).
4	Discussion of the **pros (potential benefits) and cons (risks)** of the alternatives	Knowledge of **options**	The clinician makes an effort to elicit the **patient's preferences in response** to the options that have been described. If the patient declares their preference(s), the clinician is supportive.	Examine barriers to follow-through with treatment plan	Clinician and patient discuss during the consultation.
5	Discussion of **uncertainties** associated with the decision	Knowledge of **potential benefits**	The clinician makes an effort to integrate the patient's **elicited preferences** as decisions are made. If the patient indicates how best to integrate their preferences as decisions are made, the clinician makes an effort to do so.	Physician gives patient opportunity to ask question and **checks patients understanding** of the treatment plan	Clinician and patient list the options (If 'doing nothing / deferring the decision' is possible, this option should be included in the list).

6	Assessment of the **patient's understanding** Used appropriate aids (language)	Knowledge of **potential harms**		Physician's medical language matches patient level of understanding	Clinician and patient weigh up the **pros and cons** of the different options (if applicable, also the pros and cons of 'doing nothing').
7	Exploration of the patient **preferences**	Discuss importance of benefits		Physician asks, "Any questions?"	Clinician and patient discuss the patient's expectations (ideas) and concerns (fears) about how to manage the concrete problem.
8		Discuss importance of harms		Physician asks open-ended questions	Clinician and patient clarify the source upon which medical information / recommendations are based (scientific evidence, clinician's judgement, preferences, conflicting interests).
9		Discuss **preferred role in decision making**, others involvement and their opinions		Physician checks his/her understanding of patient's point of view	Clinician and patient clarify whether the **patient understood** the information given by the clinician correctly.

10		Discuss pressure or support from others			Clinician and patient clarify whether the clinician has understood the patient's viewpoint correctly.
11		Near end of the encounter, summarize the next steps to address patient's decision-making needs			Clinician and patient make sure that the patient can ask questions and point out aspects he had not fully understood during the discussion.
12					Clinician and patient make sure that the clinician can ask questions and point out aspects he had not fully understood during the discussion.
13					Clinician and patient discuss strategies for handling the decision.

14					Clinician and patient open the decision stage leading to the selection of an option (If applicable, deferment is a possible decision).
15					Clinician and patient discuss plans for how to proceed (e.g. steps for implementing the decision, review of decision or of deferment).

Similarities in the measures are colour-coded as below:
Role in SDM identification
Explaining the clinical issue
Alternatives and treatment options
Discussion of uncertainties
Assessing patient's understanding
Patient preferences

4.1.3 Selection of items to create the preliminary tool

The research team discussed the tools to identify the most appropriate tool that covered the elements of SDM based on their understanding of SDM and the clinical scenario that was to be examined. The similarities and differences between different tools were discussed and whether they were relevant or not to a consultation about management of cFPMs. Items that were judged to relevant are highlighted in Table 4.2.

One of the main challenges in developing the SDM measure was that there was no gold standard against which SDM should be measured. The selection of the elements of SDM was based on research experience in the field and current guidelines (NICE, 2021). No research has previously been undertaken in dental paediatric consultations assessing SD. Thus, there was no precedent for the best tool.

The Elements of Informed Decision Making (IDM) was considered to be the most comprehensive and suitable tool (Braddock et al., 1999). However, it did not include all components of SDM that were judged to be important to the decision-making process, so additional items from the other tools were added. This created the preliminary observer SDM measure (Table 4.3). The components chosen align with what is considered important in SDM in the NICE guideline (NICE, 2021).

Table 4.3: The items in the preliminary Observer-SDM measure

No.	Item	Tool from which the item was derived
1	Discussion of the patient's role in decision making	IDM Informed Decision Making (Braddock et al., 1999)
2	Discussion of the clinical issues or nature of the decision	IDM Informed Decision Making (Braddock et al., 1999)
3	Discussion of alternatives	IDM Informed Decision Making (Braddock et al., 1999)
4	Discussion of the pros (potential benefits) and cons (risks of the alternatives	IDM Informed Decision Making (Braddock et al., 1999)
5	Discussion of uncertainties associated with the decision	IDM Informed Decision Making (Braddock et al., 1999)
6	Assessment of the patient's understanding	IDM Informed Decision Making (Braddock et al., 1999)
7	Physician's medical language matches patient level of understanding	Rochester Participatory Decision-Making Scale (Shields et al., 2005)

8	Exploration of patient preferences	IDM Informed Decision Making (Braddock et al., 1999)
9	Discussion of pressure or support from others	DSAT-10 Brief Decision Support Analysis (Stacey et al., 2008)
10	The clinician reassures the patient or re-affirms that the clinician will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained information prior to the encounter, the clinician supports such a deliberation process.	Observer Option 5 items (Elwyn et al., 2013)
11	Clinician and patient discuss the patient's expectations (ideas) and concerns (fears) about how to manage the concrete problem.	MAPPIN'SDM (Kasper et al., 2012)
12	Clinician and patient clarify the source upon which medical information / recommendations are based (scientific evidence, clinician's judgement, preferences, conflicting interests).	MAPPIN'SDM (Kasper et al., 2012)
13	Clinician and patient clarify whether the clinician has understood the patient's viewpoint correctly.	MAPPIN'SDM (Kasper et al., 2012)
14	Clinician and patient make sure that the patient can ask questions and point out aspects he had not fully understood during the discussion.	MAPPIN'SDM (Kasper et al., 2012)

4.1.3.1 Informed decision making (IDM) measure

The IDM measure was initially developed by Braddock et al. to assess informed decision-making in routine primary care office practice (Braddock et al., 1997). In 1999, Braddock et al. added a seventh element, which was to assess the discussion of uncertainties associated with the decision (Braddock et al., 1999). This was added as it is a crucial component for a patient's comprehensive understanding of the options. Braddock et al. have also categorised the decisions based on their nature into basic, intermediate and complex. Given that the treatment planning of cFPMs includes a discussion of possible extraction under sedation or general anaesthesia, a category of a complex decision was given to this study; thus, the seven elements were required for complex decisions (Braddock et al., 1999). In 2008, two further elements were added to the IDM measure to assess decision-making for older adults. Hence, the seven elements were sufficient for this study as the nature of the decision was for young people (Levinson et al., 2008). Previous studies that used the IDM

measure were reviewed to gain an understanding of the use of the components (Braddock et al., 2008; Ling et al., 2008; Hausmann et al., 2011; Leader et al., 2012; Borkhoff et al., 2013). This allowed an understanding of the application of the elements of the IDM measure within different clinical settings.

4.1.4 The rationale for this choice of measure

Using an SDM measure to assess the consultation was made to add structure and objectivity to the assessment and provide a framework to assess SDM. It also has the additional benefit of allowing the three different perspectives (observer/dentist/family) to be compared, which would not be possible in a purely qualitative analysis. While a tool was used to score the consultations, the analysis is descriptive rather than quantitative due to the small sample. We described the scoring patterns both within the case and across the case, as well as compared the scoring patterns for each of the different perspectives (observer/dentist/family). This will provide richer data than purely reporting aggregate scores, which will lose the nuance around individual variability.

Three preliminary tools were created to measure SDM from different perspectives (observer/dentist/family). The tools then underwent further revisions after the pilot study to produce the Observer-SDM measure, Dentist-SDM measure, and the Family-SDM measure.

4.2 Pilot study

4.2.1 Study design and setting

The pilot study involved simulated consultations in a closed clinic in the LDI orthodontic department with:

- Four orthodontic speciality trainees who performed the role of the dentist.
- A member of the research supervisory team (SB) who performed the role of a parent.
- The lead researcher (SA) who observed the consultation to complete the Observer-SDM measure and take field notes.

4.2.2 Materials and Methods

The participants provided verbal consent to video-record the consultations for the pilot. Before the consultations, information including a case summary was sent to the participants (Table 4.4). Each trainee was allocated a time for the consultation, and they were asked not to communicate until all mock consultations were complete.

The consultations were recorded in a separate surgery at the orthodontic department. The medical illustration team at the LDI was responsible for video-recording the consults and sending them to the researcher.

Table 4.4: Case summary used in pilot

Information provided	Nine-year-old boy attending with his mother Referred by GDP regarding poor prognosis mandibular right first permanent molar
Materials provided	Intra-oral maxillary and mandibular photographs Orthopantogram
Instructions	Please talk about the treatment options of the case with the parent. The purpose is to observe the approach to decision making, rather than to test your clinical knowledge. You can improvise if additional information was needed from the case as long as it sounds reasonable.

4.2.2.1 Revision of the preliminary SDM measure

The preliminary SDM measures underwent several revisions before being finalised for phase 2. The lead researcher, SA, observed and scored the mock consultations during the consultations using the preliminary Observer-SDM measure. Notes were taken regarding the usability of the measure and any ambiguities in the item descriptions. After each consultation, the dentist was asked to complete the preliminary Dentist-SDM measure and highlight any difficulties or challenges in scoring the items, Table 4.6.

After a few months, allowing a wash-out period of the lead researcher (SA) and the researcher actor (SB), the research team scored the consultations and identified any items that needed clarification. Changes and amendments in the measures and methodology after phase 1 were recorded, Table 4.9. The revision stages are summarised in Figure 4.2 in the results section.

4.2.1.2 Calibration of observer raters

The usability of the preliminary Observer-SDM measure was tested by the observer raters (SA, SB, and RB) after completion of the four mock consultations. Each consultation was scored independently to assess the ease of application of the items and consistency between raters. Inter-rater reliability scoring was performed. The data were entered in Microsoft Excel version 16.89.1 and analysed using IBM SPSS Statistics version 29. Statistics were calculated to measure the inter-rater reliability. The inter-rater agreement between the three scorers was calculated using Fleiss' Kappa.

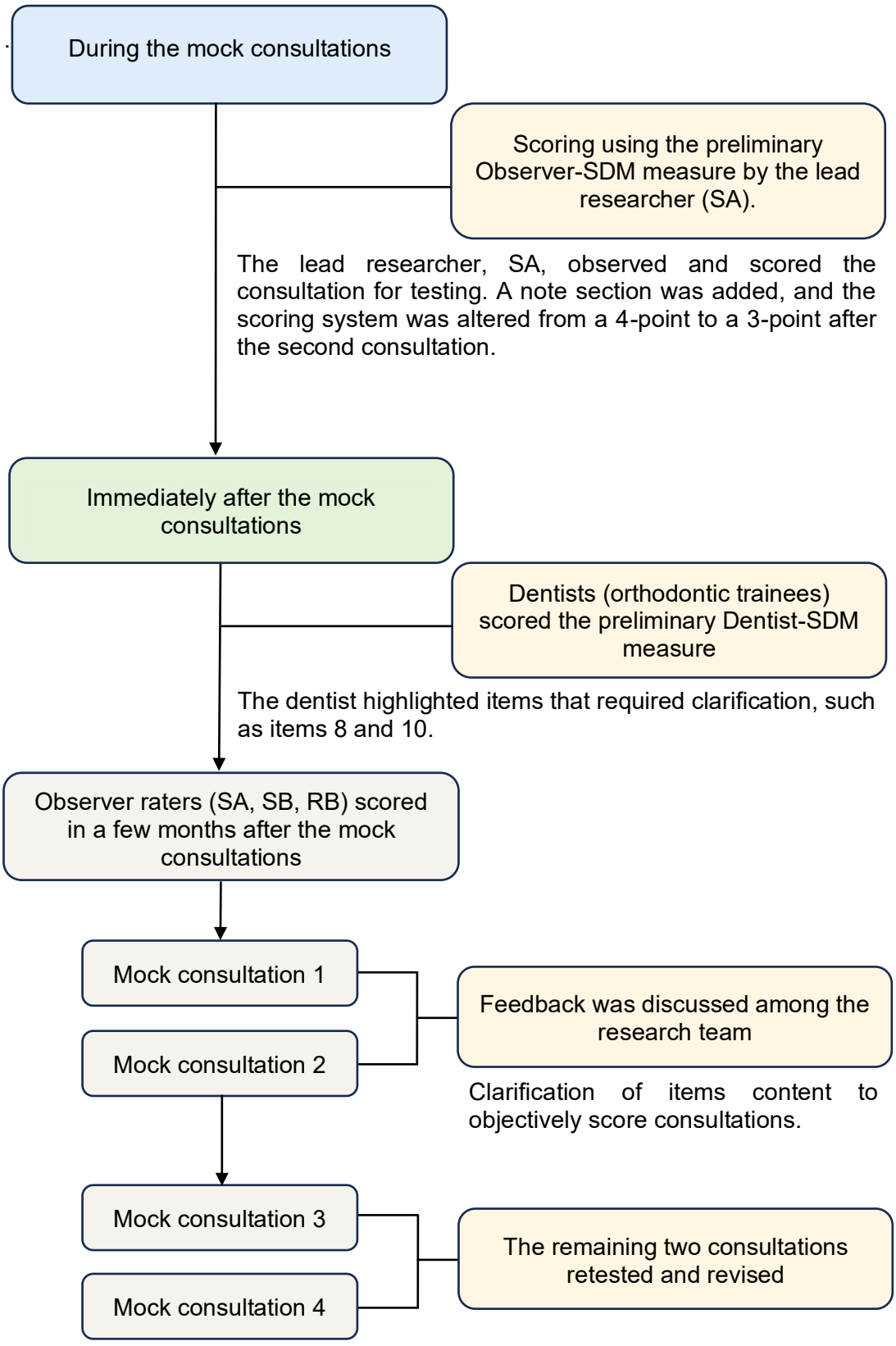
The discussion between raters was recorded, and based on the feedback, the SDM measure and supporting manual were revised and finalised. This was largely to clarify the precise meaning of items, add examples to ensure consistency in scoring, and re-order items to help in the application of the measure.

The final Observer-SDM measure was reworded to create a Dentist-SDM and Family-SDM measure covering the same items. The family version was tested by adults with no medical training background and revised to ensure the plain language explanation of the items was clear. The adults were friends and family members of the researchers. The final three versions of the measure are listed in the appendices (Appendix 10, Appendix 11, and Appendix 12).

4.2.3 Results

The stages of the development of the SDM measure during phase 1 are summarised in Figure 4.2.

Figure 4.1: Stages of SDM measures development during phase 1



4.2.4 Dentists' feedback and scoring

After the dentists' feedback on the preliminary Dentist-SDM measure, some changes were made in the order of the items and scoring scale. In the first two consultations, the dentists scored the consultations using the first version of the Dentist-SDM measure, which included a 4-point scale system. However, after taking feedback from the first two dentists, it was found easier to score the items if they were scored on a 3-point scale. Scores were represented using colours to aid visualisation. The three-point scale eliminated any uncertainties about the extent of partial completion of the item. Hence, the 3-point scoring scale was subsequently used in all versions of the SDM measures (Figure 4.3).

Figure 4.3: The 4-point and 3-point scoring system used by dentist raters in the mock consultation

4-point scale	Not covered	Partially covered	Mostly covered	Completely covered
3-point scale	Not covered	Partially covered		Completely covered

Table 4.5 displays the dentists' scoring after the mock consultations using the preliminary Dentist-SDM measure. The dentists scored some items, such as discussing the clinical issue, treatment options, risks and benefits, and assessing understanding, highly. However, other items were scored poorly, such as clarifying the source of evidence, reassurance about becoming informed, fears and concerns, and discussing support or pressures from others.

Table 4.5: Dentists, who were the orthodontic speciality trainees, scored four mock consultations using the preliminary SDM measure dentist version (NB. The order of the items is based on the first version of the SDM measure before changes were made)

Item	Description	Dentist rater			
		1	2	3	4
		4-point scale		3-point scale	
1	I discussed the patient's role in decision making during the consultation.				
2	I discussed the clinical issues or nature of the decision with the family.				
3	I discussed the alternatives in treatment options with the family.				
4	I discussed the pros (potential benefits) and cons (risks) of the alternatives with the family.				
5	I discussed with the family uncertainties associated with the decision.				
6	I clarified the source upon which medical information / recommendations are based (scientific evidence, clinician's judgment, preferences, conflicting interests).				
7	I explored the patient preferences with the family.				
8	I reassured the patient or re-affirmed that I will support the patient to become informed or deliberate about the options. / If the patient states that they have sought or obtained information prior to the encounter, I supported such deliberation process.				
9	I discussed the patient's expectations (ideas) and concerns (fears) about how to manage the concrete problem with the family.				
10	I discussed the patient the pressure or support from others.				
11	I assessed the patient's understanding associated with decision.				
12	I used a medical language that matches the patient level of understanding.				
13	I clarified to the family whether I have understood the patient's viewpoint correctly.				
14	I made sure that the patient and family can ask questions and point out aspects not fully understood during the discussion.				

