# <u>Investigating Problem-Orientated Patient Pathways,</u> Tooth<u>ache to Treatment: ImPacT Study</u>

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## **Abstract**

Almost one-third of adults will only seek professional dental care when suffering with acute dental pain rather than engaging in routine preventive dental care, so called problem-orientated dental attenders. These individuals can wait a long time before seeking care resulting in: greater impacts on everyday activities, and greater potential for serious adverse events. They can present to a range of services including emergency dental services, medical emergency departments, and general medical practitioners (GMPs). The reasons for this attendance pattern and care pathway are under-researched. To encourage these patients to engage in routine dental care it is important to build an understanding of: (1) why they only attend when symptomatic, (2) where they present and why. The aim of this thesis was to build an understanding of problem-orientated attendance to subsequently develop an intervention to encourage regular dental attendance.

This thesis involved four studies. The first was a retrospective observational study examining dental attendances at Welsh GMPs. The second and third were qualitative studies exploring: (1) problem-orientated attenders' perspectives and experiences of seeking repeated emergency dental care (2) adolescents' experiences of dental care and their future plans for dental attendance. The final study co-designed an intervention to prevent problem-orientated dental attendance.

Dental attendance rates at GMPs varied over the study period and appeared to relate to key policy change dates. Predictors of being a repeat dental attender included deprivation, residential area, and appointment outcome. Reasons for problemorientated attendance were complex and multifactorial, with overarching reasons related to knowledge and dentist characteristics. Adolescents faced multiple barriers to dental care-seeking as they transitioned to independence subsequently affecting decision-making to continue to seek regular care. Finally, an intervention was developed targeted at adolescents and young adults to encourage continued regular dental attendance as they transitioned to independence, hence preventing problemorientated attendance.

## **Dedication**

This thesis is dedicated to Ron and Margaret Currie – I know you'd be proud.

## **Acknowledgements**

This thesis would not have been possible without the contributions and support of a wide range of people. Firstly, I'd like to thank the National Institute for Health Research (NIHR) for awarding me a Doctoral Research Fellowship (DRF-2017-10-022) to complete this PhD and attend the training required. Additional funding was also received from the European Society of Endodontology Young Investigator Award, for which I am very appreciative.

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## **List of Abbreviations**

ADHS Adult Dental Health Survey

ADP Acute dental pain

APEASE Affordability Practicability Effectiveness/Cost-effectiveness Acceptability

Side effects Equity

BCT Behaviour change technique

BCTt Behaviour change technique taxonomy

CDHS Children's Dental Health Survey

CI Confidence interval

COM-B Capability Opportunity Motivation Behaviour

CPRD Clinical Research Practice Datalink

DEC Dental emergency clinic

ED Emergency department

GDP General dental practitioner

GMP General medical practitioner

HIRU Health information research unit

ICOP International Classification of Orofacial Pain

IGRP Information governance review panel

IRS Intervention recommendation statement

IMD Index of multiple deprivation

LSOA Lower layer super output area

NICE National Institute for Health and Care Excellence

OR Odds ratio

PDP Persistent dental pain

PIDAP Persistent idiopathic dentoalveolar pain

PPI/E Patient and public involvement/engagement

SAIL Secure Anonymised Information Linkage

TDF Theoretical Domains Framework

TIDieR Template for intervention description and replication

TMD Temporomandibular disorders

TMJ Temporomandibular joint

WIMD Welsh index of multiple deprivation

## **List of Definitions**

Term	Definition			
Behaviour change techniques (BCT)	The active part of an intervention that has been specifically designed to change behaviour (Michie and Johnston, 2012). The BCT must meet specified criteria so that it is identifiable, observable, replicable, irreducible. BCTs can be used alone or in combination.			
Behaviour change	Behaviour change techniques synthesised and refined into a			
technique	classification (taxonomy) which can be used as a			
taxonomy (BCTt)	standardised language for describing active ingredients in an intervention (Michie <i>et al.</i> , 2015).			
Co-creation	A form of collaborative innovation in which new concepts, products or services forming part of an intervention are developed with experts and stakeholders (Voorberg, Bekkers and Tummers, 2015).			
Co-design	The approach of actively involving stakeholders in the intervention design process.			
Co-production	Involvement of patients, public or other stakeholders in development and delivery of services to agree what is needed, where and how. This can also involve passive involvement, which is distinct from co-creation (Voorberg, Bekkers and Tummers, 2015).			
Dark logic model	A model to guide evaluation of potential harms from an intervention and their underlying mechanisms (Bonell <i>et al.</i> , 2015).			
Index of multiple deprivation (IMD)	Index of multiple deprivation (IMD) is the official measure of relative deprivation in the UK (Office for National Statistics, 2019). The scores used in IMD take into account deprivation being related to more than just poverty, and therefore combines eight different domains. These include: employment, income, education, health, community safety, geographical access to services, housing and physical environment. Scores are based on lower layer super output areas (LSOAs) with each being ranked an IMD score, the LSOA ranked 1 is the most deprived area.			
Logic model	Narrative or visual depictions of the processes involved in an intervention leading to the desired behaviour change.			
Theoretical	A synthesis of constructs from behaviour change theories.			
Domains	The TDF was developed using consensus methodology to			
Framework (TDF)	encompass a broad range of psychological theories and constructs of behaviour change so these can be easily identified by researchers (Cane, O'Connor and Michie, 2012). This helps provide an assessment of broad			
	behavioural barriers and enablers unpinning behaviour change therefore helping design of interventions.			

## **List of Publications**

Aspects of this thesis are based on, or have resulted in, published work, these include:

### Published Papers

**Currie C.C.**, Stone S.J., Durham J. (2015). 'Pain and problems: a prospective cross-sectional study of the impact of dental emergencies', *Journal of Oral Rehabilitation*, 42(12), pp 883-889.

**Currie C.C.**, Stone S.J., Connolly J., Durham J. (2017). 'Dental pain in the medical emergency department: a cross-sectional study', *Journal of Oral Rehabilitation*, 44(2), pp 105-111.

Parten N.J., Taylor G.D., **Currie C.C.**, Durham J., Vernazza C.R. (2019). 'Medical emergency department attendance of under 16-year-olds with dental problems', *Journal of Oral Rehabilitation*, 46(5), pp 433-440.

Carter E.\*, **Currie C.C.**\*, Asuni A., Goldsmith R., Toon G., Horridge C. *et al.* (2020). 'The first six week – setting up a UK urgent dental care centre during the COVID-19 pandemic', *British Dental Journal*, 228(11), pp 842-848.

**Currie C.C.**, Araujo-Soares V., Stone S.J., Beyer F., Durham J. (2021) 'Promoting regular dental attendance in problem-orientated dental attenders: A systematic review of potential interventions', *Journal of Oral Rehabilitation*, 48(10), pp 1183-1191.

**Currie C.C.**, Stone S.J., Brocklehurst P., Slade G., Durham J., Pearce MS. (2022). 'Dental Attendances of General Medical Practitioners in Wales: A 44 Year-Analysis', *Journal of Dental Research*, 101(4), pp 407-413. doi: 10.1177/00220345211044108.

**Currie C.C.**, Stone S.J., Pearce M.S., Landes D., Durham J. (2022). 'Urgent Dental Care Use in the North-East and Cumbria: Predicting Repeat Attendance', *British Dental Journal*, 323(3), pp 164-171.

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#### Book Chapter

**Currie C.C.**, Walburn J., Hackett K., McCabe R., Sniehotta F.F, O'Keefe S., *et al.* (2022). 'Intervention Development for Health Behaviour Change: Integrating

Evidence and the Perspectives of Users and Stakeholders', in *Comprehensive Clinical Psychology*. 2<sup>nd</sup> Ed, Volume 8. Amsterdam: Elsevier. doi: https://doi.org/10.1016/B978-0-12-818697-8.00177-1

## Other Outputs

Currie C.C., Vernazza C., Durham J., Stone S.J. (2019). Why scrapping NHS dental costs won't make much different to the UK's oral health crisis. Available at <a href="https://theconversation.com/why-scrapping-nhs-dental-costs-wont-make-much-difference-to-the-uks-oral-health-crisis-127573">https://theconversation.com/why-scrapping-nhs-dental-costs-wont-make-much-difference-to-the-uks-oral-health-crisis-127573</a> Article for The Conversation UK.

## **Chapter 1. Introduction & Thesis Structure**

### 1.1 Introduction

Approximately one-third of the UK population are problem-orientated dental attenders (Steele *et al.*, 2011). Problem-orientated attenders don't seek dental care on a regular preventive basis and instead only attend when suffering with acute dental pain (ADP) or dental problems. They can present to a range of health care providers, both dental and medical, and often present on a repeated basis. They can also delay care-seeking, often suffering with ADP for weeks to months (Scully, 1995; Stoller *et al.*, 2001; Cohen *et al.*, 2007; Currie, Stone and Durham, 2015) before seeking care. This attendance pattern and delayed care-seeking puts them at risk of adverse health events and is also likely to have an economic impact on the individual and wider society. The care pathways and decision-making behaviour of this cohort are under-researched, however if better understood, may help guide policy change, or intervention development to address problem-orientated attendance and encourage regular preventive care. This thesis seeks to develop an understanding of this cohort of patients, their attendance patterns, and behaviours, with the outcome of developing an intervention targeted at problem-orientated dental attendance.

### 1.2 Structure of Thesis

There are eight main chapters. Following this introduction Chapter 2 reviews the current literature surrounding adult problem-orientated dental attendance. Then Chapter 3 describes the thesis aims and objectives. The following chapters present the research undertaken including: an epidemiology study of dental patients attending general medical practitioners (Chapter 4), an adult qualitative study exploring problem-orientated dental attendance (Chapter 5), an adolescent qualitative study exploring the transition to independence on dental care-seeking (Chapter 6), and an intervention co-design (Chapter 7). The final chapter summarises the studies, their conclusions and discusses future research and next steps.

## **Chapter 2. Literature Review**

### 2.1 Introduction

The literature review focuses on adult problem-orientated attendance and is broken into six main sections:

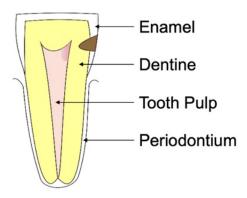
- Section 2.2 gives a brief overview of the common causes of dental pain which problem-orientated attenders suffer and present with.
- Section 2.3 covers the epidemiology of acute dental pain.
- Section 2.4 discusses potential adverse health events that problem-orientated dental attenders are at risk of due to their attendance pattern and delayed care-seeking.
- Section 2.5 covers the current literature on utilisation of dental care in relation to regular dental attenders and problem-orientated dental attenders.
- Section 2.6 discusses the potential care pathways and health care providers that problem-orientated dental attenders can present to.
- Section 2.7 discusses barriers and facilitators for dental care-seeking which may be of relevance to problem-orientated dental attenders.

Further relevant literature on adolescent dental attendance is discussed later in Chapters 5 to 7.

#### 2.2 Causes of Dental Pain

### 2.2.1 Odontogenic pain

Odontogenic, or dental pain is defined as "pain caused by lesions or disorders affecting one or more teeth and/or their immediately surrounding and supporting structures (Figure 2.1): the tooth pulp, periodontium and gingivae" (International Classification of Orofacial Pain, 2020) and is transmitted via the sensory neurones of the trigeminal nerve which elicits the painful symptoms patients complain of. The most common causes of odontogenic pain are the result of dental caries or periodontal disease, resulting in pulpal and periapical or periodontal diagnoses. The diagnostic terminology of odontogenic pain is summarised in Table 2.1.



**Figure 2.1:** Structure of a tooth showing the immediately surrounding and supporting structures. The brown shaded area indicates dental caries (tooth decay). The gingivae are the tooth gums and are not shown in the figure (diagram reproduced with permission from Prof John Whitworth).

Pain Origin	Diagnosis	Definition
	Normal Pulp	A diagnostic category for a symptom free pulp. It may not be histologically normal however clinically the tooth is considered normal.
	Reversible Pulpitis	An inflamed pulp with clinical findings suggestive that the inflammation can resolve and return to normal.
Pulpal Diagnoses	Symptomatic Irreversible Pulpitis	An inflamed pulp causing symptoms of toothache with clinical findings suggestive that the inflamed pulp is unable to heal.
"pain caused by a lesion or disorder involving the tooth pulp"	Asymptomatic Irreversible Pulpitis	An inflamed pulp causing no symptoms of toothache with clinical findings suggestive that the inflamed pulp is unable to heal.
	Pulp Necrosis	A diagnostic category for a pulp which has died and is asymptomatic.
	Previously Treated	A diagnostic category for a tooth which has been endodontically treated.
	Previously Initiated Therapy	A diagnostic category for a tooth which has had endodontic therapy initiated.
	Pulpal pain attributed to hypersensitivity/Dentine hypersensitivity	Pulpal pain due to hypersensitivity in a clinically normal pulp.
Apical Diagnoses  "pain caused by a lesion or disorder involving the periodontium: the periodontal ligament and/or the adjacent alveolar (periradicular) bone tissue"	Normal Apical Tissues	A tooth with normal apical tissues which are not sensitive to pressure and radiographically appear normal.
	Symptomatic Apical Periodontitis	Inflammation of the periodontium (usually the apical portion) causing painful symptoms in relation to pressure on the tooth.
	Asymptomatic Apical Periodontitis	Inflammation of the periodontium which does not produce clinical symptoms.
	Chronic Apical Abscess	An inflammatory reaction resulting from pulpal infection and necrosis causing no or little clinical symptoms, associated with discharge of pus via a sinus tract.
	Acute Apical Abscess	An inflammatory reaction resulting from pulpal infection and necrosis causing painful symptoms as well as pus formation and swelling.
	Condensing Osteitis	A radiographic finding which represents a localised bony reaction to an inflammatory stimulus.

Table 2.1: A summary of diagnoses related to odontogenic pain (American Association of Endodontists, 2013; International Classification of Orofacial Pain, 2020).

## Pulpal pain

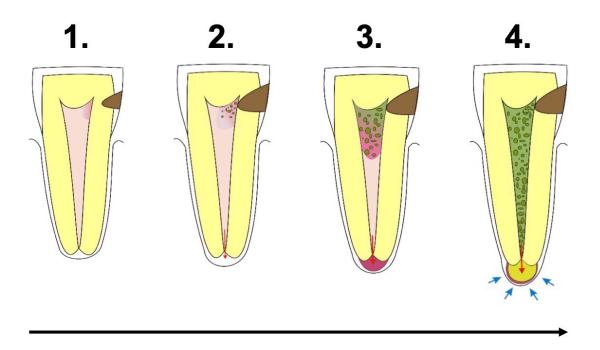
There are several types of pulpal pain which are outside the scope of this thesis. Of relevance is pulpal pain attributed to pulpitis (American Association of Endodontists, 2013). As shown in Table 2.1, pulpitis can be classified into reversible and irreversible, however recently there has been a move to reclassify this to mild, moderate and severe (Wolters et al., 2017; European Society of Endodontology et al., 2019) In reversible or mild pulpitis the painful symptoms are normally transient and are sharp, last for seconds and caused by eating or drinking cold or sweet things. Treatment usually involves removal of the cause, often dental caries, and restoration. If not treated it will often progress onto irreversible, or moderate to severe, pulpitis (Figure 2.2). When symptomatic, the pain can be similar to that of reversible pulpitis, however, will last longer, can be spontaneous and may be poorly localised to the tooth. Traditional endodontic treatment, such as root canal treatment, involves removal of the inflamed pulpal tissue and restoration. There is, however, a move towards more conservative treatment using vital pulp therapies (Allison, Stone and Pigg, 2020), although this would ideally require early presentation so there is sufficient pulpal tissue remaining with regenerative capacity.

## Periapical and periodontal pain

There are several subtypes of periodontal pain, of which periodontal pain attributed to periodontitis can be a sequala of pulpal pain. If pulpitis is left untreated then pulpal necrosis can result followed by progression of the inflammatory process into the periapical tissues, resulting in peri-radicular or periapical periodontitis (Figure 2.2). During pulpal necrosis the patient can be symptom free, which is of relevance later in this thesis as the patient will often have a period of pain associated with pulpitis, which them seemingly resolves without treatment, before the pain returns at a later date as periodontitis. In those who are symptomatic the pain is typically constant and aching and is exacerbated by pressure on the tooth (Rosenberg, 2014).

A further sequela can be formation of an apical abscess (Figure 2.2), which is dependent on the pathogens present, the host immune response and whether the patient receives successful dental treatment or not (Robinson *et al.*, 2018). In an abscess the affected periapical tissues undergo suppuration (formation of pus). In a chronic apical abscess the onset is normally gradual and there are little or no symptoms as the pus is able to discharge via a sinus tract. In contrast, in an acute

apical abscess there is rapid onset with pain, tenderness and swelling. In addition, the patient may develop cellulitis and systemic symptoms including lymphadenopathy and pyrexia. Further, more severe, sequalae of this include Ludwig's angina and cavernous sinus thrombosis, and the potential for development of sepsis. All of these require emergency hospital admission and treatment and can be fatal, these are discussed further later in this chapter.



**Figure 2.2:** The sequalae of pulpal and periapical pain showing progression in pulpal state as a result of advancing, untreated dental caries. (1) Reversible pulpitis, (2) Irreversible pulpitis, (3) Pulp necrosis/apical periodontitis, (4) Pulp necrosis/apical abscess (diagram reproduced with permission from Prof John Whitworth).

Other causes of odontogenic pain include pain attributed to periodontal disease. This is often painless, however, painful symptoms can be caused by acute exacerbations in the form of periodontal abscesses, where in addition to pain, there is suppuration, bleeding and localised swelling. Gingival pain attributed to bacterial infection can encompass necrotising ulcerative gingivitis and pericoronitis (International Classification of Orofacial Pain, 2020). Pericoronitis is a common cause of pain associated with partially erupted teeth, particularly mandibular third molars. Necrotising ulcerative gingivitis causes acute severe pain associated with necrosis and ulceration of the periodontal tissues, and is usually caused by a mixed bacterial infection and associated with poor oral hygiene, smoking, immunosuppression and severe stress (Robinson *et al.*, 2018).

## 2.2.2 Non-odontogenic pain

Non-odontogenic pain can mimic the toothache symptoms associated with ADP and it is often difficult to diagnose. Problem-orientated dental attenders most commonly present with ADP as a result of odontogenic pain (Currie, Stone and Durham, 2015) therefore non-odontogenic pain as a cause will only be briefly discussed. Non-odontogenic diagnoses which can mimic ADP include: temporomandibular disorders (TMD); maxillary sinusitis; persistent idiopathic dentoalveolar pain (PIDAP).

### Temporomandibular Disorders

TMD is a collective term for a group of musculoskeletal disorders which involve pain and/or dysfunction in the muscles of mastication, temporomandibular joints (TMJ) and associated structures (American Academy of Orofacial Pain, 2018). TMD is the most common type of non-odontogenic orofacial pain, and although typically causes pain associated with the muscles of mastication and/or TMJ it can occasionally cause referred pain which can be interpreted as toothache by the patient.

## **Maxillary Sinusitis**

Maxillary sinusitis can be caused by viral, bacterial or allergic rhinitis and can present as pain associated with maxillary molar teeth due to the position of the roots of the teeth in relation to the maxillary sinus (Rosenberg, 2014). The pain is typically described as a dull ache and is aggravated by the patient lying down or bending over. The patient may also have other signs and symptoms suggestive of sinusitis.

### Persistent Idiopathic Dentoalveolar Pain

PIDAP is a persistent pain which is localised to the dentoalveolar region and does not have an odontogenic, musculoskeletal or psychological origin (Coulter and Nixdorf, 2020). The diagnostic terminology for this condition has changed several times, previously being referred to as atypical odontalgia, primary persistent dentoalveolar pain disorder and phantom tooth pain (International Classification of Orofacial Pain, 2020). The pain is persistent and can be deep, dull or pressure-like, the tooth however, will have normal clinical and radiographic findings. This is a difficult diagnosis to make and is easily mistaken for toothache as the symptoms are very similar to those of odontogenic pain, unfortunately for this reason patients often have unnecessary dental treatment which is of no benefit and can exacerbate symptoms (Durham *et al.*, 2013). This diagnosis is also of relevance to this thesis as patients can develop persistent pain following endodontic treatment which can be

attributed to PDIAP. There is evidence that the longer a patient has preoperative pain prior to the endodontic treatment the higher the risk of PDIAP following treatment (Law *et al.*, 2015), therefore problem-orientated dental attenders may be at higher risk of this as they can delay care-seeking.

## 2.3 Epidemiology of Acute Dental Pain

The Adult Dental Health Survey (ADHS) 2009 reported that 9% of dentate adults in England, Wales and Northern Ireland were experiencing current dental pain (Steele et al., 2011), with a comparable 13% reported by the Scottish Health Survey (Scottish Government, 2020). This equates to approximately 3.8 million people and suggests there is a significant burden of acute dental pain (ADP) in the population of these countries. A similar proportion of adults also reported experiencing dental pain fairly or very often in the previous year (Steele et al., 2011), which is suggestive of a sustained societal problem rather than an isolated anomaly. More recent data for England, Wales and Northern Ireland are not available due to delays with the ADHS, however the prevalence of ADP in Scotland was 13% in 2012 (Scottish Government, 2012), with minimal fluctuation in prevalence rates up to 2020 indicating that the prevalence of ADP is stable. Slightly higher prevalence rates are reported for children in the Children's Dental Health Survey (CDHS) 2013, with 14% of 5-yearolds, 18% of 8-year-olds, 18% of 12-year-olds and 15% of 15-year-olds reporting toothache in the previous 3 months (Tsakos et al., 2015). Both the ADHS and CDHS use self-reported pain (from the patient or parent) as outcome measures and are therefore subject to reporting bias.

Direct comparison of the prevalence of ADP outside of the UK presents a challenge due to the differing definitions used for oral or dental pain, the time frames of the self-report (e.g. current or recent pain compared to lifetime experience of pain), and data being sparse and of poor quality (Pau, Croucher and Marcenes, 2003). Prevalence rates for oral and/or dental pain in large population studies, however, are reported at 13.6% in the United States (Vargas, Macek and Marcus, 2000), 11.7% in Canada (Ravaghi, Quiñonez and Allison, 2013), 24.2% in Hong Kong (McMillan *et al.*, 2006), 11.6% to 16.2% in Australia (Peres *et al.*, 2019a), 19.4% in South Africa (Ayo-Yusuf and Naidoo, 2016). For children and adolescents the pooled global prevalence of dental pain is 32.7% with wide ranges reported from 1.3% to 87.8% due to use of different self-reporting measures (Pentapati, Yeturu and Siddiq, 2021).

The prevalence of ADP varies between demographic groups, being more prevalent in younger adult age groups (Vargas, Macek and Marcus, 2000; Pau, Croucher and Marcenes, 2003, 2007; Steele et al., 2011; Ravaghi, Quiñonez and Allison, 2013; Horst et al., 2015; Raittio, Helakorpi and Suominen, 2020; Scottish Government, 2020). ADP is also associated with increasing levels of deprivation and lower socioeconomic status (Vargas, Macek and Marcus, 2000; Duncan et al., 2003; Pau, Croucher and Marcenes, 2003; Riley, Gilbert and Heft, 2003; Pau, Croucher and Marcenes, 2007; Steele et al., 2011; Ravaghi, Quiñonez and Allison, 2013; Santiago, Valenca and Vettore, 2013; Peres et al., 2019a). In children, experience of toothache is considerably higher in those who are eligible for government funded free school meals (being used as a surrogate measure for deprivation), with 27% of 5year-olds, 23% of 8-year-olds, 25% of 12-year-olds and 23% of 15-year-olds selfreporting toothache in the previous 3 months (Tsakos et al., 2015). In terms of gender, conflicting findings are reported with some studies finding female gender to be predictive of experiencing ADP (Pau, Croucher and Marcenes, 2007; Steele et al., 2011; Constante et al., 2012; Tsakos et al., 2015; Raittio, Helakorpi and Suominen, 2020) and others reporting no gender differences (Vargas, Macek and Marcus, 2000; Pau, Croucher and Marcenes, 2003; McMillan et al., 2006; Ravaghi, Quiñonez and Allison, 2013; Horst et al., 2015).

ADP is also more common in those who do not visit a dentist for regular preventive care (Duncan *et al.*, 2003; Steele *et al.*, 2011; Ravaghi, Quiñonez and Allison, 2013; Horst *et al.*, 2015), and those with dental anxiety (Steele *et al.*, 2011; Dou *et al.*, 2018).

### 2.4 Adverse Effects of Untreated Acute Dental Pain

ADP can have a significant impact of everyday life (Nuttall *et al.*, 2011b). In addition, it can lead to adverse events including serious life-threatening infections and unintentional analgesic overdose.

## 2.4.1 Impact on everyday life

ADP is known to have a high pain intensity and substantial impact on quality of life comparable to persistent or chronic orofacial pain conditions including trigeminal neuralgia (Shueb *et al.*, 2015). Known impacts of ADP on everyday life include: difficulty with function such as eating and speaking; sleep disturbance; interference with social life; reduced productivity or time off work and psychological wellbeing (Nuttall *et al.*, 2011b; Constante *et al.*, 2012; Cohen *et al.*, 2009b; Currie, Stone and

Durham, 2015; Cohen *et al.*, 2011a). Given that problem-orientated dental attenders will often delay care-seeking for ADP for weeks they will be suffering with intense pain and these impacts on everyday life for a prolonged period. Indeed, problem-orientated dental attenders have been shown to have poorer oral health related quality of life using OHIP-14 compared to regular dental attenders (Gaewkhiew *et al.*, 2017). This can lead to attempted self-management of ADP, for example use of analgesics (discussed further below), antibiotics and home remedies (such as oil of cloves, ice, salt water), as well as seeking advice from family, friends, and alternative health care providers (Stoller *et al.*, 2001; Cohen *et al.*, 2009b; Jaiswal *et al.*, 2015). In extreme cases problem-orientated attenders have also reported self-extraction of painful teeth (Gilbert, Duncan and Earls, 1998) and self-medication with substances such as petrol, urine, snuff and whiskey (Preshaw, Meechan and Dodd, 1994; Agbor and Azodo, 2011; Currie, Stone and Durham, 2015).

## 2.4.2 Severe infection and hospital admission

ADP has the potential for severe infection when untreated, this can include spread of infection to involve deep fascial spaces, mediastinitis, cavernous sinus thrombosis or a compromised airway (for example Ludwig's Angina), or systemic involvement leading to sepsis (Pogrel, Kahnberg and Andersson, 2014). The reported prevalence of these varies throughout the literature, largely being based on retrospective studies of regional maxillofacial unit service evaluations or audits. For example, patients being admitted to hospital with sepsis as a result of odontogenic infection has a reported prevalence between 16% (Byers, Lowe and Goodall, 2012) and 61.2% (Handley et al., 2009), and in a recent nationwide UK audit was reported at 45.5% (Henry et al., 2021). These infections require urgent treatment, often with the need for hospital admission for systemic treatment and/or surgical intervention requiring a general anaesthetic (Uluibau, Jaunay and Goss, 2005). Often patients will require an overnight stay in hospital and some cases will require admission onto an intensive care unit (Uluibau, Jaunay and Goss, 2005). Unfortunately, these severe infections due to ADP can result in mortality, with reported prevalence of hospital admissions between less than 1% (Kim et al., 2012; Opitz et al., 2015) and 8% (Sethi and Stanley, 1994). Given that mortality is rare, long term multicentre studies are required to be able to accurately report the prevalence associated with severe odontogenic infections.

Patients who are admitted to hospital with severe dental infections are either reported as an equal gender split (Allareddy *et al.*, 2012; Shah *et al.*, 2013) or predominantly male (Whyman *et al.*, 2014; Henry *et al.*, 2021; Christensen, Han and Dillon, 2013). They are often in the third or fourth decade of life (Allareddy *et al.*, 2014b; Henry *et al.*, 2021; Christensen, Han and Dillon, 2013), and irregular dental attenders (Uluibau, Jaunay and Goss, 2005). Male patients are also more likely to present to hospital later than female patients and have more severe infection on presentation (Kent *et al.*, 2021). Progression to severe infection requiring hospital admission is also associated with increasing deprivation (Byers, Lowe and Goodall, 2012; Whyman *et al.*, 2014; Kruger and Tennant, 2015), with evidence that this gradient is increasing over time (Moles, 2008). These demographics are comparable to those of problem-orientated attenders, which are discussed later in this chapter.

Worryingly, the number of hospital admissions due to severe dental infections is steadily increasing both in the UK (Thomas *et al.*, 2008; Robertson and Smith, 2021) and elsewhere in the world (Shah *et al.*, 2013; Allareddy *et al.*, 2014b; Whyman *et al.*, 2014; Kruger and Tennant, 2015). In England the rate of hospital admission resulting from dental infections was 5.36 per 100,000 of the English population in 2019-2020 and data reports 36,197 patients being admitted to hospital in England over the previous twenty years for surgical intervention (Robertson and Smith, 2021). A potential reason within the literature for these increasing hospital admissions was a change in dental policy causing problems with dental access (Burnham, Bhandari and Bridle, 2011). However, this was a short-term observational study and did not control for potential confounding factors and is therefore unlikely to fully explain this trend. Further qualitative research is needed to explore the reasons why patients delay care-seeking until hospital admission is required as well as understanding the barriers that this cohort of patients face to utilising routine dental care.

These hospital admissions will have an economic impact. Within the US the average charge per hospitalisation due to odontogenic infection was \$28,841 between 2003 and 2010 (Ahmad *et al.*, 2013). No data are available on the associated cost within the UK, however there will be direct (for example hospital costs) and indirect (for example time off work, loss of earnings) economic impacts to consider.

It is important to note that severe infections and complications such as these are preventable when caused by odontogenic infection, and in many cases patients have early signs and symptoms for several weeks or months before admission indicating

that dental treatment may be required (Uluibau, Jaunay and Goss, 2005; Jundt and Gutta, 2012). Indeed, a large multicentre audit within the UK found that around half of patients presenting to hospital had not sought treatment elsewhere prior to admission (Henry *et al.*, 2021). This means that these hospital admissions are avoidable if advice or operative dental treatment is carried out at an earlier stage. Indeed, there is also evidence that preceding dental intervention (for example endodontic treatment or extraction) reduces the severity of infection, length of hospital stay and need for intensive care compared to no dental treatment when admitted (Seppanen *et al.*, 2011). Interestingly, of those who do seek care from a health professional prior to admission treatment is often limited to antibiotics alone without operative dental intervention (Henry *et al.*, 2021), which may indicate that inappropriate treatment is being provided by health professionals when patients present for urgent dental care. Encouraging patients with ADP to seek dental treatment at an early stage is therefore imperative and of upmost importance in problem-orientated attenders who will tend to delay care-seeking.

## 2.4.3 Analgesia overdose

Due to pain intensity and impact on everyday life patients with ADP often selfmedicate with analgesics, with increasing pain intensity correlating with dose taken (Pape et al., 2019). The determinants for the use of analgesics have been found to be related to the impact ADP has on quality of life, perceived inability to cope, and pain intensity (Pau, Croucher and Marcenes, 2008). Patients attending dental emergency care most commonly report taking paracetamol and/or ibuprofen (Bhati et al., 2000; Nusstein and Beck, 2003; Currie, Stone and Durham, 2015; Hommez et al., 2018; Pape et al., 2019; George and Meldrum, 2020), however a range of different analgesics are often used in combination (Hommez et al., 2018). Patients can also take analgesics on a daily basis for months before seeking dental care (Preshaw, Meechan and Dodd, 1994). Interestingly, one study (Hommez et al., 2018) found that the majority of patients attending a dental emergency clinic (DEC) reported taking analysesics on the advice of a range of healthcare professionals however, there was a reported lack of knowledge around maximum daily doses of these over-the-counter medications (George and Meldrum, 2020). It is therefore of upmost importance that patients and the public are educated in this by healthcare professionals, as well as analgesia packaging containing clear concise messaging.

Unfortunately, as patients rely on analgesics for self-management of ADP this can lead to unintentional overdose. This is possibly not surprising if many are unaware of the maximum dose they are able to take. The reported incidence of this is scarce, with publications largely limited to case reports and series, audits and questionnaire based studies, however reported rates vary widely from 2.0% in primary dental care (George and Meldrum, 2020) to between 6.0% (Pape *et al.*, 2019) and 62.2% (Hommez *et al.*, 2018) in DECs. In terms of medical emergency department (ED) attendances for unintentional overdoses, 38% to 41% of patients attending have overdosed due to ADP (Siddique, Mahmood and Mohammed-Ali, 2015; O'Sullivan, Ahmed and Sidebottom, 2018) and experiencing ADP makes you 13 times more likely to accidentally overdose than any other type of pain (Vogel *et al.*, 2011).