Dentists found that the items were clear and easy to read, however, items 8 and 10 were highlighted as requiring revision by the four dentists. The issues and action taken are summarised in Table 4.6.

Table 4.6: Items requiring revision in the preliminary Dentist-SDM measure

Item 8: I reassured the patient or re-affirmed that I will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained information prior to the encounter, I supported such deliberation process.
Discussion
Raters found the item was vague when trying to score it due to there being two different descriptions of the item.
Action and rationale
Item changed to *"I reassured the patient and parent(s) that I will support them to become informed or deliberate about the options."*
This item was added from the Observer Option 5 items measure, a validated measure (Elwyn et al., 2013). However, the item was difficult to understand as it has two points. To simplify the meaning, the first sentence was used in the final SDM measure as it includes reassurance that one will be informed of the treatment options even if another dentist has previously discussed them.
Item 10: I discussed with the patient the pressure or support from others.
Discussion
Raters felt this item required clarification and was not relevant to discuss at the consultation.
Action and rationale
This element was discussed in consultations where one of the parents wanted to discuss the treatment options and plan with a partner who did not attend the consultation. Raters felt the item might be more relevant when discussing complex treatment options (e.g. orthognathic surgery or genetic testing) where there might be external pressures from other family members. For cFPM, pressure from parents may arise mainly about the modality of treatment and the need for a general anaesthetic. Even though this item was not considered to be always relevant, it was it was important and was thought to generate an interesting discussion.

4.2.5 Learning points from the mock consultations

The lead researcher, SA, scored the mock consultations using the preliminary Observer-SDM measure to test its applicability and to use as training. SA found it difficult to score all the SDM elements during the consultation, so a decision was made to seek consent to audio-record the consultations to allow the recordings to be reviewed to check the scoring. A section was added alongside the scoring boxes to add notes to aid scoring. The order of the items was changed to ease scoring in a logical manner.

4.2.6 Observer raters scoring feedback

The video recordings of the consultations were later watched by the research team (SA, SB, RB) to score the observations independently using the preliminary Observer-SDM measure with the 3-point scale in Figure 4.3. The research team then discussed their scores and identified items that were scored differently.

The observer scores for the mock consultations are displayed in Table 4.7. Trends were noted from the mock consultations; for example, some items were consistently scored poorly. The observer raters scored item 1, defining the roles in SDM, poorly throughout the consultations. Similarly, clarifying the source of information, providing support to become informed, discussing pressure or support from others, and assessing the dentists understanding were scored poorly in the consultations. Items involving providing clinical information, such as clarifying the clinical issue, treatment options, and risks and benefits were scored higher than other items. Interestingly, the dentists scored the consultations lower than the observer raters.

Table 4.7: Mock consultations observer raters (SA, SB, RB) scoring using the SDM measure

Mock observer scores			Consultations 1			Consultation 2			Consultation 3			Consultation 4		
			Observer			Observer			Observer			Observer		
			1	2	3	1	2	3	1	2	3	1	2	3
SDM items	1	Role in SDM												
	2	Clinical issue												
	3	Treatment options												
	4	Risks and benefits												
	5	Expectations and concerns												
	6	Patient preferences												
	7	Uncertainties												
	8	Source of information												
	9	Support to become informed												
	10	Pressure/support from others												
	11	Patient understanding												
	12	Language understandable												
	13	Dentist understanding												
	14	Opportunity to ask												
SDM score out of 28			**11**	**13**	**16**	**19**	**19**	**22**	**13**	**14**	**17**	**10**	**12**	**16**

4.2.7 Inter-rater reliability score

The inter-rater reliability scores ranged from fair to substantial, Table 4.8.The first mock scoring had the least agreement, however, the agreement increased afterwards, indicating raters became better calibrated. Mock 2 had the highest Kappa score, indicating substantial agreement. This could be because the dentist in Mock 2 fully covered most items in the SDM measure.

Table 4.8: Reliability testing of observer raters in the mock consultations using Fleiss Kappa score

Mock consultations	Mock 1	Mock 2	Mock 3	Mock 4
Fleiss' kappa	0.343	0.684	0.598	0.494
Agreement	Fair	Substantial	Moderate	Moderate

Differences were highlighted in items 3 and 4 of the Observer-SDM measure, in which treatment options, risks, and benefits were discussed. The research team discussed whether to include mode of treatment delivery, as well as type of treatment, as part of the treatment options discussion. Other differences in scoring were identified in items assessing the patient's and dentist's understanding, items 11 and 13. It was agreed that understanding is summarising and checking if comprehension is fully met.

Scoring SDM was found to be challenging as each scorer perceived items differently. To address this and improve the validity of scoring, a manual for the observers was developed to explain exactly what each item meant and how to apply it. The manual included descriptions of items, definitions, and examples specifically for discussion about management of cFPMs based on the research team's clinical knowledge and experience. The wording and descriptions were informed by the explanations and manuals of the different measures included in the SDM measure.

Despite the development of the manual, the research team felt consensus scoring would be more robust than a single rater. It was agreed that the three research team members would listen to the audio and read the transcript to independently score the consultations in phase 2, then discuss the items and their individual scores to reach a consensus score.

4.2.8 Summary of alterations in methodology after Phase 1

Table 4.9 summarises the changes in the SDM measure and data collection methods as a result of phase 1.

Table 4.9: Changes in the SDM measures and methodology after Phase 1

Changes in the SDM measures	Reason for the change
Order of items	To ease application
Scoring scale from a 4-point to a 3-point scale	To ease scoring
Addition of an overall satisfaction at the end of the dentist and family SDM measures	To provide a general overview of the consultation
Addition of a note section in the observer SDM measure	To provide space for notes and discussion
Amendments in methodology	Reason for the amendment
To audio-record the consultations	To allow accurate scoring by going back in the audio.
To transcribe the consultations	To ease scoring with the audio-recordings and to be used for further qualitative analysis.
Observer scoring as consensus	To eliminate inter-rater variation
Manual development	To aid scoring and standardisation between consultations

Chapter 5 Phase 2: Observer, dentist and family perceptions of SDM consultations about compromised first permanent molars

The objectives of the second phase of the study were:

- To measure SDM in clinical consultations between young people, parents, and dentists.
- To compare perceptions of parents and dentists to an observer in consultations about management of cFPMs.

5.1 Study design

Cross-sectional observational study using descriptive analysis.

5.1.1 Population and setting

Children presenting with cFPMs were referred to paediatric dentistry, orthodontic, or joint orthodontic paediatric clinics to plan to restore or extract the cFPM. A clinical examination and consultation were undertaken to facilitate discussion about management. A consecutive sample of children scheduled for a consultation appointment was recruited for this study.

This was a multi-centre study carried out at Leeds Dental Institute (LDI) and Pinderfields General Hospital (PGH), Wakefield. The LDI runs as a partnership between the University of Leeds and Leeds Teaching Hospitals NHS Trust. It is a dental hospital providing treatment by all dental specialities. PGH is part of Mid Yorkshire NHS Teaching Hospital Trust, and the Oral and Facial Department provides specialist treatment in orthodontics and oral surgery. Observations were undertaken in consultation clinics in the orthodontic department and the Joint Orthodontic-Paediatric Dentistry (JOP) clinic in both sites, and the paediatric dentistry department at LDI.

Purposive sampling was undertaken using a maximum diversity approach based on the key characteristics:

- Age of the young person with cFPM.
- The severity of the cFPMs.
- Clinical setting (paediatric dentistry, orthodontics, JOP clinic).

Each consultation between the young person with cFPM, their parents and the dentist was one observation.

5.1.1.1 Sample size

Approximately 10-12 consultations were expected to give an adequate representation of usual clinical practice, so this was set as the target sample size, with the option to undertake further observations if more variation in practice was observed than expected. No power tests were performed as there was no hypothesis or data on which to base this. As no previous research was done in using a quantitative tool qualitatively, the sample size was decided until trends were observed.

5.1.1.2 Eligibility criteria

The inclusion and exclusion criteria for participants for the study are as follows:

Inclusion criteria

A. Young people aged 7-11 years with at least one cFPM requiring a decision; attending with a parent or legal guardian who can provide consent; people who are able to speak and understand English.
B. Parents or legal guardians attending with the young people who can provide consent; people who are able to speak and understand English.
C. Dentists involved in the consultation, including paediatric dentists or orthodontists who are consultants, specialists, speciality trainees or postgraduates.

Exclusion criteria

A. Young people who are not willing to take part; young people with cFPMs requiring acute treatment (as this may limit the discussion of options); young people with craniofacial conditions or significant medical histories if the condition was judged to have an impact on treatment options.
B. Parents or guardians who cannot or do not consent to take part.
C. Other dentists including undergraduates, dental core trainees and dentists from other specialities.

5.2 Materials and Methods

5.2.1 Recruitment and enrolment

All young people who met the inclusion criteria were informed about the study through a participant information sheet which was delivered at least one week before their scheduled consultation appointment. Separate information sheets were developed for the legal guardians, young people and dentists (see Appendix 4, Appendix 5, Appendix 3).

On the day of the scheduled consultation appointment, families who were happy to participate returned a reply slip to the receptionist indicating they were happy to be approached by the lead researcher, SA. Following that, the lead researcher discussed the study with the young person and their parent or legal guardian and answered any questions related to the research. Once the participants confirmed they were happy to participate in the study, written consent was obtained. The parent or legal guardian was asked to sign a consent form (Appendix 6), and the young person was asked to sign an assent form (Appendix 8).

At the time of the consultation, basic information about the consultation was collected (Appendix 9). The lead researcher observed all the consultations but did not participate or influence the consultation. Dentists were encouraged to follow their regular consultation practice. The consultations were audio-recorded to allow subsequent observer scoring (Appendix 10). After the consultation was completed, the dentist and family were asked to complete the Dentist-SDM and the Family-SDM measures, respectively (Appendix 12, Appendix 11).

The Family-SDM measure was expected to take 5-10 minutes to complete, depending on the parent or legal guardian's comprehension level. The Dentist-SDM measure was expected to take 3-5 minutes to complete, which was done immediately after the consultation. The SDM measures were completed independent of each other, the dentists completed the Dentist-SDM measure in the surgery, while the family completed the Family SDM measure in the reception area.

5.2.2 Data collection

Potential participants were identified from the consultant clinic patient list in paediatric dentistry, orthodontics, and the JOP clinics. Participants were filtered based on age

and reason for referral on the patient's referral document, which was available in the patient's electronic record.

The lead researcher observed and audio-recorded the consultations after obtaining written consent and assent. The audio recordings were transcribed using a University of Leeds-approved transcription company, which is compliant with the University's Data Protection Policy, Transcription City LTD. The transcriptions were used to support scoring by the observers and subsequent agreement on a consensus score.

5.2.2.1 The roles of the research team and participants in completing the SDM measures

Observer-SDM measure

The lead researcher, SA, observed the consultations and took notes to aid future research in language and communication skills assessments; these included sketching the dental clinic, the starting body language of all participants, body language changes, and loss of eye contact.

The Observer-SDM measure was completed by the research team, SA, RB, SB by reading through the transcripts and scoring the consultations independently, then listening to the audio-recordings together and reaching consensus in items scored differently. The Observer-SDM measure included some space for notes, which the research team used to record their reasons for decisions as they listened to the consultation audio.

Dentist-SDM measure

The Dentist-SDM measure was completed by the dentist participant immediately after the patient left the surgery. In consultations where more than one dentist was involved, the dentists completed the SDM measure together.

Family-SDM measure

The Family-SDM measure was created to be completed by the guardian with the young person's input if they are willing to. This was completed in the reception area once the consultation ended.

5.2.3 Data management

The lead researcher identified potential participants from the clinic lists. The records were then accessed to obtain contact information. Personal data, including names and signatures, was collected on the consent form and stored in a locked cabinet in the office of the School of Dentistry, University of Leeds. Personal data, such as the participants' NHS numbers and appointment dates, was kept in an Excel spreadsheet in a password-protected drive only accessible to the lead researcher. This was kept separately from the anonymised research data.

Once potential participants were identified from the clinic lists, the participants' contact details were used to send an invitation letter, but contact details were not stored. The only personal data stored were the names and NHS numbers of each young person. No personal data was obtained from the parents or legal guardians, and no personal data was obtained from the dentists.

The audio-recordings were transferred to the university encrypted drive and deleted immediately from the audio recorder. Transcriptions were anonymised, and personal data was deleted. The transcriptions will be kept for 3 years to allow time for secondary qualitative analysis and publication. Each participant was assigned a unique identifier number for the study. This was used in all documentation to ensure data was collected, stored and analysed anonymously. Only the lead researcher had access to the spreadsheet that could link names to the study identifier.

5.2.4 Data analysis

The data were entered in Microsoft Excel version 16.89.1 and analysed using IBM SPSS Statistics version 29. Data were analysed descriptively.

The scoring agreement between the observer raters (SA, SB, RB) was calculated for each of the consultations. This was done by identifying the agreement in each item across the 12 consultations and then categorising them into full agreement, partial agreement, and no agreement. Full agreement is when the three observer raters score the items similarly. Partial agreement is when one observer rater scored the item differently, but two raters scored similarly. However, no agreement is reached when none of the observer raters have a similar score. Then, percentages were obtained for each category to allow comparisons.

In the items when the observer raters partially agreed, the disagreement was either a one-point difference or a two-point difference. For example, a one-point difference is when two observer raters scored an item 2 in the Observer-SDM measure, but the third observer rater scored it as a 1. A two-point difference is when the third observer rater scored the item as a 0 in the previous example.

The intra-rater reliability testing was performed 6 months after scoring the consultations by the three observer raters using the Observer-SDM measure. Six months was agreed to be enough time for a wash-out period and to reduce recall bias. Three consultations were randomly chosen using an online randomising generator. This corresponds to 25% of the consultations. Weighted Kappa was used to measure the intra-rater reliability score between the initial observers' and reliability scores.