Patients who unintentionally overdose due to ADP tend to be aged 30-39 years (Siddique, Mahmood and Mohammed-Ali, 2015; O'Sullivan, Ahmed and Sidebottom, 2018) and the most common analgesics are ibuprofen (76.6%) and paracetamol (32.4%) (Hommez *et al.*, 2018), which would be in keeping with those most frequently used for ADP. Female patients are both significantly more likely to take analgesics for ADP (Nusstein and Beck, 2003) and to overdose unintentionally than male patients (Shone *et al.*, 2011; Hommez *et al.*, 2018). The reasons for this are unknown. Patients who delay seeking care for ADP are significantly more likely to overdose on analgesics (Hommez *et al.*, 2018). Reasons for delaying care-seeking are unknown, however over half of patients admitted with an unintentional overdose report having a dentist they were unable to get an appointment with (O'Sullivan, Ahmed and Sidebottom, 2018) meaning that access could play a part.

Health literacy is known to be significantly associated with unsafe use of prescription only medications (Davis *et al.*, 2006) and analgesics, along with lower sociodemographic status (Shone *et al.*, 2011). In particular adolescents and young adults are reported to have a poor understanding of over-the-counter medication use and dosage (Gilbertson *et al.*, 1996; Huott and Storrow, 1997; Wilson *et al.*, 2010; Shone *et al.*, 2011).

In terms of outcome of analgesic overdose, from those who attend a medical ED, two-thirds require admission for treatment, with a mean length of stay of 1.22 nights (O'Sullivan, Ahmed and Sidebottom, 2018). Where possible, patients are referred to the maxillofacial team for appropriate dental management as an inpatient, however the majority decline treatment and instead opt to see their own dentist on discharge

(O'Sullivan, Ahmed and Sidebottom, 2018), it is unknown how many of these patients having had urgent management in EDs do then subsequently attend for definitive dental care. This could in theory create a cycle of repeated experience of ADP and self-management with analgesic use, putting the patient at further risk if dental treatment is not sought.

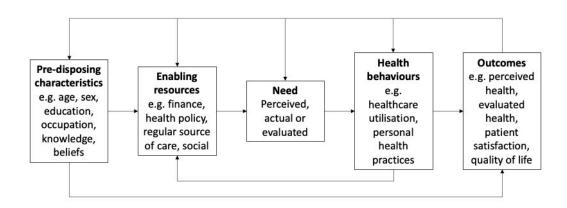
### 2.5 Utilisation of Dental Care

Healthcare utilisation is defined as the quantification or description of the actual use of healthcare services (Carrasquillo, 2013). Linked to utilisation is access which is the ability to make use of services in a timely manner to achieve best possible health outcomes (Institute of Medicine, 1993) in proportion to community or individual healthcare needs (Watt, 2007). Access is linked to the wider organisation of health services as well as to individual level factors such as knowledge and ability to pay for care (Allebeck, 2013). Utilisation and access are distinct concepts however are linked as access is required to allow utilisation (Lutfiyya *et al.*, 2019). This section will therefore cover access to, and utilisation of, dental care in terms of regular dental attendance and problem-orientated attendance. The following section will then cover utilisation and access in terms of where problem-orientated dental attenders can access care.

### 2.2.1 Models of health service utilisation and access

Studies examining dental care utilisation often use models of health service use. The main one used in dental research, as well as wider healthcare literature, is Andersen's Behavioural Model of Health Service Utilisation (Andersen, 1995; Andersen and Newman, 2005). This model shows how social, individual and system factors can influence utilisation of health services. Within the model there are three factors: predisposing characteristics (factors existing prior to illness); enabling resources; and need (Figure 2.3). The model explains that an individual may be more or less predisposed to seek care, for example by age, education, or beliefs, but that they also need to have the enabling resources for this, for example the ability to pay for, or services they can access. In addition, actual utilisation of health services will then only occur if the person needs care or treatment, which may be perceived as a need by them, or determined as a need by a clinician. Predisposing, enabling and need interact to determine health behaviours, such as utilisation of care or personal health practices, an example of this in dentistry would be toothbrushing, which then impact on outcomes such as quality of life. This model is widely used in health

services research and has empirical evidence to supports its use in dental research (Baker, 2009).



**Figure 2.3:** Andersen's model of health service utilisation (Andersen, 1995). Adapted from (Marshman, Baker and Robinson, 2014; Worsley, Robinson and Marshman, 2017).

Predisposing, enabling and need can be described at the individual and contextual level, whereas health behaviour and outcome are described only at the individual level. Need may also be influenced by environmental factors, for example water fluoridation will effect dental utilisation (Worsley, Robinson and Marshman, 2017). Predictors of utilisation can sometimes overlap between predisposing characteristics and enabling resources, such as income which can be considered as enabling in terms of ability to pay, but can also be a predisposing in terms of whether someone seeks care (Gilbert, Branch and Orav, 1990; Baker, 2009). Within the model, it is also recognised that these health behaviours and outcomes feed back into the central process due to, for example, health outcomes being able to affect health beliefs as well as perceived and actual need.

Need is a complex area in dental utilisation. Those clinically most in need of dental services are less likely to receive it (Gilbert, Duncan and Vogel, 1998), and need can be predictive of utilisation in both a positive and negative direction depending on the outcome measurements and treatment category used (Gilbert, Shelton and Duncan, 2002; Gilbert *et al.*, 2003). For example, high need measured in terms of lost or broken restorations can predict dental utilisation for restorative care in a positive direction because the outcome is associated with previous dental treatment (Gilbert, Shelton and Duncan, 2002). Whereas, in the same study, need measured in terms of ADP and its associated symptoms can predict utilisation for a dental cleaning in a negative direction because it is associated with delayed or non-attendance. In addition, when considering self-reported perceived need conflicting findings are

reported, with some patients reporting high perceived need being more likely to seek regular dental care (Gregory, Gibson and Robinson, 2007; Lundegren et al., 2013), and others being less likely to (Marshman et al., 2012). This could be interpreted in two ways: (1) those with high perceived need seek regular dental attendance for reassurance of their maintained good oral health (are the "worried well"), or (2) those who do not seek care have high perceived need because they are aware they likely need dental treatment because of their non-attendance. For this reason and the potential for reverse causation study design needs to be considered when interpreting the literature using Andersen's model. Indeed, a limitation within the literature is that utilisation was often measured using cross-sectional studies (Hajek, Kretzler and König, 2021), therefore it is difficult to ascertain temporality and causation, such as the link between dental utilisation and need. An additional limitation is that utilisation is often measured as whether or not someone attended dental services within a set time period (i.e., the past 12 months) (Jang, Kim and Kim, 2021), sometimes with no distinction between attending for routine preventive care or urgent dental care (Guiney et al., 2011). This makes it challenging to relate some of the literature on utilisation specifically to problem-orientated dental attendance compared to regular attendance.

## 2.5.1 Regular dental attendance

There are several benefits to receiving regular preventive dental care. Dental diseases are preventable, therefore regular advice from a dentist on oral health behaviours and intervention, such as application of fluoride varnish, can reduce the need for invasive dental treatment (Harris, Pennington and Whitehead, 2017). Regular dental attendance is associated with better oral health outcomes including: quality of life using OHIP-14 and number of missing teeth (Sanders, Spencer and Slade, 2006); reduced numbers of decayed teeth and toothache experience (Unell *et al.*, 1999); improved social and psychological indicators, for example ability to speak, eat and worry less about oral health (Richards and Ameen, 2002). Patients with a regular source of dental care are also significantly less likely to experience ADP (Constante *et al.*, 2016), need to access emergency dental services (Powers *et al.*, 2000) and are more likely to seek care early if they do have ADP (Cohen *et al.*, 2011a). In addition, the longer regular dental care is maintained across the life course the stronger the effect of improved oral health (Thomson *et al.*, 2010).

Current guidelines suggest that dental check-up or recall intervals in the UK should be based on individual patient risk of oral and dental diseases, being between 3- and 24-months for adults (NICE, 2004). However, six monthly recalls are often used as established practice (Clarkson *et al.*, 2009). These differences in recommendations and practice can make interpretation of the dental utilisation literature challenging. According to NICE guidelines it is possible for patients to seek care every two years if they are considered low risk and these patients would certainly be considered regular dental attenders, however some studies use one year as a cut off for regular attendance (Hajek, Kretzler and König, 2021), meaning that incorrect interpretation of the data is possible.

In the most recent ADHS almost two-thirds of UK adults reported attending a dentist for regular check-ups, leaving around one-third (27%) as problem-orientated dental attenders and less than 2% as never attenders (Morris. et al., 2011). A more recent report highlighted a higher percentage (84%) of adults as visiting a dentist in the previous 12-months (Public Health England, 2018), however this did not distinguish between reasons for attendance (e.g. routine or urgent) and the sample was recruited from primary dental care and therefore could under-represent problemorientated and dental non-attenders. Older adults report seeking regular dental care more commonly than younger adults (Hadler-Olsen and Jönsson, 2021), with regular dental attendance being lowest in those 25- to 34-years-old (Morris, et al., 2011). A gender difference in regular dental attendance was also reported, with more women seeking regular dental care than men, also reported elsewhere (Scully, 1995; Guiney et al., 2011; Currie, Stone and Durham, 2015; Nayee, Kutty and Akintola, 2015). Subtly different predictors of dental utilisation are reported between genders, with employment status being a predictor for males but not females, and age being a predictor for females but not males (Guiney et al., 2011), dental anxiety and financial concerns are also reported as a barrier to dental utilisation in females more than males (Hakeberg and Wide Boman, 2017), however there is variation in these reports throughout the literature.

Dental utilisation varies throughout the world with global estimates of regular utilisation at 54% (Reda *et al.*, 2018). There is a wide range in dental utilisation reported between 11% and 94% which is associated with developmental status of the country (Reda *et al.*, 2018). Dental utilisation has reduced within the UK recently due to the COVID-19 pandemic causing all dental practices to close during lock down

(Chief Dental Officer, 2020) and operating on a reduced basis once reopened due to risk of transmission with aerosol generating procedures (NHS England and Improvement, 2021). During this period of dental practice closure dental treatment was only offered for urgent and emergency dental care (Carter *et al.*, 2020), forcing patients into a problem-orientated attendance pattern. The most recent data indicate that there has been a decrease of almost 70% in terms of courses of dental treatment delivered in 2020 to 2021 (NHS Digital, 2021). Whether this will result in long term behaviour change in some leading to increase rates of problem-orientated attendance is unknown.

Predisposing characteristics associated with regular dental care use include: older age, white race, urban location, higher education level, employment, income and higher self-rated health (Newman and Gift, 1992; Gilbert, Duncan and Vogel, 1998; Guiney et al., 2011). Enabling characteristics for regular care-seeking include the ability to pay for dental care (Newman and Gift, 1992; Gilbert, Duncan and Vogel, 1998; Guiney et al., 2011). In addition, supportive family structures, higher health literacy, and good general and oral health are associated with regular dental utilisation regardless of country or worldwide region (Reda et al., 2018). Regular dental attenders also tend to value their oral health more than irregular attenders (Edwards, Randall and McNeil, 2021), which may indicate that they have a higher perceived need for preventive dental care in terms of Andersen's model. Indeed, those who attended for regular dental care in a longitudinal study had increased perceived need specifically for a check-up, as well as better self-rated and evaluated dental health (Gilbert et al., 2003). This could be the result of them believing they need regular, preventive care therefore attending for check-ups and because of their regular care-seeking behaviour. In addition, the health behaviours of regular dental attenders have been compared to those with chronic illness, with the need to know their current dental health status as part of a "checking cycle" (Gibson et al., 2000). This would again fit with the concept that regular attenders understand and acknowledge the specific need for a dental check-up as opposed to only seeking care with specific problems.

#### 2.5.2 Problem-orientated dental attendance

Problem-orientated dental attenders tend to be male and in the third or fourth decade of life (Allareddy *et al.*, 2014a; Currie *et al.*, 2016; Currie, Stone and Durham, 2015; Morris. *et al.*, 2011; Sun *et al.*, 2015), with a general decreasing prevalence as age

increases (Morris. *et al.*, 2011). The fact that problem-orientated attenders are more likely to be male fits with wider medical literature whereby a health behaviour paradigm has already been described related to masculinity and men being less likely to seek care from a general medical practitioner (GMP) (UCL Institute of Health Equity, 2013; Baker *et al.*, 2014). A socio-economic gradient is also seen in rates of problem-orientated attendance, with those from the most deprived areas being more likely to attend in this manner (Bullock *et al.*, 2001; Morris. *et al.*, 2011; Currie, Stone and Durham, 2015), which is discussed further in the following section.

In contrast to regular attenders, problem-orientated dental attenders are more likely to suffer with ADP (Duncan *et al.*, 2003), have poorer oral health and oral health related quality of life (Gilbert *et al.*, 1997; Bullock *et al.*, 2001; Thomson *et al.*, 2010; Gaewkhiew *et al.*, 2017). If these patients could change their attendance habits and become regular attenders, their oral health and associated quality of life would likely improve, and their risk of further disease may reduce if preventive advice from the dentist is followed.

Reduced utilisation of dental services is associated with lower socioeconomic status, racial minorities, male gender, rural location and lower education level (Lutfiyya et al., 2019). In terms of Andersen's model, predisposing characteristics for being a problem-orientated attender include race, gender and being frustrated with previous dental care, and enabling characteristics include the ability to pay and dental anxiety (Gilbert et al., 2003; Singh and Brennan, 2021). In terms of need, self-reported dental problems, oral pain and discomfort, oral functional limitations (such as difficulty chewing) and poor self-rated oral health are associated with a higher probability of problem-orientated dental attendance and a lower probability of seeking regular dental care (Gilbert et al., 2003). Therefore, in contrast to regular dental attenders, problem-orientated attenders seek care when they have a perceived need in relation to a *specific problem*, rather than perceived need for a check-up. In addition, perceived need related to dental problems can predict utilisation dependent on whether the individual considers the problem something that can wait or not. Signs and symptoms of dental abscesses and/or toothache are associated with a higher probability of dental utilisation, compared to dissatisfaction with appearance of the teeth which has a lower probability of utilisation (Gilbert, Duncan and Vogel, 1998). Furthermore, the perceived relevance of oral health is associated with dental attendance, with ADP increasing relevance and therefore initiating potential dental

attendance in non-attenders (Gregory, Gibson and Robinson, 2007). This may imply that ADP can influence perception of need in problem-orientated attenders initiating them to seek care, whereas although they may be dissatisfied with their dental appearance this is seen as something which can wait. Indeed, in a cross-sectional study those with high levels of perceived treatment need were less likely to be regular dental attenders (Marshman *et al.*, 2012), which may indicate that problem-orientated attenders are aware that they are likely to need treatment, but this alone is not enough to initiate regular attendance.

Access to dental care is also of relevance in terms of Andersen's model. Access can be considered in a number of ways: (1) Enabling factors influence *potential access*; (2) Actual use of services is a health behaviour outcome (*realised access*); (3) When health outcomes improve access can be considered as *effective access* (Worsley, Robinson and Marshman, 2017). Perceived problems accessing a dentist are associated with increased oral health impacts and can also influence oral health and dental utilisation via a number of indirect pathways in Andersen's model (Marshman *et al.*, 2012). This study was carried out in an area and time where access was not considered a problem as the volume of NHS dentists matched that of patient need. Given that living in a rural area is associated with reduced dental utilisation (Lutfiyya *et al.*, 2019) it would be interesting to look closer at dental utilisation related to access in a similar manner to Marshman *et al.* (2012) in rural areas where access can be considered a true barrier. In addition, given the change in dental access during the COVID-19 pandemic access may influence dental utilisation even more in the future and may warrant further studies.

Dental utilisation and problem-orientated attendance can be related to socioeconomic status. This can be a predisposing characteristic, however an enabling resource related to this is the ability to pay for dental treatment. Indeed, there are clear income related inequalities in dental utilisation (Guiney *et al.*, 2011; Hakeberg and Wide Boman, 2017) and those who are less able to afford care are less likely to access regular dental care and instead attend in a problem-orientated manner (Worsley, Robinson and Marshman, 2017). There is therefore a clear link between problem-orientated dental attendance and oral health inequalities which is explored further in the following section.

### 2.5.3 Dental utilisation and oral health inequalities

Oral health inequalities are a global health problem (Peres et al., 2019b; Watt et al., 2019) and there is substantial evidence that dental caries, periodontal disease and oral cancer disproportionately affect the most poor and marginalised in society with clear links to socioeconomic status which remain even when controlling for other risk factors (Klinge and Norlund, 2005; Conway et al., 2008; Schwendicke et al., 2015; Costa et al., 2018). The pathways to these inequalities are complex (Guarnizo-Herreño et al., 2021) and under-researched (Public Health England, 2021) but can be attributed to structural determinants (e.g., policies), intermediate determinants (e.g., social class, income, education, psychosocial factors), and proximal determinants (e.g., diet, alcohol, smoking, immune response) (Peres et al., 2019b). Although there is some debate as to how much of a part dental utilisation plays in oral health inequalities, it is likely to have a modest effect when measured as an influence on number of teeth (Guarnizo-Herreño et al., 2021) and it is agreed that it will contribute to some extent given that a social gradient also exists in utilisation (Harris, Pennington and Whitehead, 2017) with patients who are regular dental attenders tending to be from higher socioeconomic groups (Jamieson and Thomson, 2006). In addition, there is evidence that reducing barriers to regular dental attendance in low socioeconomic groups may reduce oral health inequalities (Donaldson et al., 2008), although this has a less profound effect when applied in isolation (Guarnizo-Herreño et al., 2021).

Dental utilisation relates to the inverse care law, which states that "the availability of good medical care tends to vary inversely with the need for it in the population served" (Tudor Hart, 1971). Dental practices tend to be set up in urban, affluent areas serving those who need them the least (Jones, 2001; Landes and Jardine, 2010; Watt *et al.*, 2019) and having a greater distance to travel to dental services reduces access for the more deprived (Worsley, Robinson and Marshman, 2017).

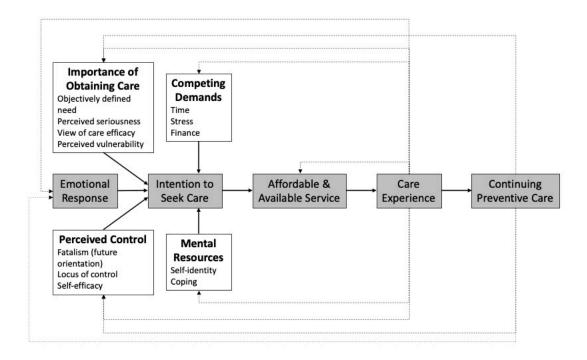
Racial and ethnic disparities also exist with resulting oral health inequalities partly related to dental utilisation via: (1) creation of inequitable access; (2) discrimination leading to psychosocial barriers; (3) impact on dentist-patient relationship and treatment decision-making (Jamieson *et al.*, 2021). Intersectionality describes a person's identity as being composed of multiple social elements which interact with one another, rather than being separate independent entities (Kapilashrami, Hill and Meer, 2015), and this is important to consider in oral health inequalities as there is

evidence of inequalities within already marginalised groups (Muirhead *et al.*, 2009). There is a sparsity of oral health research examining intersectionality (Muirhead *et al.*, 2020), however there is some evidence that this will affect dental utilisation. Patients with disabilities who access urgent dental care are associated with increased deprivation and poorer oral health (Worsley, Robinson and Marshman, 2017). In addition, patients who are male, younger and non-white are less likely to have a dental visit in the last year (Sabbah *et al.*, 2019), although the authors theorised that these were confounders and therefore missed the potential for intersectionality to be investigated (Muirhead *et al.*, 2020). Clearly there is need for further research looking at intersectionality and dental utilisation leading to poorer oral health and how this can be overcome.

There are several theories of relevance to oral health inequalities including materialist, cultural or behavioural, psychosocial and life course explanations (Sisson, 2007). The materialist explanation focuses on factors within the external environment, outside of a person's control, for example direct and indirect costs of dental care or cost of a healthy low sugar diet. Cultural or behavioural explanations emphasise behaviour and lifestyle choices, with people from low socioeconomic backgrounds being more likely to engage in damaging or risky behaviours, such as poor dental self-care, diet, smoking and alcohol use. The psychosocial perspective states that psychological stress is higher in those from more deprived backgrounds and as such are at higher risk of disease both directly and indirectly. Finally, the life course perspective argues that health is related to prior living conditions from conception onwards, and as a result, inequalities arise from a combination of materialist, behavioural/cultural and psychosocial factors across the life course.

By use of Andersen's model it has been shown that the impact of socioeconomic status (predisposing characteristics: social class, qualifications and income) on need (perceived and evaluated), use of services (health behaviour) and perceived oral health outcomes (quality of life measured via OHIP-14) is indirect (Baker, 2009). However, use of the this model to explain the inequalities in dental utilisation has been critiqued and a further dynamic conceptual model produced (Harris, Pennington and Whitehead, 2017). On the individual level (Figure 2.4) the importance of obtaining care, the emotional response to the prospect of seeking care, and perceived control over whether the individual can receive care interact to determine the intention to seek dental care. At this point there is a balance between competing

demands (e.g. time, stress and finance) against internal resources (e.g. coping, self-identity). This can reduce the intention to seek care, which is then further affected by availability and affordability of dental care services, and then by experiences when the individual seeks care (as well as previous care-seeking experiences) (Muirhead et al., 2013). Harris et al. (2017) theorise that these factors will have differential burdens on individuals based on social background, therefore explaining why those from lower socioeconomic backgrounds are less likely to utilise regular dental care.



**Figure 2.4:** Micro-level model explaining inequalities in dental utilisation (adapted from Harris, Pennington and Whitehead, 2017).

In addition to this, the authors also highlight the importance of meso-level and macro-level constructs in dental utilisation related to inequalities (Harris, Pennington and Whitehead, 2017). Meso-level constructs are social processes and community structures including: social norms and sanctions; obligations, expectations and trust; information channels; social structure; neighbourhood fabric. Macro-level constructs include population-wide structures and policies, such as health policy, employment, transport and social capital available to communities. It is theorised that when individuals are from the most deprived areas and have socioeconomic circumstances that promote problem-orientated attendance it is the meso-level factors which are the prime determinants of dental utilisation (Harris, Pennington and Whitehead, 2017). As an example, people from the most deprived areas with higher levels of dental disease will have reduced oral health function as a result, however this will be normalised and seen as having a lower impact as a result of social norms compared

to those from more affluent areas (Gibson *et al.*, 2000; Harris, Pennington and Whitehead, 2017), which may explain why dental care for ADP is delayed. In addition, stigma attached to poor oral health, which may be seen as socially unacceptable, can heighten emotions when those from the most deprived areas seek dental care causing anxiety and widening the professional gap between the patient and the dentist (Harris, Pennington and Whitehead, 2017) meaning that the patient-dentist relationship is even more important in this patient group. Barriers to dental utilisation are discussed further later in this chapter.

There is no doubt that oral health inequalities are a priority for oral health research and that efforts are needed on a global level to begin to address these, with calls recently for upstream interventions, policy change and reform to oral healthcare services (Watt *et al.*, 2019). Indeed, there is evidence that individual level interventions can widen inequalities as those with a higher education level and wealth are more likely to respond to individual approaches because they have more control over their lives (Marmot and Bell, 2011). Furthermore, dental utilisation and other factors such as diet and oral hygiene contribute to oral health inequalities, but addressing these alone won't solve inequalities without considering the "cause of the cause", i.e. the social distribution of the causes of disease which will require action on the wider social determinants of health (Marmot and Bell, 2011).

Problem-orientated attenders tend to live in the most deprived areas therefore oral health inequalities, as well as wider health inequalities, are likely to be of relevance and need to be considered throughout this thesis and the research carried out. Any intervention designed must take inequalities into consideration to avoid potentially widening any gaps that already exist. It is also important, however, to remember that problem-orientated attendance is not an attendance pattern confined to just those from most deprived areas (Currie, Stone and Durham, 2015), therefore it will be important to consider views and experiences of problem-orientated attenders from across the social gradient. This also fits with the proposed "proportionate universalism" approach to tackle health inequalities (Marmot, 2010), whereby the aim should be to include everyone in society to improve overall health but be mindful to work harder to include those from the most deprived areas.

## 2.6 Current Potential Care Pathways for Acute Dental Pain

When patients experience ADP, they fall into the remit of unscheduled urgent and emergency dental care. Unscheduled refers to the fact that dental problems can

present either inside or outside of normal working hours (Public Health England, 2019). Urgent and emergency dental conditions are defined as those likely to cause deterioration in either oral or general health therefore requiring the need for timely intervention to reduce this risk and to reduce complications (Scottish Dental Clinical Effectiveness Programme, 2013). Urgent dental care is split into three categories of need: emergency, urgent and routine care which are summarised in Table 2.2 (Scottish Dental Clinical Effectiveness Programme, 2007; NHS England and NHS Improvement, 2019).

Category	Timescale	Provider	Examples
Emergency	Assessment within 60 minutes	Primary dental care, emergency dental clinic or, if out-of-hours, then a local dental emergency clinic or another agreed provider such as oral and maxillofacial on-call	Trauma, significant orofacial swelling, post-extraction bleeding, and dental conditions resulting in acute systemic illness or severe trismus
Urgent	Assessment within 24 hours	Primary dental care, emergency dental clinic or, if out-of- hours, then a local dental emergency clinic	Dental and soft tissue infections with no systemic involvement, severe ADP which cannot be controlled with selfmanagement, fractured teeth with pulpal exposure
Routine	Assessment within 7 days	Primary dental care, emergency dental clinic or patient self- help where appropriate	Mild or moderate pain, minor dental trauma, loose or displaced dental restorations

**Table 2.2:** Categories of urgent and emergency dental care in the UK (Scottish Dental Clinical Effectiveness Programme, 2007; NHS England and NHS Improvement, 2019).

Patients who are experiencing ADP often present to general dental practitioners (GDPs) and they may choose to access emergency treatment in primary care either through the NHS or may choose to access privately funded treatment. They may also decide to attend secondary care 'walk-in' access clinics frequently found in NHS funded dental hospitals or community dental services (referred to as dental emergency clinics (DEC) throughout this thesis). Patients will decide which of these services to go to, but little is known about their motivations and what factors they take into consideration in making these decisions.

The literature on care pathways in urgent dental care is scarce and suggests there is confusion among patients as to how to access care (Public Health England, 2019),

and that multiple care providers can be seen before obtaining relief from ADP (Pau, Croucher and Marcenes, 2000). This confusion around access may result in patients seeking care from a variety of different healthcare providers including: GMPs, pharmacists, and emergency departments (ED, also known as accident and emergency). Some of these healthcare providers may be able to offer advice but will not be able to offer definitive dental treatment. In addition, there are wider economic burdens of patients inappropriately attending costly services e.g., the ED for dental problems, or attending multiple services for the same problem. Understanding some of the decisions that patients make when accessing treatment for ADP may help gain greater understanding of patient's priorities and facilitate interventions that guide and direct patients to the most appropriate healthcare provider for their problem.

As mentioned above, ADP does not just occur during normal working hours and patients may need to seek care out-of-hours. This type of emergency provision is in place and advice can be accessed via NHS 111, but availability and access to services are likely to have significant variation geographically (Stobbart *et al.*, 2015) and may impact upon how patients seek care.

The literature on the various healthcare settings patients can seek urgent and emergency dental care are discussed throughout this section.

## 2.2.1 Emergency dental care

NHS England is responsible for commissioning urgent dental care, with management via Local Area Teams. In primary dental care urgent treatment falls under a band 1 NHS urgent treatment charge for the patient, corresponding to 1.2 units of dental activity for the dentist (see Appendix A for a summary of NHS Dental Charge Regulations). Unfortunately, there is wide variation in access to urgent dental care across England (Public Health England, 2019).

Responsibility for NHS unscheduled urgent dental care has varied in England in relation to changes in dental contracts. In the 1990s dental practices had responsibility for providing urgent dental care to patients registered at their practice, however they had no responsibility for those who were unregistered, instead local commissioners had to decide on provision of unscheduled dental care for these patients. In 2006 a new dental contract was introduced (Department of Health, 2005) which moved responsibility for out-of-hours urgent dental care to Primary Care Trusts (now Local Area Teams). In the same changes the concept of patient registration

was also 'lost' as from 2006 dental practices are only responsible for providing urgent dental care in hours to those who were undergoing an active course of treatment at the practice. Patients are advised to contact the dental practice where they usually seek dental care during working hours to request urgent care, however whether this is provided will then vary depending on practice capacity in time and contract value. This change could, therefore, create an access barrier to problem-orientated attenders seeking emergency dental care in primary care.

The literature on care-seeking for ADP in dental services is largely from secondary care DECs, with little reported in primary care, particularly since the major contractual changes in 2006. Most studies are also clinical audits or service evaluations rather than research (Matthews *et al.*, 1992) and are often cross-sectional in design (Austin *et al.*, 2009), and the findings are therefore limited.

In terms of demographics, young adults tend to utilise urgent dental care the most, with patients aged 24- to 59-years-old being more likely to attend (Worsley, Robinson and Marshman, 2017). Patients tend to be male, in the third or fourth decade of life, unemployed and complaining of toothache (Austin et al., 2009; Nayee, Kutty and Akintola, 2015; Pape et al., 2019; Currie, Stone and Durham, 2015; Guivarc'h et al., 2020). The majority of urgent dental care patients report only rarely attending a dentist for routine check-ups, or that they only attend a dentist when in pain (Austin et al., 2009; Nayee, Kutty and Akintola, 2015; Pape et al., 2019; Guivarc'h et al., 2020). A sizeable proportion of those using urgent dental care services will therefore fit the definition of problem-orientated dental attenders and unsurprisingly this indicates that urgent dental care services, in particular DECs, are places that this patient group seeks care. However, in one study in England almost half of the patients at a DEC reported having a dentist (Currie, Stone and Durham, 2015). Access to urgent dental treatment in primary care may therefore be part of the problem with around half of DEC attendees reporting an inability to access care (Gibson, Blasberg and Hill, 1993; Nayee, Kutty and Akintola, 2015). It could be that appointment times and availability in primary care may be less flexible than for routine dental treatment. Alternatively, this could indicate patient confusion over NHS dental registration status, as at the time of the study patient registration no longer existed yet around one half believed they were "registered" (Currie, Stone and Durham, 2015). In the same study onethird of patients reported accessing the same DEC previously and 13% for the same problem. Repeated attendance has been reported elsewhere being between 23%

and 64% (Widström *et al.*, 1988; Scully, 1995; McCartan, Harrison and Daly, 2000; Guivarc'h *et al.*, 2020), this is likely to create an economic burden on the NHS, however research has not yet been carried out to establish the impact of this. The pre-existent social gradient in dental utilisation persists into urgent dental care. Higher levels of deprivation lead to increasing need for access to urgent dental care (Tramini *et al.*, 2010; Landes, 2014; Worsley, Robinson and Marshman, 2017) and deprivation is linked with greater perceived and evaluated need for urgent care and therefore increased utilisation both in the UK and internationally (Rocha *et al.*, 2013; Worsley, Robinson and Marshman, 2017).

Symptoms seem to drive urgent dental care attendance, with unmanageable pain being a substantial part of this (Pau, Croucher and Marcenes, 2000). When attending for urgent care patients' main expectations are to identify and gain symptom relief, as well as seek reassurance that their pain is not from a serious source (Anderson, 2004). Actual access to urgent care is related to level of deprivation, greater need and higher patient satisfaction (Worsley, Robinson and Marshman, 2017). Patient satisfaction could partly explain repeated attendances seen in urgent dental care located in secondary care due to patients reporting trust in dentists working in this setting (Guivarc'h *et al.*, 2020). However, there is also evidence that those who attend for urgent dental care receive suboptimal treatment and subsequently reattend for extraction (Worsley, Robinson and Marshman, 2017). This, again, is likely to have an economic impact however has not been studied.

Almost two-thirds of patients attend DECs as a first choice of urgent dental care provider (Guivarc'h *et al.*, 2020). There are several proposed reasons as to why patients may choose to attend a secondary care urgent dental service rather than primary care, including: a perceived inability to access primary care; DECs being open access with no need to make an appointment; trust in dentists at DECs; and financial difficulties as treatment at DECs is often free of charge due to service funding arrangements (Matthews *et al.*, 1992; Gibson, Blasberg and Hill, 1993; Scully, 1995; Persson, 2000; Sayers, Rowland and Djemal, 2004; Austin *et al.*, 2009; Nayee, Kutty and Akintola, 2015; Guivarc'h *et al.*, 2020). Suggested reasons by patients for being unable to access urgent services in primary care include: being unable to get an appointment within an emergency/urgent timeframe (Table 2.2); believing that GDPs do not offer urgent appointments, or NHS dental care; and, historically, patients not being registrants of a dental practice (Matthews *et al.*, 1992;

Pau, Croucher and Marcenes, 2000; Sayers, Rowland and Djemal, 2004; Austin *et al.*, 2009; Nayee, Kutty and Akintola, 2015). These reasons could indicate an element of patient misunderstanding surrounding access to urgent dental care, as well as actual access barriers. Knowledge of DECs may also be a reason for patients to attend (and re-attend) as the majority of patients report self-referring to services (Thomas *et al.*, 1997; McCartan, Harrison and Daly, 2000; Sayers, Rowland and Djemal, 2004; Nayee, Kutty and Akintola, 2015), often on advice from family and friends (Gibson, Blasberg and Altom, 1993; Austin *et al.*, 2009). In addition, referral by other health services may also play a part with evidence of patient referrals from GMPs, GDPs, NHS Direct (now NHS 111) and other hospital services reported in the literature (McCartan, Harrison and Daly, 2000; Austin *et al.*, 2009; Nayee, Kutty and Akintola, 2015). This could indicate lack of consistency in urgent dental care pathways.

Before deciding to seek urgent dental care the reported duration of symptoms can vary, with patients attending either within one to three days of onset (Matthews *et al.*, 1992; Scully, 1995), or delaying seeking treatment for a longer period of time and waiting more than two weeks, sometimes months (Gibson, Blasberg and Hill, 1993; Scully, 1995; Currie, Stone and Durham, 2015; Hommez *et al.*, 2018). The reasons why patients can delay treatment for this long is under-researched, and clearly warrants further exploration in qualitative studies. This, in turn, would allow interventions or policy change to be designed to encourage care-seeking at an earlier stage.

The most common diagnoses at urgent dental care clinics are acute apical periodontitis or abscess, and acute pulpitis conditions (Matthews *et al.*, 1992; Gibson, Blasberg and Hill, 1993; Matthews, Peak and Scully, 1994; Tramini *et al.*, 2010; Currie, Stone and Durham, 2015; Pape *et al.*, 2019). Treatments are most commonly tooth extractions or temporary dressings and pulp extirpations (Gibson, Blasberg and Hill, 1993; Thomas *et al.*, 1997; Sayers, Rowland and Djemal, 2004; Nayee, Kutty and Akintola, 2015). Patients are aware that often the treatment they will receive at DECs is temporary (Anderson, 2004), and these temporary treatments may contribute to the re-attendance patterns observed (Scully, 1995; Currie, Stone and Durham, 2015), as this cohort of patients typically will not attend for completion of treatment with a GDP. Global estimates of percentage of uncompleted treatments vary from 13 to 40% of treatments initiated in DECs (Gibson, Blasberg and Altom,

1993; Guivarc'h *et al.*, 2020). Ultimately this could indicate that either once symptoms are relieved the perceived need for problem-orientated attenders to seek care is lost, or that these patients wish to seek follow-up dental care but barriers exist to them attending primary care. Further work is needed to understand potential barriers and what may influence them to change their attendance behaviour.

## 2.6.1 Out-of-hours urgent dental care

There is a requirement for patients to be able to access urgent dental care outside of working hours. Out-of-hours dental care in England is currently accessed via NHS 111 (previously NHS Direct), and/or regional out-of-hours emergency dental services which may be managed and delivered by dental nurses. Within England management of NHS 111 calls for dental care vary by region (Public Health England, 2019). Different services exist in the remainder of the UK, with Scotland offering an NHS 24 service (NHS Inform, 2021), Wales NHS 111 and/or local dental helplines dependent on area (NHS 111 Wales, 2021), and Northern Ireland via dental practices (Health and Social Care Board, 2020). In 2016 NHS England reviewed unscheduled dental care and found wide regional variation in services and therefore recommended change in service provision (NHS England and NHS Improvement, 2019). Commissioning arrangements for this service are via Local Area Teams, explaining why the service varies by region. The majority of patients accessing outof-hours dental care will be managed with advice only via telephone triage, and those requiring dental treatment will be given an appointment at a dedicated out-of-hours dental service. There is little research within out-of-hours dental care in the UK, with the majority of studies being in the 1990s prior to the 2006 English primary care contract reforms which changed provision of out-of-hours care. Whilst there are a few studies looking at local service arrangements there are no studies comparing the different regional arrangements (Public Health England, 2019).

Patients who access out-of-hours dental care most commonly complain of "toothache" (Austin *et al.*, 2009; Worsley *et al.*, 2016) and believe that their problem is either "urgent" or "very urgent" (Austin *et al.*, 2009). From the limited literature available, the demographics of out-of-hours attendees are comparable to those seeking in-hours urgent dental care, being largely male, from the more deprived areas and aged 20- to 44-years-old (Worsley *et al.*, 2016). In contrast, over half of out-of-hours attendees are regular dental attenders (Austin *et al.*, 2009; Worsley *et al.*, 2016), and there is a much lower rate of repeat attendance out-of-hours at 3%

(Worsley et al., 2016). This may indicate that problem-orientated attenders are less likely to access this service, however the reasons for this are unknown. Despite patients being satisfied with the out-of-hours service when they attend (Austin et al., 2009; Worsley et al., 2016), worryingly, a large proportion report little or no improvement in their symptoms (Anderson, Thomas and Philips, 2005) and 33% of patients receive inappropriate treatment with over half being prescribed antibiotics alone (Tulip and Palmer, 2008). In addition, the majority of antibiotics prescribed are clinically inappropriate (McKay et al., 2020). Reasons for high rates of antibiotic prescription in this setting are complex and relate to thirty-one different factors which are outside the scope of this thesis, however examples include: habits; running late; financial burden; patient satisfaction; competing demands and patient influence (Thompson et al., 2020). The lack of patient reported improvement and level of inappropriate treatment indicates a failure in the service and the potential for driving repeated emergency dental attendance as well as antimicrobial resistance.

A major barrier to dental care-seeking out-of-hours is that the public is largely unaware of how to access the service. The majority of out-of-hours attendees are aware of NHS 111 but only 21% were actually referred there by NHS 111, with the majority being recommended these services by family or friends (Austin *et al.*, 2009). In a more recent study only 7% of a UK sample contacted NHS 111 when experiencing dental problems out-of-hours and over half (54%) were unaware of how to contact out-of-hours dental care (Grossman *et al.*, 2018). This situation may be compounded by the variable and often limited amount of information available from primary dental care practices when closed either via voicemail or on their website (Aldallal, Aldallal and Khajah, 2017). Clearly, awareness and guidance on how to access out-of-hours care is required.

Interestingly, Grossman *et al.* (2018) found that only 6% of their UK sample preferred out-of-hours be accessed via NHS 111. This indicates a discrepancy between public preference for out-of-hours dental care and the current system offered, which is in keeping with the reported limited reduction in ED attendances and urgent care use following NHS 111 pilots (Adams *et al.*, 2013). In addition, the public report an overwhelming preference for seeking urgent dental care from their usual dental practice (Grossman *et al.*, 2018), with advice and reassurance being as important as symptom relief when accessing out-of-hours care (Anderson, 2004), however a lack of information at out-of-hours dental services has been reported (Austin *et al.*, 2009).

This highlights the importance of involvement of stakeholders including patients and public in service design, and consideration should be given to the current design and how this could be improved to maximise its effectiveness and improve current care pathways.

It should be noted that during the COVID-19 pandemic when dental practices were forced to close accessing urgent dental care both in and out-of-hours was via NHS 111, this may have increased public awareness and experience of the service (Carter *et al.*, 2020) however the overall impact of this is unknown.

# 2.6.2 Medical emergency departments (EDs)

Patients can attend medical EDs with dental problems, and in some cases attendance here may be warranted if the patient is suffering with a facial swelling, dental trauma, or prolonged bleeding following a dental extraction (Scottish Dental Clinical Effectiveness Programme, 2007). Patients can, however, also attend with dental complaints that would be more appropriately managed by a dentist (American Dental Association, 2014; Barnett et al., 2014). Attendance at EDs may be inappropriate for a number of reasons. For example, EDs are not equipped with a dental chair nor do they have access to any dental instruments for examination or to aid diagnosis let alone equipment for treatment unless there is a maxillofacial unit. Radiographic investigations are also likely to be limited to larger exposures e.g., panoramic views as it is unlikely that an ED will have facilities for intra-oral radiography. A lower dose to achieve the same diagnosis may have been possible if the patient had attended a dental setting (The Ionising Radiation (Medical Exposure) Regulations, 2017). Dental treatment is also not possible in an ED, both owing to the lack of equipment and also the fact that EDs are often staffed by non-dentally trained personnel. As a result, analgesics and antibiotics are frequently prescribed in an attempt to manage symptoms rather than manage the underlying cause (Pennycook et al., 1993; Hocker et al., 2012; Barnett et al., 2014; Roberts et al., 2018). In addition, often in ADP the underlying cause is inflammatory meaning that antibiotics are not indicated and of no benefit. This could therefore be adding to issues with antimicrobial resistance (Royal College of Surgeons of England, 2012; Scottish Dental Clinical Effectiveness Programme, 2016; Segura-Egea et al., 2018).

There is a paucity of research on dental ED attendances in the UK (Bassey *et al.*, 2020) and a large proportion of the literature is based in the US. Here the health care system operates via a "fee-for service" basis, and is mainly funded via insurance

schemes from private companies, however the unemployed and lower socioeconomic groups may not have access to insurance plans and may or may not qualify for Medicaid (Currie *et al.*, 2012). The differing healthcare systems between the UK and US therefore create some limitations when reviewing the literature. Again, studies are largely cross-sectional in nature or clinical audits or service evaluation.

Within the UK, the number of ED attendances for dental problems is approximately 0.10% of all A&E attendances (Health and Social Care Information Centre, 2015; Currie et al., 2016), reducing to around 0.7% when patients who were admitted for treatment (and therefore with a justified attendance) are excluded (Currie et al., 2016). ED doctors report seeing between 1 to 5 dental patients per week, or 6 to 10 per month (Patel and Driscoll, 2002). Within the US attendance rates are higher at 1.65% of all ED attendances in 2010 (American Dental Association, 2013), with the number of attendances continuing to increase (American Dental Association, 2015). This increase in attendance rates could explain the large proportion of studies here. There is also evidence that patients re-attend the ED for dental problems. In the North-East of England 10% of attendances are repeat (Currie et al., 2016), and in the US rates of up to 50% are reported (Sun et al., 2015). There is also evidence in the US that repeat attenders may spread their attendance over various hospitals (DeLia et al., 2016), meaning that the reported incidences of repeat attenders may be underestimated. These attendances are likely to have an economic burden on society, which is again under-researched in the UK, however the British Dental Association have estimated a cost of approximately £18 million per year (British Dental Association, 2017). In the US the cost of ED visits for dental problems are reported at \$459 per patient (Davis, Deinard and Maiga, 2010). The total annual cost for ED visits is approximately \$306.3 million (\$33.3 million for periodontal disease (Elangovan et al., 2011), \$163 million for pulpal and periapical disease (Nalliah et al., 2011) and \$110 million for dental caries (Nalliah et al., 2010)). Studies to date have not considered the indirect costs associated with these ED attendances.

In terms of sociodemographic characteristics, those who utilise the ED for dental problems in the UK tend to be male, aged between 16- and 24-years-old and from the most deprived areas (Currie *et al.*, 2016). Repeat attenders tend to be slightly older in the fourth decade and from the most deprived areas (Currie *et al.*, 2016). Similarities therefore exist in the patient demographic attending the ED to those

attending dental emergency services and of problem-orientated attenders in the UK. These demographics are also comparable to the literature elsewhere in the world with the majority of patients being male, from a lower socioeconomic class, and in the third or fourth decade of life (Verma and Chambers, 2014; Sun *et al.*, 2015; Darling, Singhal and Kanellis, 2016; DeLia *et al.*, 2016; Amen *et al.*, 2021).

Little qualitative research has been carried out with patients seeking dental care at EDs, therefore reasons for attendance here are under-researched. One qualitative study in the US, however, found that patients were often repeat attenders as they were unable to pay for definitive treatment from a dentist, meaning that they rely on EDs for palliative management of their ADP leading to a cycle of repeat attendance (Sun et al., 2015). This would be in keeping with other authors' suggestions of ED attendances being due to financial barriers in the US (Anderson et al., 2011; Hong et al., 2011; Lee et al., 2012; Okunseri et al., 2012; Seu, Hall and Moy, 2012; Wall, 2012; American Dental Association, 2013, 2014; Pajewski and Okunseri, 2014; Lewis et al., 2015) and that the majority of patients seeking dental care at an ED have a low income (Cohen et al., 2008, 2011a). Given the differences in healthcare systems between the UK and the US the barriers and reasons for attendance may be different. ED attendances in the US are also associated with higher pain intensity, history of repeated dental problems and pain having a high interference with everyday life (Cohen et al., 2011a, 2011b), therefore the pain experience may play a role in decision-making around where to seek care for ADP. In addition, those without a regular dentist had significantly higher odds of seeking care from an ED rather than a GDP for dental problems, with the majority reporting that they were unable to get a dental appointment (Cohen et al., 2011b), which could indicate problems with access for those without a regular source of care. Interestingly, even though the majority of patients attending ED are treated with analgesics and antibiotics (Amen et al., 2021), in a UK patient cohort no specific expectation of receiving antibiotics at emergency appointments was reported (Anderson, 2004), this may indicate that patients attending the ED believe they will receive dental treatment and therefore health literacy may be important to consider. Other suggestions for ED attendances include immediacy of treatment at an ED (Trivedy et al., 2012) and dental anxiety or phobia (Patel and Driscoll, 2002). Patients who attend the ED for dental complaints are also more likely to have other chronic medical conditions, such as hypertension, depression, asthma and diabetes (DeLia et al., 2016; Amen et al., 2021). This could be an example of health inequalities whereby people from the

most deprived areas are more likely to seek dental care from the ED *and* be more likely to have other health problems. Alternatively, it could indicate that patients seek care from the ED for more than one problem at a time, one of which is dental.

In terms of Andersen's model, a systematic review (Akinlotan and Ferdinand, 2020) found that predisposing factors contributing to adult ED attendance for dental problems include age (20-44 years-old), lower education, unemployment or low income. Enabling factors include health or no insurance, low dental provider density, rural area and lack of regular dental care. Need factors include high pain severity and impact on daily life, presence of dental disease and poor oral hygiene, and chronic health conditions.

Dental ED attendances tend to be more common on a weekend in the UK (Currie *et al.*, 2016) or on an evening or weekend in the US (Lewis, Lynch and Johnston, 2003; Elangovan *et al.*, 2011; Hong *et al.*, 2011; Wall, 2012; Okunseri *et al.*, 2013a), which may indicate that out-of-hours access is a reason for ED attendance. There are some inconsistencies with this, however, with some US studies finding weekdays being more common for dental ED attendances (Davis *et al.*, 2010; Hocker *et al.*, 2012; Walker *et al.*, 2014). In addition to this, it has been shown that over time dental ED attendances have moved from being more common on a weekend, to being spread more evenly over the entire week, with significantly fewer weekend attendances reported (Wall, 2012). Therefore, other barriers must also exist.

When patients attend an ED for treatment of a dental condition they are often seen by a medically trained doctor rather than a dentist or maxillofacial team member (Nasr *et al.*, 2013), studies have therefore questioned whether patients receive the best treatment when presenting to an ED (Trivedy *et al.*, 2012; Barnett *et al.*, 2014). Indeed, over half of ED doctors have no training in examination or management of dental problems (Patel and Driscoll, 2002; Samaei *et al.*, 2015), and when presented with dental scenarios such as a facial swelling of odontogenic origin, a large proportion would not provide the appropriate treatment and over half would prefer to refer the patient to a dental specialty (Patel and Driscoll, 2002). This is in keeping with a large proportion of dental diagnoses at EDs being unspecified diagnoses (Patel and Driscoll, 2002; Currie *et al.*, 2016; Roberts *et al.*, 2018; Amen *et al.*, 2021), indicating a potential lack of knowledge and/or confidence in diagnosis of dental problems. According to guidance (Scottish Dental Clinical Effectiveness Programme, 2007; NHS England and NHS Improvement, 2019) some dental emergencies are

appropriate to seek ED care for (Table 2.2) and ED doctors are largely in agreement with this, reporting dental trauma and facial swellings appropriate for ED management but other dental complaints such as bleeding and toothache inappropriate (Trivedy et al., 2012), which could be problematic given the disagreement for management of post-operative bleeding and the potential for incorrect management of facial swelling (Patel and Driscoll, 2002). This, combined with the number of patients seeking dental care at EDs, indicates that further training for ED doctors is clearly warranted, which the medical profession agree with (Patel and Driscoll, 2002; Trivedy et al., 2012; Nasr et al., 2013). This training could include management of appropriate dental problems at EDs but could also provide an opportunity for intervention development and delivery aiming to reduce repeat patient attendances at EDs for dental problems.

Following an ED attendance, patients will be advised to see a dentist for definitive treatment, this ED attendance is therefore an extra unnecessary step in the care pathway for some dental complaints. Of importance is whether these patients follow advice given and seek dental care or not. This has not been studied within the UK, but in the US the majority of Medicaid patients who attended an ED with non-traumatic dental complaints did not seek dental care within 6 months, either returning to the ED or reporting no follow-up care at all (Pajewski and Okunseri, 2014). This indicates that barriers exist to patients accessing dental care following an ED attendance, but further research is required to fully understand these patient care pathways, the reasons for attendance at the ED and barriers they face to accessing dental care.

## 2.6.3 General medical practitioners

Patients may also visit their general medical practitioner (GMP) when experiencing dental problems. Attending a GMP with dental problems poses the same problems as attending a medical ED as dental treatment is not available and GMPs are not trained in diagnosis or management of dental problems. Current guidance in the UK (British Medical Association, 2020) states that GMPs are not responsible for treating dental problems and that they should not attempt to manage dental problems. Instead, they should advise patients who attend to contact a dentist or the local dental emergency services or refer them to secondary care or the ED where appropriate. Dental attendances at GMPs have been studied in more depth in the

UK than other healthcare providers. Some gaps in the literature remain however, which are highlighted below.

GMPs in England report seeing between two and five dental patients per week, often for complaints related to denture problems, caries and periodontal disease (Bater, Jones and Watson, 2005). In a larger study over a 10-year period there were 288,169 GMP consultations for dental problems in the UK, equating to an attendance rate of 6.06 consultations per 1000 patient-years (Cope et al., 2016). A change in attendance rates was also noted over this 10-year period, with attendance rates initially increasing up to 2008 to a peak of just under 7.00 consultations per 1000 patient-years, before starting to decrease to approximately 4.5 consultations per 1000 patient-years by 2013. As this study was only carried out over a 10-year period it is difficult to fully examine changes over time and potential causes. This study may also not be representative of the entirety of the UK as the Clinical Practice Research Datalink (CPRD) dataset was used which contains GMP practices largely based in England (77.4%), with only a minority in the devolved nations. Outside of the UK, around 7% of the US population has visited a GMP for a dental complaint (Cohen and Manski, 2006). These GMP attendances will have an economic burden similar to ED attendances, and although formal economic evaluation has not been carried out the British Dental Association estimate the annual cost to be over £26 million (British Dental Association, 2016).

In contrast to attendances elsewhere for urgent dental care, females are more likely to present to GMPs with dental complaints (Anderson, Richmond and Thomas, 1999; Cope *et al.*, 2016), and demographic and socioeconomic status does not appear to predict GMP attendance in the US (Cohen *et al.*, 2011a). However, as discussed, the healthcare system here is different to the UK and therefore may not be comparable. Other studies in the UK have not considered markers of deprivation or socioeconomic status in relation to GMP attendances. The typical age range is comparable to attendances elsewhere with patients aged 20-29 years-old being the most common attenders (Cope *et al.*, 2016). This could indicate that the patient demographic seeking dental care from GMPs is different to that of problemorientated attenders, however there is evidence that patients seeking care from GMPs are irregular dental attenders (Cope *et al.*, 2018) and deprivation clearly requires closer examination.

Reasons patients seek dental care from GMPs include: interpretation of symptoms: understanding of scope of practice; access to timely dental care; affordability of dental care; complex and unfamiliar dental care systems; dental anxiety; dissatisfaction with dental care and poor dentist-patient relationships (Bell et al., 2008; Cohen et al., 2011b; Cope, Butt and Chestnutt, 2018; Cope et al., 2018). This indicates that dental care-seeking from GMPs is related to a complex interaction between individual patient factors, the structure of the healthcare system they are seeking care from and the wider context where this interaction occurs (Cope et al., 2018), it is therefore possible that healthcare policy will play a role in attendance patterns. Although patients agree that GDPs are best placed to treat problems related to the teeth or gums, there is some confusion as to who to consult with other oral or jaw conditions (Cope et al., 2018), often believing that GMPs are better able and trained for this (Bell et al., 2008). Previous studies on attendance rates at GMPs have included all oral and dental problems and therefore may capture patients attending due to this belief. It would therefore be interesting to examine attendance rates specifically in those attending for conditions relating to the "teeth and gums" only and therefore the conditions the public believe GDPs are definitely best placed to treat. Urban or rural location has not been considered in UK based studies on GMP attendances which requires further exploration.

Similar to the ED, dental diagnoses recorded by GMPs are often unspecified (Davis *et al.*, 2010) which could again indicate GMP uncertainty in diagnosing dental problems. Additionally, treatment for dental patients who present to GMPs is limited, with over half of consultations resulting in a prescription for an antibiotic (Andersen, 2000; Cope *et al.*, 2016). Given that the majority of patients who seek dental care from a GMP are reported as having pulpitic symptoms these antibiotic prescriptions are likely to be inappropriate (Thomas *et al.*, 1996). Patients aged 40-59 years-old are more likely to be prescribed an antibiotic, as are repeat dental attenders, which could indicate that a cycle of repeat attendance for antibiotics is created, with each subsequent attendance reinforcing the behaviour (Cope *et al.*, 2016). This has also been reported in the wider medical literature (Little *et al.*, 1997). Other appointment outcomes have not been considered, for example formal referral to other services, which could theoretically decrease repeat attendance if the patient receives the dental treatment they require.

## 2.6.4 Pharmacists

A final place patients can seek advice from when suffering with ADP or dental problems is a pharmacist. Pharmacists are unable to offer definitive dental treatment, however they can offer advice on self-management of dental complaints and can assist with signposting to appropriate healthcare services. In addition, they are easily accessible by the public, with no requirement to make an appointment and 89% of England's population living within 20 minutes' walk of a pharmacy (Pharmaceutical Services Negotiating Committee, 2021). Of relevance is also that over 99% of those living in the most deprived areas are within 20 minutes' walk and the accessibility of community pharmacies is greatest in the highly deprived areas therefore meaning that pharmacists can also play a role in reducing oral health inequalities. Despite this potential there is little research within the area, with studies largely limited to postal questionnaires.

In the UK, approximately three-quarters of pharmacists report advising the general public on oral and dental health more than once a week (Dickinson, Howlett and Bulman, 1994, 1995). More recently, in the North-East of England, pharmacists report seeing a variable rate of dental patients, however over half will see at least 11 patients per week (Maunder and Landes, 2005). Globally the rate of dental presentations to pharmacists varies between 20 and 80% (Cohen *et al.*, 2009a; Freeman *et al.*, 2017).

Patients suffering with ADP for a long period of time, with the highest pain intensity and who experience the greatest impact on everyday life are more likely to seek advice from a pharmacist (Cohen *et al.*, 2009a). Interestingly, those aged 21- to 34-years-old are least likely to seek advice from a pharmacist (Cohen *et al.*, 2009a), this age group is in keeping with the age profile of problem-orientated attenders and those who are most likely to access other healthcare services, therefore may indicate that pharmacists are a potentially under used source of advice in this patient group.

Of those who seek advice from a pharmacist, one of the most common complaints is ADP (Maunder and Landes, 2005; Mann, Marcenes and Gillam, 2015) and the majority ask about self-management, in particular which medications to take and how they can treat the dental problem on their own, only a small minority ask about where to seek dental treatment (Cohen *et al.*, 2009a). This is in keeping with problem-orientated attenders often delaying treatment and instead trying to self-manage the problem. The majority of pharmacists advise the patient to see a dentist (Maunder

and Landes, 2005; Mann, Marcenes and Gillam, 2015), however almost one-quarter will also refer to a GMP (Maunder and Landes, 2005), therefore the ideal care pathway is not being followed in all cases. In addition, although pharmacists often know the location of nearby dental practices to suggest (Maunder and Landes, 2005; Mann, Marcenes and Gillam, 2015), they often do not know how patients access emergency dental care (Maunder and Landes, 2005). Interestingly, when advice from a pharmacist is sought the overwhelming majority follow their advice and report that it helped (Cohen *et al.*, 2009a) which indicates that pharmacists may have an important role to play when patients present with ADP. Indeed, the overwhelming majority of pharmacists agree that their role should include oral health promotion, however also request further training in order to do this (Maunder and Landes, 2005; Buxcey *et al.*, 2012; Rajiah and Ving, 2014; Mann, Marcenes and Gillam, 2015; Taing *et al.*, 2016; Freeman *et al.*, 2017). Importantly, the public also agree that pharmacies are a good place for oral health promotion and signposting (Sturrock *et al.*, 2017).

An initial pilot study of an oral health promotion intervention in community pharmacies in deprived areas of the North-East of England found acceptability to be good with a large proportion of the public attending reporting an intention to change their oral health behaviours as a result (Sturrock *et al.*, 2017). The majority of those receiving the intervention were, however, older adults who were regular dental attenders and therefore do not fit the profile of problem-orientated attenders. Nevertheless, pharmacies appear to be a potentially important health care service in care pathways to urgent dental care but further research is needed, particularly in relation to problem-orientated dental attenders.

# 2.7 Barriers and Facilitators for Regular Dental Care-Seeking

The reasons why patients attend in a problem-orientated manner are underresearched. To date the research is largely from the US where the healthcare
system is different and may therefore not be generalisable to the UK or is from the
UK but prior to the 2006 English and Welsh dental contract changes. One recent
qualitative study (van der Zande et al., 2020) in the UK has recently been published,
with the research carried out in parallel to the work presented in this thesis. From the
published research factors which may explain problem-orientated attendance
include: dental anxiety; lack of trust in dentists; embarrassment; lack of perceived
need; affordability of dental care; motivation; language barriers (Freidson and

Feldman, 1958; Finch *et al.*, 1988; Cohen *et al.*, 2007; Nuttall *et al.*, 2011a; Hill *et al.*, 2013; van der Zande *et al.*, 2020). Of upmost importance is that a dynamic "web of causation" exists between factors for non-attendance meaning that barriers change over time and that one single barrier is unlikely to explain problem-orientated attendance, and when present in combination, behaviour change is even more challenging (van der Zande *et al.*, 2020). Central to this web of causation is the perceived importance of oral health, which may be pivotal to overcoming other barriers (van der Zande *et al.*, 2020). This final section of this chapter discusses the literature and relevant theory related to these factors.

## 2.7.1 Dental anxiety, trust and embarrassment

The terms dental anxiety and dental fear are often used interchangeably however subtle conceptual differences exist between the two (Armfield and Heaton, 2013). Dental anxiety is the emotional state which precedes a dental encounter, when a threat is either unclear or not immediately present, whereas dental fear is the actual response to a specific dental object or situation, for example a dental local anaesthetic injection (Armfield and Heaton, 2013; Silveira et al., 2021a). Patients can, therefore, experience both dental anxiety and dental fear dependent on the context, i.e., a fear response will be created because of something they are anxious about. Patients may also suffer with dental phobia (odontophobia/dentophobia) which is a more narrowly defined and diagnosed mental disorder comprising marked fear or avoidance of dental care which either significantly interferes with the patient's function or causes considerable distress (American Psychiatric Association, 2013). Whilst dental anxiety and fear is relatively common, diagnosed dental phobia is rare and these patients are very unlikely to access routine dental services even when suffering with ADP (Armfield and Heaton, 2013). As a result, they are likely to encompass a very small specific subgroup of problem-orientated or, indeed, nonattenders and are therefore outside the scope of this thesis. Throughout the remainder of this thesis the concept of dental fear and/or anxiety will be referred to as dental anxiety.

According to the validated "Seattle System" (Table 2.3) there are four different groups of patients who suffer with dental anxiety (Locker, Liddell and Shapiro, 1999; Milgrom, Weinstein and Heaton, 2009). Patients with dental anxiety often mention trust issues with dentists as an additional and interwoven barrier (van der Zande et

al., 2020), indeed the Seattle System for dental anxiety highlights the intricate relationship between the two.

Type of Dental Anxiety	Features	
Fearful of specific stimuli	Fear associated with a clearly identifiable aspect of dental care e.g., dental drill, local anaesthetic injection, pain associated with treatment.	
Fearful of a medical catastrophe	Specific identifiable fear related to a medical event e.g., fearful of medical emergency during dental treatment, allergic reactions to dental local anaesthetics, choking on dental instruments, inability to breathe with rubber dam.	
Generalised dental anxiety	These patients are unable to identify one particular aspect of treatment they are fearful of, and a key component is worry. Patients in this category will worry about the dental procedure, their own behaviour, if they can manage their anxiety, what treatment they may need in the future and what the dental team think of them.	
Distrustful of dental personnel	These patients may appear argumentative or suspicious of dentists and they also worry about what the dental team think of them. They may not report that they are anxious or appear dentally anxious in the usual sense however they are fearful of loss of control or self-esteem.	

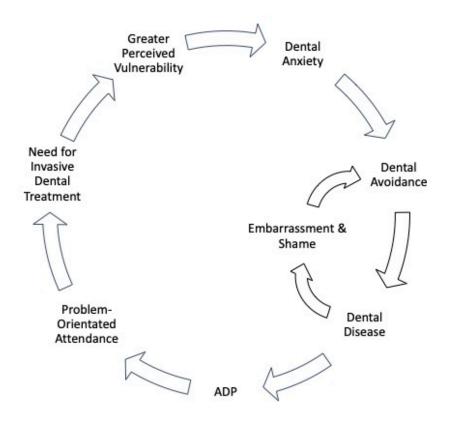
**Table 2.3:** The Seattle System of Dental Anxiety (Locker, Liddell and Shapiro, 1999; Milgrom, Weinstein and Heaton, 2009).

The aetiology of dental anxiety is complex and multifactorial and may result from both exogenous and endogenous sources (Beaton, Freeman and Humphris, 2014). Exogenous sources include previous traumatic dental experiences, particularly during childhood and adolescence (Thomson *et al.*, 2009; Oliveria *et al.*, 2017), and indirect vicarious experiences such as anxiety learnt from parents. Endogenous sources include genetic heritability, personality traits and cognitive ability (Beaton, Freeman and Humphris, 2014). Interestingly, a negative experience as a result of the dentist's behaviour is more likely to lead to dental anxiety during childhood, whereas pain associated with dental treatment is more likely to lead to dental anxiety in adulthood (Berggren and Meynert, 1984). It is important to note, however, that not all patients with dental anxiety recall a negative dental experience (Armfield, 2010) highlighting the multifactorial aetiology.

In the most recent ADHS just over one-third of respondents had moderate dental anxiety (Nuttall *et al.*, 2011a), however prevalence varies from 4% to just over 40% (Moore *et al.*, 1993; Armfield, Slade and Spencer, 2009). Suggested reasons for this variation include: study design; cultural, social and economic differences between populations studied; definition and instrument used (Silveira *et al.*, 2021a). The global estimated prevalence of dental anxiety in adults is 15.3%, with a higher prevalence in females (Silveira *et al.*, 2021a). Gender differences are hypothesised to be related to cultural norms and social desirability (Torriani *et al.*, 2014) and

differences in pain perception and painful experiences (Liddell and Locker, 1997). Prevalence is also higher in younger people (Nuttall *et al.*, 2011a; Murad, Ingle and Assery, 2020) consistent with the typical age group of problem-orientated attenders. Age requires careful interpretation, however, as studies are cross-sectional and in particular age groups and in pooled estimates the trend is no longer significant (Silveira *et al.*, 2021a). Severe dental anxiety does, however, differ between young and older adults (Silveira *et al.*, 2021a), suggesting that dental anxiety decreases with age. Suggested reasons for this include an aging or cohort effect, a decrease in anxiety facing dental procedures (Locker, Liddell and Burman, 1991), and increased time for positive dental experiences to overcome negative ones (Liddell and Locker, 1997). Further longitudinal studies are required to examine this age effect further. Finally, a social gradient also exists, with people from a lower socioeconomic background having a higher reported prevalence (Nuttall *et al.*, 2011a).