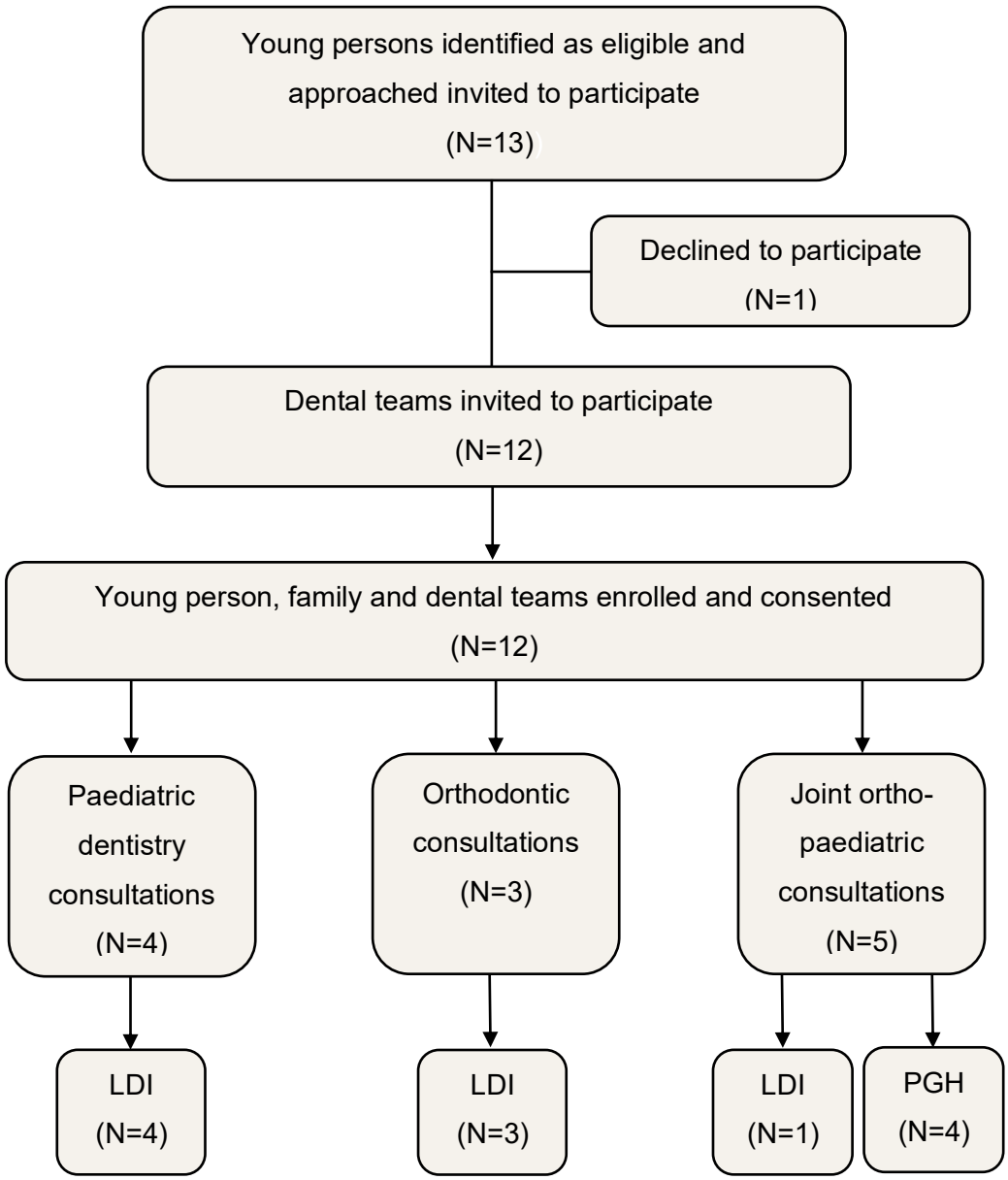
Table 5.1: A summary of the data analysis plan

Measures	Variables and items	Analysis method
Sample characteristics	Age, gender, accompanying person, number of molars affected, the clinical speciality, staff grade, hospital, consultation stage, and time required for the consultation.	Frequency and percentages
SDM items	The 14 items of the Family-SDM measure, Dentist-SDM measure, and Family-SDM measure.	Frequency and percentages
Satisfaction scores	The satisfaction scores of the dentists and families from a scale of 5.	Mean and standard deviation
Comparison of SDM scores	The scores between the families, dentists, and observers for each consultation with the identification of trends across different clinics, specific items, and across consultations.	Visual comparison using colour coded schemes
Observer raters' agreement in scoring	The independent scores of the observer raters three observer raters for each consultation were labelled as full agreement, partial agreement or no agreement.	Frequency in each category and percentage
Intra-rater reliability testing	Three consultations (25% of total sample) were re-scored six months after the initial scoring by the three observer raters.	Weighted Kappa
Time of the consultation to SDM score	The total time of the consultation, excluding pauses, in relation to the total SDM score for each consultation	Normality testing and Pearson Correlation test

5.3 Results

Twelve consultations were observed and scored from the three perspectives. Recruitment from the orthodontic clinic was lower than expected, but this was balanced by including five consultations from the JOP clinic (Figure 5.1). Recruitment from the two hospitals was not equal because participant recruitment was initially planned only at the LDI. However, there were insufficient participants that met the inclusion criteria, so a second site was added to aid recruitment.

Figure 5.1: Participant flow and recruitment



5.3.1 Demographics

Characteristics of the participants included in the consultations are summarised in Table 5.2. Most of the young people were brought to the clinic by their mothers. The JOP clinics included an orthodontist and a paediatric dentist.

Table 5.2: Characteristics of participants involved in clinical consultations

Young person characteristics						
	Age in years					
Age of young people	7	8	9	10	11	
Number of young people	1	2	3	4	2	
Gender	Female	5	Male	7		
Accompanying carer	Mother	9	Father	2	Both	1
Number of affected molars	1-2	5	3-4	7		
Consultation and dentist characteristics						
Consultation stage	First visit	7	Follow up	5		
Staff grade	ST	6	Consultant	5	Both	1
Hospital	LDI	8	PGH	4		
Speciality	Paediatric dentistry	4	Orthodontics	3	JOP	5

5.3.2 Consultation characteristics

The paediatric dentistry and orthodontic consultations were new patient assessments arising from external referrals, usually from a general dentist. In the joint clinic, most young people had already been seen in an orthodontic or paediatric dentistry department but had then been referred onwards for a joint consultation to reach a treatment decision.

During the consultation, the number of molars affected in each young person was recorded. The molars were impacted by caries, enamel defects, or both, with varying degrees of severity. Table 5.3 summarises other parameters which may have influenced the treatment decision, including the diagnosis of each tooth and additional factors affecting the consultation.

The young person in consultation J5 was being investigated for possible conductive cardiac defects due to the sudden death of his sibling. Conductive cardiac defects would not impact the management of cFPMs, unlike structural defects, owing to no increased risk of infective endocarditis. The young person also had autism and some distraction was noted during the consultation. Nevertheless, the discussion about cFPM treatment options showed similar trends to those of previous consultations.

5.3.3 Young person's input in the Family-SDM measure

The Family-SDM measure was completed mainly by the legal guardians of the young persons. Only 2 young people were involved in answering the Family-SDM measures. These were the young people in consultations P4 and J1. In the remaining consultations, the legal guardians completed the Family-SDM measure without input from the young person. This could be due to the time taken to complete the consultations, including waiting time and the need for radiographs. At the end of the consultation, most young people were tired and wanted to leave the hospital; thus they were not willing to complete the SDM measure along with the parents.

Table 5.3: Information affecting the consultation discussion

ID	Age	Notes about the consultation
P1	9	• Four affected molars, 3 with poor prognosis.
P2	10	• Multiple carious lesions in the primary dentition. • The parent asked to discuss the options first with their partner before deciding on the plan.
P3	8	• Multiple carious lesions in primary dentition. • Three molars with poor prognosis.
P4	7	• Mild hypodontia with 2 teeth missing. • Four molars affected, 2 with good prognosis and 2 with poor prognosis. • Parent with a senior medical background.
O1	10	• Two affected molars with poor prognosis.
O2	10	• Two affected molars with poor prognosis. • Has enamel hypoplasia of 1 mandibular premolar.
O3	11	• Poor oral hygiene and severe crowding. • Four molars affected, 2 with good prognosis and 2 with poor prognosis.
J1	8	• Four affected molars with poor prognosis. • Young person was very anxious. • Mild crowding and class II division 2 incisor relationship.
J2	11	• Severe crowding in the maxillary arch. • Class II division 2 incisors and class II molar relationship. • Three molars affected with a questionable prognosis.
J3	10	• Moderate crowding in the maxilla with space loss in the right quadrant. Mild crowding in the mandible. • Class II molar relationship. • Two molars affected with poor prognosis located on the upper right and lower left quadrants.
J4	10	• Anxious about treatment.
J5	9	• History of sudden death of his 20-year-old sibling, thought to be possibly a conductive cardiac condition so the young person is being evaluated for cardiac conditions. • Autistic – allowed examination but there were some distractions.

5.3.4 Ratings of SDM in the consultations

The family, dentist, and observers' ratings for SDM in the 12 consultations are demonstrated in Table 5.4, Table 5.5 and Table 5.6, respectively. A summative SDM score for each consultation is given, however, it is acknowledged that each item does not necessarily have the same weighting. The SDM score was calculated to allow direct comparison between consultations but is not validated to be used for quantitative analysis.

The observer ratings were generally lower than the dentist and family ratings. Comparing different consultations in different settings, from the observer's perspective, the orthodontic consultations scored the lowest compared to paediatric and joint clinics. Joint clinic consultations scored the highest observer scores.

Paediatric consultations took the longest, while orthodontic consultations took the shortest time. Similar findings were noted when rating the consultations in LDI and PGH. No specific trends were noted when rating the consultations based on the number of molars affected and the complexity of the decision.

5.3.4.1 Family ratings for SDM and satisfaction

Across all items, families reported very high scores, indicating a positive perception of their involvement in the decision-making process regarding cFPMs. A uniform high level of satisfaction, with all consultations receiving a score of 5/5 (Median = 5, IQR = 0), was ranked by families in all the consultations, irrespective of case complexity.

5.3.4.2 Dentist ratings for SDM and satisfaction

Similar to the family reports, dentists tended to rank items higher than observer ratings. The lowest scores were observed for items 1 and 10. Despite these lower scores, other items were ranked highly by dentists, suggesting a positive overall view of the SDM process. Dentists’ satisfaction scores ranged from 3 to 5 (Median = 4, IQR = 1), indicating some variability in the satisfaction levels.

Table 5.4: Family ratings of clinical consultations

Family scores			Consultation											
			Paediatric dentistry				Orthodontics			JOP				
Item description			P1	P2	P3	P4	O1	O2	O3	J1	J2	J3	J4	J5
SDM items	1	Role in SDM												
	2	Clinical issue												
	3	Treatment options												
	4	Risks and benefits												
	5	Expectations and concerns												
	6	Patient preferences												
	7	Uncertainties												
	8	Source of information												
	9	Support to become informed												
	10	Pressure/support from others												
	11	Patient understanding												
	12	Language understandable												
	13	Dentist understanding												
	14	Opportunity to ask												
SDM score out of 28			**28**	**25**	**28**	**24**	**25**	**28**	**28**	**28**	**26**	**28**	**28**	**28**
Overall satisfaction scores (out of 5)			**5**	**5**	**5**	**5**	**5**	**5**	**5**	**5**	**5**	**5**	**5**	**5**
Length of consultation in minutes			45	43	23	52	22	23	13	24	35	38	34	20
Staff grade			ST	ST	ST	ST	Cons	Cons	Cons	Cons	Cons	Both	ST	ST
Number of FPM affected			4	2	3	4	2	2	1	4	3	2	4	4
Age of the young person in years			9	10	8	7	10	10	11	8	11	10	9	9

SDM: Shared Decision-Making
P: Paediatric dentistry clinic
O: Orthodontic clinic
JOP: Joint Orthodontic Paediatric Clinic
ST: Speciality trainee
Cons: Consultant

The 3-point scale used in the SDM measures			
3-point scale	Not covered	Partially covered	Completely covered

Table 5.5: Dentist ratings of clinical consultations

Dentist scores			Consultation											
			Paediatric dentistry				Orthodontics			JOP				
Item description			P1	P2	P3	P4	O1	O2	O3	J1	J2	J3	J4	J5
SDM items	1	Role in SDM												
	2	Clinical issue												
	3	Treatment options												
	4	Risks and benefits												
	5	Expectations and concerns												
	6	Patient preferences												
	7	Uncertainties												
	8	Source of information												
	9	Support to become informed												
	10	Pressure/support from others												
	11	Patient understanding												
	12	Language understandable												
	13	Dentist understanding												
	14	Opportunity to ask												
SDM score out of 28			**24**	**20**	**17**	**16**	**19**	**19**	**23**	**20**	**19**	**21**	**19**	**15**
Overall satisfaction scores out of 5			**4**	**4**	**4**	**4**	**5**	**5**	**4**	**5**	**4**	**5**	**3**	**3**
Length of consultation in minutes			45	43	23	52	22	23	13	24	35	38	34	20
Staff grade			ST	ST	ST	ST	Cons	Cons	Cons	Cons	Cons	Both	ST	ST
Number of FPM affected			4	2	3	4	2	2	1	4	3	2	4	4
Age of the child in years			9	10	8	7	10	10	11	8	11	10	9	9

SDM: Shared Decision-Making
P: Paediatric dentistry clinic
O: Orthodontic clinic
JOP: Joint Orthodontic Paediatric Clinic
ST: Speciality trainee
Cons: Consultant

The 3-point scale used in the SDM measures			
3-point scale	Not covered	Partially covered	Completely covered

Table 5.6: Observer ratings of clinical consultations

Observer scores			Consultations											
			Paediatric dentistry				Orthodontics			JOP				
Item description			P1	P2	P3	P4	O1	O2	O3	J1	J2	J3	J4	J5
SDM items	1	Role in SDM												
	2	Clinical issue												
	3	Treatment options												
	4	Risks and benefits												
	5	Expectations and concerns												
	6	Patient preferences												
	7	Uncertainties												
	8	Source of information												
	9	Support to become informed												
	10	Pressure/support from others												
	11	Patient understanding												
	12	Language understandable												
	13	Dentist understanding												
	14	Opportunity to ask												
SDM score out of 28			**12**	**10**	**6**	**10**	**4**	**3**	**3**	**10**	**12**	**15**	**8**	**8**
Length of consultation in minutes			45	43	23	52	22	23	13	24	35	38	34	20
Staff grade			ST	ST	ST	ST	Cons	Cons	Cons	Cons	Cons	Both	ST	ST
Number of FPM affected			4	2	3	4	2	2	1	4	3	2	4	4
Age of the person in years			9	10	8	7	10	10	11	8	11	10	9	9

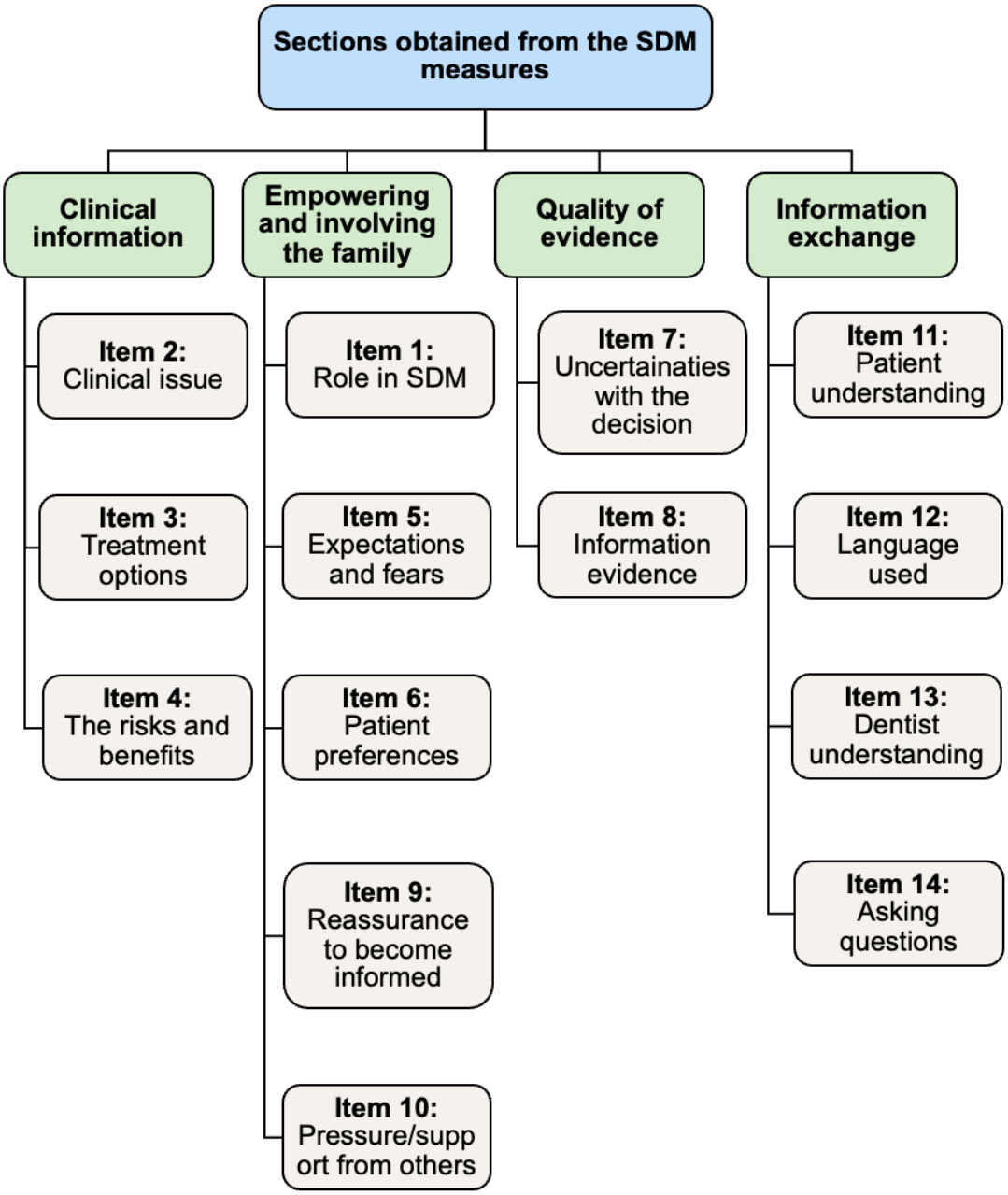
SDM: Shared Decision-Making
P: Paediatric dentistry clinic
O: Orthodontic clinic
JOP: Joint Orthodontic Paediatric Clinic
ST: Speciality trainee
Cons: Consultant

The 3-point scale used in the SDM measures			
3-point scale	Not covered	Partially covered	Completely covered

5.3.5 Items grouping for interpretation

To aid interpretation of the results, the items have been grouped into domains, which are clinical information, empowering and involving the family in the consultation, quality of evidence and information exchange (Figure 5.2). However, it has been noticed that there is an overlap between the items measuring SDM.