Dental anxiety is widely reported as a barrier to dental care-seeking and a reason for delayed attendance (Freidson and Feldman, 1958; Finch et al., 1988; Bullock et al., 2001; Schuller, Willumsen and Holst, 2003; Armfield, Spencer and Stewart, 2006; Armfield, Stewart and Spencer, 2007; Nicolas et al., 2007; Pohjola et al., 2007; Armfield, 2012; Nayee, Kutty and Akintola, 2015). Those with dental anxiety have poorer oral health (Eitner et al., 2006; Armfield, Stewart and Spencer, 2007; Armfield, Slade and Spencer, 2009; Armfield, 2013). In addition, dental anxiety can lead to a cycle of dental avoidance (Figure 2.5), which in turn increases anxiety due to feelings of embarrassment or shame and the need for more invasive dental treatment when urgent dental care is sought, which is perceived to be uncontrollable, unpredictable, dangerous and disgusting increasing patient vulnerability (Berggren and Meynert, 1984; Locker, 2003; Moore, Brodsgaard and Rosenburg, 2004; Armfield, 2006, 2013; Armfield, Stewart and Spencer, 2007; Silveira et al., 2021b). This vicious cycle of increasing dental anxiety and avoidance therefore highlights the importance of intervening early when dental anxiety is lower. Indeed, given that dental anxiety often originates in childhood or adolescence (Locker et al., 1999; Thomson et al., 2009; Oliveria et al., 2017; Silveira et al., 2021b) intervening here may prevent this cycle from establishing and may be easier to overcome.



**Figure 2.5:** The cycle of dental avoidance as a result of dental anxiety (adapted from Armfield, Stewart and Spencer, 2007; Armfield, 2013).

Embarrassment around poor oral health is also reported by those without dental anxiety (Calladine, Currie and Penlington, 2022) and can be a final barrier to emerge in the "web of causation". This leads to the patient worrying about the appearance of their teeth and as such not wanting to seek dental care due to concerns over being judged or reprimanded by the dentist (Finch *et al.*, 1988; van der Zande *et al.*, 2020), it is therefore important to consider this emotion as a potential barrier in all patients.

When patients who are dentally anxious seek dental care, dentists report considerable stress associated with carrying out treatment (Brahm *et al.*, 2012). This is likely to be compounded when patients attend for urgent dental care where time and resources may be limited, creating a barrier for dentists to be able to employ interventions to reduce anxiety, alongside the need for invasive dental treatment. This in turn could potentially increase dental anxiety further adding to the cycle of dental avoidance. Dental anxiety is also a factor associated with antibiotic prescribing in urgent dental care, whereby patients request antibiotics in an attempt to delay treatment (Thompson *et al.*, 2020). Interestingly, urgent dental care attenders with high dental anxiety report wanting help with anxiety management, but do not consider non-pharmacological interventions to be of benefit to them, instead preferring pharmacological approaches (Harding *et al.*, 2015) which are unavailable

in this setting. The fact that they believe non-pharmacological approaches to not be of benefit may also indicate the complex web of causation for problem-orientated attendance (van der Zande et al., 2020) whereby simply targeting dental anxiety alone is unlikely to change their attendance behaviour. Problem-orientated attenders with dental anxiety presenting to urgent dental care may therefore be unlikely to receive treatment which helps to overcome anxiety and encourage regular dental attendance, instead increasing pre-existing dental anxiety and worsening the cycle of dental avoidance.

As highlighted by previous studies (Freidson and Feldman, 1958; Finch *et al.*, 1988; van der Zande *et al.*, 2020) dental anxiety is unlikely to be the sole reason for problem-orientated dental attendance and is often reported in combination to other barriers regardless of the severity of the anxiety (Armfield and Ketting, 2015). Finally, it should be noted that not all patients with dental anxiety are problem-orientated attenders (Ragnarsson, 1998; Schuller, Willumsen and Holst, 2003; Armfield, Stewart and Spencer, 2007) which suggests that some patients are able to manage their anxiety and seek regular dental care. The reasons for this are unknown, however could perhaps represent those where dental anxiety is the *only* barrier to care and is more manageable to overcome in isolation. In addition, problem-orientated attenders experience more anticipatory anxiety than regular dental attenders (Gibson *et al.*, 2000), therefore perhaps as regular dental attendance is maintained and a good dentist-patient relationship established, the patient is able to manage their dental anxiety.

### 2.7.2 Perceived need

In the most recent ADHS two-fifths of respondents felt there was nothing wrong with their teeth and therefore had no reason to seek dental care (Morris. *et al.*, 2011). Similarly, in the most recent GP Survey just over one-fifth of respondents reported not attempting to make a dental appointment because they did not need one (NHS England, 2021), with this figure remaining the same at around one-fifth in all surveys since 2012 (NHS England, 2012). This indicates that perceived need is a barrier to care-seeking which has been established and not changed for over ten years. Indeed, whether patients believe they need to seek dental care plays an important role in decision-making (Finch *et al.*, 1988; Bullock *et al.*, 2001) and it has been hypothesised that dental care is considered less important that other medical

services by society and as such is a lower priority (Andersen and Newman, 2005). The literature around perceived need is discussed earlier in the chapter.

Need for dental care may be linked to how important oral health is considered to be, those who deem oral health to be "not relevant" to them then consider it a low priority (Gregory, Gibson and Robinson, 2007). Oral health as a priority will also fluctuate over time in relation to competing demands (van der Zande *et al.*, 2020), and if oral health is considered to be important then planned dental visiting may also increase.

Perceived need for dental care is also an important area to consider in older adults. Research carried out examining barriers to dental utilisation in adults over 65-years-old had demonstrated that the biggest predictors of dental utilisation in this age group are perceived need and importance of oral health (Kiyak, 1987; Gilbert *et al.*, 1994; Andersen and Newman, 2005). As adults get older tooth loss and dental disease is considered to be part of the ageing process (Scambler, 2016), and the age-illness rule in symptom appraisal means that symptoms, such as acute dental pain, may be attributed to age therefore care seeking is then less likely (Leventhal *et al.*, 2007). Older patients are also more likely to have multiple co-morbidities, and oral health is therefore considered less important in this context (Kiyak and Reichmuth, 2005). Nevertheless, as with patients of all ages multiple barriers to dental care seeking exist in this older patient group, including: affordability of dental care; access and location; past dental experiences; citizenship and right to health care (Kiyak and Reichmuth, 2005; Borreani *et al.*, 2008, 2010).

Given that a web of causation exists in planned dental attendance (van der Zande *et al.*, 2020) it is important to note that other barriers to dental care, such as anxiety and cost, can be overcome if someone believes they need to seek dental care (Finch *et al.*, 1988). In the case of problem-orientated dental attendance this increase in need may be the presence of ADP which can't be managed with self-care, resulting in an urgent care attendance. This is in keeping with oral health being considered to be "not relevant" until pain brings the mouth into consciousness (Gregory, Gibson and Robinson, 2007). A key question, therefore, may be how to increase the perception of need for dental care when ADP is not present.

## 2.7.3 Affordability of dental care

The need to pay for dental care is reported as a barrier to care-seeking throughout the literature, both in the UK and elsewhere in the world (Finch *et al.*, 1988; Bullock

et al., 2001; Croucher and Sohanpal, 2006; Nuttall et al., 2011a; van der Zande et al., 2020). In the most recent ADHS just over one-quarter of respondents reported cost having an impact on their decision-making around what type of dental treatment to have, and nearly one-fifth said the cost of care caused them to delay care-seeking (Nuttall et al., 2011a). These proportions increase to around one-third and onequarter respectively when looking at the typical age group of problem-orientated attenders or those who have irregular dental attendance patterns. Affordability of dental care is also a reason why patients consult non-dental providers where care is free of charge (Cope et al., 2018). Introduction of free dental treatment could therefore be considered to be one way of encouraging regular dental attendance, particularly given that willingness to pay for preventive care is lower than curative dental treatment (Mittal et al., 2021). In Scotland free dental check-ups were introduced in 2006 (The National Health Service (Dental Charges) (Scotland) Amendment Regulations 2006) costing an average of £46 per adult resulting in a 3.2% increase in dental check-ups in comparison to the rest of the UK (Ikenwilo, 2013). Of interest, however, is that there was also an increase in the number of patients attending for private check-ups and in those who were already exempt from dental charges, indicating that the removal of the cost is unlikely be the only factor at play here. Perhaps the potential for associated media coverage of the policy change may have also raised awareness of dental care, and therefore indirectly increased utilisation (Currie et al., 2021). Scotland has recently made all dental treatment free to those under 26-years-old (Scottish Government Primary Care Directorate, 2021) and similarly, Wales introduced free dental care to those under 25-years-old and over 60-years-old in 2001 (National Health Service, 2006), however the changes in dental utilisation following these have not been investigated.

Although the cost of care can be reported as a barrier to all patients, affordability of dental care is often a barrier to those who are from lower socioeconomic groups (Nuttall *et al.*, 2011a) and may therefore play a role in oral health inequalities, although does not fully explain it (Harris, Pennington and Whitehead, 2017). Indeed, socioeconomic position and employment are considered to be central to the web of causation onto which other barriers are layered (van der Zande *et al.*, 2020). Interestingly, as with other barriers the cost of care is often not in isolation.

Closely linked to this is a reported confusion over the actual cost of dental care, which in turn leads to anxiety associated with cost, as well as a sense of mistrust in

dentists (Finch *et al.*, 1988). Dental contract reforms have taken place since this study, however available resources and mistrust in dentists related to dental charges remains a barrier (van der Zande *et al.*, 2020). Additional patient quotes from this study also demonstrate confusion over the cost of dental care, therefore this barrier may remain and requires further exploration.

Linked to affordability of dental care is importance of oral health. If importance of oral health is considered low and there are competing demands around ability to pay for treatment then the cost of care will be seen as a dominating barrier (van der Zande *et al.*, 2020). In problem-orientated attenders, perhaps when ADP is present, the immediate importance of oral health is increased and the cost of dental care as a barrier can be overcome as payment can be justified. Therefore, if the importance of oral health and the need for regular dental attendance can be increased the cost of a dental check-up may also be justified. This would be in keeping with reports of increased willingness to pay for a dental cleaning in older adults who understand the links between oral and systemic health (Mittal *et al.*, 2021). However, in patients from lower socioeconomic backgrounds this may not be the case where oral health can be seen as important yet cost remains a true barrier that cannot be overcome (van der Zande *et al.*, 2020). Nevertheless, cost and affordability as a barrier warrants further investigation, and how this may link to other barriers.

#### 2.7.4 Motivation

Motivation is what causes initiation, persistence, direction and vigour of a behaviour (Colman, 2015). According to PRIME (Plans, Responses, Impulses and Inhibitions, Motives, Evaluations) theory (West and Brown, 2013) motivation can be considered as either reflective or automatic, with reflective motivation involving conscious processes such as plans and evaluations, and automatic motivation relating to subconscious processes such as emotions (Michie, Atkins and West, 2014). The decision to seek dental care therefore relates to reflective motivation, however, will have elements of automatic motivation in relation to emotions experienced, for example with dental anxiety.

Motivation can be seen as a facilitator for preventive dental attendance. Regular dental attenders report having motivation to seek dental care in order to protect themselves from developing dental disease (Finch *et al.*, 1988), which can either be motivation to promote their dental health, or to avoid negative consequences of non-attendance. This therefore implies that regular dental attenders must have an

appreciation of why oral health is important, or what the consequences of not seeking dental care can be. It has been suggested that problem-orientated dental attenders can also have the motivation to seek dental care however this alone is not enough to initiate care-seeking behaviour due to other competing demands (Harris, Pennington and Whitehead, 2017). This would be in keeping with PRIME theory whereby someone can make a plan to do something, however whether they then generate the impulses to do it will depend on competing plans, evaluations, motives and inhibitions and impulses at that time (West and Brown, 2013). This again highlights the web of causation which exists around planned dental visiting (van der Zande *et al.*, 2020).

This discrepancy between being motivated and actually carrying out a behaviour is known as the intention behaviour gap (Sheeran, 2002). In psychology, a behavioural intention is someone's motivation to carry out a particular behaviour, which encompasses the direction (e.g., make a dental appointment or not) and the intensity (e.g., how much time and effort someone is willing to expend in order to make a dental appointment). Generating an intention to carry out a behaviour is therefore important for that behaviour to occur, however there is empirical evidence that people can intend to do something and then not do it (inclined abstainers), or conversely not be motivated but still carry out a behaviour (disinclined actor) (Sheeran, 2002; Sheeran and Webb, 2016). Factors associated with intention realisation (i.e., the intention translating into a behaviour) are wide ranging, however examples include the contents or structural features of the specified behavioural goal (e.g., how specific or optimistic a goal is) and goal difficulty (e.g., the availability of resources, skills, time). Motivation is therefore likely to play an important role in initiating an intention to change a behaviour and become a regular dental attender, however is likely to only be a small part of a bigger picture.

## 2.8 Summary

In summary, although evidence is starting to emerge around problem-orientated dental attendance there remains some gaps within the literature. These include the decision-making process, barriers and facilitators around problem-orientated attendance, delayed care-seeking and the subsequent decision to seek urgent care. In addition, the specific care pathways that problem-orientated attenders go through when they decide to seek dental care, along with the reasons for these, are not fully understood.

This thesis aims to address these gaps by use of:

- An epidemiology study (Chapter 4) looking at GMP attendances for dental problems, specifically those affecting the "teeth and gums" and therefore the dental conditions the public report knowing are best treated by a GDP.
   Specifically, this study examines changes over a 44-year period to allow observation of potential causes, such as policy change, as well as examination of factors that predict repeated attendance at a GMP for dental problems, including variables which have not yet been considered (deprivation, rural area, appointment outcome).
- A series of qualitative studies exploring: (Chapter 5) reasons and decision-making around problem-orientated attendance, delayed care-seeking, decision to seek care and care pathways through urgent dental care; (Chapter 6) the transition to independence during adolescence and the associated barriers and facilitators to dental attendance behaviour when regular attenders become problem-orientated attenders.
- Intervention development (Chapter 7) targeted at preventing problemorientated attendance in adolescents and young adults who are current regular dental attenders.

# **Chapter 3. Aims and Objectives**

## 3.1 Aim

To build an understanding of problem-orientated dental attendance and associated care pathways to facilitate intervention development to reduce problem-orientated attendance.

## 3.2 Objectives

- 1. To examine patient attendances at GMPs over a 44-year period to identify trends in attendance and predictors of patient attendance and repeat attendance at a GMP for ADP.
- To critically explore emergency dental patients' perspectives of, and explanations for, seeking repeated problem-orientated care for ADP, instead of regular preventive care.
- 3. To explore adolescents' experiences of dental care, dental disease and future plans regarding dental attendances.
- 4. To co-design an intervention based on the evidence base and findings within this thesis to prevent problem-orientated dental attendance.

# Chapter 4. Patient Attendances for Dental Problems at General Medical Practitioners in Wales: a 44-Year Analysis

## 4.1 Introduction

When patients experience ADP there are a range of healthcare professionals they can present to as well as GDPs. One of which may be their GMP (Anderson, Richmond and Thomas, 1999; Cope *et al.*, 2015, 2016). The reasons a patient may choose to seek care from a GMP rather than a dental professional include: patient interpretation of their symptoms; perceptions of the scope of practice of GMPs; the comparative ease of navigating medical and dental systems; previous dental care experiences; willingness and ability to pay for dental treatment (Bell *et al.*, 2008; Cope *et al.*, 2015, 2018). GMPs report seeing patients for dental problems as often as once a week, through to once every few months, with increases and decreases in attendance rates also reported over time related to: changes in dental access; practice triaging systems; patient education (Cope *et al.*, 2015). The attendance rate for GMP attendances for dental problems across areas of the UK from 2004 to 2013 is 6.06 consultations per 1000 patient-years (Cope *et al.*, 2016), with previous reports of 6.90 per 1000 patient-years in Wales in 1996 (Anderson, Richmond and Thomas, 1999).

## 4.2 Objectives

- 1. To identify the frequency of patient attendances, and repeat attendances, at GMPs with ADP in Wales.
- 2. To identify the sociodemographic factors associated with patient attendance, and repeat attendance, to GMPs with ADP in Wales.
- 3. To establish if patient location has an effect on patient attendance at GMPs with ADP in Wales.
- 4. To identify the common dental diagnoses patients attend GMPs with in Wales.
- To investigate any changes in attendances rates at GMPs in Wales for ADP between 1974 and 2017 and relate these to changes in healthcare provision and policy change.

#### 4.3 Methods

#### 4.3.1 Study design

A retrospective observational study was completed using the "GP dataset" within the Secure Anonymised Information Linkage (SAIL) databank.

## 4.3.2 Ethical approval

Approval was granted by the Health Information Research Unit (HIRU) Information Governance Review Panel (IGRP), which is an independent panel comprising a range of organisations, including the National Research Ethics Service (Ford *et al.*, 2009). This panel reviews studies submitted to SAIL to check compliance with Information Governance, a range of Standard Operating Procedures and data management policies (Ford *et al.*, 2009).

#### 4.3.3 Data extraction

Data were identified and extracted from the dataset by a SAIL analyst before being made available for analysis within the SAIL portal. All patient attendances for dental problems were included in the data extraction plan between the event dates of 1st January 1974 and 31st December 2017. Identification of relevant patient attendances was by use of dental and orofacial Read codes (version 2) and keyword search (Appendix B). Read codes are based on the Read clinical classification, which was developed based on medical terms and language, and includes and cross references all of the other widely used medical classifications, such as ICD classifications. They are used to code details of multiple demographics, investigations, therapeutics and operative treatments of individual patients (Chisholm, 1990). Read codes related to non-dental pathologies of the oral cavity were not included in the data extraction plan. For the purposes of this thesis, Read codes relating to persistent dental/orofacial pain (previously referred to as chronic dental/orofacial pain), such as TMD were dropped from the dataset during data cleaning, this was to allow separate analysis of persistent dental/orofacial pain (PDP; a summary is provided in Appendix C).

For each dental Read code identified the following covariates were also extracted from the SAIL dataset:

- Patient ID (supplied as a double encrypted NHS number for data protection)
- Week of birth
- Gender
- Welsh index of multiple deprivation (WIMD)
- Office for National Statistics Urban/Rural classification code 2001 (Office for National Statistics, 2004)
- Date of attendance
- GMP practice code

For each dental Read code identified all other Read codes associated with that attendance were also included in the dataset, this was to capture any other relevant Read codes to that patient attendance, such as antibiotic prescriptions and referrals.

At the time of data extraction, the SAIL GP dataset covered 76.9% of GMP practices in Wales, equating to 79.4% of the Welsh population registered with a GMP practice. The population submitting data to SAIL is comparable to the general Welsh population in terms of gender, age, and WIMD (Table 4.1).

	All Welsh Practices (%)	SAIL Practices (%)			
Gender					
Male	49.90	49.86			
Female	50.10	50.14			
Age Range					
0-17 years	20.14	20.22			
18-64 years	60.28	60.55			
>65 years	19.58	19.23			
WIMD Quintile					
1 (most deprived)	19.09	20.30			
2	18.67	18.53			
3	18.64	18.77			
4	17.73	16.19			
5 (least deprived)	18.12	18.61			

**Table 4.1:** Comparison of demographics for SAIL practices to all Welsh GMP practices.

## 4.3.4 Data cleaning and analysis

A period of data cleaning was undertaken prior to data analysis. Data cleaning and analysis was with STATA v15 (StataCorp LP, College Station, TX, USA), and was carried out within the SAIL portal. Data cleaning commenced in April 2018, and analysis was completed by April 2020.

Patient age at attendance was calculated using the week of birth and the date of attendance, with the age at the previous birthday being used in all analyses. Patient gender was included rather than sex as data were coded as: 0 not known; 1 male; 2 female; 3 indeterminate/anticipated sex change; 9 not specified.

The rate of dental attendances were calculated as: number of attendances over time; percentage of all attendances within the SAIL dataset; and attendance rate. The attendance rate was calculated as per an incidence rate with the annual rate of dental consultations per 1000 patient-years reported to allow direct comparison with previous studies (Anderson, Richmond and Thomas, 1999; Cope *et al.*, 2016). The denominator to calculate the attendance rates was calculated using data from the Welsh Demographic Service (WDS) dataset available through SAIL. This dataset contains all primary care events coded with Read codes by GMPs. This allowed

calculation of the total patient-years for all attendances at all GMPs registered with SAIL by year. For partial annual data, e.g. where a patient entered the dataset part way through a calendar year, the amount of time they had contributed to that year was included by calculation of the proportion. For example, where a patient had entered the dataset in the 7<sup>th</sup> month of the year they were considered to have contributed 0.5 patient-years (6 months). Data were not available from the WDS dataset on patient location or age, therefore attendance rates could not be calculated for these variables and are presented as number of attendances instead. Attendance rates were plotted on graphs over time to examine changes over the study period.

A patient was defined as a repeat attender if they had more than one attendance in a 12-month period. This was based on the decision that if the GMP attendance for ADP was not appropriate the GMP would have advised the patient to seek dental care at the first attendance, and therefore any subsequent attendances would more than likely have been inappropriate. A unique variable was generated which identified all repeat attenders by 12-month period for analysis.

Read codes relating to outcome of the appointment were also included in the dataset. These included Read codes for prescription of an antibiotic, and for referral to another healthcare professional or setting. These were used to generate unique variables indicating whether a patient had received an antibiotic prescription or a referral as an outcome of their appointment for use during data analysis.

Patient location was considered using the Welsh Index of Multiple Deprivation 2011 (WIMD) quintiles (Welsh Government, 2011) and the Office for National Statistics Urban/Rural definition (Office for National Statistics, 2011). WIMD is the official measure of relative deprivation of small areas of Wales (Welsh Government, 2011). Index of multiple deprivation (IMD) is used throughout the UK to measure deprivation and scores take into account deprivation being related to more than just poverty, and therefore combines eight different domains (Office for National Statistics, 2019). These include: employment, income, education, health, community safety, geographical access to services, housing and physical environment. There are 1896 lower layer super output areas (LSOAs) in Wales, with each being assigned a ranked WIMD score, with 1 being the most deprived area, and 1896 being the least deprived. Within the SAIL dataset these ranks are available as quintiles, which were used for analysis of relative multiple deprivation. Therefore a patient from a WIMD

quintile 1 was from the 20% most deprived areas of Wales, and a patient from WIMD quintile 5 was from the 20% least deprived areas.

The Office for National Statistics Urban/Rural classification 2001 (Office for National Statistics, 2004) was developed following the 2001 census to allow an urban/rural definition for statistical analysis. It divides geographical areas into urban and rural categories. Areas which are classified as urban are all physical settlements with a population of 10,000 or more, the remainder are classified as rural (Bibby and Shepherd, 2005). The classification further subdivides areas by settlement type and sparsity, with the super output area classification used within the SAIL portal (Figure 4.1). Sparsity categorises the settlement types by density profile into sparse, or less sparse. Settlements in a sparse setting have a particularly low number of households, and therefore may have implications on availability of services (Office for National Statistics, 2016).

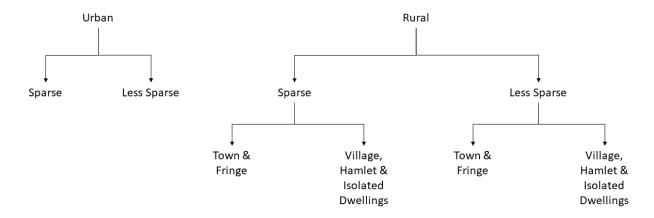


Figure 4.1: ONS Urban Rural Classification 2001 by Super Output Areas.

For the purposes of data analysis the full ONS classification was used, as well as the broad definitions of urban or rural. Urban codes were grouped together separately from rural codes and a dummy variable created to indicate either an urban (1) or rural (0) location.

GMP practice codes were used to calculate the number of patients seen per practice per calendar year, and practices which saw more than the mean plus the standard deviation of patients per year were defined as practices having a higher than usual number of dental patients for further analysis.

For data protection purposes any counts of less than five were not permitted out of the SAIL portal for analysis and publication, therefore Read codes were grouped into larger diagnostic code groups (Table 4.2) to overcome this limitation where possible. Where regrouping was not possible counts and percentages were denoted as "<5", and the total number of Read codes or patient attendances for that variable adjusted so a count of <5 was equal to zero. This was done to prevent calculation of the true frequency outside of the SAIL portal and for this reason, some total counts on subgroup analyses do not correspond to the overall number of Read codes or patient attendances. Where more than one Read code was associated with a patient attendance the Read codes were re-grouped as per Table 4.2 to ensure that only one diagnosis was associated with that attendance.

All data were analysed initially using basic descriptive and inferential statistics, including Chi-Square testing. To examine potential predictors of repeat attendance, antibiotic prescribing and onward referral univariate and multivariable logistic regression modelling was performed to obtain odds ratios and confidence intervals, as well as likelihood ratio testing to test possible interactions. For logistic regression the binary response variable was whether a patient was a repeat attender or not, by 12-month period, or whether an antibiotic had been prescribed or referral made. Explanatory variables were gender, age, WIMD, urban/rural, antibiotic prescription, referral, and potential confounders and interactions between age, gender, WIMD and urban/rural were assessed. Interaction models and likelihood ratio testing were performed within the logistic regression modelling, with stratified analyses where an interaction was present and significant from the likelihood ratio test. For age, analysis was completed using categorical age groups within the logistic regression model. The referent age group was set to <10 years to allow initial exploration of the effect of increasing age, which identified a non-linear relationship and therefore an additional fractional polynomial transformation was used for the continuous form of the age variable for in depth analysis. Logistic regression modelling was repeated with adjustments for any potential confounders, which would be included in the final regression model where a larger than 10% change was observed on the odds ratio following its' inclusion.

## 4.4 Results

#### 4.4.1 Data cleaning

All patient attendances associated with dental Read codes were downloaded from the SAIL databank into the SAIL portal for cleaning and analysis. Data cleaning is summarised in Figure 4.2.

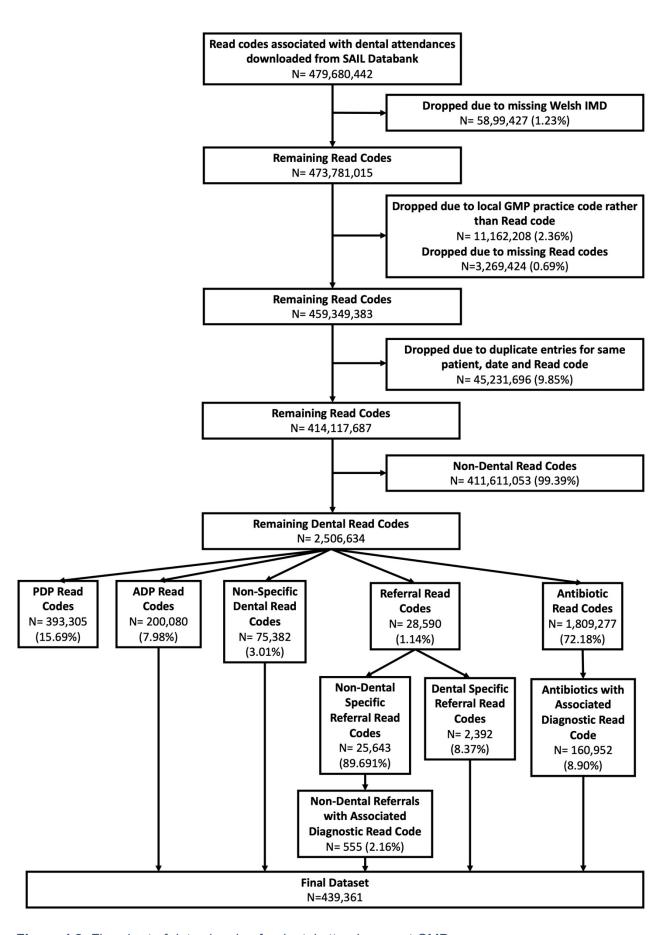


Figure 4.2: Flowchart of data cleaning for dental attendances at GMPs.

Observations that did not have a WIMD were dropped from the dataset as it was assumed that the associated Read codes may be for non-Welsh residents, for example, people travelling from England into Wales. Incomplete Read codes or diagnostic codes that were a local practice code with no free text description were also dropped from the dataset as the reliability of the description of the Read code could not be determined. Due to the data extraction technique used by the SAIL data analyst the downloaded Read codes for the cohort of individuals included all GMP records for their life course, therefore 99.39% were Read codes associated with a non-dental attendance and were dropped from the dataset. Out of the remaining dental Read codes, 7.98% were for ADP, 15.69% were for PDP, 3.01% were non-specific dental codes, 1.14% were referral codes, and 72.18% were antibiotic prescription read codes.

Out of the referral codes 8.37% were for referrals to dental services, the remainder were referrals to non-specific secondary care or other services. For these non-dental referrals any that were made within one month of a dental attendance were kept in the dataset and the remainder were dropped as they either occurred prior to a dental read code being recorded, or occurred over a month after a dental read code and were therefore likely to be related to a medical referral than a dental one. The same data cleaning process was carried out for antibiotic prescription Read codes, with the addition of only antibiotics that would reasonably be prescribed for a dental infection over the time course studied being included in the final dataset (Scottish Dental Clinical Effectiveness Programme, 2016). The timescale of a month was used to capture patients returning to the GMP following their original dental attendance for further management. A month was used as opposed to a week as on examination of the dataset there were observations of patients attending towards the end of a week with a dental read code, and then returning the following week for a dental referral or a change/addition of an antibiotic.

Following all data cleaning the Read codes were grouped together as per Table 4.2 to allow for overlap within diagnoses and referral types, and also to overcome limitations within the SAIL portal whereby counts of less than 5 were deemed to be a potential breach of patient identifiable information and therefore could not be extracted from the portal (Ford *et al.*, 2009). Read codes for non-specific dental diagnoses (e.g., "tooth symptoms") were grouped together to form a "Non-specific dental Read code" group.

Read Code	Read Code Description	Total Number in Dataset	Group	
1912	Toothache	24,246	Toothache	
J020	Pulpitis	219		
J0200	Pulpal abscess	50		
J024	Acute apical periodontitis	15,979		
1914	Dental swelling	2,021	Dental abscess	
J0250	Dental abscess	123,210		
J0251	Dentoalveolar abscess	261	-	
J0332	Paradental abscess	83		
J083	Oral cellulitis and abscess	280	-	
75112	Surgical removal of wisdom tooth	6,385	Pericoronitis	
J0331	Acute pericoronitis	483	-	
J0340	Chronic pericoronitis	738		
1913	Bad teeth/caries	1,231	Caries	
J010	Dental caries	9,242	Garles	
J01y1	Sensitive tooth dentine	39	Dontino Hyporconsitivity	
			Dentine Hypersensitivity	
J03	Gingival/periodontal disease	1,679	Gingival/Periodontal diseases	
J065	Alveolitis of jaw	1,787	Alveolitis of jaw	
J080	Stomatitis	6,507	Stomatitis	
S8363	Broken tooth injury	642	Dental trauma	
191	Tooth symptoms	73,900	Non-specific dental Read	
J05y	Other specified dental disorder	4,998	codes	
J052	Dental diseases/conditions	1,482		
8HT4	Referral to orthodontic clinic	193	Referral to orthodontics	
8HoA	Referral orthodontic service	10		
8Hv9	Private referral to oral surgeon	168	Private referral to	
8HVD	Private referral to maxfax	269	oral/maxillofacial surgeon	
8Hn13	Fast track referral head and	448	Fast track referral head and	
0111113	neck cancer	440	neck cancer	
8Ho4	Referral oral surgery service	137	Referral to oral surgeon	
8Ho1	Referral restorative dental	16	Referral to specific dental	
01101	service	10	service	
8Ho2	Referral dental conservation service	<5	Convice	
8Ho3	Referral paediatric dental service	<5		
H8o5	Referral endodontic service	<5	1	
8Ho6	Referral dental sedation service	7	1	
8Ho7	Referral periodontal service	<5	1	
8Ho8	Referral prosthodontic service	0	1	
8Ho9	Referral dental radiology service	<5		
8Hd	Admission to hospital	374	Admission to hospital	
8H2k	Admission oral surgery	148	Admission oral surgery	
	emergency		emergency	
8H3u	Non urgent oral surgery admission	748	Non urgent oral surgery admission	
8HT	Referral to clinic	28	Non-specific referral	
8HTE	Referral to other clinic	<5	ī .	
8HTZ	Referral to clinic NOS	<5	1	
8H2	Further care referral NOS	36	1	
8H20	Referral needed	91	-	
8Hk	Referred to service	5	1	

8Hkj	Informal referral, signposted to other agency	<5	
8H1	Referral to other care	9	
8IH5	Referral declined	241	Referral declined
e15	Phenoxymethylpenicillin	12,504	Phenoxymethylpenicillin
e3	Broad spectrum penicillin	102,878	Broad spectrum penicillin
e3z & e3a	Amoxicillin	7,870	Amoxicillin
e91 & e95	Erythromycin	12,965	Erythromycin
e1	Metronidazole	24,726	Metronidazole
8BGB	Antibiotic indicated	9	Antibiotic indicated

**Table 4.2:** Grouping of READ codes for entire dataset 1974-2017. (NB: the Read Code for clindamycin was included in the dataset however there were no observations remaining for this following data cleaning).

#### 4.4.2 Attendance rates

Over the study period from 1974 to 2017, there were 439,361 Read codes associated with ADP attendances at GMPs in Wales. 44.40% of these were diagnostic ADP Read codes, 18.29% were non-specific dental Read codes (i.e. "tooth symptoms"), 0.67% were referral Read codes and 36.63% were antibiotic prescription Read codes. These accounted for 288,147 patient attendances and 204,025 patients over the study period. The overall attendance rate was 2.60 attendances per 1000 patient-years (95% CI 2.59-2.61).

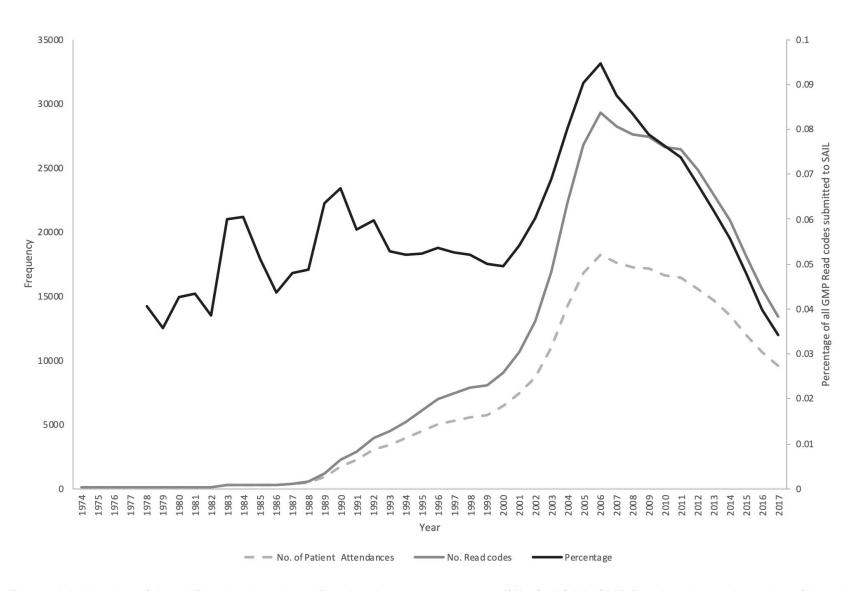
The majority of patients attended once (39.61%) or twice (39.25%) to their GMP for ADP (Table 4.3).

No. of Times Attended	No. of Patients	Percent (%)
1	80,818	39.61
2	80,075	39.25
3	17,946	8.80
4	11,961	5.86
5	4,527	2.22
More than 5	8,698	4.26
Total (No. patients)	204,025	100.0

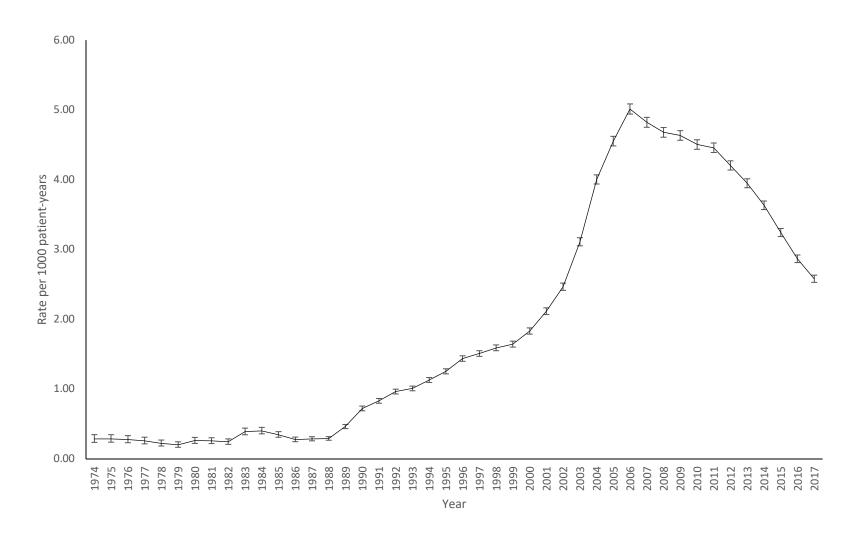
**Table 4.3:** Number of times patients attend their GMP with ADP. Data are displayed as number of attendances per patient.

The number of Read codes and patient attendances per year is shown in Figure 4.3 and the attendance rate over time is shown in Figure 4.4 with associated 95% confidence intervals. Both the number of Read codes and patient attendances increased from 1988, with a marked increase from 2000 through to 2006. At the peak of attendance in 2006 the attendance rate was 5.01 patient attendances per 1000 patient-years (95% CI 4.94-5.09). A gradual decline is then seen from 2006 onwards. The number of ADP Read codes per year expressed as a percentage of all GMP Read codes submitted to SAIL is also shown, this takes into account the

variation in number of practices submitting to the SAIL databank over the study period. Data on the number of GMP practices submitting to SAIL prior to 1978 are unavailable, however the number of Read codes as a percentage of all Read codes still shows a marked increase from 2000, with a decline seen from 2006. When considering the change over time as an attendance rate per 1000 patient-years the same trend is seen as for number of patient attendances, meaning that the observed trend is not explained by population size.



**Figure 4.3:** Number of dental Read codes, dental Read codes as a percentage (%) of all SAIL GMP Read codes, and number of dental patient attendances per year over the 44-year period studied.



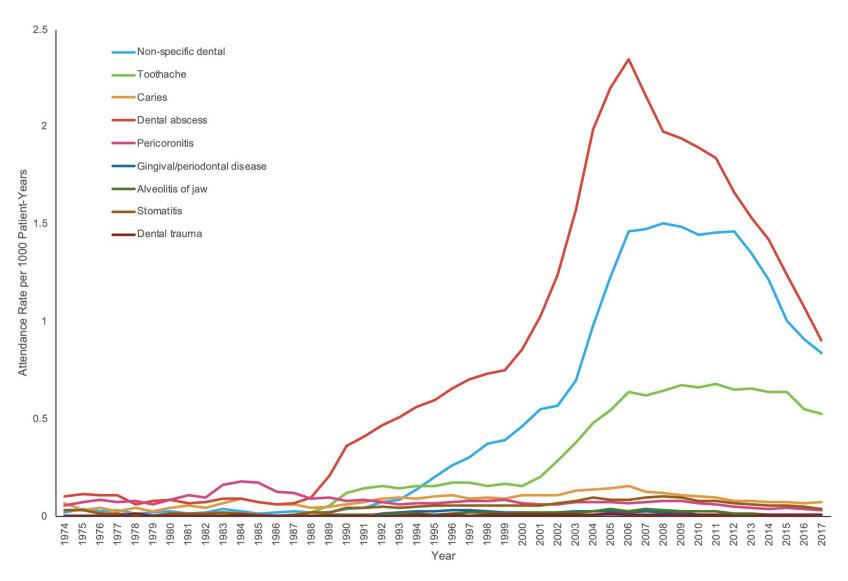
**Figure 4.4:** Attendance rate for all dental attendances over the study period with 95% confidence intervals.

## 4.4.3 Diagnoses

The diagnostic dental Read codes that patients attended with is shown in Table 4.4. The number of patients attending with dental abscess increased from 1988 up to 2006 then decreased, similarly the number of patients attending with non-specific dental Read codes and toothache also increased up to 2006, but then remained at a similar frequency for several years before beginning to decrease (Figure 4.5). All other Read codes remained at a relatively constant frequency over the study period.

Read code	No. of Patient Attendances	Percent (%)
Dental abscess	125,855	45.69
Toothache	40,494	14.70
Caries	10,473	3.81
Pericoronitis	7,606	2.76
Stomatitis	6,507	2.36
Alveolitis of jaw	1,787	0.65
Gingival/periodontal disease	1,679	0.61
Dental trauma	642	0.23
Dentine hypersensitivity	34	0.01
Non-specific dental Read codes	80,380	29.18

**Table 4.4:** Breakdown of diagnostic dental Read codes patients attended their GMP with over the study period.



**Figure 4.5:** Change in diagnostic ADP Read codes over the study period. Dentine hypersensitivity has been excluded due to presence of counts less than 5.

## 4.4.4 Sociodemographic factors

More patients attending to their GMP with ADP were female, equating to 239,207 (54.44%) Read codes or 158,008 (54.84%) patient attendances. The overall attendance rate for female patients was 2.85 attendances per 1000 patient-years (95% CI 2.83-2.86) compared to 2.37 attendances per 1000 patient-years (95% CI 2.24-2.38) for male patients. All patients within the dataset were identified as either male or female, there were no non-specified or non-binary genders. Female patients remained the majority over the 44-year period studied, except prior to 1990 where the attendance rates appear similar between genders (Figure 4.6). Male patients more commonly attended with caries and dentine hypersensitivity (Table 4.5).

Read code	Male		Female	
	No. of Patient Attendances	Percent (%)	No. of Patient Attendances	Percent (%)
Dental abscess	60,058	47.72	65,797	52.28
Toothache	17,728	43.78	22,766	56.22
Caries	5,636	53.81	4,837	46.19
Pericoronitis	2,556	33.61	5,050	66.39
Stomatitis	2,542	39.07	3,965	60.93
Alveolitis of jaw	785	43.93	1,002	56.07
Gingival/periodontal disease	728	43.36	951	56.64
Dental trauma	214	33.33	428	66.67
Dentine hypersensitivity	21	62.77	13	37.23
Non-specific dental Read codes	34,933	43.46	45,447	56.54

**Table 4.5:** Breakdown of diagnostic dental Read codes by gender.

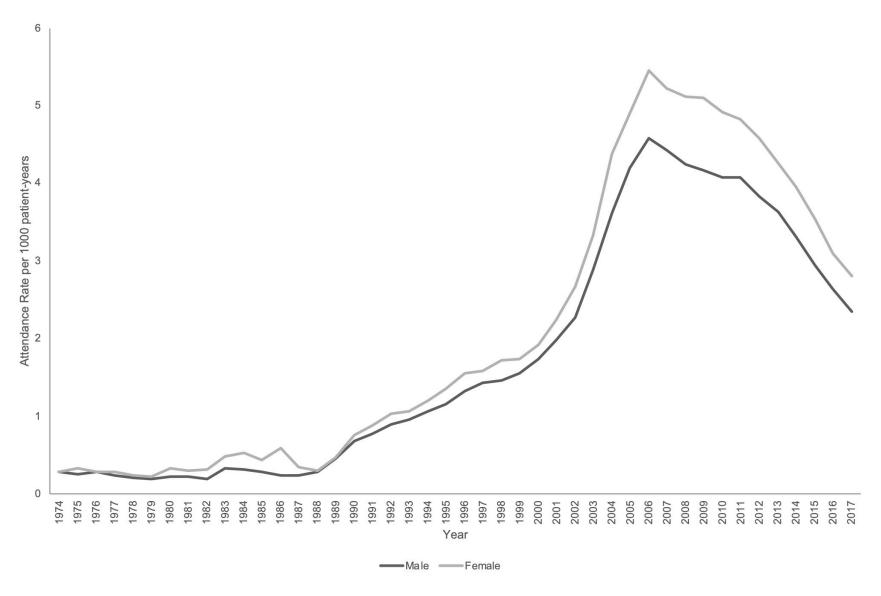
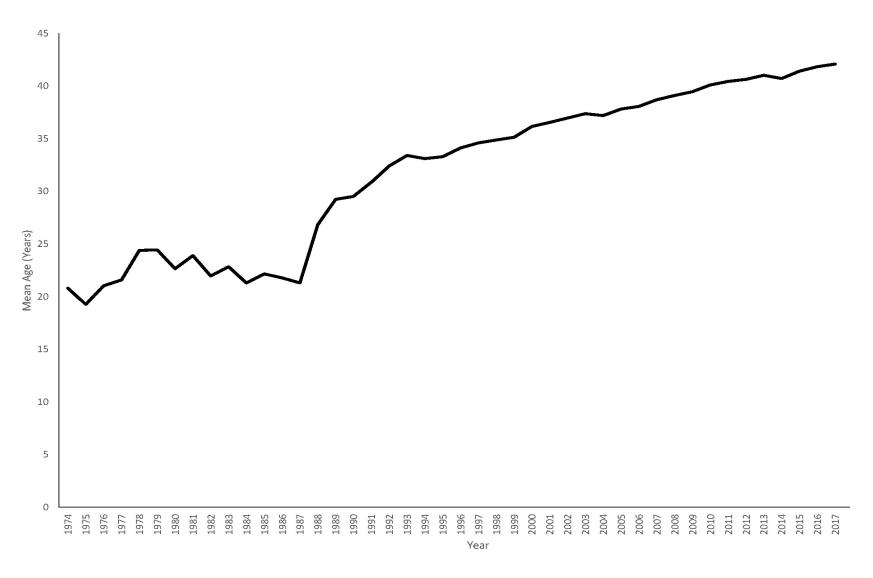


Figure 4.6: Attendance rate for dental patient attendances by gender over the 44-year period studied.

The mean patient age was 38.32- (SD 19.21, range 0 to >100 [exact age range not permitted out of SAIL portal due to counts <5]) years-old. Over the study period, the mean patient age increased from 20.80- to 42.09-years-old (Figure 4.7). A similar trend with an increase in mean age was observed when broken down by sociodemographic factors (Figure 4.8-Figure 4.10). Across the study period mean age was similar between genders (Figure 4.8), patients from the least deprived areas tended to be older than those from the most deprived areas (Figure 4.9), and those from rural areas tended to be older than those from urban areas (Figure 4.10).



**Figure 4.7:** Mean patient age for dental attendances over the 44-year period studied. Large standard deviations were noted for each time point ranging from 12.51 to 19.45.

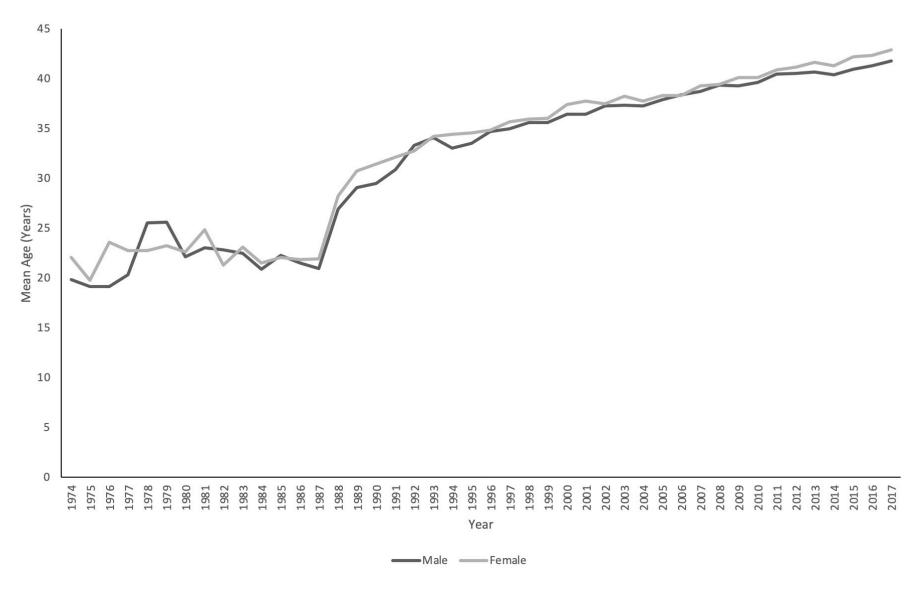


Figure 4.8: Change in mean age by gender of dental patients over the study period.

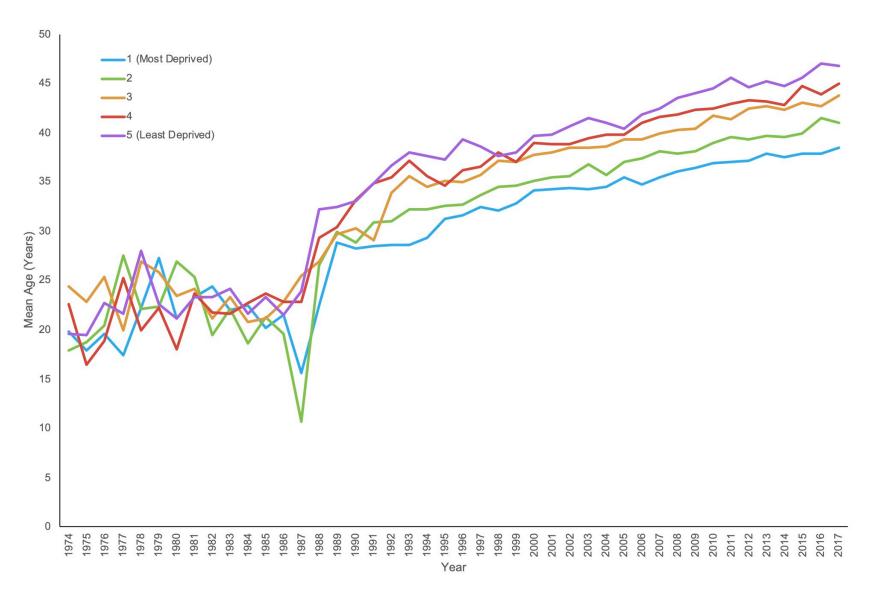


Figure 4.9: Change in mean age by WIMD quintile of dental patients over the study period.

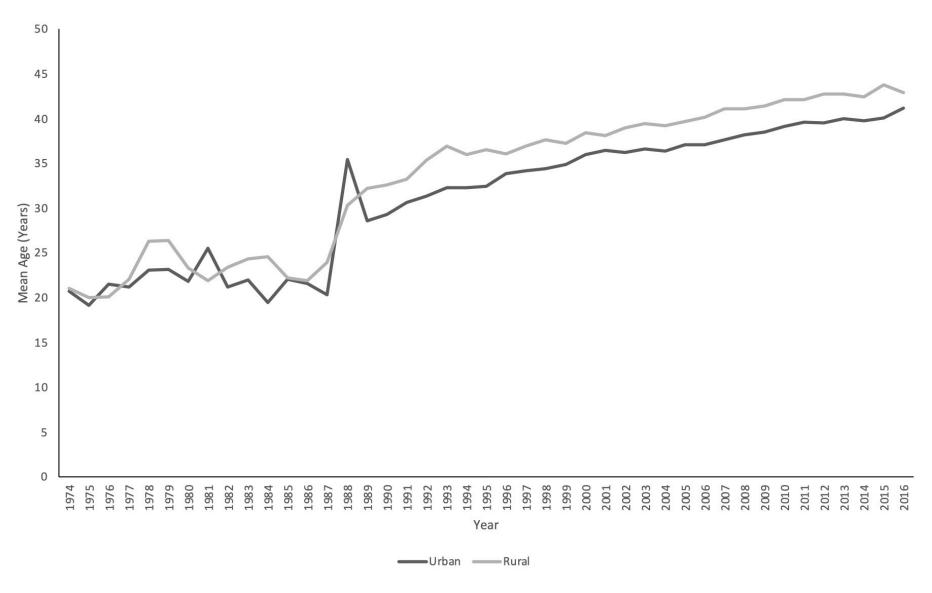
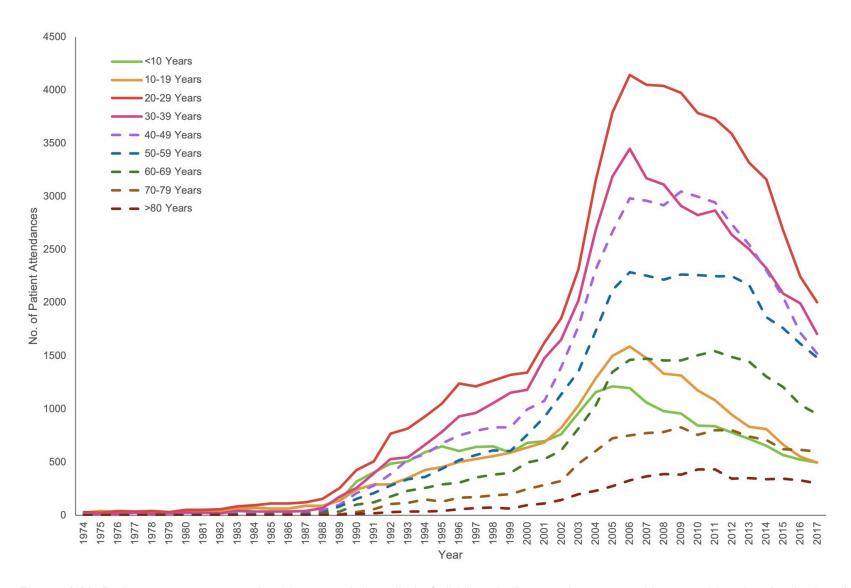


Figure 4.10: Change in mean age by rurality of dental patients over the study period.

When considering age in 10-year groups, from 2006 when overall attendance rates begin to decrease, the number of patients aged below 39-years-old decrease, whereby the number of patients aged 40-years-old and above remain relatively stable (Figure 4.11). Breakdown of diagnostic Read code by age group is shown in Figure 4.12. Caries, stomatitis and dental trauma were most commonly diagnosed for those under 10-years-old, with all other diagnoses following the same trend with 20–29-year-olds forming the majority.



**Figure 4.11:** Patient age groups over the 44-year period studied. Solid lines indicate patient groups 39-years-old and under, broken lines indicate patient groups 40-years-old and over.

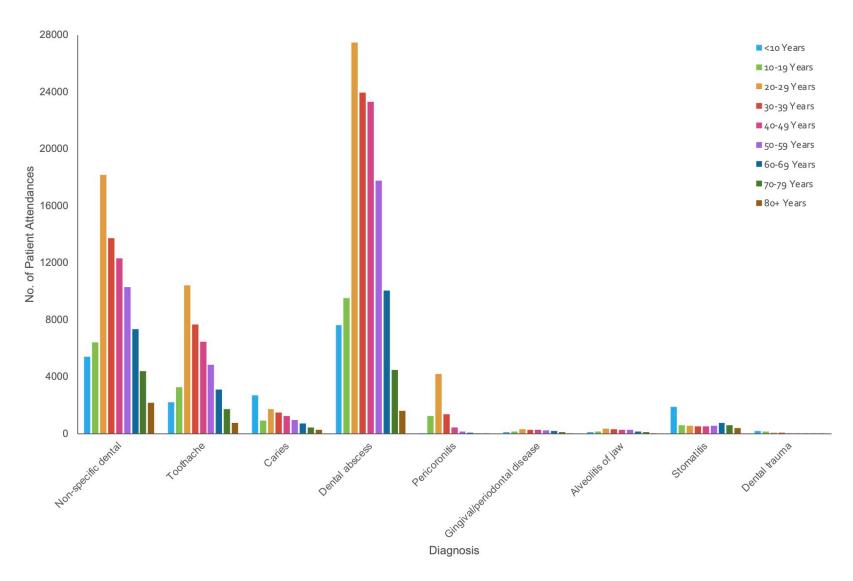


Figure 4.12: Breakdown of diagnostic Read codes by age group. Dentine hypersensitivity has been excluded due to presence of counts less than 5.

The majority of patients attending for ADP resided in the most deprived areas of Wales (Table 4.6). With WIMD the expected frequencies would be 20% per quintile, therefore the difference from the expected value was non-significant (X² (4df, n=0.509, p=0.49), there was, however, a much lower percentage in the least deprived quintile.

WIMD Quintile	No. of Patient Attendances	Percent (%)
1 (most deprived)	69,995	24.29
2	60,139	20.87
3	65,879	22.86
4	52,048	18.06
5 (least deprived)	40,086	13.91

Table 4.6: Breakdown of patient attendances for WIMD quintile.

Breakdown of diagnosis Read code by WIMD is shown in Figure 4.13, the most deprived quintiles had higher numbers of patients diagnosed with toothache, caries and dental abscess, as well as non-specific dental Read codes. Other ADP Read codes had a more equal split between WIMD quintiles. This may be indicative of oral health inequalities.

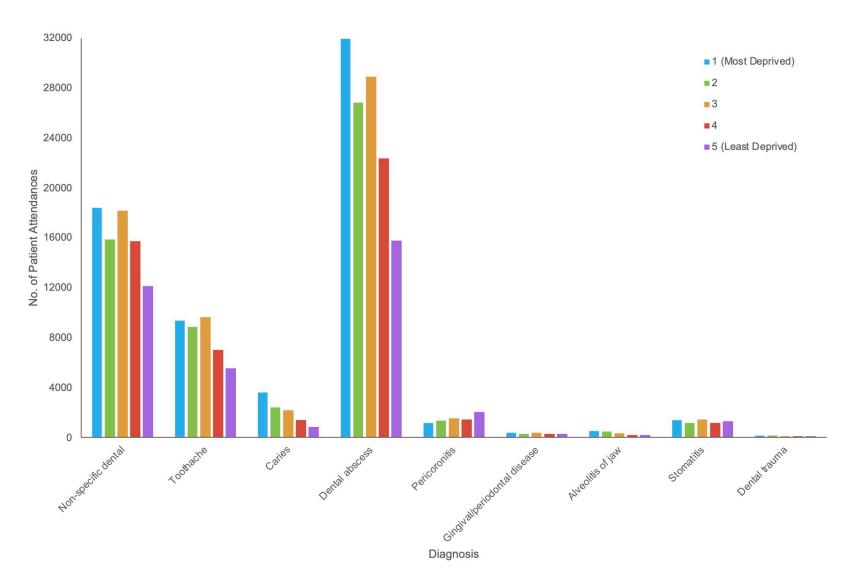


Figure 4.13: Breakdown of diagnostic dental Read codes by WIMD Quintile. Dentine hypersensitivity has been removed due to counts of less than 5.

The majority of patients lived in urban areas (Table 4.7). When WIMD was considered per urban or rural location there was a significant difference in breakdown of WIMD (Figure 4.14;  $X^2$  (4df, n=65,000) p<0.0001), in urban areas patients were most commonly from the most deprived areas, and in rural areas patients were most commonly from areas in the middle quintile of WIMD.

Urban/Rural	No. of Patient	Percent	Urban/Rural	
Definition	Attendances	(%)	No. of Patient Attendances	Percent (%)
Urban; Sparse	13,968	4.85	171,602	59.55
Urban; Less Sparse	157,634	54.71	171,002	39.33
Town & Fringe; Sparse	18,183	6.31		40.45
Town & Fringe; Less Sparse	42,417	14.72		
Village, Hamlet & Isolated Dwellings; Sparse	34,848	12.09	116,545	
Village, Hamlet & Isolated Dwellings; Less Sparse	21,097	7.32		

**Table 4.7:** Breakdown of urban and rural locations as defined by the 2001 Urban/Rural Classification.

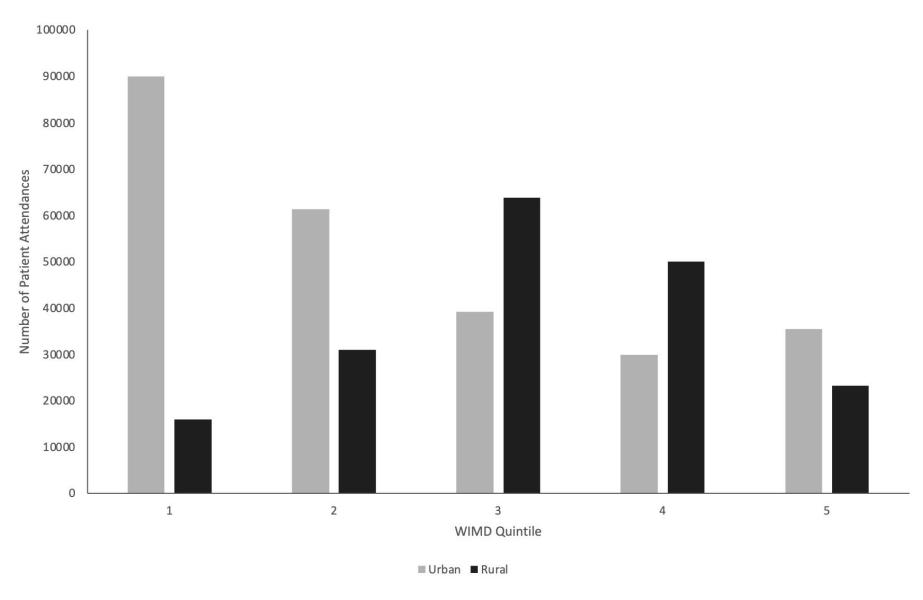


Figure 4.14: Comparison of WIMD for dental patients by urban and rural locations as defined by the 2001 Urban/Rural Classification.

Change over time for WIMD is shown in Figure 4.15. All WIMD quintiles showed an increase in attendance from 1989, with a sharp increase from 2000. Attendances then begin to decline from 2006, with a sharper decline observed in the more deprived quintiles. In addition, over the period 2000 to 2006 there was more of an increase in the more deprived quintiles, which may indicate an increase in oral health inequalities over the time period, which does not fully resolve following the decline from 2006.

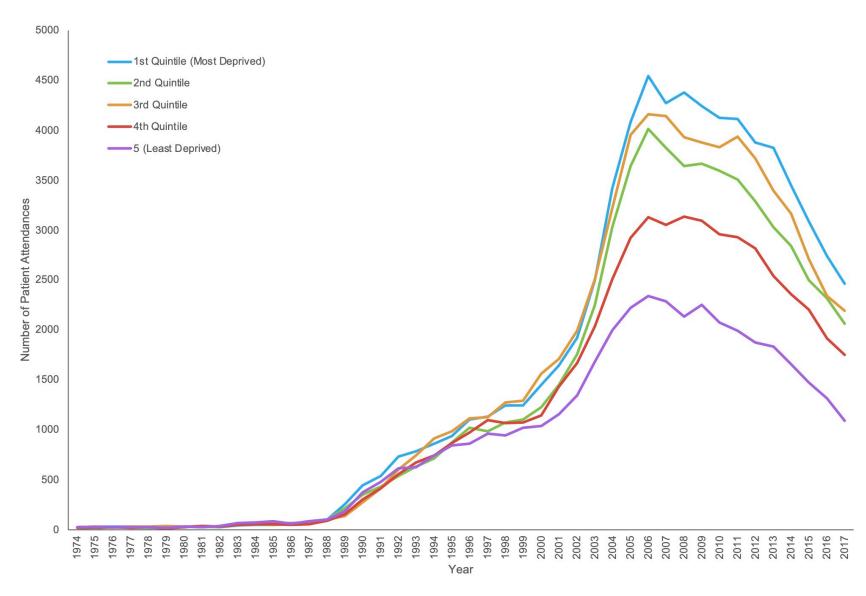
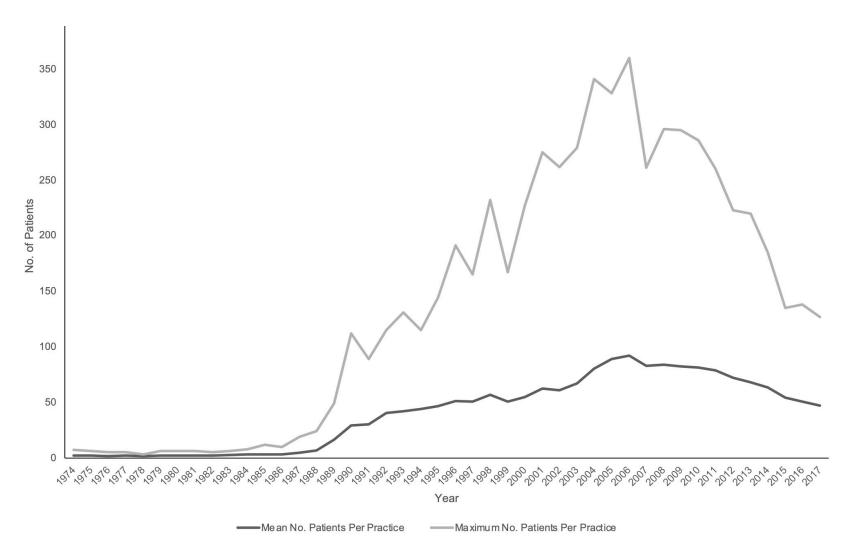


Figure 4.15: Changes in WIMD for dental patients attending GMPs over the study period.

The number of patients seen per practice varied (mean 69 patients per year, SD 54), with some practices seeing less than five dental patients per year, whereas others would see up to 360 dental patients per year (Figure 4.16). Practices which had a high number of dental attendances, defined as seeing more than 123 patients per year (mean number of attendances plus the standard deviation), saw a majority of female patients (56.16%), most commonly living in the 2<sup>nd</sup> quintile of WIMD (24.92%). Using univariate logistic regression high demand practices were more likely to see patients from rural locations (OR 0.81; 95% CI 0.79-0.83; p<0.0001).