Figure 5.2: The grouping of items into domains



5.3.5.1 Clinical Information

These items (2,3,4) focus on exchanging factual medical information about the patient's condition and treatment options. Across the observed consultations, most discussions within the paediatric dentistry and JOP clinical setting demonstrated a comprehensive clinical information exchange. Dentists in this setting consistently addressed the clinical issues, discussed treatment alternatives, and outlined the pros and cons of each option. However, there was less emphasis on addressing the clinical issue, treatment options, risks and benefits in the orthodontic clinic consultations.

5.3.5.2 Empowering and involving the family in the consultation

Items 1, 5, 6, 9 and 10 of the SDM measure address patient empowerment and involvement in the decision-making process. This focuses on supporting families to share their expectations and define their roles in the discussion, ultimately empowering them to actively participate in the decision-making process. Observations across all consultations revealed a consistent pattern: a lack of explicit discussion regarding the roles within the shared decision-making process. This was reflected in the uniformly poor scores for Item 1 of the Observer-SDM measure. Additionally, dentists' efforts to reassure patients and support their informed deliberation were generally rated poorly in item 9 in the Observer-SDM measure. Similarly, Item 10, assessing the discussion of external pressures or support, consistently received a score of zero across all consultations in the Observer-SDM measure. Items 5 and 6, addressing patient expectations, concerns, and preferences, exhibited variable scores but were predominantly rated as 'partially covered' in the Observer-SDM measure.

5.3.5.3 Quality of evidence

The quality of evidence provided to patients, encompassing discussions of uncertainties and information sources, was assessed through items 7 and 8 of the SDM measure. The discussion of uncertainties in item 7 associated with the decision showed score variability. A notable discrepancy was evident between dentist self-ratings and observer ratings, with dentists consistently scoring themselves slightly higher. Across all consultations, there was no evidence of dentists clarifying the source of medical information or recommendations. This was consistently reflected in scores of zero for this item in the Observer-SDM measure; however, both dentists and families scored this item higher.

5.3.5.4 Information exchange

Exchanging information was evaluated through items 11, 12, 13, and 14. A contrast emerged between observer ratings and participants' (dentist and family) ratings for items 11 and 13, which assessed mutual understanding. While observers rated this aspect poorly, dentists and families gave high ratings, indicating a potential discordance in perceptions. The use of lay language was partially covered, with some instances of use of medical terminology observed. Similarly, Item 14, addressing opportunities for patient questions, was also partially covered.

5.3.6 Scoring agreement

The scoring agreement between the observers was calculated for each of the consultations (Table 5.7).

Partial agreement indicates that two of the three raters had the same rating, whereas no agreement meant the raters all scored the item differently. Items that were scored poorly (items 1, 8, 10) had the highest agreement. In items where there was variation across consultations in whether the SDM step was performed, tended to have more variation in how they were scored by the observer raters. No agreement was seen in some consultations for items 5 (17%), 12 (8%), and 14 (8%).

In the cases where the observer raters partially agreed, the third observer had only a one-point difference most (96%) of the times. For example, two observers scored an item 2, and the third observer rater scored it as a 1.

Table 5.7: Observers agreement across the 14 items.

		Number of consultations (%)		
Items	**Description**	**Full agreement**	**Partial agreement**	**No agreement**
1	Role in SDM	**12 (100%)**	0 (0%)	0 (0%)
2	Clinical issue	**6 (50%)**	6 (50%)	0 (0%)
3	Treatment options	**7 (58%)**	5 (42%)	0 (0%)
4	Risks and benefits	**8 (67%)**	4 (33%)	0 (0%)
5	Expectations and concerns	**7 (58%)**	3 (25%)	2 (17%)
6	Patient preferences	**6 (50%)**	6 (50%)	0 (0%)
7	Uncertainties	**7 (58%)**	5 (42%)	0 (0%)
8	Source of information	**10 (83%)**	2 (17%)	0 (0%)
9	Support to become informed	**10 (83%)**	2 (17%)	0 (0%)
10	Pressure/support from others	**10 (83%)**	2 (17%)	0 (0%)
11	Patient understanding	**6 (50%)**	6 (50%)	0 (0%)
12	Language understandable	**8 (67%)**	3 (25%)	1 (8%)
13	Dentist understanding	**9 (75%)**	3 (25%)	0 (0%)
14	Opportunity to ask	**8 (67%)**	3 (25%)	1 (8%)

5.3.7 Intra-rater reliability

The intra-rater reliability results ranged from 0.774 to 0.81 (Table 5.8), corresponding to substantial agreement according to the interpretation scale by Landis and Koch (Landis and Koch, 1977).

Table 5.8: Intra-rater reliability score of three consultations

Consultation	Weighted Kappa
1	0.774
2	0.811
3	0.756

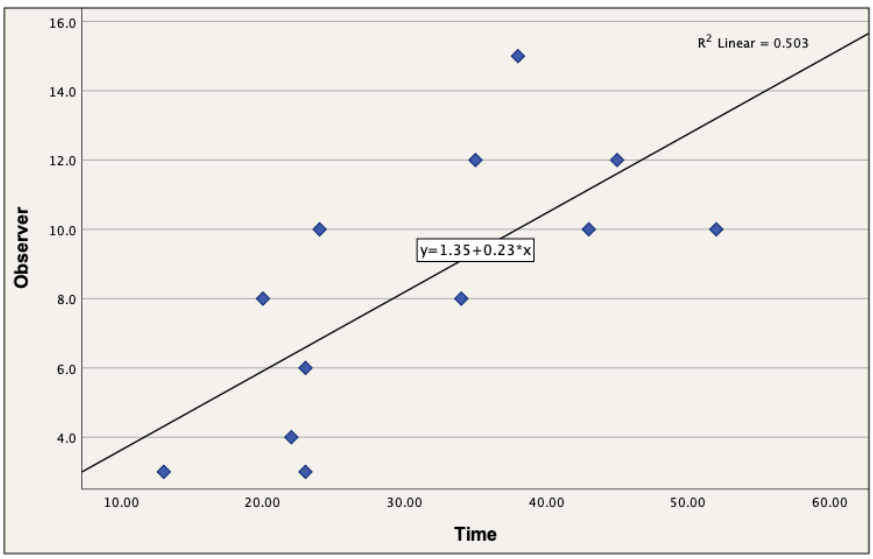
5.3.8 Length of the consultations

The length of the consultation was recorded from the time the family entered the clinic until the consultation was complete. The timer was paused if the young person was required to leave the clinic to take radiographs or needed to use the toilet. The consultation time ranged from 13 to 52 minutes, with a mean average of 31 ± 11.9 minutes. Time was normally distributed as assessed by Shapiro-Wilk's test ($p>0.05$) and confirmed by the Q-Q plot visually.

The total observer ratings ranged from 3 to 15 points out of 28. The observer total scores were normally distributed, as assessed by the Shapiro-Wilk's test ($p>0.05$) and confirmed visually by the Q-Q plot.

Correlation between the total observer scoring and the time length of the consultation was calculated using the Pearson Correlation. While it is acknowledged the sample size was small and the summative SDM score may not be valid, this correlation was felt to be useful to provide some indication of whether the length of the consultation impacted on the SDM score. The correlation was not statistically significant ($p=0.709$) (Figure 5.3).

Figure 5.3: Scatter plot of the total observer scores and the time length of the consultations showing correlation



Chapter 6 Discussion

No previous studies have examined SDM in the paediatric dental environment. We chose consultations about compromised first permanent molars (cFPMs) in young people aged 7-11 because this area is complex and often requires multiple disciplines. Discussing this issue involves a three-way consultation between the young person, the carer, and the dentist. The present study revealed differences in perceptions of whether SDM was performed, depending on the perspective of families, dentists, or observers. Notably, observers ranked the consultations poorly on certain SDM items, while families provided high scores. Dentist ratings fell between these two extremes.

The consultations included in the study were obtained from hospitals with access to specialist dental services. The young people were referred to these clinics due to the complexity of their clinical presentation and the availability of multidisciplinary teams.

6.1 Reflection on the methods

This section provides a detailed discussion and critique of the study's methodology. It outlines the rationale behind the eligibility criteria used for participant selection, as well as the development and evaluation of the SDM measurement tools. The strengths and limitations of the overall research approach are also addressed.

6.1.1 The rationale behind participant selection

People younger than 7 years old were excluded because the FPM might not have erupted in the oral cavity yet. People older than 11 years old were also excluded because this age group has passed the stage for interceptive extraction of the cFPM, limiting the treatment options available for management. Recruiting young people in the 7-11 age group was chosen because it was expected that there would be a more consistent approach to the discussion of treatment options across the different consultations, which would aid standardised application of the SDM scoring.

The dentist and carer's consent and the young person's assent were required prior to participation in the study. However, one parent who was approached declined to take part because her daughter was very anxious about the appointment, and the parent did not want to exacerbate the child's anxiety. Young people with cFPM presenting

with severe pain, swelling, or acute symptoms were excluded because this could limit the discussion of options. During acute appointments, the focus is on immediate pain relief and addressing the urgent problem, thus affecting the SDM process.

The medical condition of the young person was also considered when determining eligibility for inclusion in the study. Young people with significant medical conditions that were judged to have an impact on the treatment options were excluded. An autistic 9-year-old who was non-verbal was also included. This patient was being evaluated for conductive cardiac conditions, as their sibling had experienced a sudden death thought to be due to a conductive cardiac defect. This young person was included because normal discussion was possible between the dentist and the mother, with only minor distractions from the young person. The young person did not report pain and had not been diagnosed with structural cardiac defects that would affect the treatment plan. However, it was noted that SDM requires a distraction-free environment, particularly when complex medical decisions are made, and this consultation was scored poorly by the observers. Nevertheless, the consultation showed similar trends to those involving young people with no relevant medical history. Further research is needed to explore the impact of different types of distractions (environmental, patient-related, clinician-related) on SDM outcomes.

The observations were conducted across different clinics, allowing for the analysis of trends across specialities and the assessment of the SDM process among patients with more complex decision-making, particularly those attending the joint clinic. This approach enabled comparisons between specialities and clinics.

6.1.2 SDM measure development

The rationale for using an SDM measure in this study was to provide a consistent assessment of the consultations, from both an objective observer perspective and a subjective dentist and family perspective. The measure provided structure for assessing the content of the consultation, and by looking at each item individually rather than creating an aggregate score, it was possible to examine each aspect of the SDM process.

It was challenging to find a single tool that encompassed all the relevant SDM elements that were felt to be important for the clinical issue, so the Observer-SDM

measure was developed by adapting the Informed Decision Making (IDM) measure and incorporating additional items from other tools. These items were selected to capture the essential components of SDM. While this approach negates the previous validation process of the IDM, the intent was to use it for descriptive analysis and identifying trends rather than quantitative analysis. Psychometric testing to validate the measures was not possible from the data generated in this study due to the small sample size. However, if it is felt that this tool encompasses SDM better than existing measures, then validation of this tool could be undertaken to allow it to be used in future research.

The Family-SDM and Dentist-SDM measures were developed by adapting the Observer-SDM measure. This approach allowed the production of comparable data across the three perspectives, but it is recognised that the family and dentist versions were not developed from validated tools that aimed to measure these perspectives, so the measures may not capture these groups' perceptions accurately. The measures were refined through input from dentists, friends, and families to adjust the wording and ensure comprehension. Involving patients and the public more actively during the development of the Family-SDM measure would have been ideal, for example, to examine the understanding of the concepts underpinning each item, but this was not feasible within this research. This may have affected the validity of the results from the Family-SDM measure. Furthermore, it was noted that families were in a rush when scoring their consultation, likely due to the time required for the appointment and a desire to get home. This hurried scoring of the Family-SDM measure could have resulted in a less thorough reading of the questionnaire and thought about the score awarded for each item. The high scores from families may also be attributed to satisfaction with the dentist's communication style rather than the consultation content.

6.1.3 Sample size

No power calculation was performed as the analysis was primarily descriptive. The sample size of 12 consultations was judged to provide a reasonable representation of how clinical consultations for cFPM are conducted because similar discussions and practices were observed. Clear trends emerged across the consultations, particularly from the observer's perspective, so adding more consultations was not expected to

change the overall findings significantly. The aim of the sample was to capture a wide variety of situations, as opposed to volume.

The sample was also determined by the time constraints for recruiting and collecting the data. Each consultation took between 13 and 52 minutes to observe and an additional equal amount of time to listen to the audio recording and score the consultation. Given the timeframe and resources available for the study, a larger sample size would have been impractical.

6.2 Key findings

The results were organised into broad domains to facilitate an in-depth discussion of the items while considering the overlap between the SDM measure items. The domains were clinical information, empowering and involving the family, the quality of evidence, and information exchange.

6.2.1 Clinical information

The clinical information provided in the consultations involved discussing the clinical issue, treatment options, risks, and benefits. In the paediatric dentistry clinics and JOP, paediatric dentists provided in-depth explanations of the clinical issue. Paediatric dentists demonstrated a more in-depth explanation of clinical issues compared to orthodontists. Several factors may contribute to this observation.

The current literature explains the roles of orthodontists and paediatric dentists in the treatment planning of cFPMs (Lakhani et al., 2023; Noar et al., 2023). While both professionals work collaboratively to ensure early diagnosis and treatment planning for the best possible outcomes, the roles differ. Paediatric dentists play an important role in diagnosing cFPM and assessing the long-term prognosis. They also assess a child's capacity to undergo treatment and evaluate whether extraction is necessary based on clinical and patient factors (Lakhani et al., 2023). Orthodontists, on the other hand, liaise with paediatric dentists or general dental practitioners to integrate the cFPM management into the orthodontic plan. They advise on the timing and implications of cFPM extractions in relation to malocclusion and the SPM eruption (Lakhani et al., 2023). Hence, orthodontists in this study may have assumed that the referrer had already discussed the diagnosis.

Time constraints may also play a role. Orthodontic consultations are typically scheduled for 30 minutes, during which the orthodontist must examine, diagnose and agree on a treatment plan, then complete any paperwork. In contrast, paediatric dentistry consultations are usually allocated 60 minutes. The observed orthodontic consultations took between 13 and 23 minutes. This difference in allocated time could influence the depth of discussion regarding the clinical issue, treatment options, risks, and benefits. While time is often cited as a barrier to SDM (Caverly and Hayward, 2020), research suggests that even brief interventions can be effective (Légaré et al., 2018). Additionally, a Cochrane review on interventions for increasing SDM by healthcare professionals indicates that limited time may be needed for effective SDM implementation (Légaré et al., 2018). This suggests that while adequate time is essential, efficient strategies can facilitate SDM within shorter consultations.