**Figure 4.16:** The mean and maximum number of dental patients seen per GMP practice by year. Some practices had higher rates of dental attendances compared to the mean of all practices.

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# 4.4.5 Seasonality

The most common month of attendance was January (Figure 4.17), which was statistically significant (Walter & Elwood test (n=1,070,311) P<0.05). The most common week of attendance (Figure 4.18) was the first week of the year (2.42% attendances), followed by the last two weeks of the year (week 51 2.20%; week 52 2.04%).

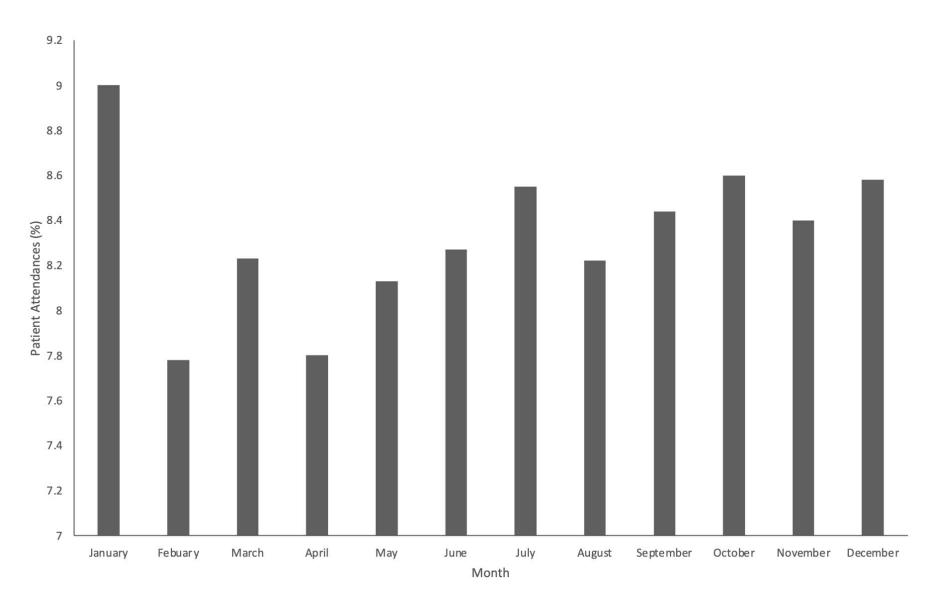


Figure 4.17: Month of attendance for all dental patients over the study period.

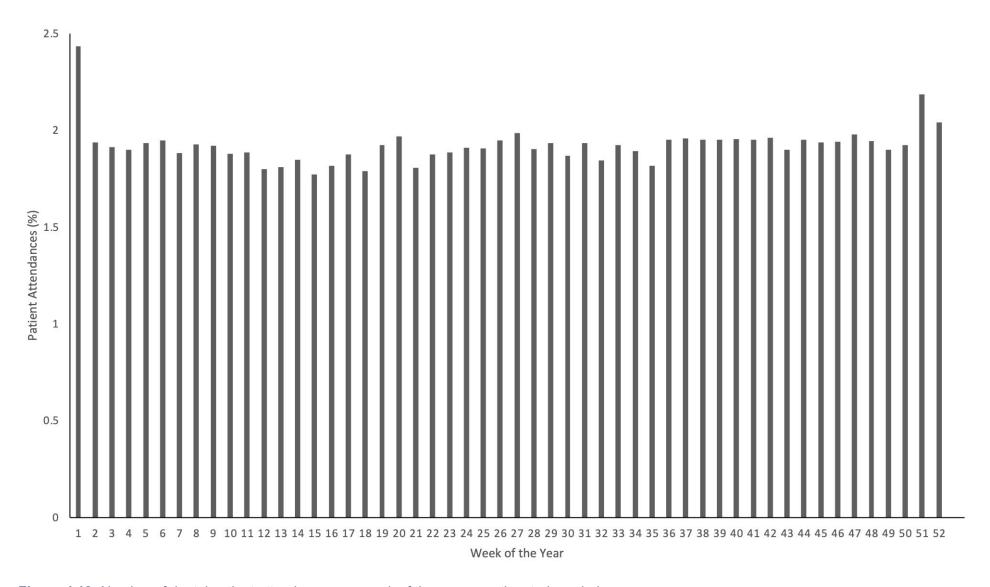


Figure 4.18: Number of dental patient attendances per week of the year over the study period.

The most common days of attendance were Monday and Friday (Figure 4.19), which were also statistically significant (Walter & Elwood test (n=1,070,311) P<0.0001). The most common month, week and day of attendance remained similar from 1990 onwards once the dataset included more values per year.

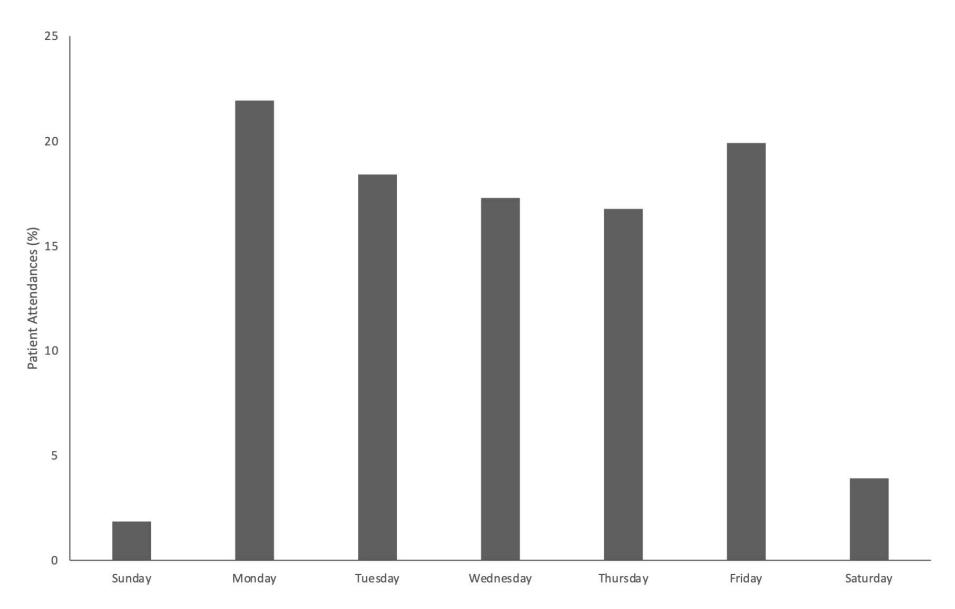


Figure 4.19: Day of attendance for all dental patients over the study period.

## 4.4.6 Repeat attenders

Within the dataset there were 37,985 repeat attendances, defined as more than one attendance in a 12-month period, these attendances equated to 26,312 patients (12.90%). Appointments defined as a repeat attendance were most commonly associated with an antibiotic prescription (38.90%) and acute dental (35.63%) Read codes. Out of the acute dental Read codes, the most common diagnosis associated with a repeat attendance was dental abscess (59.20%). The majority of repeat attenders were female (57.15%), and resided in the most deprived areas, however this was non-significant when compared to the expected values of 20% per quintile  $(X^2)$  (5df, n=0.413, p=0.36) (Table 4.8). Just over half of repeat attenders resided in urban areas (Table 4.9).

WIMD Quintile	No. of Patients	Percent (%)
1 (Most Deprived)	6,442	24.48
2	5,504	20.92
3	6,170	23.45
4	4,804	18.26
5 (Least Deprived)	3,392	12.89

**Table 4.8:** Breakdown of WIMD quintile for repeat attenders.

ONS Urban/Rural Classification	No. of Patients	Percent (%)
Urban, less sparse	13,367	50.80
Urban, sparse	1,292	4.91
Town and fringe, less sparse	3,920	14.90
Town and fringe, sparse	2,068	7.86
Village, hamlet and isolated dwellings, sparse	3,655	13.89
Village, hamlet and isolated dwellings, less sparse	2,010	7.64

**Table 4.9:** Breakdown of ONS Urban/Rural Classification for repeat attenders.

Over the study period there was a sharp increase in number of repeat attenders following 2000, with an increase in proportion of patients being repeat attenders (Figure 4.20). The number of repeat attenders then decreased following 2006, with a slight lag in decrease for non-repeat attenders.

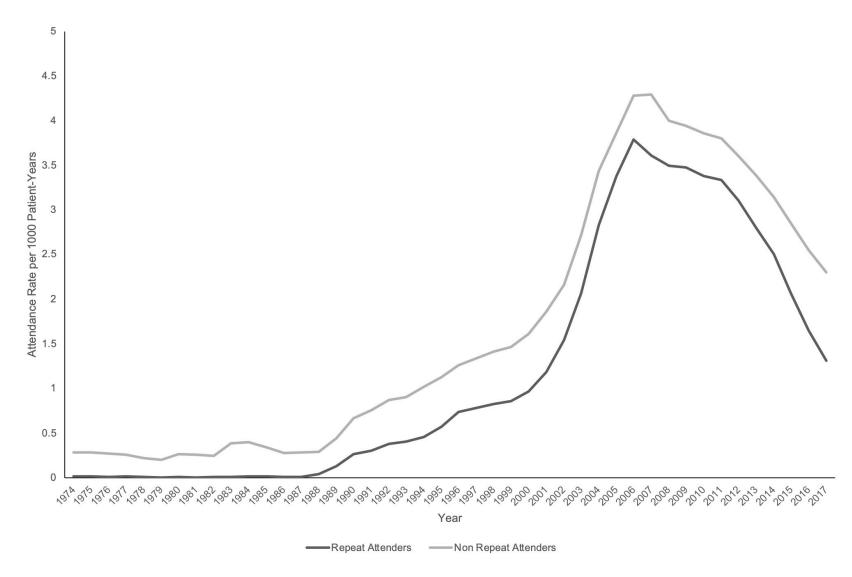


Figure 4.20: Number of dental patients attending GMPs classified as repeat and non-repeat attenders over the study period.

Repeat attendance was associated with living in the most deprived areas: relative to the most deprived quintile, the odds ratio for repeat attendance was 0.87 in the least deprived quintile (95% CI 0.86-0.89). Repeat attenders were also less likely to be from urban (OR 0.84, 95% CI 0.83-0.85, p<0.0001) locations. There was no difference in gender for repeat attenders (OR 0.99, 95% CI 0.98-1.00, p=0.20).

Within multivariable logistic regression, when considering WIMD and rurality together for prediction of being a repeat attender an interaction was noted which was significant (LR test: LR Chi²(4)=376.64, p<0.0001). The stratified analysis for this interaction is shown in Table 4.10. Therefore, when living in an urban area, decreasing WIMD (and therefore increasing levels of deprivation) increases the odds of being a repeat attender. In rural areas, deprivation appeared to have a smaller effect, except for the middle quintile (WIMD 3). When including potential confounders in the model none had a larger than 10% effect on the OR for repeat attendance or WIMD quintile and rurality interaction (results of the full regression analysis is given in Table 4.11).

WIMD	Odds Ratio	95% Confidence Interval
Urban		
1	1.22	1.19-1.25 (p<0.0001)
2	1.20	1.67-1.23 (p<0.0001)
3	1.14	1.11-1.18 (p<0.0001)
4	1.06	1.03-1.09 (p<0.0001)
5	Ref	
Rural		
1	1.08	1.04-1.13 (p<0.0001)
2	1.15	1.12-1.19 (p<0.0001)
3	1.22	1.19-1.26 (p<0.0001)
4	1.17	1.13-1.21 (p<0.0001)
5	Ref	

**Table 4.10:** Stratified analysis for WIMD and rurality interaction for repeat attendance.

	Univariate Analysis		Adjus	sted for Age	9	Adjusted for Urban/Rural		Adjusted for Gender			Adjusted for WIMD				
	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
WIMD															
1	Ref														
2	1.02	1.01-1.04	<0.05	1.01	1.00-1.03	0.112	0.99	0.97-1.01	0.239	1.02	1.01-1.04	<0.05			
3	1.08	1.06-1.10	<0.0001	1.06	1.04-1.08	<0.0001	0.99	0.97-1.01	0.372	1.08	1.06-1.10	<0.0001			
4	1.02	1.01-1.04	<0.01	1.00	0.98-1.02	0.959	0.94	0.92-0.96	<0.0001	1.03	1.01-1.04	<0.05			
5	0.87	0.86-0.89	<0.0001	0.85	0.83-0.87	<0.0001	0.83	0.82-0.85	<0.0001	0.87	0.85-0.89	<0.0001			
Urban/Rur	al	I	I		I	I			1		I	I			1
Urban	0.84	0.86-0.89	<0.0001	0.85	0.84-0.86	<0.0001				0.84	0.83-0.85	<0.0001	0.83	0.82-0.84	<0.0001
Gender		I	I		<u>I</u>	I			ı		I	I		I	I
Male	0.99	0.98-1.00	0.20	1.00	0.98-1.01	0.422	0.99	0.98-1.00	0.402				0.99	0.98-1.00	0.154
Age Group	)	I	I		l	I			I			I	l	I	I
<10	Ref														
10-19	1.31	1.26-1.35	<0.0001				1.30	1.26-1.35	<0.0001	1.31	1.26-1.35	<0.0001	1.31	1.26-1.35	<0.0001
20-29	1.56	1.52-1.61	<0.0001				1.57	1.52-1.61	<0.0001	1.56	1.52-1.61	<0.0001	1.56	1.52-1.61	<0.0001
30-39	1.70	1.65-1.75	<0.0001				1.69	1.65-1.74	<0.0001	1.70	1.65-1.75	<0.0001	1.69	1.65-1.74	<0.0001
40-49	1.76	1.70-1.80	<0.0001				1.74	1.69-1.79	<0.0001	1.76	1.71-1.81	<0.0001	1.76	1.71-1.81	<0.0001
50-59	1.75	1.70-1.80	<0.0001				1.73	1.67-1.78	<0.0001	1.75	1.70-1.80	<0.0001	1.75	1.70-1.80	<0.0001
60-69	1.67	1.62-1.73	<0.0001				1.64	1.59-1.70	<0.0001	1.67	1.62-1.73	<0.0001	1.68	1.63-1.74	<0.0001
70-79	1.49	1.43-1.54	<0.0001				1.46	1.40-1.52	<0.0001	1.49	1.43-1.54	<0.0001	1.50	1.44-1.56	<0.0001
>80	1.31	1.25-1.38	<0.0001				1.29	1.22-1.36	<0.0001	1.31	1.25-1.38	<0.0001	1.33	1.26-1.40	<0.0001
Appointme	nt Out	come	I				1	I	1	ı	I	I	ı	I.	I
Antibiotic	2.53	2.50-2.56	<0.0001	2.52	2.49-2.55	<0.0001	2.52	2.49-2.55	<0.0001	2.53	2.50-2.56	<0.0001	2.53	2.49-2.56	<0.0001
Referral	0.75	0.70-0.81	<0.0001	0.74	0.69-0.80	<0.0001	0.78	0.72-0.84	<0.0001	0.75	0.70-0.81	<0.0001	0.76	0.70-0.82	<0.0001

 Table 4.11: Logistic regression to identify potential confounders for repeat attendances with adjustments in multivariable model.

A fractional polynomial transformation was used for the logistic regression model for age as a continuous variable, which showed the relationship between repeat attendance and age to be non-linear. The same trend was noted when considered as 10-year age groups (Table 4.11). Increasing age up to 50-years-old was associated with an increasing odds of being a repeat attender. Once patients were 50-years-old and above increasing age then had a decreasing odds of being a repeat attender (Figure 4.21).

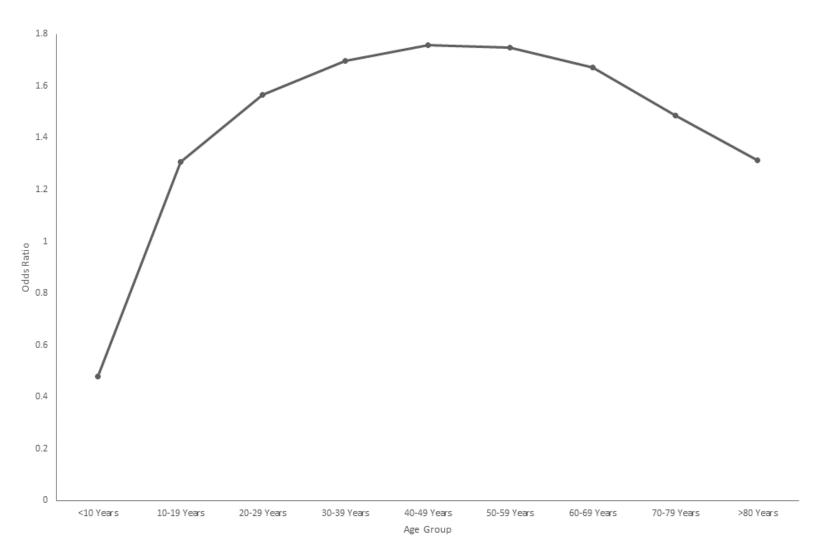


Figure 4.21: Odds ratio for being a repeat dental attender related to age group (all p<0.0001).

Univariate analysis was used to consider the impact of the outcome of the GMP appointment on repeat attendance. Prescription of an antibiotic increased the odds of being a repeat attender over two-fold (OR 2.53, 95% CI 2.50-2.56, p<0.0001), with 27.62% of initial appointments and 48.55% of repeat attendances including a Read code for a prescription of an antibiotic. This may imply that repeat attendance is associated with prescription of an antibiotic on the subsequent attendance. Referral to another service decreased the odds of being a repeat attender (OR 0.75, 95% CI 0.70-0.81, p<0.0001), with 0.80% of initial appointments and 0.50% of repeat attendances including a Read code for a referral. There was no evidence of confounding in relation to antibiotic prescriptions or referrals (Table 4.11).

When considering GMP practices that had a high number of dental patients per year (more than the mean number of attendances plus standard deviation; 123 attendances) only 2.33% of their patients were repeat attenders, therefore repeat attendance may not necessarily be associated with practices which see a higher number of dental patients per year than others.

#### 4.4.7 Antibiotics

There was a total of 160,952 antibiotic prescription Read codes in the dataset, of which 81,008 were prescribed on the same date as a dental Read code. The breakdown of antibiotics prescribed is shown in Table 4.12. Antibiotics were most commonly prescribed following a diagnosis of dental abscess (56.06%), or following a non-specific dental Read code (24.55%) or toothache (14.24%). Other diagnoses associated with prescription of an antibiotic were caries (2.22%), pericoronitis (0.60%), dentine hypersensitivity (<0.01%), gingival or periodontal disease (0.49%), alveolitis of the jaw (0.75%), stomatitis (1.04%) and dental trauma (0.06%).

Antibiotic	Prescribed foll attendance	owing a dental	Prescribed on the same day of attendance			
	No. of Prescriptions	Percent (%)	No. of Prescriptions	Percent (%)		
Broad spectrum antibiotics	102,878	63.92	50,649	62.52		
Metronidazole	24,726	15.36	14,797	18.27		
Erythromycin	12,965	8.06	6,056	7.48		
Phenomethylpenicillin	12,504	7.77	5,883	7.26		
Amoxicillin	7,870	4.89	3,623	4.47		
Antibiotic indicated	9	0.01	<5	<5		

**Table 4.12:** Breakdown of antibiotics prescribed over the study period.

Antibiotics were more commonly prescribed on a Monday, and least prescribed on a Sunday (Table 4.13).

Day	No. of Prescriptions	Percent (%)
Monday	37,001	22.99
Tuesday	30,184	18.75
Wednesday	27,615	17.16
Thursday	27,309	16.97
Friday	34,573	21.48
Saturday	3,992	2.48
Sunday	278	0.17

**Table 4.13:** Antibiotics prescribed per day over the study period.

Patients who were prescribed an antibiotic tended to be female (54.25%;  $X^2$  (1df, n=4.0274) p<0.05), and aged between 20- and 29-years-old (21.95%;  $X^2$  (8df, n=1900) p<0.0001). Patients also tended to be from the more deprived areas of Wales (Table 4.14;  $X^2$  (4df, n=391.6752) p<0.0001) and from a rural location (Table 4.15;  $X^2$  (1df, n=869.479) p<0.0001).

WIMD Quintile	No. of Prescriptions	Percent (%)
1 (Most Deprived)	37,959	23.58
2	34,033	21.14
3	39,598	24.60
4	29,586	18.38
5 (Least Deprived)	19,776	12.29

**Table 4.14:** Breakdown of WIMD for patients prescribed an antibiotic.

ONS Urban/Rural Classification	No. of Prescriptions	Percent (%)
Urban	72,017	44.74
Rural	88,935	55.26

Table 4.15: Breakdown of ONS Urban/Rural classification for antibiotic prescriptions.

The results of the full regression analysis are given in Table 4.16. Antibiotic prescriptions were associated with living in the most deprived areas: relative to the most deprived quintile, the odds ratio for a prescription was 0.91 in the least deprived quintile (95% CI 0.89-0.93). Antibiotic prescriptions were also less likely to be from urban (OR 0.83, 95% CI 0.82-0.84) locations. Gender was not predictive of being prescribed an antibiotic (OR 1.01, 95% CI 1.00-1.02). Antibiotics were most likely to be prescribed for those 40-49 years-old (OR 1.70, 95% CI 1.65-1.76) or 50-59 years-old (OR 1.73, 95% CI 1.67-1.78).

Within multivariable logistic regression modelling an interaction was present between WIMD and rurality for antibiotic prescribing (LR Test Chi²(4)=264.16, p<0.0001), and the stratified analysis is shown in Table 4.17. In urban areas increasing WIMD (and therefore decreasing levels of deprivation) decreased the odds of being prescribed an antibiotic. In rural areas patients from the 3<sup>rd</sup> quintile had the highest odds for being prescribed an antibiotic. To take into consideration that patients in rural areas were more likely to be repeat attenders, and that repeat attenders had twice the odds

of being prescribed an antibiotic, an adjustment for repeat attendance was added to this model, however this did not alter the odds ratio by more than 10%. Repeat attendance in rural areas is therefore not a confounder and may sit in the causal pathway explaining why patients who had an increased odds of being a repeat attender then also had increased odds of being prescribed an antibiotic.

Univa	ariate Analy	sis .	Adjus	Adjusted for Age Adjusted for Urban/Rural		Adjusted for Gender			Adjusted for WIMD					
OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
Ref														
1.04	1.03-1.07	<0.0001	1.04	1.02-1.06	<0.0001	1.01	0.99-1.03	0.282	1.05	1.03-1.07	<0.0001			
1.12	1.10-1.14	<0.0001	1.10	1.08-1.12	<0.0001	1.02	1.01-1.04	<0.05	1.12	1.01-1.14	<0.0001			
1.05	1.03-1.07	<0.0001	1.03	1.01-1.05	<0.001	0.96	0.94-0.98	<0.0001	1.05	1.03-1.07	<0.0001			
0.91	0.89-0.93	<0.0001	0.89	0.87-0.90	<0.0001	0.87	0.85-0.89	<0.0001	0.91	0.89-0.93	<0.0001			
Rural	I	I		I	I		I	I	l		I		ı	1
0.83	0.82-0.84	<0.0001	0.84	0.83-0.85	<0.0001				0.83	0.82-0.84	<0.0001	0.81	0.80-0.82	<0.0001
•									<u> </u>					I
1.01	1.00-1.02	<0.05	1.02	1.00-1.03	<0.05	1.02	1.00-1.03	<0.05				1.01	1.00-1.02	<0.05
oup	l	l		l	l		l	l			I		I	I
Ref														
1.28	1.24-1.33	<0.0001				1.28	1.24-1.33	<0.0001	1.29	1.24-1.33	<0.0001	1.29	1.24-1.33	<0.0001
1.45	1.41-1.49	<0.0001				1.45	1.41-1.50	<0.0001	1.45	1.41-1.50	<0.0001	1.45	1.41-1.49	<0.0001
1.58	1.53-1.62	<0.0001				1.57	1.53-1.62	<0.0001	1.58	1.53-1.63	<0.0001	1.58	1.53-1.62	<0.0001
1.70	1.65-1.76	<0.0001				1.69	1.64-1.74	<0.0001	1.71	1.66-1.76	<0.0001	1.71	1.66-1.76	<0.0001
1.73	1.67-1.78	<0.0001				1.71	1.65-1.76	<0.0001	1.73	1.68-1.78	<0.0001	1.73	1.68-1.79	<0.0001
1.65	1.59-1.70	<0.0001				1.62	1.56-1.67	<0.0001	1.65	1.60-1.71	<0.0001	1.66	1.60-1.71	<0.0001
1.43	1.37-1.49	<0.0001				1.40	1.35-1.46	<0.0001	1.43	1.37-1.49	<0.0001	1.44	1.38-1.50	<0.0001
1.23	1.16-1.30	<0.0001				1.20	1.14-1.27	<0.0001	1.23	1.17-1.30	<0.0001	1.24	1.17-1.31	<0.0001
	Ref 1.04 1.12 1.05 0.91 Rural 0.83 1.01 oup Ref 1.28 1.45 1.58 1.70 1.73 1.65 1.43	Ref 1.04 1.03-1.07 1.12 1.10-1.14 1.05 1.03-1.07 0.91 0.89-0.93  Rural 0.83 0.82-0.84  1.01 1.00-1.02  oup  Ref 1.28 1.24-1.33 1.45 1.41-1.49 1.58 1.53-1.62 1.70 1.65-1.76 1.73 1.67-1.78 1.65 1.59-1.70 1.43 1.37-1.49	Ref	Ref	Ref	Ref         0.0001         1.04         1.02-1.06         <0.0001         1.04         1.02-1.06         <0.0001           1.12         1.10-1.14         <0.0001	Name	Name	Note   Note	Name	Note   Note	No.   No.	No.   No.	Note   Note

Table 4.16: Logistic regression to identify potential confounders for antibiotic prescriptions with adjustments in multivariable model.

WIMD	Odds Ratio	95% Confidence Interval	Adjusted for Repeat Attendance, OR (95% CI)
Urban			
1	Ref		
2	1.01	0.99-1.04 (p=0.198)	1.02 (1.00-1.04, p=0.108)
3	1.00	0.98-1.03 (p=0.954)	1.02 (1.00-1.04, p=0.208)
4	0.92	0.90-0.95 (p<0.0001)	0.95 (0.93-0.98, p<0.005)
5	0.87	0.85-0.89 (p<0.0001)	0.91 (0.88-0.93, p<0.0001)
Rural			
1	Ref		
2	1.03	0.99-1.07 (p=0.135)	1.02 (0.98-1.06, p=0.386)
3	1.08	1.04-1.12 (p<0.0001)	1.05 (1.02-1.09, p<0.005)
4	1.03	0.99-1.06 (p=0.182)	1.01 (0.97-1.05, p=0.605)
5	0.90	0.86-0.94 (p<0.0001)	0.91 (0.87-0.95, p<0.0001)

**Table 4.17:** Stratified analysis for antibiotic prescription and WIMD and rurality interaction (Reference term of living in the most deprived areas, WIMD 1).

The number of prescriptions for antibiotics followed a similar trend over time to the number of overall patient attendances, with an increase in prescriptions from 1988 to 2006, followed by a gradual decline to 2011, and a sharp decline from 2011 to 2017 (Figure 4.22).

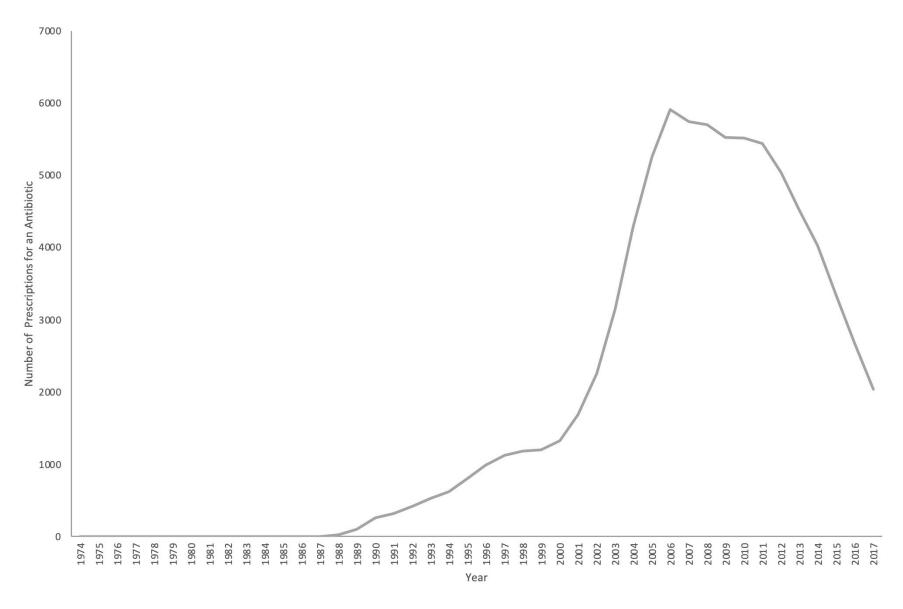


Figure 4.22: Number of prescriptions for antibiotics for dental attendances over the study period.

### 4.4.8 Referrals

A summary of the referral codes used for patients over the 44-year period is shown in Table 4.18. There were a total of 2,947 referral Read codes over the period studied, of which 1,924 were on the same date as a dental Read code. The majority of referrals were for non-specific dental Read codes (45.11%) or dental abscess (27.80%), the remaining referrals were for toothache (9.95%), caries (9.88%), pericoronitis (4.46%), gingival/periodontal disease (0.51%), alveolitis of the jaw (0.22%), stomatitis (1.82%) and dental trauma (0.26%).

Referral	No. of Referrals	Percent (%)
Non-urgent oral surgery admission	748	25.38
Fast track referral for head and neck cancer	448	15.20
Private referral to oral/maxillofacial surgeon	437	14.83
Admission to hospital	374	12.69
Referral declined	241	8.18
Referral to orthodontics	203	6.89
Non-specific referral	181	6.14
Admit oral surgery emergency	148	5.02
Referral to oral surgeon	137	4.65
Referral to specific dental service	30	1.02

Table 4.18: Breakdown of the referral Read codes in the dataset.

Prior to 1990, no patients with dental Read codes were recorded as being referred to another service, following this there was an increase in the number of referrals up to 2003, followed by a decline in number and then a further increase from 2008 through to 2017 (Figure 4.23).

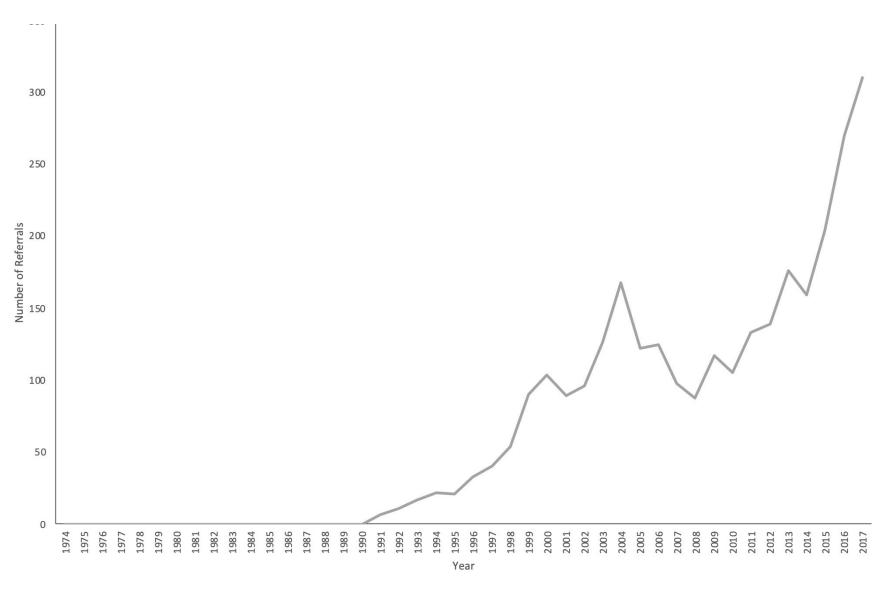


Figure 4.23: Number of all referral Read codes to other healthcare professionals/settings for dental attendances over the study period.

Patients who were referred tended to be female (61.89%; X<sup>2</sup> (2df, n=2900) p<0.0001). Referrals also tended to be made for those living in the most deprived areas of Wales (Table 4.19; X<sup>2</sup> (4df, n=141.43) p<0.0001) and in an urban location (Table 4.20; X<sup>2</sup> (1df, n=343.33) p<0.0001).

WIMD Quintile	No. of Referrals	Percent (%)
1 (Most Deprived)	900	30.54
2	680	23.07
3	499	16.93
4	423	14.35
5 (Least Deprived)	445	15.10

Table 4.19: Breakdown of number of referrals by Welsh Index of Multiple Deprivation Quintile.