The paediatric dentists provided comprehensive information concerning the risks and benefits of the various treatment modalities, including the type of anaesthesia for the planned procedures. Their involvement in the actual dental treatments necessitates their role in the decision-making process regarding the execution of these treatments. Conversely, orthodontists may view their function as merely advisory, focusing on predicting dental development rather than determining the methods for implementing the treatment itself (Noar et al., 2023). In some consultations, the discussion of treatment options was partially covered because the FPMs were deemed to have a poor prognosis, so the discussion of restorative treatment was sometimes omitted. However, ideally all treatment options, even those that may not be suitable for this particular individual, should be thoroughly discussed (NICE, 2021).

Families and dentists scored SDM in items relating to the clinical issue, treatment options and risks and benefits higher than the observers. Dentists may have perceived that these items were covered because they discussed the treatment options, they felt were relevant to the individual. Families may have scored the items high because they were happy with the dentist's communication style or the overall consultation experience, or because they were unaware of the information that had not been covered (Williams et al., 1998). Furthermore, high scores on the Family-SDM measure could result from the perceived level of care given and time commitment, including the appointment itself, time to travel to the hospital and time

taken for any radiographic procedures, which may give families a sense they were being well cared for (Williams et al., 1998).

6.2.2 Empowering and involving the family

Of the five items in the SDM measure related to empowering and involving the family (discussing the roles of the dentists and families in the SDM process, exploring families' expectations and fears, discussing patient preferences, offering reassurance to become informed, and addressing any potential support or pressure from others) two items demonstrated significant variation in scoring and are discussed in further detail below.

6.2.2.1 Role in SDM

A crucial initial step in the SDM process involves establishing clear participant roles and responsibilities. This clarification ensures that patients and families understand their contribution to the decision-making process is important and valued, empowering them to actively participate and share their perspectives, values, and preferences (Chung et al., 2021). A discrepancy emerged between observer and participant scores for discussing roles in the decision-making process. Observers consistently scored this item as zero across all consultations, indicating roles were not discussed.

Conversely, families consistently scored this item as two, suggesting they understood their role in the SDM process. It is possible that the families interpreted routine introductions or explanations of the purpose of the visit as defining roles because all consultations started with an introduction and then an explanation of the reason for the referral. Alternatively, families may be hesitant to question their role when it is not explicitly defined due to the perceived authority of the dentist.

Different dentists scored the item differently, indicating that some people felt that they did it, and others recognised that they did not adequately define their roles in SDM. Some dentists may have recognised the need for a more in-depth discussion of roles and patient and family engagement, whereas others did not feel this was needed.

This discrepancy in dentist scoring may also stem from a misinterpretation of what is meant by defining roles. The measure intends to capture an explicit discussion of roles and active efforts by the dentist to strengthen patient engagement.

The lack of explicit role definition may hinder developing a genuinely collaborative decision-making process, potentially impacting treatment adherence and the child's long-term oral health (NICE, 2021).

The challenges in defining roles align with broader challenges observed in SDM implementation. A hypodontia study found that existing care pathways often lack adequate support for clinicians in enacting the steps of SDM, including defining roles (Barber et al., 2019). Inconsistencies in how SDM is defined and interpretted could contribute to discrepancies between clinician practice and observer interpretation of role definition (Moumjid et al., 2007). Furthermore, the practical challenges in implementing SDM, particularly in complex cases such as those involving mental health disorders, could hinder explicit role discussions (Penzenstadler et al., 2020). While families in this study perceived a clear understanding of their role, the objective judgment by observer raters that role definition was absent suggests a potential gap between perceived and actual practice. This underscores the need for greater emphasis on role clarification within SDM training and implementation strategies, echoing the findings of Jacobs et al. (2023) regarding the importance of shared understanding among patients, carers, and healthcare professionals in SDM processes.

6.2.2.2 Pressure or support from others

The influence of family, friends or other people is an essential consideration in SDM consultations (Stacey et al., 2008). Observers and dentists rated this item poorly across all the consultations. In consultations P1 and P2, the observers rated this item as partially covered because the parents requested to discuss the treatment options further with their partners, so the involvement of others was initiated by the carers themselves rather than the dentists.

Dentists may perceive that discussing the role of others is irrelevant to this particular clinical consultation or to the general discussion. However, it may be considered more important when discussing more complex issues, such as genetic testing for familial genetic diseases or more complex treatments, such as orthognathic surgical procedures.

Discussing support or pressures from others related to the young person has both positives and negatives. It is beneficial to help the young person's self-confidence and communication skills. This discussion can also assist in accessing other resources for emotional and financial support, and it encourages the decision-maker to think through the options and determine what is important. Support from others can help make the treatment successful (Guimond et al., 2003). However, the negatives of discussing this matter include the pressure to pursue treatment, the challenges of managing social pressures, and the complexity of family relationships where parents may disagree (Stacey et al., 2008).

6.2.3 Quality of evidence

The quality of evidence domain includes items relating to the discussion of uncertainties associated with the decision and the evidence base for information exchanged at the consultation.

6.2.3.1 Uncertainties associated with the decision

The discussion of uncertainties was scored variably, with families providing the highest scores and dentists scoring higher than observers. To achieve a high score on this item, the expected discussion should have covered the uncertainties surrounding outcomes for the available treatment options. This includes acknowledging what is known and unknown about managing cFPMs and being transparent about uncertainties. For the extraction of cFPM, this could include a discussion about the potential residual space if the SPM does not erupt mesially and uncertainties around the need for compensating extractions (Noar et al., 2023).

The observers' scores suggested they did not observe a full and comprehensive discussion regarding uncertainties, which aligns with the existing literature (Jacobs et al., 2023). A scoping review paper examined SDM for children with medical complexity in community health services, which focused on its definition, implementation, and barriers. The study found that uncertainty, caused by unclear diagnoses, prognoses, and treatment outcomes, is a major obstacle to shared decision-making (Jacobs et al., 2023).

Discussing uncertainty is important for ethical, relationship, and clinical matters. It improves decision-making, strengthens the professional-patient trust, and improves healthcare outcomes (Tversky and Kahneman, 1974). Healthcare providers find it

difficult to discuss uncertainty with patients and families due to multiple factors. The healthcare culture often relates uncertainty to ignorance and failure, discouraging professionals from openly acknowledging it (Simpkin and Schwartzstein, 2016). Medical and dental education focuses more on facts and solutions than on communicating uncertainty. (Simpkin and Schwartzstein, 2016). Professionals might worry that discussing uncertainty may overwhelm or confuse patients, leading to mistrust (Gordon et al., 2000). Lack of time, training, emotional impact, causing anxiety, and concerns about the professional image are other factors (Politi et al., 2007). These factors collectively contribute to the reluctance of professionals to discuss uncertainty, despite its importance in SDM.

Although many practitioners find it uncomfortable to discuss uncertainty, and many feel that communicating uncertainty will confuse patients, explaining uncertainty results in higher patient satisfaction and patient engagement (Tversky and Kahneman, 1974; Gordon et al., 2000).

A cross-sectional study explored physicians' reactions to uncertainty about treatment options in internal medicine. It revealed that anxiety from uncertainty was influenced by gender, residency status, and hours worked per week. Reluctance to disclose uncertainty was associated with higher levels of education (Politi and Légaré, 2010).

The higher scores awarded by families and dentists could be attributed to their perception that the uncertainties were adequately addressed, a lack of awareness that there is uncertainty, or their openness to accepting uncertainty. An observational study by Gordon et al (2000) aligns with the findings of this study. It highlights that physicians' expressions of uncertainty, when paired with positive communication, can increase patient satisfaction. This suggests that patients may perceive uncertainty as being addressed effectively, even if observers rate the level of uncertainty low (Gordon et al., 2000).

The families' high scores in uncertainty discussion could be from their perception that uncertainties were acknowledged and managed during the interaction. If patients are unaware of the presence of uncertainty or believe it is being handled competently, they are likely to feel reassured and satisfied (Gordon et al., 2000). This connection underscores the importance of how uncertainty is communicated and perceived in clinical encounters. Health care providers' ability to handle uncertainty constructively,

can shape patients' experiences and satisfaction, regardless of observers evaluation observers evaluation (Gordon et al., 2000).

The observational cross-sectional study by Gordon et al (2000) indicates that patients' openness to discussing uncertainty is influenced by their characteristics, such as their desire for information, educational level, and active involvement in care. Patients who are more educated, have a greater desire for information, and ask or give more information during visits are associated with physicians expressing more uncertainty. Even though the educational background and parents' characteristics were not recorded in this study, some families were more open to engaging in discussions about uncertainties.

6.2.3.2 Source of information

Understanding the source of information provided during shared decision-making consultations is essential for patient comprehension and informed decision-making. Patients should be made aware of the level of evidence underpinning the information they are given, for example, whether it is based on scientific evidence, the dentist's judgment, or professional guidelines (Hoffmann et al., 2014; Noar et al., 2023). The importance of providing high-quality information during SDM is emphasised, which implicitly includes clarifying the source (Elwyn, Glyn et al., 2012). During SDM consultations, professionals should define the problem and present options, including clarification of the source to strengthen this process (Dennison Himmelfarb et al., 2018). Transparency regarding the source of information empowers patients to critically evaluate it and make decisions aligned with their values and preferences, which is particularly crucial in complex medical situations like oncology (Politi et al., 2012). Patients who know the source can judge its reliability and feel more secure (Hoffmann et al., 2014).

The present study found that dentists made limited efforts to clarify the source of information during consultations despite the availability of the RCS guideline (Noar et al., 2023). Dentists may have assumed (correctly or incorrectly) that patients did not need or want this information. The evidence base for the current RCS guideline is mixed, with reliance on lower levels of evidence such as retrospective studies, case reports, and expert opinion. While these resources provide valuable insight, they are not as robust as randomised control trials or systematic reviews (Noar et al., 2023).

Many of the referenced studies, such as those by Patel et al. (2017) and Normando et al. (2010) rely on small sample sizes, which may reduce the generalisability. Even though the available evidence is of low to moderate quality, acknowledging and explaining this to the patient demonstrates transparency and trust, which are essential to SDM (Légaré et al., 2011).

6.2.4 Information exchange

Health literacy is a cornerstone of effective shared decision-making, as the NICE guidelines emphasise (NICE, 2021). This section discusses the differences in perceptions between the observers, dentists and families about information exchange, understanding and language used.

6.2.4.1 Family and dentist understanding

Observers' assessments highlighted a critical communication gap in the consultations. Both the evaluation of patient understanding and the confirmation that dentists had understood the family's perspective were consistently rated low. The NICE guidelines (2021) recommend several methods for assessing patient understanding, all centred around encouraging patient participation and confirming comprehension. The dentist's use of medical dialogue tended to be lengthy, presenting a list of complex information with limited opportunity for clarification by the families. Attempts to assess understanding were absent throughout the consultations. This observation underscores the importance of fragmenting information and actively confirming patient comprehension, particularly when conveying complex medical information. The 'chunk and check' technique promoted by NICE involves breaking down complex information into smaller, more digestible 'chunks'. After presenting each chunk, the healthcare professional checks the patient's understanding before proceeding (NICE, 2021). This iterative process allows patients to process information gradually, ask clarifying questions, and express concerns. "Chunk and check" promotes active patient engagement and helps ensure that medical information is conveyed effectively, even in complex situations. It also provides opportunities to tailor the discussion to the patient's needs and health literacy level (NICE, 2021). By incorporating this technique, dentists can facilitate more meaningful SDM and improve patient comprehension.

Assessment of understanding was often passive and included only at the end. This elicited a simple "*No, thank you*" answer but did not allow for adequate assessment of understanding. A more effective approach would have been to actively engage the family by asking

"What are your thoughts about the treatment options?"

This open-ended question encourages families to demonstrate their comprehension and participate more fully in the decision-making process (NICE, 2021).

In addition to open-ended questions, the teach-back technique provides another valuable tool for assessing understanding (NICE, 2021). This method encourages active participation by having families reiterate the information in their own words, allowing dentists to confirm comprehension. The NICE guidance (2021) provides a framework for integrating the teach-back method into dental education, offering a practical approach to improving consultation techniques and fostering shared decision-making.

6.2.4.2 Language used in consultations

The language used in consultations varied considerably, potentially creating challenges for families with diverse educational backgrounds. The use of complex terms by some dentists likely impaired understanding, highlighting the importance of consistently using clear, simple language to facilitate shared decision-making (Paredes et al., 2018).

The use of numerical data in consultations demonstrated some positive alignment with NICE guidance (NICE, 2021). Several dentists effectively communicated probabilities using natural frequencies, stating, '1 in 6 children have this condition' rather than using percentages. This approach enhances patient understanding by presenting information in a more concrete and relatable manner (NICE, 2021). Furthermore, consistent use of visual aids, such as radiographs, were used to explain the condition and prognosis of the FPMs, supporting the young person and carers comprehension.

The use of medical terminologies can make patients feel less in control, increasing their perceived severity of the condition. Medical terminology influence treatment preferences by affecting patients' perceptions of severity, fear, and urgency, with

more medical terms driving invasive management choices and less medical terms encouraging conservative approaches (Nickel et al., 2017).

6.3 Strengths and limitations

This study provides valuable insights into SDM consultations within the context of paediatric dentistry. The use of an SDM measure allowed both objective and subjective scoring of consultations in a systematic way.

The relatively small sample of 12 consultations was appropriate for the purpose, which was to examine current practice and identify potential trends. It is recognised that the sample is not large enough to be considered representative, however, it is unlikely that a much larger sample would substantially change the findings. The observations were undertaken in two hospitals in Yorkshire, which may impact the transferability of the results to other areas where clinical practice may be different.

Recruiting participants within the timeframe proved challenging in the orthodontic and JOP clinics due to a lack of eligible participants. Recruitment from the LDI orthodontic clinics was undertaken through new patient clinics and a limited number of people with cFPM were referred for advice. The JOP clinics at LDI were held once every two weeks, and multiple clinics were cancelled due to staff annual leave or holidays. To address the recruitment challenges, PGH was added as an additional recruitment site, which required obtaining site approval over several extra months.

6.3.1 Clinical specialities and settings

Recruiting participants from the orthodontic department might have skewed the Observer-SDM scores negatively. This could be due to the difference in expected roles. However, orthodontists are expected to confirm the patient's existing knowledge, including the discussion of restorability in cFPMs. This could have been avoided by recruiting participants from JOP clinics only. On the other hand, SDM should be practised by every healthcare provider concerning a non-urgent medical matter. Even though location can be a limiting factor, this allowed comparison of SDM in consultations between the different clinics as patients were referred for the same clinical condition, cFPMs.

6.3.2 Potential biases

Sampling bias may have been introduced by selecting participants from only two hospitals in one geographic area, which might not fully represent the broader population of families with young people receiving treatment for cFPM. All consecutive eligible families were invited to participate and only one family refused.

The measurement tool and data collection method may have also introduced some biases. The Observer-SDM measure was completed after the families and dentists had already provided their scores, which could have potentially introduced observer bias for the lead researcher, who was aware of the families' and dentists' perceptions of the shared decision-making process. To manage this, the observer scoring was completed after a 'wash out' period of at least 2 weeks and the family and dentist scores were not reviewed prior to observer scoring. The two other observers were blinded to the family and dentist scores.

6.3.3 Challenges defining and measuring SDM

Defining and evaluating shared decision-making is inherently complex, presenting significant challenges for research in this area. The interpretative nature of what constitutes "shared" decision-making complicates the development of reliable and valid measures (Jacobs et al., 2023). There are ongoing debates around how to operationalise and measure SDM most accurately, with a lack of consensus on the core components.

6.3.3.1 Observer-SDM challenges

Although various tools have been used to assess shared decision-making but no single tool was judged to be ideal for this study (Gärtner et al., 2018). Despite extensive calibration and training, scoring the Observer-SDM measure proved time-consuming. The training calibration process using mock consultations helped identify areas where there was a lack of agreement on the exact meaning and application of some of the items. This was managed through discussion and then developing a manual to define each item. The observers scored the consultations independently, referring to the transcriptions and the manual, and then reached a consensus where there was partial or no agreement on the items. There was less disagreement in items

where the behaviour was not demonstrated at all but more where there was partial fulfilment of an item.

The perspective of the observer raters and their personal beliefs may have influenced the scoring. For example, the observers are all dentists so their assessment of the language used by the dentists may have been different to scorers who are not in the dental field.

Assessing shared decision-making more comprehensively may have benefited from incorporating non-verbal cues, such as body language, and use of tone and language in addition to the analysis of the content of the discussion. However, this was not feasible within this study's timeline. The inability to fully capture both verbal and non-verbal aspects of the decision-making process represents a limitation of the study methodology.

6.3.3.2 Family and dentist SDM measures challenges

The family and dentist SDM measures measured their perceptions of the decision-making process, complementing the observer-SDM assessment. However, there are some limitations to these measures. Initially, the family and dentist versions of the SDM measure were developed from the Observer-SDM measure and reworded after phase 1. Thus, the family and dentist SDM measures are not based on validated measures that aim to these perspectives.

Unlike the observers, the family and dentists were not trained or calibrated and they were only given 5-10 minutes to answer the questionnaire. There may have been a misunderstanding of items or a tendency for participants to provide responses that they felt were desirable.

High family scores on the family-SDM measure could be a result of genuine satisfaction with the SDM process, stemming from a sense that their concerns were fully addressed and a clear plan was established. Another interpretation is that a positive consultation experience may lead to higher ratings, even if the actual degree of shared decision-making is limited (Feldman, 2014). A positive experience includes a comfortable environment, respectful communication, and adequate time for

discussion and questions. Patients who feel comfortable and respected during the consultation are more likely to be satisfied with the SDM process (Feldman, 2014).

An additional factor affecting the perception of the families is trust in the healthcare provider. A strong patient-provider relationship built on trust is essential for successful SDM (Rundle-Thiele and Russell-Bennett, 2010). When patients trust their healthcare provider's expertise and believe their best interests are being considered, they are more likely to be satisfied with the decision-making process, even if the outcome is not what they initially hoped for.

The limited time available for completing the measure, administered at the end of consultations ranging from 13 to 52 minutes, which included time for radiographs and waiting, may have led families to rush through the questionnaire. This time constraint could have inadvertently inflated the scores because raters did not take the time to read the questions and consider their answer.

Similarly, the dentist SDM measure also faces some limitations. Dentists may not have fully understood the items and how to score each one. Dentists' ratings of the SDM process could be influenced by factors such as time constraints, workload and a desire to appear competent.

6.3.4 Limitations of SDM in young people

The young people’s input was not fully captured in this study. This poses a limitation in the study by not fully capturing the family’s perception, which includes parents and the young person involved. Designing a Family-SDM measure with items comparable to the Observer and Dentist SDM measures was challenging, as it was difficult to ensure that the individual items were understandable for the age range 7-11 years. Thus, designing a SDM measure for the young person with comparable items pose another layer of complexities in ensuring understanding. Previous research indicate that young people want to be involved in decision-making about treatment concerning them (Taylor et al., 2025). However, this was a qualitative study involving young people aged 12 to 16 years, with a range slightly older than this study (Taylor et al., 2025). Acknowledging this, perhaps adding a question or two in the Family-SDM measure targeted for the young person would add more context in the young person’s perspective in SDM. Most SDM measures do not attempt to capture young people

experience, but it is important to address in future research because the decision about treatment should involve the young person (Taylor et al., 2025).

6.4 Implications for clinical practice

The results of this study show that not all the items of SDM are practiced in consultations about cFPM. The observer-SDM scores suggest a need for improvement in the way dentists engage families in the decision-making process. If SDM was not fully implemented, families and persons in need of care may not have had a clear understanding of the available treatment options, their risks and benefits, and their values and preferences may not have been fully incorporated into the final treatment decision.

6.4.1 Potential barriers to SDM in practice

It is helpful to consider the COM-B model to understand the barriers to effective implementation of SDM (Michie et al., 2011). This model states that for any behaviour to occur, three conditions must be met: capability, opportunity, and motivation. Capability refers to the individual's psychological and physical ability to perform the behaviour. Opportunity encompasses the external factors, including the physical and social context that enables the behaviour, and motivation includes internal processes that allow and direct behaviour (Michie et al., 2011).

In the context of SDM, a deficiency in any of these components can act as a barrier. For example, if dentists lack sufficient knowledge or skills in SDM techniques, the clinical environment doesn't allow enough time for SDM discussions, or the dentists are not motivated to engage patients in a shared decision-making process, effective SDM will be difficult to achieve.

6.4.1.1 Integrating COM-B with SDM Findings

The COM-B model can be used to analyse the findings related to SDM implementation in practice. This could be related to:

1. Capability:

Dentists may lack a clear understanding of what SDM means or how to implement it in practice. They may not have received adequate training in SDM or may not have the required skills.

2. Opportunity:

It refers to whether the healthcare system and clinical setting facilitate SDM. This includes considering external factors such as available time and established processes that promote open discussion and collaborative deliberation between dentists and families.

3. Motivation:

It is essential to consider the factors that drive dentists to engage in SDM. While SDM could be used as a performance indicator, its subjective nature and the difficulty in demonstrating and measuring its consistent application make it challenging to implement as such.

6.4.2 Effects of not implementing SDM

When SDM is not fully implemented, several negative consequences can arise such as suboptimal treatment choices, decreased satisfaction, and increased anxiety and uncertainty (NICE, 2021). Firstly, patients may receive treatment that does not align with their values, preferences, or lifestyle, leading to dissatisfaction and poor attendance (Shay and Lafata, 2015). For example, a family may have preferred a more conservative approach to treatment, such as restoring a cFPM, but the dentist proceeded with a more invasive option without fully discussing the alternatives and considering the family's views. Another example is assuming that the young person would not cooperate and recommending a more invasive treatment under general anaesthesia rather than explaining options such as treatment on the dental chair or with conscious sedation.

Not practising SDM can result in unnecessary procedures or treatments that may not benefit the individual (Shay and Lafata, 2015; NICE, 2021). Furthermore, patients who feel excluded from decision-making may experience frustration, distrust, and a sense of empowerment (Ozdemir et al., 2021). A lack of SDM can heighten patient anxiety and uncertainty about their care (Hoffmann et al., 2014). Patients may feel unsure about the rationale for the recommended treatment, the risks and benefits, and whether it aligns with their personal goals and values (Hoffmann et al., 2014).

6.4.3 Integrating SDM into routine care

Several strategies can promote SDM integration into routine care. Allocating sufficient consultation time for discussions about treatment options and allowing patients to have opportunities to ask questions and empowering them to express their preferences is essential (Barber, 2019; Alsulamy et al., 2020; Rajagopal and Kelly, 2020; Jacobs et al., 2023). Rushing through consultations limits the ability to have meaningful discussions and provide patients with the information they need to make an informed choice. It is crucial to adopt a patient-centred communication style that empowers patients to express their values and get involved in the discussions. For example, adhering to the SDM steps in the NICE guidance provides valuable insight (NICE, 2021). Encouraging a team-based approach with dental nurses and other staff can support the implementation of SDM by distributing the workload.

6.4.4 Influence of cultural factors

Cultural factors can affect how SDM is practised. Patients from different backgrounds may have varying preferences for their role in decision-making. Some may want the healthcare provider to be the primary decision-maker, while others value sharing the decision. Dental teams should be aware of these cultural differences and adjust their approach accordingly. For instance, in some Asian cultures, patients may be more comfortable with a paternalistic model, where the dentist takes a more directive role (Ozdemir et al., 2021). Conversely, in Western cultures, patients often expect to be more actively involved in decision-making (Jacobs et al., 2023).

Socioeconomic status (SES) significantly impacts SDM between families and healthcare providers. Families with lower income, less education, and inadequate insurance coverage report lower instances of SDM compared to their higher SES counterparts (Yin et al., 2012; Smalley et al., 2014). Parents' educational level significantly influences SDM between families and healthcare providers. Families with less than a high school education report lower SDM engagement compared to those with more than a high school education (Smalley et al., 2014). These disparities may be caused by a lack of understanding and communication challenges, which make it hard for families to involved in SDM. Addressing educational disparities is crucial to improving SDM outcomes and ensuring fair healthcare for all families (Smalley et al., 2014).

6.5 Implications for education and training

The findings from this study indicate a need for enhanced education and training in SDM across the dental profession, particularly in areas related to patient empowerment and information evidence. As the results demonstrate, scores were consistently lower on items assessing the extent to which dentists actively involved families in decision-making, such as exploring preferences, providing opportunities for questions, and confirming understanding. This suggests a critical area for improvement in dental education. Incorporating SDM into undergraduate and postgraduate dental curricula could help ensure that future and current dentists possess the knowledge, skills, and attitudes to engage patients in SDM effectively (Xiao et al., 2024). Additionally, dental education should emphasise the importance of dentists clearly explaining the sources of the information they provide to patients. The study found that dentists did not explicitly state whether their treatment recommendations were based on scientific evidence, clinical experience, professional guidelines, or personal preferences. This lack of transparency makes it difficult for patients to fully understand the reasoning behind the recommendations, hindering their ability to participate meaningfully in the decision-making process.

6.5.1 Undergraduate training

Undergraduate dental programmes should include teaching the principles of SDM early and throughout the curriculum. This could involve role-playing exercises, simulated patient encounters, and opportunities to observe and reflect on SDM in clinical practice (Xiao et al., 2024). Additionally, building students' communication skills, including active listening, empathy, and the ability to present treatment options in an unbiased manner, is crucial for effective SDM. Some training recommendations are listed in Table 6.1.

A cross-sectional study by Sin et al. (2021) evaluated the knowledge and attitudes of UK dentists and dental students toward SDM. It revealed generally positive attitudes towards SDM but gaps in knowledge and training. Only about one-third of respondents had received SDM training, with students expressing greater interest in learning more. The study highlights the need to integrate SDM into dental curricula preparing undergraduates for collaborative decision-making in clinical practice (Sin et al., 2021).

Table 6.1: Undergraduate SDM training recommendations

Training recommendation	Explanation
Role-playing exercises	Scenarios where students practice discussing patient preferences, answering questions and checking for understanding.
Observation and reflection on SDM in clinical practice	Observing healthcare providers showing effective SDM skills and reflecting on the discussion.
Training on patient empowerment	Modules focused on techniques and skills that encourage patient participation. For example: open ended questions, clear explanation of options, teach back, check and chunk
Explaining the evidence base	Training on communicating scientific evidence supporting different treatment options.

6.5.2 Postgraduate training

Like undergraduate training, postgraduate programmes should also incorporate advanced SDM training. However, in postgraduate programs, SDM training should focus on applying SDM principles in complex cases and specific patient scenarios, such as young people with cFPMs (Table 6.2).

Table 6.2: Postgraduate training recommendations

Training recommendation	Explanation
Advanced communication skills training	Gaining knowledge and skills in discussing challenging conversations and preferences.
Case-based discussion	A group discussion of real-life cases to explore challenges and benefits of SDM in different clinical settings.
Reflection	Reflecting on their own SDM practise to encourage improvement.

6.5.3 Continuing professional development

Continuing professional development is vital in reinforcing SDM skills and ensuring dentists stay up to date with the latest evidence and best practices. CPD activities focused on SDM should be accessible to all dental professionals. Activities include workshops, e-learning modules, and peer-to-peer learning opportunities. Workshops and seminars can provide hands-on practice with SDM techniques, such as SDM tools, to measure their SDM process in clinic and receive feedback for improvement.

Ultimately, a multifaceted approach to SDM education and training, spanning undergraduate, postgraduate, and continuing professional development, is needed to ensure dental professionals have the competencies to effectively engage patients in SDM.

6.6 Implications for future research

This study highlights several important areas for future research to enhance our understanding of SDM in dentistry and improve its implementation.

First, more research is needed to explore patients' perspectives and experiences of SDM in dental consultations. Qualitative studies employing interviews or focus groups with parents/caregivers could provide valuable insights into their needs and expectations regarding SDM.

Second, further research is needed to investigate dentists' perceptions of SDM. Understanding whether dentists recognise the importance of SDM, perceive barriers to its implementation, or identify training needs is essential for developing effective strategies to promote SDM. The study results show that dentists and families scored the SDM consultations highly; hence, changing a practice that is not perceived as an issue could be challenging. Research exploring dentists' attitudes and beliefs about SDM could help identify levers for change and tailor interventions to address specific challenges. If, as hypothesised, dentists do not perceive a problem with current SDM practices, change will be challenging to achieve, so understanding their perspectives is a critical first step.

Finally, future research should focus on developing and testing interventions to promote SDM in paediatric dentistry. Research could explore the effectiveness of decision aids tailored to specific paediatric dental procedures, such as managing cFPM. Additionally, studies could evaluate the effectiveness of the SDM measures and their application in routine dental consultations.

Chapter 7 Conclusions

This study represents a pioneering effort, being the first to comprehensively investigate shared decision-making within the paediatric dental environment, particularly in the context of complex cases such as compromised first permanent molars. Its unique contribution lies in examining different perspectives, including observers, families and dentists, across various clinical settings and specialities, including teaching hospitals and joint clinics, thereby providing robust data from multiple viewpoints.

Consultations regarding cFPMs often miss key elements of shared decision-making. These include clearly defining each person's role in the decision-making process, checking if the patient/family understands the treatment options, and understanding what the patient/family values and prefers. Dentists need to actively involve families in the decision-making process. Dentists also need to be clear about whether their recommendations come from scientific evidence, their own experience, guidelines, or personal beliefs.

The findings reveal a significant gap between perceived and actual SDM practices, with notable discrepancies among dentists, families, and observers. There is a discrepancy between how dentists think they practice SDM and how observers judge that they practice it. Dentists tend to overestimate their use of SDM, while families report high satisfaction.

Recognising the barriers to SDM in practice, including limited time, the consultation process, knowledge gaps, and insufficient skills, is crucial for promoting change in practice and behaviour. This will promote interventions and policymakers to drive families and dentists to engage in SDM. Acknowledging that families are satisfied with the consultations, provides more challenges to drive behaviour change in decision making.

Future research should explore:

1. Parents'/caregivers' perspectives on effective application of SDM in paediatric dentistry.
2. Dentists' views on SDM and barriers to implementation.

3. Developing and testing interventions to improve SDM, such as communication skills training for dentists and decision aids for specific procedures.

Appendices

Appendix 1 Ethical approval letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mrs Soumiah Alkandari
7 Bentcliffe Close
Leeds
LS17 6QT

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

31 January 2023

Dear Mrs Alkandari

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

Study title:	**Observer, dentist, and families' perception of shared decision-making consultations about compromised first permanent molars**
IRAS project ID:	**321063**
Protocol number:	**N/A**
REC reference:	**23/WA/0034**
Sponsor	**University of Leeds**

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

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

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

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

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **321063**. Please quote this on all correspondence.

Yours sincerely,

Tracy Biggs

Approvals Specialist

Email: HCRW.approvals@wales.nhs.uk

Copy to: *Mrs Jean Uniacke*

Appendix 2 Recruitment letter and reply slip

Recruitment Letter and reply slip v2 20/01/2023

NHS
The Leeds Teaching Hospitals
NHS Trust

UNIVERSITY OF LEEDS

DATE

Dear [name of young person] and parents,

A team of researchers are trying to find out more about how young people and their families make choices about dental care for poorly back teeth.

We understand that {NAME} has some poorly back teeth and is due to come to the Leeds Dental Institute to talk about the different treatment options. We would like to invite you to take part in our research. This would mean that you give us permission to sit in and observe your dental appointment. We would just be watching the appointment, not taking part, so it will not change your dental appointment at all.

It is totally up to you if you wish to take part. It is fine if do decide you do not want to take part. This will not affect your dental care in any way.

There are more details about the research in the Information Sheet enclosed with this letter.

I will come to see you when you check in at the Leeds Dental Institute. I can answer any questions you might have and then you can decide if you would like to take part. If you have any questions before then please feel free to contact me using the details below.

Please fill the reply slip and bring it to your child's appointment if you wish to find out more about taking part.