ONS Urban/Rural Classification	No. of Referrals	Percent (%)		
Urban	2208	74.92		
Rural	739	25.08		

Table 4.20: Breakdown of ONS Urban/Rural classification for referrals.

Slightly more referrals were for those aged 20-29 years-old and 50-59 years-old, and the fewest referrals were made for those under 19-years-old and over 70-years-old (Table 4.21;  $X^2$  (8df, n=427.49) p<0.0001). Repeat attenders were significantly less likely to be referred to another service ( $X^2$  (1df, n=1100) p<0.0001).

Age Group	No. of Referrals	Percent (%)
<10 years	240	8.14
10-19 years	294	9.98
20-29 years	455	15.44
30-39 years	366	12.42
40-49 years	409	13.88
50-59 years	454	15.41
60-69 years	378	12.83
70-79 years	219	7.43
80+ years	132	4.48

**Table 4.21:** Breakdown of number of referrals by age group.

The results of the full regression analysis are shown in Table 4.22. Using univariate logistic regression modelling referrals were least likely to be made for patients from the middle WIMD quintile (OR 0.57, 95% CI 0.51-0.63), p<0.0001), and more likely in urban areas (OR 2.16, 95% CI 1.99-2.35, p<0.0001), and female patients (OR 0.73, 95% CI 0.68-0.79, p<0.0001).

Within multivariable logistic regression modelling an interaction between WIMD and rurality was again noted (LR Test Chi<sup>2</sup>(4)=32.39, p<0.0001) and the stratified analysis is shown in Table 4.23. Patients living in an urban location had a decreased odds of being referred if they lived in mid to less deprived areas (WIMD 3 or 4), and patients

living in a rural location had increased odds of being referred in they lived in the least deprived areas (WIMD 5).

	Univariate Analysis			Adjusted for Age			Adjusted for Urban/Rural			Adjusted for Gender			Adjusted for WIMD		
	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value	OR	95% CI	P Value
WIMD		1	1		1	1		1			ı		ı	1	1
1	Ref														
2	0.87	0.78-0.96	<0.005	0.84	0.76-0.93	<0.001	0.86	0.77-0.95	<0.005	0.86	0.78-0.95	<0.005			
3	0.57	0.51-0.63	<0.0001	0.54	0.48-0.60	<0.0001	0.56	0.50-0.63	<0.0001	0.57	0.51-0.63	<0.0001			
4	0.62	0.55-0.70	<0.0001	0.58	0.52-0.65	<0.0001	0.63	0.56-0.69	<0.0001	0.62	0.55-0.69	<0.0001			
5	0.89	0.80-1.00	0.052	0.82	0.73-0.92	<0.001	0.82	0.78-0.93	<0.0001	0.89	0.79-0.99	<0.0001			
Urban/	Rural	ı	ı	ı	ı	ı	1	ı		1	ı	ı			
Urban	2.16	1.99-2.35	<0.0001	2.24	2.06-2.44	<0.0001				2.17	2.00-2.36	<0.0001	2.14	1.96-2.33	<0.0001
Gende	r	l	l	l	l	I					l	I		I	I
Male	0.73	0.68-0.79	<0.0001	0.74	0.69-0.80	<0.0001	0.73	0.67-0.78	<0.0001				0.73	0.68-0.79	<0.0001
Age Gr	oup	I	I	l	I	I		I			I	1		I	I
<10	Ref														
10-19	0.97	0.82-1.16	0.763				0.97	0.81-1.15	0.686	1.00	0.84-1.19	0.987	0.97	0.82-1.51	0.722
20-29	1.85	1.58-2.16	<0.0001				1.86	1.59-2.17	<0.0001	1.90	1.63-2.22	<0.0001	1.83	1.57-2.14	<0.0001
30-39	1.85	1.57-2.18	<0.0001				1.83	1.56-2.16	<0.0001	1.89	1.61-2.23	<0.0001	1.83	1.55-2.16	<0.0001
40-49	1.55	1.32-1.82	<0.0001				1.49	1.27-1.75	<0.0001	1.60	1.36-1.87	<0.0001	1.51	1.29-1.77	<0.0001
50-59	1.10	0.94-1.29	0.233				1.04	0.89-1.22	0.626	1.13	0.97-1.33	0.118	1.05	0.90-1.23	0.554
60-69	0.83	0.71-0.98	<0.05				0.76	0.65-0.90	<0.005	0.84	0.72-0.99	<0.05	0.77	0.66-0.91	<0.001
70-79	0.73	0.60-0.87	<0.001				0.67	0.56-0.81	<0.0001	0.74	0.62-0.89	<0.0001	0.69	0.56-0.80	<0.0001
>80	0.51	0.41-0.63	<0.0001				0.47	0.38-0.58	<0.0001	0.53	0.43-0.66	<0.0001	0.47	0.38-0.58	<0.0001

**Table 4.22:** Logistic regression to identify potential confounders for referrals with adjustments in multivariable model.

WIMD	Odds Ratio	95% Confidence Interval			
Urban					
1	Ref				
2	0.94	0.84-1.05 (p=0.28)			
3	0.78	0.68-0.89 (p<0.0001)			
4	0.83	0.72-0.96 (p<0.05)			
5	0.92	0.80-1.04 (p=0.19)			
Rural					
1	Ref				
2	1.26	0.92-1.72 (p=0.14)			
3	0.93	0.69-1.25 (p=0.62)			
4	1.07	0.80-1.44 (p=0.64)			
5	1.71	1.26-2.33 (p<0.0001)			

**Table 4.23:** Stratified analysis for referral and WIMD and rurality interaction. (Reference term of living in the most deprived areas, WIMD 1).

8.18% of referrals were declined by the patient. Of these, the most common diagnostic Read codes were dental abscess (54.17%), non-specific dental read codes (29.17%), and toothache (16.67%). Patients who declined a referral were significantly more likely to be female (70.54%; X² (1df, n=25.19) p<0.0001) and living in an urban location (68.05%; X² (1df, n=9.73) p<0.01). 26.97% of declined referrals were from repeat attenders, however there was no significant difference between repeat and non-repeat attenders with regards to declining a referral (X² (1df, n=0.519, p=0.471).

#### 4.5 Discussion

### 4.5.1 Attendance rates and changes over time

Over the 44-year period studied there were a total of 288,147 patient attendances to GMPs in Wales for ADP, equating to an overall attendance rate of 2.60 patient attendances per 1000 patient-years. The number of patients attending their GMP for ADP initially increased from 1988, with a sharp increase from 2000 up to a peak of attendances in 2006. Following this attendance rates sharpy decreased. This equates to a mean of 92 patients per practice at the peak of patient attendances in 2006, decreasing to a mean of 47 patients per practice at the end of the study in 2017, however considerable variation in number of patients per practice were observed, which is in keeping with findings for the rest of the UK (Cope *et al.*, 2016). The decrease in attendance rates from 2006 was initially only observed in those under 40-years-old, with a delayed sequential decline in attendances seen in increasing older age groups following 2008. Attendances in patients above 70-years-old appears to remain stable following 2006 with no obvious decrease noted towards the end of the dataset. Older adults living in rural locations are more likely to be problem-orientated dental attenders, particularly if they have a lower education level

and have difficulty in accessing regular dental services (Arcury *et al.*, 2012), which may explain why this patient group seek care from their GMP. Following 2006 they may not receive the same information as younger patients, or if they do receive the same information are not willing or able to change their behaviour in comparison to their younger counterparts. In addition, when considering WIMD the decrease from 2006 appears to affect the more deprived quintiles, with a more gradual decrease in attendances noted from those living in the less deprived areas. This may indicate that whatever initiated the change in attendance rate from 2006 had the biggest impact on younger adults living in more deprived areas.

The reasons why patients may seek care from a GMP rather than GDP when suffering with ADP are multifactorial and also similar to the reasons patients become or maintain problem-orientated attendance as found in the qualitative work package and discussed in the following chapter (Chapter 5). Patient self-reported reasons for seeking dental care from a GMP include: patients' understanding of their symptoms; perceptions of the scope of practice of GMPs and GDPs; complexities and unfamiliarity's with the dental care system in comparison to medical care; availability of (urgent) dental care; dental anxiety; dissatisfaction with previous dental care; and willingness and ability to pay for dental treatment (Pau, Croucher and Marcenes, 2000; Bell et al., 2008; Cohen et al., 2009c; Cope, Butt and Chestnutt, 2018; Cope et al., 2018). GMP reported views of why patients seek medical care for dental problems include: issues with dental access or comparative ease of access of medical services; practitioner preference; financial concerns; perceived need for antibiotics; referred or poorly differentiated pain (Cope et al., 2015). In addition, GMPs have previously reported seeing an increase in dental patients when there have been disruption of local NHS dental services, and a decrease when dental access improves, practice triaging systems are improved, or there are patient education interventions to signpost to the most appropriate healthcare services for their complaint (Cope et al., 2015).

Although these reasons may explain why a patient would choose to seek care from a GMP for dental pain rather than a GDP, not all of them will explain the changes in attendance patterns seen over the time course studied. For example, dental anxiety, dissatisfaction with previous dental care, practitioner preference and referred or poorly differentiated pain are all unlikely to change on a population level, and are therefore unlikely to explain the large increase and decrease observed in number of

patients seeking care from a GMP. In addition, although ability to pay for dental treatment may change, willingness to pay may not. The remaining factors, however, may cause population changes over time, for example if policy change or a population level intervention is introduced.

The initial increase in attendances from 1988 may be due to an increase in number of GMP practices in Wales beginning to use computerised patient management systems and therefore electronic capture of Read codes, as well as an increase in the number of practices submitting data to SAIL (Figure 4.3). In 1990 changes were made to NHS dental services, with the introduction of capitation payments (National Health Service, 1990), meaning that GDPs were remunerated for the number of patients registered at their practice, resulting in an increase in the number of patients registered with a dentist (Tickle, 2012) this is therefore unlikely to explain the increase in attendances at GMPs from 1990. As GDPs over performed in response to the changes in 1990 there was a 'clawback' of fees in 1992, which led to a dispute between GDPs and the Department of Health, and access problems in dentistry first began to appear, which was at its peak by 2004 (Tickle, 2012). This could therefore explain the initial increase from 1992 and the sharp increase from 1999 seen in GMP attendances for ADP if dental access became problematic for patients. Additional policy changes within this time period included devolution of the Welsh NHS in 1999, and introduction of free dental check-ups to patients under 25-years-old and over 60years-old in 2001 in Wales (National Health Service, 2006). The introduction of free check-ups appears to not have had an effect on patient attendance at GMPs within this dataset, however if there was a dental access problem this could have masked the impact of introduction of free check-ups.

In 2006 a new dental contract was introduced which introduced units of dental activity, alongside the losses of patient registration and capitation payments (National Health Service, 2005). This contract change was seen unfavourably by dentists (House of Commons Health Select Committee, 2008) and is reported as making more GDPs move from NHS to private dental practices (Tickle, 2012), which would have worsened the access problems currently faced in Wales. This, however, does not coincide with the attendance rates observed, as from 2006 GMP attendances for ADP started to dramatically decline. It may, however, explain some of the increased attendances pre-2006 when GDPs became aware of the plans for contract change and began to move into the private sector.

An additional change to the 2006 contract in Wales was local Health Boards taking on responsibility for determining where new services could be provided and for provision of out of hours dental services rather than individual practices (National Assembly for Wales, 2016). Prior to 2006 GDPs would have decided where to set up a dental practice, therefore access was better in areas of higher wealth and therefore less deprived areas. Access across Wales has now improved in relation to deprivation (Jo, Kruger and Tennant, 2020) and this could explain the reduction in patient attendances at GMPs across all WIMD quintiles and the sharper decrease in the more deprived quintiles. There are no data freely available on urgent dental care in Wales prior to 2006, however post 2006 the number of patients receiving urgent dental treatment in primary care increased (StatsWales, 2019a), this may indicate that access to urgent care improved, and therefore may explain the reduced rate of attendances to GMPs, particularly for diagnoses such as dental abscess and toothache (Figure 4.24). These changes are demonstrated in Figure 4.25.

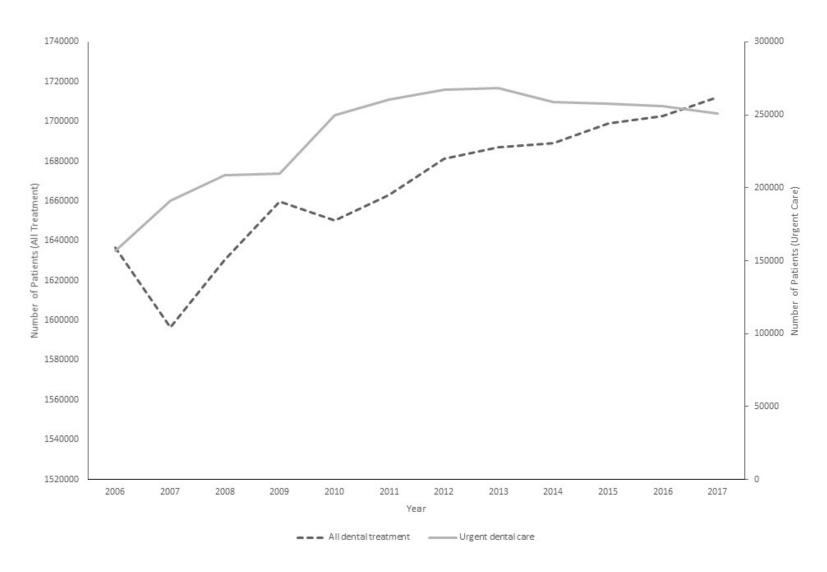
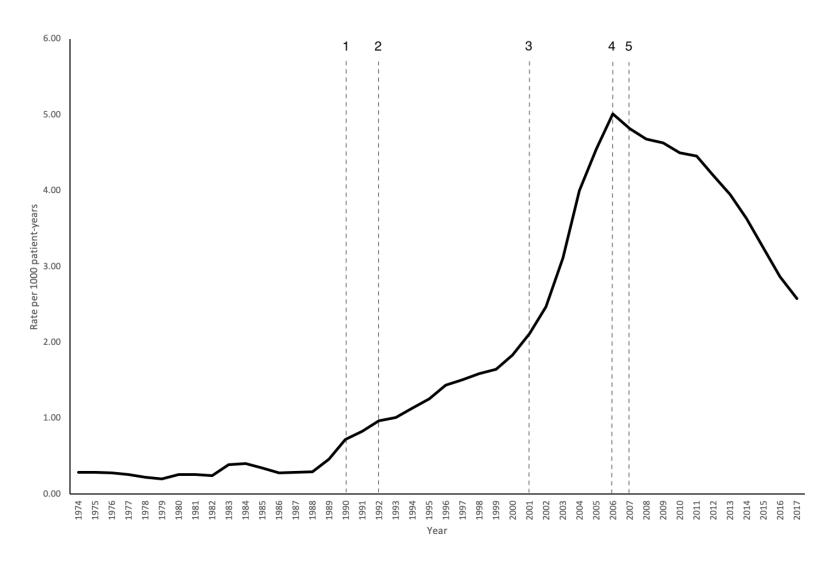


Figure 4.24: The number of patients receiving all dental treatment and urgent dental treatment from GDPs in Wales (StatsWales, 2019a, 2019b, 2019a).



**Figure 4.25:** Attendance rates for dental attendances over the study period with key policy change dates labelled: (1) Introduction of capitation payments in NHS dentistry. (2) Clawback of GDP fees due to overperformance. (3) Introduction of free dental check-ups to under 25 and over 60-year-olds in Wales. (4) Introduction of a new NHS dental contract and change in provision of dental care in Wales. (5). Introduction of Welsh NHS direct.

In 2007 Welsh NHS direct was introduced (NHS Direct Wales, 2017), this may account for some of the changes seen in patient attendance to GMPs, as if a patient was suffering with ADP they may decide to phone NHS direct, who may then either provide them with access to urgent care, or direct them to seek care from a GDP rather than a GMP, thereby improving health literacy. This could also account for the changes seen in the younger population whereby they may have searched for advice online and found NHS direct. Indeed, a freedom of information request from Welsh NHS Direct shows that the majority of patients attending the service were from younger age groups, with an increase over time in number of phone calls from younger patients (Figure 4.26) (Welsh Ambulance Service NHS Trust, 2019). In addition, in a similar service in England patients were most commonly from younger age groups and more deprived areas (Worsley et al., 2016). However, even if signposting to services has improved, recent Welsh data suggests that 20% of 18-25 year-olds who present to urgent dental care don't have a GDP or haven't tried to contact a dentist (Morgan and Monaghan, 2019).

Data are freely available on the number of patients receiving treatment from a GDP in Wales from 2006 (Figure 4.24), which shows an initial drop in number of patients immediately after the contract change in 2006, but then an increase following 2007, this initial drop could reflect GDPs adjusting to the new dental services contract followed by the introduction of NHS direct, with better signposting to services, and would correspond to the decrease in GMP attendances observed. The ADHS data also confirms that more people in Wales are seeing a GDP over time, with just over a third seeing a GDP for regular check-ups in 1978, rising to just under one-half in 1988, to almost 60% in 1998, and by 2009 over two-thirds reported seeing a GDP regularly (Chenery and Treasure, 2011). This survey is, however, subject to reporting bias. The number of referrals made by GMPs also increased from 2008, therefore the decrease in attendances could also be accounted for by patients seeing a GMP and being referred to a dental service. The decreasing antibiotic prescribing rate also coincided with the increasing referral rate and therefore could indicate that some of the changes seen were a result of GMP behaviour change, possibly as a result of the introduction of GMP guidance when patients present with dental complaints. Indeed, when this guidance was produced it is possible the GMPs may have stopped offering appointments for dental complaints, or could have changed their coding habits to ensure a referral was included for example. Given the steep trajectories in attendance rates the reasons underpinning them may be multifactorial

and include both the policy changes discussed as well as the management of dental patients by GMPs and their coding behaviour.

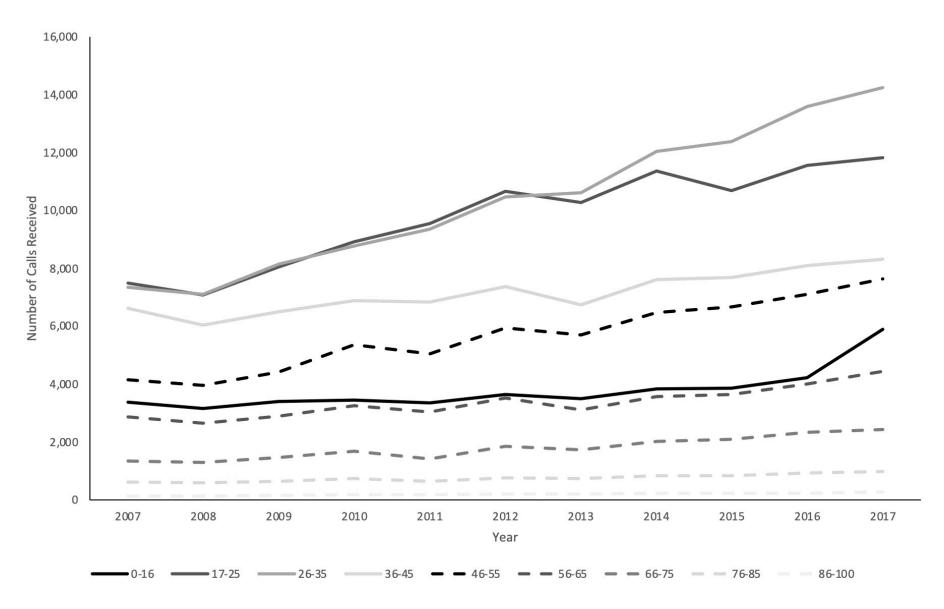


Figure 4.26: Number of phone calls to NHS Direct Wales by age group (Welsh Ambulance Service NHS Trust, 2019).

The decrease in attendances at GMPs for dental problems from 2006 is not exclusive to Wales. Data analysis using the Clinical Practice Research Datalink (CPRD), which contains information on GMP attendances for 77.4% of GMPs in England, 11.6% in Scotland, 7.6% in Wales and 3.4% in Northern Ireland, found an initial increase in attendance rates between 2004 and 2008, then a decline from 2008 to 2013, with an overall attendance rate of 6.06 dental consultations per 1000 patient-years (Cope et al., 2016). The attendance rate in this study is likely to be higher due to all dental related Read codes being included rather than excluding PDP diagnoses. The decrease in attendances in this study is unlikely to be explained by the introduction of NHS Direct, as in England this service was introduced in 1999 with full nationwide coverage by 2000 (NHS Direct, 2008). This does, however, raise the possibility that the decrease noted in Wales is actually part of a UK-wide decrease in attendances, however the reason for this decrease is unknown. In addition, attendance rates between GMP practices can vary significantly as seen in Wales, and also in the rest of the UK from 0.06 to 29.8 dental consultations per 1000 patient-years (Cope et al., 2016), therefore the change in attendance patterns seen over the 44-year period may have affected only certain practices.

Previous GMP attendance rates for dental consultations in Wales were reported as being as high as 6.90 per 1000 patient-years in 1999 (Anderson, Richmond and Thomas, 1999), which is higher than the rate of 2.60 found here, this is most likely due to two reasons: the size of the SAIL dataset at the time of analysis; and inclusion of chronic/persistent orofacial pain Read codes. The SAIL dataset has increased in the size of the population it covers. In 1999 when the first study was completed the SAIL dataset covered only 0.3% of GMP practices in Wales, and at the time of data collection for this study it covered 75-80% of all GMP practices. This includes addition of retrospective data once a practice begins to submit data to SAIL.

Both previous studies on dental patient attendances at GMPs included consultations for chronic/persistent orofacial pain, which were excluded for the purpose of this study. The attendance rates reported here are therefore more likely to be accurate of dental consultations for ADP only, reflecting those which patients acknowledge GDPs are best placed to treat. Analysis of the Read codes from this dataset associated with chronic/persistent orofacial pain are summarised in Appendix C, with an attendance rate of 4.22 patient attendances per 1000 patient-years found. Therefore, if this attendance rate is combined with that found for ADP, the overall

attendance rate (6.82 patient attendances per 1000 patient-years) is similar to those reported elsewhere, indicating that dental patients attend their GMP more frequently for chronic/persistent, rather than acute, dental pain.

### 4.5.2 Typical patient demographics and location

Over the study period the mean patient age was 38-years-old, with the majority of patients being in the 3<sup>rd</sup> or 4<sup>th</sup> decade of life, which is in keeping with dental attendees at GMPs in the rest of the UK (Cope *et al.*, 2016), at medical EDs (Allareddy *et al.*, 2014a; Pajewski and Okunseri, 2014; Walker *et al.*, 2014; Sun *et al.*, 2015; Currie *et al.*, 2016; Darling, Singhal and Kanellis, 2016; DeLia *et al.*, 2016) and the typical age profile for problem-orientated dental attenders (Currie, Stone and Durham, 2015; Nayee, Kutty and Akintola, 2015). There was an increasing age of attendance observed with the mean age increasing from just under 21-years-old to 42-years-old by the end of the study period. The decrease in attendances following 2006 was mainly seen in younger adults, which would account for the increasing mean age of patients.

The majority of patients were female (54.4%), which would be in keeping with other studies on dental GMP attendances (Anderson, Richmond and Thomas, 1999; Cope *et al.*, 2016), as well as wider healthcare literature whereby female patients are more likely to consult with a GMP than male patients (Dixon Woods *et al.*, 2005; Pinkhasov *et al.*, 2010). Female patients report more dental anxiety than male patients (Nuttall *et al.*, 2011a), which may also explain the increased proportion of female patients seeking dental care from a GMP if they are trying to avoid dental treatment (Cope *et al.*, 2018). However, given the large sample size of the dataset, and the small difference of just under 5% between genders, the difference noted between genders may not be clinically significant.

Almost one-quarter of patients were from the most deprived areas of Wales. This is the first study to consider deprivation level as an indicator for dental GMP attendances, however patients from more deprived areas are more likely to seek care from medical EDs (Lang *et al.*, 1997; O'Brien *et al.*, 1997; Currie *et al.*, 2016). The reasons for patients being most commonly from the more deprived areas may be due to: dental disease and pain being more prevalent (Vargas, Macek and Marcus, 2000; Steele *et al.*, 2011); fewer seeking regular care from a GDP (being registered with a GDP) (Morris. *et al.*, 2011); poorer health literacy (Sørensen *et al.*, 2015). Prior to the 2006 contractual change dental access in more deprived areas may have

also been poorer as GDPs could decide where to set up dental practices, potentially leading to more practices being set up in wealthy areas. Conversely, the 2006 dental contract change may also have disadvantaged those from more deprived areas, as the contract was a disincentive for established NHS practices to take on new patients who had a high burden of dental disease due to the payment for one or multiple restorations being the same (Appendix A).

Patients with poorer general health are more likely to be irregular dental attenders (Hakeberg and Wide Boman, 2017) and in addition, patients from more deprived areas may have poorer general health leading them to seek care from their GMP more frequently (Dixon Woods *et al.*, 2005), which has been shown to increase the likelihood of the patient then seeking care from their GMP for dental pain (Cohen *et al.*, 2011a). In addition, frequent consultations with a GMP for co-morbidities could in turn lead to the patient having a stronger or more trusted doctor-patient relationship, making them more likely to consult with their GMP for their dental problems, or believing that accessing a GMP would be easier than a GDP (Cope *et al.*, 2018). Older adults are also more likely to have co-morbidities they would be seeing their GMP regularly for, which may account for their attendance rate not decreasing as in the other patient groups. Dental anxiety is also more common in those from a more deprived sociodemographic background (Nuttall *et al.*, 2011a), which may again account for more patients from deprived areas seeking care from a GMP in order to avoid dental treatment (Cope *et al.*, 2018).

The second most common WIMD quintile was the middle quintile (22.86%). Financial barriers may also partly explain the trend seen in WIMD, whereby those in the 3<sup>rd</sup> quintile may not be able to afford dental care and may also not qualify for free dental care under the NHS, whereas those in the 2<sup>nd</sup> quintile may receive free care. Data show that 72% of Welsh dental practices in 2017 were accepting private patients, whereas only 17% were accepting charge exempt NHS patients and 15% accepting NHS patients, with variation across the health boards (Owen *et al.*, 2019). Therefore, patients may not be able to access NHS dental care but be unable to afford private dental care. Patients in the middle quintile of WIMD may also find making appointments outside of working hours more difficult, and as result may seek care from their GMP instead of a GDP where access is seen as being more accommodating of appointment times (Cope *et al.*, 2018).

When considering deprivation by rurality, significantly more patients in rural areas were from the middle quintile of WIMD, whereas in urban areas more were from the most deprived quintile. This may indicate that deprivation has a bigger effect on attendance rates for dental patients at GMPs in urban areas, where dental access is less likely to be a problem. This change in deprivation associated with rural locations may also be explained by limitations in use of WIMD in rural Wales where deprived people tend to be more geographically dispersed, and may be disproportionately affected by some of the deprivation indicators used in WIMD in comparison to those living in urban areas (Jones, 2015).

# 4.5.3 Repeat attenders

The majority of patients attended their GMP either once (39.61%) or twice (39.25%) with ADP, and 12.90% of all patients were defined as repeat attenders. The most common reason for a repeat attendance was for prescription of an antibiotic, and the most common diagnosis was dental abscess. The reason for repeated attendance may therefore be that following an initial GMP appointment as no definitive dental treatment could be carried out the patients return when symptoms worsen and antibiotics are then prescribed. This may also represent the cyclical nature of dental abscesses with patients reattending during acute exacerbations for prescriptions of antibiotics.

Predictors for becoming a repeat attender included living in a rural location, or a more deprived, urban area. Living in a rural location may make accessing dental services more challenging, resulting in more frequent and repeat attendances at a GMP. Indeed, dental practices report difficulties in recruiting and retaining dentists in rural areas (Owen *et al.*, 2019). In addition, people living in rural areas are more likely to consider oral health to be less important (Heaton, Smith and Raybould, 2004), and therefore may not attend a dentist for regular check-up appointments, instead opting to seek care from a GMP when they have dental pain instead. This is in keeping with US literature (Cohen *et al.*, 2009c) where it has also been shown that people living in rural areas are less likely to see a GDP for preventive care (Vargas, Ronzio and Hayes, 2003; Heaton, Smith and Raybould, 2004; Caldwell *et al.*, 2016; Khan, Thapa and Zhang, 2017), however are just as likely to have a GMP they see for usual care as their counterparts living in urban areas (Caldwell *et al.*, 2016; Khan, Thapa and Zhang, 2017). This could explain why high demand practices were more likely to see patients from rural locations. However, access to all healthcare services when living

in a rural area in Wales can be problematic (Public Health Wales Observatory, 2007), and therefore is not just limited to dental services. The number of dental and medical practices in the local health boards in Wales is shown in Table 4.24, the health board with the highest rural population (Powys Teaching) has more dental practices than medical practices, however the dental practices listed may not necessarily be accepting new patients. In 2017 only 15% of Welsh dental practices were accepting NHS patients, with variation across the health boards from 3% (Cardiff and Vale) to 52% (Cwn Taf), and 21% of practices reported having waiting lists, ranging from one month to three years (Owen *et al.*, 2019).

Health Board	Population (person per km <sup>2</sup> )	Living in Rural Isolation	Dental Practices	Patients per Dental Practice	Medical Practices	Patients per Medical Practice
Abertawe Bro Morgannwg University	531,858 (496.25)	5.0%	73	7286	77	6907
Aneurin Bevan University	587,743 (378.25)	4.9%	79	7440	90	6530
Betsi Cadwaladr University	696,284 (113.22)	21.3%	85	8192	119	5851
Cardiff & Vale University	493,446 (1046.91)	2.1%	68	7257	67	7365
Cwm Taf Morgannwg University	299,080 (558.48)	0.6%	38	7871	48	6231
Hywel Dda University	384,239 (66.54)	40.2%	49	7842	55	6986
Powys Teaching	132,515 (25.58)	52.5%	24	5521	17	7795

**Table 4.24:** The number of dental and medical practices by health board in Wales (Public Health Wales Observatory, 2013, 2016; NHS Wales, 2019b, 2019a, 2019c).

Levels of deprivation and becoming a repeat attender may again be linked to the reasons discussed above for deprivation and links to increased burden of dental disease, health literacy, and irregular attendance with a GDP. In addition, patients from deprived backgrounds are given very little, if any, information on their dental problem when they attend a GMP (Cohen *et al.*, 2009c), as well as have shorter consultations, not be referred on for further care (Scott, Shiell and King, 1995) and are more likely to be given a prescription for an antibiotic (Unsworth and Walley, 2001; Kumar, Little and Britten, 2003; Mangrio *et al.*, 2009; Koller *et al.*, 2013; Shallcross *et al.*, 2017; Mölter *et al.*, 2018).

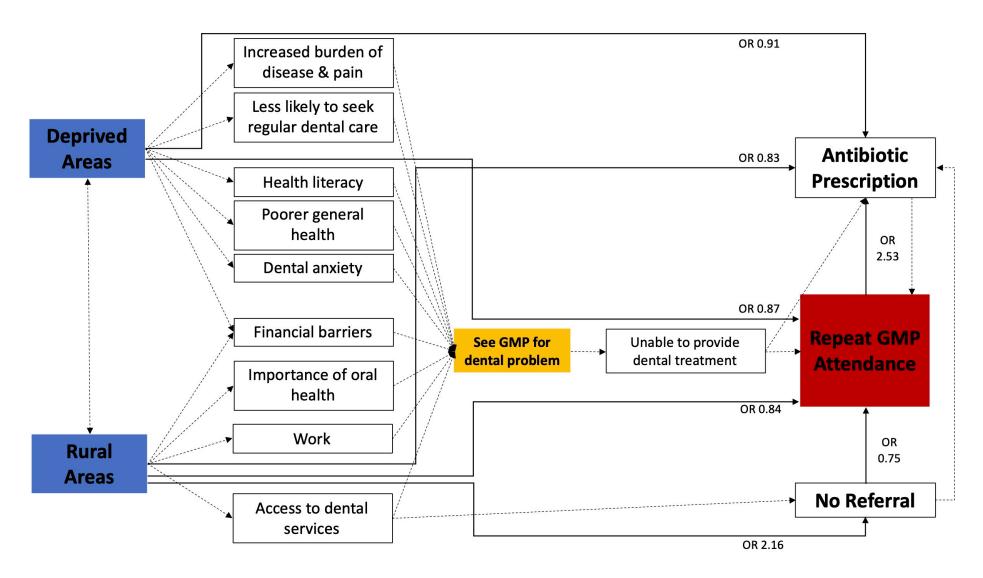
Patients who were repeat attenders in rural locations were more likely to be from the middle quintile of WIMD, therefore deprivation may have less of an effect in rural areas, or may be more poorly represented by WIMD. However, as discussed above, those in the 3<sup>rd</sup> quintile may not qualify for free dental treatment, and it is reported that patients from rural areas report cost as a barrier to accessing dental care more than those living in urban areas (Heaton, Smith and Raybould, 2004). This may explain why patients in the 3<sup>rd</sup> quintile in rural areas access dental care from their GMP most commonly. Alternatively, this could again demonstrate some of the limitations associated with WIMD in rural areas.