Thank you and best wishes

Soumiah Alkandari

Email: dnsalk@leeds.ac.uk
Telephone Paediatric Dentistry Department: 0113 343 5667

ETHICAL APPROVAL NUMBER 1

Participant Reply Slip

PLEASE COMPLETE AND RETURN THE REPLY SLIP TO THE RESEARCHER ON THE DAY OF THE APPOINTMENT

Study: Observer, dentist and families' perception of shared decision-making consultations about compromised first permanent molars

☐ **I am interested find out more about in taking part**

Name of parent / guardian:

Name of young person:

Date:

Appendix 3 Participant information sheet (Dentist)

Information Sheet (dentist) v3 20/07/2023

NHS
The Leeds Teaching Hospitals
NHS Trust

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Information Sheet for Dentists

Study: Observer, dentist and families' perception of shared decision-making consultations about compromised first permanent molars
Name of Researchers: Soumiah Alkandari, Dr. Richard Balmer, Dr. Sophy Barber
Research Sponsor: School of Dentistry, University of Leeds
IRAS ID: 321063

We would like to invite you to take part in our research. Before you decide whether to take part, we would like to explain why the research is being undertaken and what participation would involve.

What is the purpose of the study?

Deciding about treatment for children with compromised first permanent molars is complex and requires different factors to be considered. This study aims to find out more about how decisions are made during consultations for young people with compromised first permanent molars. We will observe the interaction between young people, family members and the dental team. We aim to recruit young aged 7-11 years with at least one compromised first permanent molar.

We will use a shared decision-making tool to help us objectively score components of the clinical consultation. We will also ask the dentist and families to answer questions about their perception of the consultation process after the clinic once the consultation is complete.

Who is doing the study?

Soumiah Alkandari is leading this study as part of the requirements for her Professional Doctorate degree. Her supervisors are Dr Richard Balmer (Consultant Paediatric Dentist) and Dr Sophy Barber (Consultant Orthodontist). The sponsor for the research is the University of Leeds.

Why have I been asked to participate?

We are inviting dentists and families who are involved in consultations about the management of compromised first permanent molars to take part.

What will be involved if I take part in this study?

Soumiah will talk to the family about being involved in the research. If they are happy to take part, consent will be obtained from the parent. The young person will be asked for their assent. Soumiah will observe the clinical consultation. She will be a passive observer and will not affect the consultation process in any way. You are encouraged to follow your normal clinical practice.

Following the consultation, Soumiah will ask you to complete a short questionnaire about your perception of the consultation. This will take less than 5 minutes.

We would like to audio-record the clinical consultation. This will allow the research team to work together to score the components of the consultation using a shared decision-making tool. The recordings will be stored until the completion of Soumiah's degree, which is for 1 year after the end of data collection. They will not be shared with anyone else. You will be given the opportunity to listen to your own audio recording if you wish.

We would also like to type up (transcribe) the audio-recordings. This would be undertaken by a University of Leeds-approved professional transcription company with the necessary data-sharing agreements in place. We will remove your name and all identifiable information from the transcript so it is fully anonymised. Anonymised transcripts will be kept for 3 years to allow time for analysis then destroyed. Only the research team will have access to the transcripts.

The transcripts will allow us to look at what was talked about in the consultation in more detail later. It is up to you whether you give your permission for us to use anonymised quotes in any future research reports.

What are the advantages and disadvantages of taking part?

Although there might not be a direct benefit to you, we hope the results of this study will help us understand how shared decision-making is practiced in consultations about compromised first permanent molars. We are very happy to share our findings with you.

The only disadvantage of taking part of this study is time filling the questionnaire after the consultation. All results will be reported anonymously.

Will I be paid for taking part?

No financial rewards will be provided for participating in this study.

Can I withdraw from the study at any time?

You may withdraw from the study up to the point of data analysis for any reason and without any explanation. You can contact a member of the research team to request that you are withdrawn and your data will be removed.

IRAS ID: 321063

Information Sheet (dentist) v3 20/07/2023

Will the information obtained in the study be confidential?

All data collected during the study will be confidential. Consent forms will be kept in a locked filling cabinet within the School of Dentistry.

A unique anonymous study identifier will be created for each child participant in the consultation. This will be used on all study documentation to allow anonymous data collation and analysis. Only the researcher will be able to link the study identifier and participant details.

Audio-recordings will be stored on a password protected drive on a University of Leeds computer. They will only be accessible to the lead researcher, Soumiah. The recordings will not be transcribed, only used for review by the research team. Audio-recordings will be kept until the end of the study and the completion of Soumiah's degree.

Confidentiality will only be breached in circumstances where this is judged to be necessary, for example, regarding safeguarding issues or gross breach of patient care.

What are your choices about how your information is used?

You can stop being part of the study until the point of data analysis, which might take 2 months after taking part. You do not need to give any reason if you want to stop taking part.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to dpo@leeds.ac.uk

What will happen to the results of the study?

The results of the study will be reported in Soumiah's thesis. If you would like to find out the results of the study, please let Soumiah know. We intend to share the results more widely through conference presentation and publication in a scientific peer reviewed journal.

Who has reviewed this study?

This study was reviewed by the {ADD DETAILS}

Ethical approval number:

IRAS ID: 321063

Information Sheet (dentist) v3 20/07/2023

Ethical approval date:

Complaints procedure

If you have any concerns regarding the research, in the first instance please discuss these with the lead researcher or supervisors.

Soumiah Alkandari: dnsalk@leeds.ac.uk
Dr. Richard Balmer: R.C.Balmer@leeds.ac.uk
Dr. Sophy Barber: S.K.Barber@leeds.ac.uk

If you still have concerns or do not wish to raise your concerns with the research team you can contact an independent representative from the School of Dentistry for advice.
Professor Peter Day
P.F.day@leeds.ac.uk

Professor Day has both clinical and research expertise. He can manage any concerns or provide information about the complaint procedure.

If you would like any more information about the study or if you have any concerns, please contact:

Soumiah Alkandari
Email: dnsalk@leeds.ac.uk
Telephone Paediatric Dentistry Department: 0113 343 5667

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

IRAS ID: 321063

Appendix 4 Participant information sheet (Family)

Information sheet (family) v3 20/07/2023

NHS The Leeds Teaching Hospitals NHS Trust

UNIVERSITY OF LEEDS

Information Sheet for Families

Study: Observer, dentist and families' perception of shared decision-making consultations about compromised first permanent molars
Name of Researchers: Soumiah Alkandari, Dr. Richard Balmer, Dr. Sophy Barber
Research Sponsor: University of Leeds
IRAS ID: 321063

We would like to invite you and your child to take part in our research. Before you decide, please read more about our research together. After this we are happy to answer any questions that you or your child might have.

It is totally up to you and your child whether you would like to take part. If you or your child does not want to take part this will not change your child's dental treatment at all.

What is the purpose of the study?

It can be difficult for dentists and families to pick the best dental treatment for children with poorly back adult teeth. This study wants to find out more about how dentists and families make choices together.

It's your right to be involved in making choices about your child's care. To make a decision, you need to know what the options are and what might happen if you don't want treatment. Shared decision making is when health professionals and patients work together to make choices about treatment. It puts you and your child at the centre of decisions about your child's treatment and care.

We would like to watch and audio-record your child's dental visit to assess how shared decision making is being practiced.

We would like to include children aged 7-11 years and any family members who are part of the consultation.

Who is doing the study?

Soumiah Alkandari is leading this research as part of a student study. Her supervisors are Dr Richard Balmer and Dr Sophy Barber. They are both senior dentists. This research study is in part fulfilment of a Professional Doctorate in Paediatric Dentistry Degree.

IRAS ID: 321063

Information sheet (family) v3 20/07/2023

Why have we been asked to participate?

We are inviting you and your child to take part because your child has some poorly back adult teeth that may require dental treatment.

What will be involved if we take part in this study?

Soumiah will tell you a bit more about the study then you and your child can decide whether you want to take part. If you or your child do not want to take part that is no problem at all and it will not affect your child's dental care. If you and your child are happy to take part, Soumiah will help you to fill in the consent.

Soumiah will then sit in for your normal dental appointment. She will not say anything but she will audio-record the discussion between you, your child and the dentist. The recording is just so that we can remember everything that was said. You will be given the opportunity to listen to your own audio recordings if requested.

Following your child's appointment, Soumiah will ask you to complete a short questionnaire. This will ask you how you felt the appointment went. This will not be shared with the dental team. The questionnaire will take less than 5 minutes.

We would like to type up the audio-recording of your dental appointment. This would be undertaken by a University of Leeds-approved professional transcription company with the necessary data-sharing agreements in place. This will mean we can look at what was talked about in more detail later. We would remove your names and all identifiable information from so no-one would know it was you. Only the research team would be able to read the typed up version. This will be kept for up to 3 years. You can let us know if you are happy for us to use anonymised quotes from the consultation.

What are the advantages and disadvantages of taking part?

There might not be a direct benefit to you in taking part but we hope this work will help the dental team talk to other people about their poorly back teeth.

The only disadvantage of taking part is the time to fill out the questionnaire after the consultation. Your child's dental appointment will not be changed in any way by taking part.

Will we be paid for taking part?

No, there is no payment for taking part.

Can we withdraw from the study at any time?

IRAS ID: 321063

You or your child can withdraw from the study up to the point of data analysis, which might take up to 2 months after taking part. You can request us to stop audio-recording or Soumiah to stop observation if you wish during the consultation. This can be for any reason and you do not need to tell us why. Please just contact Soumiah using the details below.

Will the information obtained in the study be confidential?

The data collected during the study will be stored safely. Your consent forms will be kept in a locked filling cabinet in the School of Dentistry.

Your child will be given a code that will be used on all the research information. This will mean we do not use your child's name so no-one will know the information is about your child. Only the researcher will be able to link the code and your child's name together.

Audio-recordings will be stored safely on a password protected University of Leeds computer. The recording will only be accessible to the lead researcher Soumiah. Recordings will be kept until Soumiah completes her degree, which is one year after the study ends.

Very rarely, we might feel that it is important to share some of the information from your consultation. This would only be because we feel it is in the best interest of your child for other people to know. If we want to share something, we will talk to you about why we think it is important to share the information. We will ask your permission to share information and explain what we would like to share and with whom.

How will we use information about your child?

We will need to use information from your child and the dentist for this research project.

Information, including your child's name and NHS number, will be obtained. People will use this information to do the research or to check your child's records to make sure that the research is being done properly.

People who do not need to know who you or your child is will not be able to see your child's name or contact details. Your child's data will have a code number instead.

We will keep all information about your child safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you and your child took part in the study.

What are your choices about how your information is used?

You or your child can stop being part of the study until the point of data analysis, which might take 2 months after taking part. You do not need to give any reason if you or your child wants to stop taking part.

Information sheet (family) v3 20/07/2023

We need to manage your child's records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your child's information is used?

You can find out more about how we use your child's information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2020/08/My_data_and_research.pdf.
- and https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf.
- by asking one of the research team
- by sending an email to dpo@leeds.ac.uk

What will happen to the results of the study?

The results of the study will be reported in Soumiah's thesis. If you would like to find out the results of the study, please let Soumiah know.

We would like to share our important findings with dentists through conference presentation and a report in a dental journal.

Who has reviewed this study?

This study was reviewed by the {ADD DETAILS}

Ethical approval number:

Ethical approval date:

Complaints procedure

If you / your child have any concerns regarding the research, you should discuss these with the lead researcher (Soumiah Alkandari):
dnsalk@leeds.ac.uk

Research supervisors:
Dr. Richard Balmer: R.C.Balmer@leeds.ac.uk
Dr. Sophy Barber: S.K.Barber@leeds.ac.uk

If you / your child still have concerns, you can contact the Patient Advice Liaison Service (PALS) team. The team are independent from the research and can answer any questions you might have. PALS provide free advice about raising a concern or making a complaint.

Leeds Teaching Hospitals NHS Trust

Tel: 0113 2066261 (Mon-Fri 9.00am – 4.30pm)
0113 2067168 (Voicemail service outside working hours)

IRAS ID: 321063

Email: patientexperience.leedsth@nhs.net

Write to: Patient Relations Department, Trust Headquarters, St. James' Hospital Leeds, LS9 7TF

If you or your child would like any more information about the study or if you have any concerns, please contact:

Soumiah Alkandari
Email: dnsalk@leeds.ac.uk
Telephone Paediatric Dentistry Department: 0113 343 5667

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

Appendix 5 Participant information sheet (Young person)

Information Sheet (Young person) v2 20/07/2023

NHS The Leeds Teaching Hospitals NHS Trust

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Information Sheet for young people aged 7-11 years

Study Title: Observer, dentist, and families' perception of shared decision-making consultations about compromised first permanent molars

This project wants to find out what you and your family think of the talk you have with the dentist about your poorly back teeth.

Why are we doing this study?

We want to find out what you think of the talk you will have with the dentist about your poorly back teeth. We would like to know what your family and the dentist think of this talk. We are asking young people aged 7 to 11 years old to take part.

Who is doing the study?

We are a team of dentists at the University of Leeds.

What will happen?

Chat with you:

- We will check that you are happy to take part. We will also check that your parents are happy for you to take part.
- We will ask you to sign a form to confirm you are happy before we start.
- We will talk to you about the study and answer any questions you have.

See the dentist:

- One of our team members will sit in the same room and record the chat between you and the dentist. This will only record your voices.
- Your dentist will have a look at your teeth and talk to you about what can be done.
- If you want, you can listen to the recording we have made.

Questionnaire:

- Once the dentist has finished talking to you, we will ask you to answer a few questions with your family.
- This will take less than 5 minutes.

ETHICAL APPROVAL NUMBER 1

Typing up the recording:

- We would like to type up the voice recordings. This will mean we can look at what was talked about in more detail later.
- We would remove your name so no-one would know it was you. Only the research team would be able to read the typed up version.

How will this study help me?

Taking part will not directly help you. We hope you taking part will help dentists to talk to other people about their poorly back teeth.

The results of this study will help us understand what is important to people with poorly back teeth when talking to their dentist.

Taking part in this study will need a little bit of extra time to fill out the forms. Taking part will not change your dental appointment or choices in any way.

What if I don't want to take part in the study anymore?

Just tell your mum, dad, carer, dentist, or dental nurse at any time.

You do not need to give a reason. You will still have the same dental care in the clinic.

How will my information be used?

When we collect the information, we will make sure it is stored in a safe place.
Only the people doing the research study can look at it.

We will use the information to write a report to tell dentists about our research. No one will know you were in the study.

Very rarely, we might feel it is important to share some information with other people. This would only be if we felt this was in the best interest of you and your family. We would talk to you and your family first about why we think it is important. We would explain what we would like to share and who with.

Will anyone else know I'm doing this?

The people in our research team will know you are taking part. The dentist looking at your teeth in the clinic will also know, and if it is okay, we will record the talk between you and the dentist.

No one else will know because we will not use your name or address.

Did anyone else check if the study is OK to do?

The study has been checked by several people to make sure it is alright. This includes the University and a Research Ethics Committee.

How can I find out more about this study?

Your mum, dad, carer or other grownups you trust may be able to answer your questions. The dentist, dental nurse, and research team can also help you find out more about this study.

Thank you for taking the time to read this – please ask any questions if you need to.

Appendix 6 Consent form (Family)

Consent form (Family) v3 20/07/2023

NHS
The Leeds Teaching Hospitals
NHS Trust

UNIVERSITY OF LEEDS

Parental consent

Form is to be completed by parent/legal guardian

Study: Observer, dentist and families' perception of shared decision-making consultations about compromised first permanent molars
Name of Researchers: Soumiah Alkandari, Dr. Richard Balmer, Dr. Sophy Barber
Research Sponsor: School of Dentistry, University of Leeds
IRAS ID: 321063

Participant Identification Number:

Please initial box

1. I confirm that my child and I have read the information sheet dated 20/07/2023 (version 3) for the above study. We have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that our participation is voluntary and that we are free to withdraw at any time without giving any reason, without our dental care or legal rights being affected. ☐
3. I understand that the information collected about us will be used to support other research in the future and may be shared anonymously with other researchers. ☐
4. I understand that research data collected during the study may be looked at by individuals from University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. We give permission for these individuals to have access to my records. ☐
5. My child and I are happy to take part in the above study. ☐
6. We are happy for the clinical consultation to be audio-recorded. We are happy for this recording to be typed up and stored for up to 3 years (*your names will not be included*). ☐
7. We agree to anonymised quotes being used in the research. ☐

IRAS ID: 321063

1 copy for the participant; 1 copy for the site file

Signatures

Name of parent	
Relationship to child	
Signature	
Date	

Person taking consent	
Job title	
Signature	
Date	

Appendix 7 Consent form (Dentist)

Consent form (dentist) V3 20/07/2023

NHS
The Leeds Teaching Hospitals
NHS Trust

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CONSENT FORM (Dentist)

Study: Observer, dentist and families' perception of shared decision-making consultations about compromised first permanent molars
Name of Researchers: Soumiah Alkandari, Dr. Richard Balmer, Dr. Sophy Barber
Research Sponsor: School of Dentistry, University of Leeds
IRAS ID: 321063

Participant Identification Number:

Please initial box

1. I confirm that I have read the information sheet dated 20/07/2023 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐
3. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐
4. I understand that research data collected during the study may be looked at by individuals from University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. ☐
5. I agree to take part in the above study. ☐
6. I agree that the clinical consultation can be audio-recorded then transcribed and anonymised for further qualitative analysis. I understand the anonymised transcript may be kept for up to 3 years. ☐
7. I agree to anonymised quotes from the consultation being used in research reports. ☐

Signatures

Name of Participant	Date	Signature
Name of Person seeking consent	Date	Signature

1 copy for the participant; 1 copy for the site file

Appendix 8 Assent form (Young person)

Assent form (Young person) V2 20/07/2023

NHS
The Leeds Teaching Hospitals
NHS Trust

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Young person assent and consent form

Assent form for 7-11 year-olds (assent means saying that you agree to do something)

Study: Observer, dentist and families' perception of shared decision-making consultations about compromised first permanent molars

This project wants to find out what you and your family think of the talk you have with the dentist about your poorly back teeth.

Participant Identification Number:

Please ***circle YES*** if you agree with the statement and **NO** if you do not agree (your parents can help you).

			
1.	Have you read (or had read to you) about this project?	YES	NO
2.	Has someone else explained this project to you?	YES	NO
3.	Do you understand what the project is about?	YES	NO
4.	Have you asked all the questions you want?	YES	NO
5.	Have you had your questions answered?	YES	NO
6.	Do you understand that it is OK to stop taking part any time?	YES	NO
7.	Do you understand that even if you do not take part in this study, you can still have your dental treatment?	YES	NO

IRAS ID: 321063

1 copy for the participant; 1 copy for the site file

Appendix 9 Data collection tool - Information about the consultation

Consultation information v1 26/10/22

Consultation information

Consultation number:

Information about consultation

Date of consultation		**Clinic**	☐ Paediatric Dentistry ☐ Orthodontics ☐ JOP
Dentist specialty	☐ Paediatric Dentistry ☐ Orthodontics	**Grade**	☐ Consultant ☐ Specialty trainee ☐ Postgraduate
Appointment type	☐ First appointment about first permanent molars ☐ Follow up appointment		

Information about young person and parent

Age (years)	
Gender	
Parent(s) at appointment	

Information about first permanent molars (to be completed by dentist)

Please describe the clinical presentation of the first permanent molars

UR6 (16)	
UL6 (26)	
LL6 (36)	
LR6 (46)	

Please provide any other information that influenced your discussion of treatment options that you think might be useful (e.g. other dental issues, social / medical history, anxiety, previous experiences)

IRAS ID: **321063**

Appendix 10 SDM measure (observer)

SDM measure (observer) v1 26/10/2022

Rater name:	Consultation Clinic: ☐ Paediatric Clinic ☐ Orthodontic Clinic ☐ Joint Clinic
Consultation identifier:	
Consultation duration:	

	Item	Not at all		Completely covered	Notes
1	The dentist and patient discussed their role in decision making during the consultation.	0	1	2	
2	The dentist and patient discussed the clinical issues or nature of the decision together.	0	1	2	
3	The dentist discussed the alternatives in treatment options with the patient.	0	1	2	
4	The dentist discussed the pros (potential benefits) and cons (risks) of the alternatives with the patient.	0	1	2	
5	The dentist discussed the patient expectations (ideas) and concerns (fears) about how to manage the problem.	0	1	2	
6	The dentist explored the patient preferences.	0	1	2	
7	The dentist discussed with the patient the uncertainties associated with the decision.	0	1	2	
8	The dentist and patient clarified the source upon which medical information / recommendations are based (scientific evidence, clinician's judgement, preferences, conflicting interests).	0	1	2	
9	The dentist reassured the patient that the dentist will support the patient to become informed or deliberate about the options.	0	1	2	
10	The dentist discussed with the patient the pressure or support from others.	0	1	2	
11	The dentist assessed the patient understanding associated with decision.	0	1	2	
12	The dentist used a medical language that matches the patient level of understanding	0	1	2	
13	The dentist and patient clarified whether the dentist has understood the patient viewpoint correctly.	0	1	2	
14	The dentist made sure that the patient can ask questions and point out aspects not fully understood during the discussion.	0	1	2	

IRAS ID: **321063**

Appendix 11 SDM measure (family)

SDM measure (family) v1 26/10/22

Participant identifier: Date:

We would like to know more about your experience of your dental appointment.
Please read each of the statements below together.
Please pick a score for each one - there is no right or wrong answer.
We will not share your scores with the dental team.

	Not at all	A bit	Totally
The dentist talked about our role in making choices about dental treatment.	0	1	2
The dentist told us enough about the poorly back teeth.	0	1	2
The dentist talked about the different treatment options with us.	0	1	2
The dentist talked about the benefits and risks of the different treatment options.	0	1	2
The dentist asked us about our hopes and concerns about treatment.	0	1	2
The dentist asked us about our preferences and what is important to us.	0	1	2
The dentist talked to us about anything that is not known about poorly back teeth or different types of dental treatment.	0	1	2
The dentist told us where their information had come from. They told us the basis for their recommendations about treatment.	0	1	2
The dentist helped us to find out and think about the options.	0	1	2
The dentist checked if there is anyone else who might help us to decide about dental treatment.	0	1	2
The dentist checked that we understood what we need to decide.	0	1	2
The dentist used the right language to help us understand.	0	1	2
The dentist checked they had understood us correctly.	0	1	2
The dentist made sure that we could ask questions.	0	1	2

Overall, I was satisfied with this consultation.

Not at all				Completely
1	2	3	4	5

IRAS ID: **321063**

Appendix 12 SDM measure (dentist)

SDM measure (dentist) v1 26/10/22

Participant identifier: Date:

We would like to know more about your experience of the consultation.
Please read each of the statements below together then provide a score.
All answers will be kept confidential and will be anonymous to everyone except the research team.

	Not at all	Partially	Completely
I discussed the patient and parent(s) role in decision making during the consultation.	0	1	2
I discussed the clinical issues or nature of the decision with the patient and parent(s).	0	1	2
I discussed the alternatives in treatment options with the patient and parent(s).	0	1	2
I discussed the pros (potential benefits) and cons (risks) of the alternatives with the patient and parent(s).	0	1	2
I discussed the patient's and parent's expectations (ideas) and concerns (fears) about how to manage the concrete problem.	0	1	2
I explored the patient 's and parent's preferences.	0	1	2
I discussed any uncertainties associated with the decision with the patient and parent(s).	0	1	2
I clarified the source upon which medical information / recommendations are based (scientific evidence, clinician's judgement, preferences, conflicting interests).	0	1	2
I reassured the patient and parent(s) that I will support them to become informed or deliberate about the options.	0	1	2
I discussed with the patient and parent any pressure or support from others.	0	1	2
I assessed the patient and parent(s) understanding associated with decision.	0	1	2
I used a medical language that matches the patient's and parent's level of understanding	0	1	2
I clarified to the patient and parent(s) whether I have understood their viewpoint correctly.	0	1	2
I made sure that the patient and parent could ask questions and point out aspects not fully understood during the discussion.	0	1	2

Overall, I was satisfied with this consultation.

Not at all				Completely
1	2	3	4	5

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Appendix 13: SDM measure (observer) manual

SDM measure (observer) manual v1 29/05/2024

The items included in this SDM observer sheet are:

Item 1:
The dentist and patient discussed their role in decision making during the consultation.

0 The behaviour is not covered: Discussion of role preferences occurs too late in the consultation. The roles are taken without any communication on this topic. Examples: Dentist: The dentist makes no attempt to find out the role the patient would like to play. Patient: the patient passively accepts the role assigned to him without questioning.
1 The behaviour is partially covered: The preferred role model is explicitly made a subject of in the consultation, and the patient's motives behind a specific preference are disclosed. Examples: Dentist: Would you prefer to take the decision yourself or shall I take it for you? Patient: "... I want to take your opinion into consideration because it's you who have to support me during treatment."
2 The behaviour is fully covered: A deeper discussion of role distribution and signals made by the participants is picked up. Moreover, the dentist undertakes efforts to strengthen patient autonomy. Examples: Dentist: "I see you would like me to decide. Nevertheless, I still want to ask you again: What would you need to make your decision on your own?"

Item 2:
The dentist and patient discussed the clinical issues or nature of the decision together.

0 The behaviour is not covered: No discussion of the clinical issues or nature of the decision occurs between the dentist and the patient. Examples: Dentist: The dentist makes no attempt to discuss or explain the concerns about the issue and the nature of the decision. Patient: the patient passively listens to the plan with no explanation of the concerns.
1 The behaviour is partially covered: A brief discussion about some of the concerns, experiences, or specific problems is undertaken by the dentist or the patient. Examples: Dentist: "...we are going to talk about this specific issue today... this has happened because..." Patient: "... I am concerned about this specific problem..."
2 The behaviour is fully covered: A deeper discussion of the issues, the specific concerns, the experience of the issues is undertaken between both the dentist and the patient. The dentist encourages the patient to get involved in this discussion. Examples: Dentist: "…today we are going to discuss the specific issue you have, what are your concerns with this, what would you like to know…"

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Patient: "…my main concerns are… we have gone through a lot and the experience of having this was…"

Item 3:
The dentist discussed the alternatives in treatment options with the patient.

0 The behaviour is not covered: The listing of the alternatives is omitted or comes too late in the consultation.
1 The behaviour is partially covered: The list of alternatives is either incomplete or poorly structured.
2 The behaviour is fully covered: The alternatives are completely listed in a well-structured way and include individual comments that seem useful for the patient.

Item 4:
The dentist discussed the pros (potential benefits) and cons (risks) of the alternatives with the patient.

0 The behaviour is not covered: The benefits and risks of the alternatives are not subject in the consultation.
1 The behaviour is partially covered: The pros and cons are mentioned incompletely or/and not systematically.
2 The behaviour is fully covered: The pros and cons are discussed systematically and clarification of the likelihood of their occurring with detailed explanation.

Item 5:
The dentist discussed the patient expectations (ideas) and concerns (fears) about how to manage the problem.

0 The behaviour is not covered: No exploration of the patient's expectations and worries can be observed.
1 The behaviour is partially covered: The patient's expectations and worries are explored superficially (using open questions). Examples: Dentist: "…What are you afraid of? What do you think we can do? Do you have any ideas?"

2 The behaviour is fully covered:
The expectations and/or worries are an explicit part of the consultation. Ideas and statements regarding the patient's worries are discussed in depth.

Examples:
Dentist: "…Regarding this issue, what is worrying you the most? How is this affecting you? What are you hoping for to get this right?"

Item 6:
The dentist explored the patient preferences.

0 The behaviour is not covered:
No exploration of the patient's preferences and values can be observed.

1 The behaviour is partially covered:
The patient's preferences are explored superficially (using open questions).

Examples:
Dentist: "…What do you prefer? What would you like to do?"

2 The behaviour is fully covered:
Preferences and values are explicitly part of the consultation and statements regarding the patient's preferences are discussed in depth.

Examples:
Dentist: "…How do you think this option would fit in? Do you prefer this option over the others? Why would you prefer this?"

Item 7:
The dentist discussed with the patient the uncertainties associated with the decision.

0 The behaviour is not covered:
No exploration of the patient's uncertainties associated with the decision can be observed.

1 The behaviour is partially covered:
The decision uncertainties were explored superficially (using open questions).

Examples:
Dentist: "…Even though this decision was made, there are uncertain possibilities that this might happen…"

2 The behaviour is fully covered:
The decision uncertainties were discussed in depth, including clear comments that support the decision and the patient while explaining the risks and referencing the knowledge.

Examples:
Dentist: "…Given that we have decided on this option, there are specific uncertainties that might happen, which include…How do you feel about these…We can go through them in detail together to help you understand the decision being made…"

Item 8:
The dentist and patient clarified the source upon which medical information / recommendations are based (scientific evidence, clinician's judgement, preferences, conflicting interests).

0	**The behaviour is not covered:** No reference is made to the origin of a recommendation or information provided in the consultation.
1	**The behaviour is partially covered:** The source of a recommendation or information is mentioned superficially (e.g., from a medical point of view or based on our institute's experience or personal experience). Examples: Dentist: "…according to my clinical experience, this usually happens…"
2	**The behaviour is fully covered:** A conclusion is drawn from the source and explanations are detailed Examples: Dentist: "…these risks are based according to recent guidelines which are…, and this goes along my clinical experience in this field… referencing figures, leaflets and information sheets or websites for the patient to look into…"

Item 9:
The dentist reassured the patient that the dentist will support the patient to become informed or deliberate about the options.

0	**The behaviour is not covered:** Reassuring the patient about being informed is not made a subject of the consultation.
1	**The behaviour is partially covered:** The dentist reassures the patient too late during the consultation or reassures the patient superficially. Examples: Dentist: "…I will explain the options for you now…Is that okay?"
2	**The behaviour is fully covered:** The patient is reassured that they will be informed about the options at the beginning of the discussion and throughout the discussion at each stage. Examples: Dentist: "…I will go through all the options with you now; it might seem like a lot to take in, but please be reassured that we will go through them all in detail. If you have any questions in between, please ask right away…"

Item 10:
The dentist discussed with the patient the pressure or support from others.

0	**The behaviour is not covered:** Pressures or support from others regarding the decision-making was not part of the consultation.

1	**The behaviour is partially covered:** The dentist explores possible pressures or support from other members but does not discuss this further. Examples: Dentist: "…Is there anyone you feel would affect your decision..."
2	**The behaviour is fully covered:** Explicit statements signify that the has support or pressure from others, and this is explored deeply with the dentist. Examples: Dentist: "…you have stated that there is someone who might affect your decision, how would you like us to proceed? Would you like to discuss this further with them or do you prefer this to be discussed with us only?"

Item 11:
The dentist assessed the patient understanding associated with decision.

0	**The behaviour is not covered:** The patient's understanding is not made a subject of the consultation.
1	**The behaviour is partially covered:** The patient's understanding of the given information is checked superficially, using empty phrases, or was checked very late during the consultation. Dentist: "How well did you understand that?"
2	**The behaviour is fully covered:** The clinician makes sure of the patient's understanding at each stage. Thus, is achieved cooperatively.

Item 12:
The dentist used a medical language that matches the patient level of understanding.

0	**The behaviour is not covered:** The dentist used medical language repetitively.
1	**The behaviour is partially covered:** The dentist used a few medical language phrases.
2	**The behaviour is fully covered:** The dentist used simplified medical language throughout the consultation and the patient understood the discussion.

Item 13:
The dentist and patient clarified whether the dentist has understood the patient viewpoint correctly.

0 The behaviour is not covered: The dentist's understanding is not made a subject of the consultation.
1 The behaviour is partially covered: The dentist's understanding of the given information is checked superficially, using empty phrases. Examples: Dentist: "Did I understand you well?"
2 The behaviour is fully covered: Particular attention is paid to specific aspects. Individual aspects are put into context with the patient's contributions. Examples: Dentist: "Did I cover all the aspects you were expecting? Have I covered your concern regarding this…"

Item 14:
The dentist made sure that the patient can ask questions and point out aspects not fully understood during the discussion.

0 The behaviour is not covered: No attempt was made to check understanding of the patient by asking the patient if he has any questions throughout the consultation.
1 The behaviour is partially covered: The dentist's asks the patient is they have any questions at the end of the consultation. Examples: Dentist: "Do you have any questions?"
2 The behaviour is fully covered: The dentist makes sure the patient has time to ask questions throughout every stage of the consultation. Examples: Dentist: "Do you have any questions…I will proceed to the next option, if you have any questions, please let me know and feel free to interrupt…"

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