In terms of outcome of the GMP appointment, patients who were not referred on to another service were more likely to become repeat attenders. This may be because they are unable to access the dental care they require, and therefore re-attend to their GMP when their symptoms return or worsen. Prescription of an antibiotic was also associated with repeat attendance, which is in keeping with the rest of the UK (Cope et al., 2016). This has been demonstrated in the wider healthcare literature to encourage repeat attendance for conditions such as sore throat and ear infections where antibiotics would not routinely be indicated (Little et al., 1997; Williamson et al., 2006). It has also been reported by some GMPs to be a factor which encourages repeat GMP dental attendance (Cope et al., 2015). However, in this dataset, as the majority of subsequent repeat attendances were for prescription of antibiotics, this may indicate reverse causation, with patients re-attending due to their symptoms not resolving, and GMPs therefore prescribing antibiotics on repeat attendance. The prescription for antibiotics may be indicated on the subsequent attendance if the patient had a dental abscess which was worsening, and the GMP suspected spreading or systemic infection, however it is unknown from this dataset if this was the case. Patients who lived in rural areas were more likely to be prescribed antibiotics, and less likely to be referred to another service. This again may indicate an access problem for dental care in these areas, with patients seeking dental care from their GMP, and the GMP having nowhere to refer the patient so instead prescribing antibiotics, which would not resolve the dental problem, therefore requiring repeat attendance when the pain returns.

The number of repeat attenders increased in a similar fashion as the overall number of attendances, however from 2000 a sharp increase in repeat attenders was noted which resulted in a larger proportion of patients between 2000 and 2006 attending for

more than one consultation in a year. Following 2006 the number of repeat attenders dropped, with the number of non-repeat attenders decreasing from 2007. Therefore, the changes from 2000 seemed to encourage repeat attendance, and from 2006 seemed to discourage repeat attendance. The predictors for repeat attendance included being prescribed an antibiotic and not being referred to another service. Following 2006 there was a gradual decrease in number of antibiotics prescribed by GMPs, and following 2008 there was an increase in number of referrals. Therefore, the decrease in attendances could be partly explained by change in GMP prescribing or referral behaviour, with repeat attendance no longer being encouraged. In addition, if GMPs were prescribing antibiotics due to a lack of access for referrals, this increase in referrals and decrease in number of antibiotic prescriptions could indicate an improvement in access during this period, explaining the theoretical change in GMP behaviour. Another explanation for the change in antibiotic prescriptions could be partly explained by a large multicentre antibiotic prescribing intervention that started in Wales in 2007/2008 in 70 practices, with a resulting decrease in antibiotic prescriptions in the intervention practices (Butler et al., 2012). The education component of the intervention from this study has since been incorporated into further GMP resources provided by the Royal College of General Practitioners, which may again explain the continued decrease in prescriptions if more GMPs were exposed to the intervention (Royal College of General Practitioners, 2019). In addition, there has been a notable increase in the number of antibiotic awareness campaigns globally since 2008 (Huttner et al., 2019), therefore this increased awareness may have resulted in a decrease in antibiotic prescribing for dental patients. The change in antibiotic prescribing rates observed is also in keeping with the rest of the UK, where a decrease is observed from 2008 (Cope et al., 2016), meaning that this change in antibiotic prescribing behaviour may not be exclusive to GMPs in Wales.

A theoretical causal framework summarising and linking the factors discussed above to explain initial and then repeat GMP attendance for dental problems is shown in Figure 4.27.



**Figure 4.27:** Theoretical causal framework based on the analysis carried out and the current literature showing potential explanations for initial and then repeat GMP attendance related to patient sociodemographic factors. Dashed arrows indicate theoretical links, solid arrows indicate observed relationships within the dataset with odds ratios provided.

#### 4.5.4 Diagnoses and seasonality

The most common diagnosis was dental abscess (45.65%). Dental abscess could describe a range of severities of dental infection, from a localised dental sinus, through to a facial swelling. Patients may have decided to seek care from the GMP for this due to misconceptions about their symptoms (Cope, Butt and Chestnutt, 2018; Cope *et al.*, 2018) because symptoms may mainly affect the soft tissues, for example a draining sinus may be mistaken for an ulcer or blister, and a larger facial swelling may not be obviously linked to a grossly carious, but asymptomatic tooth.

The frequency of dental abscesses increased up to 2006 and then began to decrease. This increase may be due to the overall increase in numbers of patients seeking dental care from a GMP over this time period, but may also be due to an increase in the prevalence of dental abscesses which was reported to have occurred during this time period (Thomas *et al.*, 2008), particularly in the more deprived patients who were also less likely to be admitted to hospital urgently (Moles, 2008).

The second most frequent diagnoses were non-specific dental Read codes (29.18%). Patients can present to their GMP with dental complaints alongside appointments for other co-morbidities (Cope et al., 2015), and this figure may represent GMPs coding the main focus of the appointment and including a more generic Read code indicating other (dental) problems the patient mentioned. This may also partly explain the lack of reduction in patient attendances following 2006 in older patients, as these patients would be more likely to have other co-morbidities they may see a GMP for. A second reason for use of non-specific dental Read codes could reflect GMPs concerns regarding treating dental problems (Cope et al., 2015), through reported lack of knowledge or training and therefore uncertainty as to the correct diagnosis and therefore correct Read code to record. The use of non-specific dental diagnoses when doctors see dental patients is in keeping with other studies in other medical healthcare settings, such as medical EDs (Anderson et al., 2011; Hong et al., 2011; Sun et al., 2015; Currie et al., 2016; Darling, Singhal and Kanellis, 2016; DeLia et al., 2016). To add to this, GMPs report prescribing antibiotics due to fear of complications of disease (Lopez-Vazquez, Vazquez-Lago and Figueiras, 2012), need for a "quick fix" and diagnostic uncertainty (Teixeira Rodrigues et al., 2013). This may account for the high number of antibiotics being prescribed, particularly for nonspecific dental diagnoses. This highlights that dental patients seeking care from GMPs may not be the most appropriate place for them to attend. Indeed, they are

often limited in treatment they can carry out to prescription of analgesics or antibiotics, and advice to seek care from a dentist, and this has been shown to increase re-attendance at medical EDs (Sun *et al.*, 2015), which may also be the case for GMPs. This may also link to the decreased likelihood of re-attendance when a referral to another service is made, as the patient then receives definitive dental treatment and has no need to return to the GMP, in comparison to when an antibiotic is prescribed, which may only provide temporary relief, making the patient more likely to re-attend when symptoms present again.

The most common days of attendance were Monday and Friday, which is in keeping with the rest of the UK (Cope et al., 2016), however has changed since a previous study in 1999 when weekends were more common for dental attendances at GMPs (Anderson, Richmond and Thomas, 1999). Patients may be more likely to seek care for dental pain on a Monday or Friday as these dates are immediately prior to, or after, a weekend, when patients may believe that (urgent) dental care is not available, as discussed in the literature review and in the following chapter. Fewer patients may access care on a weekend due to either reduced access to care, or a belief that there is no access to primary care over a weekend. This would correspond with the increase in number of attendances to medical EDs observed on a Saturday and Sunday (Currie et al., 2016). The most common month of attendance was January, which is similar to the rest of the UK (Cope et al., 2016). The most common weeks of attendance were the 1st week in January, and the last two weeks of December, which may coincide with reduced access to healthcare services over the Christmas period. These common dates of attendance may have workforce implications to consider to ensure there is availability of healthcare professionals during these times of high demand, or conversely, to increase availability on the other dates to increase access.

#### 4.5.5 Strengths, limitations and implications for intervention development

A strength of this study is the large sample size that was available for analysis over a long period of time, meaning that issues with statistical power were not a concern, and external validity of the study is increased. This did, on the other hand, mean that statistical testing could produce significant p values which are not clinically significant.

Findings from this study heavily rely on accurate Read code reporting by GMPs, and there may be coding imperfections present, and different GMPs and practices may

have different coding habits. Indeed, standard rules for recording clinical codes in primary care do not exist (SAIL Databank, c2021). At the start of the study period there may have been a limited number of practices using computerised patient management systems, and therefore data for some dental patients may be under recorded. This has, however, been taken into account by use of attendance rates for examining number of overall patient attendances over the study period, with the same pattern of attendance noted between the attendance rate and actual number of patients. In addition, additional Read codes, such as referrals, may not necessarily be recorded by the GMP if a verbal signpost to other services is made rather than a formal written referral. It is therefore possible that more patients had informal referrals suggested than included in analysis. Given the large number of non-specific dental Read codes reported, and GMPs reluctance to manage dental patients, it is possible that incorrect diagnostic Read codes could have been used for dental problems, and therefore there could be bias introduced in analysis of dental diagnoses. In addition, GMPs could theoretically code more than one diagnostic Read code for a dental attendance to ensure the correct diagnosis is captured. This was taken into account during data cleaning whereby diagnostic Read codes were regrouped to ensure only one diagnosis was included meaning that diagnoses are more likely to be underestimated than overestimated in the analysis presented.

Bias may also have been introduced during the data cleaning process. Some assumptions had to be made about subsequent patient attendances where no dental Read codes were recorded, however these patients re-attended within a short period of time between a dental Read code and a referral or antibiotic prescription. This could mean that patients were returning to their GMP with other non-dental problems for which they were subsequently referred or prescribed an antibiotic. Or equally, data may have been excluded where a patient re-attended after a period of greater than a month for subsequent referral or prescription, however as the dental Read code was not recorded again the patient's data was dropped from the dataset. Local diagnostic GMP codes without a full written description, or incomplete Read codes had to be excluded as their meaning could not be reliably defined, and patients without a WIMD were also excluded. In addition, due to data protection counts of less than five patients could not be included in analysis and this restricted subgroup analyses for certain diagnoses and appointment outcomes.

Attendances at GMPs for dental problems appear to be declining in both Wales and also the rest of the UK (Cope et al., 2016), however the reason for the decline cannot be clearly determined. Given that the ADHS has not been repeated since 2009 it is not possible to extrapolate population level oral health trends to the SAIL dataset beyond this point therefore it is unknown if this decrease in attendance rate is actually related to a decrease in dental disease. Nevertheless, if patients are becoming less likely to seek care from a GMP for dental problems then an intervention sited at or focussed on GMP practices may not be required, and in addition if the reason for the decline can be clearly identified then elements of this could be integrated into further interventions and/or policy change. If an intervention is needed to discourage GMP attendance for dental pain then this could relate to health care professional behaviour such as encouraging dental referrals and discouraging antibiotic prescriptions where not indicated to try and reduce repeated GMP attendance. As repeat GMP attendance appeared to be associated with living in deprived and urban areas, specific interventions may be targeted in these locations. In addition, as repeat attendances were associated with living in rural areas, policy change may be needed here to increase dental access. Other interventions may target particular patient groups, such as those who have dental anxiety or phobia and therefore seek GMP care to try and avoid dental care.

#### 4.6 Conclusions

In conclusion, in Wales patients attend a GMP for dental problems with an overall attendance rate of 2.60 patient attendances per 1000 patient-years. These patients are more likely to be from deprived areas and in the 3<sup>rd</sup> or 4<sup>th</sup> decade of life, and present with a dental abscess. Just over 10% of patients are repeat attenders at their GMP, and these patients are more likely to be from an urban and deprived area, or rural area. The outcome of a GMP appointment may predict repeat attendance when an appropriate referral is not made, or antibiotic prescribed. The rate of attendances decreased following 2006, with the largest impact on patients under 40-years-old, and from more deprived areas. These changes over time may be partly explained by key policy change dates.

Given that dental attendances at GMPs are decreasing this may not be the most appropriate or important place for an intervention targeted at problem-orientated dental attenders. To understand this attendance pattern and where these patients seek care from a qualitative study was carried out which is presented in the following

chapter. This epidemiological study was published in the Journal of Dental Research (Currie *et al.*, 2022a; Appendix D).

# Chapter 5. Understanding Repeated Problem-Orientated Attendance

#### 5.1 Introduction

The reasons why patients do not seek regular dental care, and instead attend in a problem-orientated manner are under-researched, and factors within the literature which may partly explain this attendance pattern include: dental anxiety, lack of perceived need for treatment, financial issues, access to services, motivation and language barriers (Freidson and Feldman, 1958; Finch *et al.*, 1988; Cohen *et al.*, 2007; Nuttall *et al.*, 2011a; Hill *et al.*, 2013). This, however, is largely based on research from the US where the healthcare system is substantially different, and on UK research carried out in 1988, with NHS dental contracts having changed significantly since then. Recent research in this area has found trust in dentists and embarrassment to be further reasons for problem-orientated attendances, but more importantly that a "web of causation" exists between reasons for non-attendance (van der Zande *et al.*, 2020).

# 5.2 Objectives

- 1. To understand the reasons why patients attend in a problem-orientated manner instead of regular preventive dental care.
- To explore the care pathways leading to problem-orientated dental attendance over the life course.
- To explore barriers and facilitators contributing to decision-making behind delayed attendance for ADP.
- 4. To explore patient self-care strategies for ADP.
- 5. To explore the impact of ADP on everyday life.

#### 5.3 Methods

#### 5.3.1 Study design

This study used qualitative research methods in order to understand and explore patients' experiences of ADP and their care-seeking behaviour and pathways.

#### 5.3.2 Philosophical assumptions of qualitative methodologies

In qualitative research it is important to acknowledge the researcher's ontological and epistemological stance as it will influence the study methods and the data analysis.

Ontology is the philosophical study of the nature of reality or existence (Schwandt, 2015), and there are two extreme views: realism and idealism (Creswell and Poth, 2018). Realism suggests that there is an external reality which exists independent of

people's beliefs or understanding (Ritchie and Lewis, 2003; Schwandt, 2015), meaning that within the research context reality is independent of the researcher and there is, therefore, no connection between reality and the researcher's perception and the research process. On the other hand, idealism claims that reality is only knowable through the human mind and socially constructed meanings (Ritchie and Lewis, 2003; Schwandt, 2015) therefore reality is dependent on the researcher, and there is a close connection between the researcher's perception and the research process; the two cannot be separated. In between these two extremes lie various stances, one of which is subtle realism (Mays and Pope, 2000). This states that social phenomena exist independently of individuals' representations of them, but are only accessible via these representations (Ritchie and Lewis, 2003). Importantly this means that within research reality is represented not reproduced, the social world reality exists but the researcher cannot claim to be completely separate from it, nor are they completely isolated from it.

Epistemology is the theory and study of the nature of knowledge and how it is acquired (Green and Thorogood, 2009; Schwandt, 2015). There are again two polar views: positivism and interpretivism. Positivism states that genuine knowledge can only be founded directly on experience (Schwandt, 2015). This is often considered the basis for quantitative research, whereby there is a belief of a single, stable objective reality which exists regardless of human involvement or perception thereby allowing hypothesis testing, modelling and other quantitative scientific methods (Ritchie and Lewis, 2003). Interpretivism is typically associated with qualitative research, where it is possible for multiple realities to exist (Schwandt, 2015). Each reality is related to individual people and their perceptions, generated through their unique experiences, personal and social relations. This means that research findings can be influenced by the researcher's perspective (Ritchie and Lewis, 2003) and it is therefore important for the researcher to be aware of this and acknowledge it.

In this research my stance is subtle realism and interpretivism. I acknowledge that I am a clinician-researcher (Geddis-Regan, Exley and Taylor, 2021) and am therefore knowledgeable within the field and have experience of treating patients who are problem-orientated attenders. This in turn will impact on the data and its interpretation to some extent. However, this will be minimised by my awareness of the potential to introduce bias as well as by using inductive and deductive approaches to data analysis.

## 5.3.3 Ethical approval

Ethical approval was obtained from the Health Research Authority (IRAS 194728) and Research Ethics Committee (16/LO/1077), as well as from Newcastle Upon Tyne Hospitals NHS Trust (Ref 7841) and King's College Hospital NHS Trust's (Ref KCH16-169) Research and Development department.

## 5.3.4 Sampling procedures

As qualitative research takes a stance of interpretivism, it is important to identify a sample of the population who are able to provide a breadth of experiences reflecting particular features or groups. This is opposed to a sample which represents the population based on probability in quantitative research (Ritchie and Lewis, 2003; Green and Thorogood, 2009). A range of qualitative sampling strategies are described in the literature, and examples of these are: criterion based or purposive sampling; theoretical sampling; opportunistic or convenience sampling.

The choice of sampling technique is related to the study aim. In this study maximum variation, stratified, purposive sampling was used. This technique means that participants are chosen as they have particular features which allow detailed exploration of the question the researcher wishes to study (Ritchie and Lewis, 2003). For this research it allowed a depth and breadth of experiences to be gained, with specific attention to sociodemographic status, gender and age.

Sociodemographic status was considered using IMD (Office for National Statistics, 2019) as per the previous chapter, however, for this study English IMD was used. This has the same methodological basis as Welsh IMD. There are 32,844 LSOAs in England, each being assigned a ranked IMD score, with 1 being the most deprived area, and 32,844 being the least deprived. In this study IMD was considered in deciles, therefore an individual living in IMD decile 1 is from the 10% most deprived areas of England, and individuals from IMD decile 10 are from the 10% least deprived areas. During participant recruitment residential postcode was recorded, this allowed IMD and IMD decile to be calculated to ensure that a range of IMDs were included in the sample. For all participants their postcode was calculated using the English Indices of Deprivation 2019 classification (Ministry of Housing, Communities and Local Government, 2019).

Inclusion and exclusion criteria were set to ensure patients recruited were problemorientated dental attenders with recent urgent/emergency service use in order to gain a depth of understanding of experiences.

#### Inclusion criteria were:

- 16-years-old and above.
- Attending emergency/urgent dental services in England for ADP, which was
  defined as odontogenic pain including reversible pulpitis, irreversible pulpitis,
  non-vital tooth pain, and acute periodontal pain including gingival abscess,
  periodontal abscess, peri radicular/periapical abscess, pericoronitis, combined
  periodontal-endodontic lesions, and pulpal and periapical pain secondary to
  fractured teeth.
- Two or more emergency/urgent dental attendances in the previous 18 months.

#### Exclusion criteria were:

- Patients who were unable to converse and understand complex constructs in English.
- Patients presenting with problems associated with loose restorations, loose crown and bridgework, and problems associated with dental implants.
- Patients not complaining of ADP.
- Patients less than 16-years-old.

Two or more emergency dental attendances were required to ensure that participants recruited were frequent service users and would therefore be able to offer an indepth experience of emergency/urgent care services as well as having recent experiences they would be able to recall and reflect upon.

# 5.3.5 Qualitative data collection

There are three broad groups of methodology available to collect qualitative data: observational techniques, interviews and focus groups (Green and Thorogood, 2009; Creswell and Poth, 2018). For this study individual interviews were chosen because this method allows in depth exploration of individual participant ideologies, perceptions and rationale, as well as their motivations and decision-making (Ritchie and Lewis, 2003). As the interviews are carried out individually, they also allow the participant to discuss personal experiences away from a group setting, which may be more acceptable when asking about confidential healthcare experiences. In addition,

interviews are often considered to be more accessible to participants given that they can be carried out at a time and location of the participant's choosing (Ritchie and Lewis, 2003), which is an important consideration when working with potentially hard to reach/engage groups, which some problem-orientated dental attenders are (van der Zande *et al.*, 2020).

Semi-structured interviews were used. These are based on a series of pre-defined questions which introduce the participant to the area to be explored by use of an open question, and then follow up their response with further questions to examine particular areas of their response using prompts and probes (Ritchie and Lewis, 2003). This allows a detailed exploration but within a clear framework of questions and topics to discuss. The questions are recorded in a topic guide, which includes areas to explore within a question alongside any prompts, and the topic guide is refined as the data collection and analysis progresses.

An interview topic guide was developed, and the content checked theoretically by a collaborator with extensive experience in qualitative interviewing (CE), and clinically by a supervisor (JD). As the study was an inductive and iterative piece of work the topic guide evolved as interviews progressed in relation to the data that were gathered and analysed, the final topic guide is shown in Appendix E.

Patients had the option of either a face-to-face or telephone interview. All interviews were undertaken by myself. The first three interview transcripts were reviewed by a supervisor (JD) with extensive experience in qualitative research to ensure appropriate questioning and probing was undertaken, with feedback given before any further interviews were carried out.

On some occasions it became clear during the interviews that participants were unsure or confused about aspects of dental care, and as a result had questions they wanted to raise, these were answered at the end of the interview so as not to bias the answers to any of the following questions by giving the participant new knowledge. Once answers were given to any questions at the end of the interview their reaction or responses were recorded informally in the interview notes so they could be reflected upon within the analysis.

The mean duration of the interviews was 30 (+/- SD 8) minutes. All the interviews were recorded using a digital voice recorder (Sony ICD-SX2000) and the audio files anonymised by study ID. The interviews were transcribed verbatim by a transcription

company (JD Transcription), with files transferred using a secure university drop off system in password protected and encrypted files. Transcribed files were checked for accuracy.

# 5.3.6 Participant recruitment

Participant recruitment was carried out from December 2016 to December 2019. Patients were screened for inclusion and exclusion criteria by the clinician they were seeing for their emergency appointment, and if suitable were approached by myself for recruitment. In addition, posters (Appendix F) were used to promote the study to allow patients to self-refer during times when I was unable to attend the clinic or off site.

Patients who met the inclusion and exclusion criteria were given an information sheet and asked to sign a consent form (Appendix F). Initially a two-stage consent process was requested by the research ethics committee as a change to the proposed onestage process the research team suggested. The two-stage process requested by the ethics committee meant giving the patient 24-hours to reflect on the study information before signing and returning the consent form. This, however, created problems with recruitment, whereby patients would not return the consent form despite being interested in taking part in the study at the emergency appointment. This resulted in 15 out of 18 eligible patients *not* being recruited to the study at the start of recruitment. It was noted that patients often asked if they could sign the consent form and complete the interview on the same day, and following further discussion with patient/public representatives involved in the study it was suggested that the problems with patient recruitment were related to the target patient population being a hard-to-reach population (Shaghaghi, Bhopal and Sheikh, 2011). As such an amendment was submitted to the research ethics committee to allow consent and interview on the day of initial approach, which was approved with the stipulation that they were given a phone call 24-hours later to confirm consent.

All patients were given a £20 gift voucher for their time in the study, which was sent via Royal Mail recorded delivery following completion of the interview.

## 5.3.7 Recruitment locations

An initial purposive sample was taken from the North-East of England from the Newcastle Upon Tyne Hospitals' NHS Trust Dental Emergency Department (DEC).

This is a DEC based within a secondary care setting, however providing urgent and emergency dental care comparable to that of primary dental care.

Alongside this, recruitment was carried out in primary care in the North-East of England starting in January 2019. This was initially at one dental practice in Gateshead in an area which has a high rate of urgent dental care. Gateshead is also representative of a wide range of sociodemographic backgrounds, being ranked 47<sup>th</sup> out of 317 local authorities in England for deprivation, with 16% of residents living in the most deprived 10% of England addresses (Gateshead Council, 2019). Later in the study period from March 2019, in response to a low recruitment rate from primary care this was increased to two dental practices, with the second practice based in Northumberland. This practice again reported a high urgent care rate and was located in the most deprived lower super output area of Northumberland, falling into the most deprived 2% of England (Northumberland County Council, 2019), but also served a range of patients from different sociodemographic backgrounds. A further primary care recruitment location was the out of hours dental service, running from a Friday to Sunday evening in a community-based practice and linked to NHS 111 for Newcastle and Gateshead.

A final sample of patients were recruited from the South of England, from King's College Hospital Acute Dental Care clinic. This clinic provides a similar service to the North-East DEC and is based in Denmark Hill in Southwark, London, and provides emergency dental care to patients living throughout all of London. Recruitment was carried out at this site to allow for comparison of themes and to check for disconfirming evidence given the potential for socioeconomic and service provision differences. Recruitment began at this site in April 2019 and I was present for recruitment in person for two separate weeks. For the purposes of presenting the data both the North-East and London secondary care clinics are referred to as dental emergency clinics (DECs).

#### 5.3.8 Study sample

Recruitment and sampling in qualitative research are often continued until data saturation is reached, which is when no new data or themes are generated by data analysis, and forms part of the constant comparative method (Glaser, 1965). For this reason, a specific sample size is not required or often pre-specified in qualitative research, however a maximum number of participants can often be gauged by previous qualitative research in the same field. From previous experience it was

initially envisaged that a maximum of 15 patients per recruitment location (North-East primary care, North-East DEC, South DEC) would be required to reach data saturation (Durham and Nixdorf, 2014) and ensure a depth and breadth of views were gathered. Following the principles of the constant comparative method, data saturation was reached after 16 interviews across all the study locations.

Identification of eligible patients within primary care was more problematic than initially perceived. Despite targeting practices with high levels of urgent dental care needs, a total of 679 recruitment hours were spent at the primary care practices, resulting in only one eligible patient who was successfully recruited and interviewed. In addition, seven weekends over a period of seven months were spent in the out of hours services for recruitment, with no eligible patients attending during this period. As the constant comparative method was used, it was possible to review the reasons why recruitment from these sites was low, and on review of the interview transcripts from secondary care, it became apparent that the cohort of patients eligible for recruitment were not aware of the out of hours service, and therefore did not attend there, and in addition, would largely avoid urgent care in primary dental services (discussed further in the results). On consulting the literature other centres elsewhere in the UK also reported similar challenges in recruitment of non-regular attenders in primary care settings (Harris, 2018; Thompson, 2019). It was therefore decided to accept the one patient who was recruited from primary care and end recruitment in these sites. Nine of the patients recruited in secondary care had previously attended primary care (Table 5.1) for urgent dental care meaning that experiences were reflected in these patients.

Given the difficulties experienced with primary care recruitment a study separate to this thesis was undertaken using NHS Business Service Authority data to examine number of frequent urgent care attenders in primary dental care. This demonstrated that frequent users are largely based in rural and deprived areas (Currie *et al.*, 2022b). These data are presented in Appendix G as a peer-reviewed publication for triangulation.

Recruitment in London took place over a total of two weeks. During the first week in April 2019 there were four eligible patients, out of which three were recruited and interviewed (one was not interested in taking part). During the second week of recruitment in October 2019 there were no eligible patients, despite 139 patients attending the service. This change in number of eligible patients was thought to be

due to a service change at the clinic, whereby in August 2019 the clinic became an appointment-only service, rather than a walk-in service, meaning that patients had to ring the clinic before attending to make an appointment. This service change was likely to be an access barrier for the target patient group, discouraging problemorientated attenders fitting the inclusion criteria to attend here. As this recruitment site was primarily being used to look for disconfirming evidence, and no new ideas or themes had emerged from the interviews completed to date at this site, it was decided to accept the three patients recruited as the final number.

# 5.3.9 Qualitative data analysis

Qualitative data analysis begins as soon as data collection begins, this allows the researcher to develop hypotheses, refine questions and develop new paths of enquiry as the interviews take place, as well as to go back to previous interviews and look for further ideas or themes (Ritchie and Lewis, 2003). As part of grounded theory research the constant comparative method denotes two ways of developing theory in relation to qualitative research: inductive and deductive reasoning (Glaser, 1965). Using inductive reasoning theory is built from observations within the data, whereas using deductive reasoning theories are tested against the data (Green and Thorogood, 2009). Within true grounded theory only inductive reasoning should be used, however constructivist grounded theory recognises that the researcher will interact with the data, society and reality and therefore both approaches can be used (Charmaz, 2000). In this study both inductive and deductive reasoning was used in an iterative approach, this relates back to my ontological and epistemological stance, in that as a clinician-researcher it would be difficult to be completely isolated from the data.

Various approaches to qualitative analysis are available, and examples include framework analysis, thematic analysis, and grounded theory (Silverman, 2016). The constant comparative method is a cyclical process, whereby data are collected, analysed and coded, before further data collection, analysis and coding is repeated, which allows emergence of themes until saturation is reached (Glaser, 1965; Green and Thorogood, 2009). The principles of this were used within this study in terms of analysing the data as they were collected, which allowed refinement and revision of the topic guide, and analysis of the data until saturation of themes were reached.

For these data, alongside the constant comparative method, a thematic analysis was used with frameworks to help to organise and sort the data in a theme-by-theme and

case-by-case analysis (Silverman, 2016). This analysis helped drive the development of a conceptual model to explain problem-orientated attendance. The steps involved in each stage of this are discussed in detail below.

# Open Coding

Initially a process of familiarisation was carried out whereby the first three interview transcripts were read several times to allow myself to become fully immersed in the data. Following this open coding was used. To do this each transcript was read and then areas of text were assigned codes line by line (Figure 5.1). These codes initially were descriptive, and coding was carried out on a printed copy of the transcript. During the same period, a supervisor experienced in qualitative clinical research (SS) also carried out the same open coding procedure on four of the transcripts. This allowed me to crosscheck the validity of the coding.

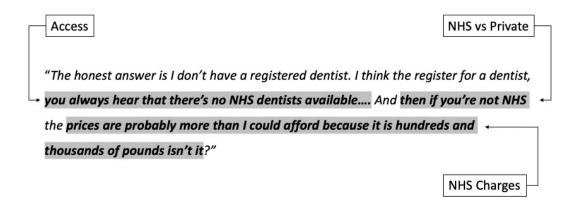
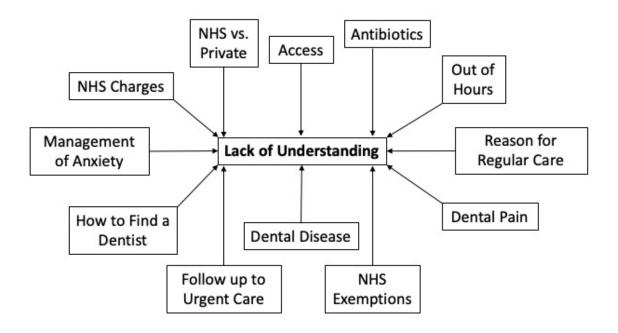


Figure 5.1: An example of open coding used in the qualitative data analysis.

### Axial Coding

Following open coding of six interviews the codes were reviewed, renamed and regrouped to created analytic or conceptual codes. Codes were grouped together if they were similar into a theme and a coding framework was drawn up. An example of a theme with associated grouped codes is shown in Figure 5.2. The coding framework was inputted into NVivo software (NVivo qualitative data analysis software; QSR International Pty Ltd. Version 11, 2016), and all remaining transcripts were then coded in NVivo according to this framework. Use of NVivo had the advantage of being able to store segments of data under assigned codes so they could be easily retrieved. As analysis continued any new codes required were created and added to the framework, and previous interview transcripts were reviewed and re-coded to incorporate the new codes.



**Figure 5.2:** An example of re-grouping of codes to create a larger theme. Twelve codes were identified as being related to a lack of knowledge, these were therefore grouped to form a larger theme on "Lack of Knowledge".

# Framework Analysis and Conceptual Model

To help organise the themes that emerged frameworks were created using Excel spreadsheets (Microsoft Office Professional Plus 2016, USA). This was used to develop theory and relationships between themes, which were then developed into a conceptual model of problem-orientated attendance. This model was built up within PowerPoint (Microsoft Office Professional Plus 2016, USA), with each participant added onto the model in subsequent slides, so that the development of the model could be tracked and refined where required. The emerging themes and thematic framework were reviewed by the supervisory team (SS, VAS, JD). The final conceptual model, with associated themes and verbatim quotations were again reviewed by the supervisory team (SS, VAS, JD), as well as by a collaborator with considerable experience in qualitative research (CE).

#### Mapping to Theoretical Domains Framework

A secondary analysis was also carried out mapping the themes generated to the Theoretical Domains Framework (TDF) (Michie *et al.*, 2005; Cane, O'Connor and Michie, 2012). This mapping exercise was done to allow examination and understanding of participants' problem-orientated behaviour and decision-making processes mapped to behavioural determinants to inform future intervention development. As discussed later in this chapter this analysis was not needed for

intervention development for this thesis and the details and results are therefore presented in Appendix H for completeness.

As is commonplace in qualitative research the data and discussion will be presented together.

# 5.4 Data and Discussion

# **5.4.1 Summary**

The majority of interviews (n=12) were carried out over the telephone due to patients not wishing to complete the interview immediately post-operatively following local anaesthesia and dental treatment. The remainder were carried out face-to-face. The summary characteristics of the interviewed patients is shown in Table 5.1.

Study ID	IMD Decile	Gender	Age	Occupation	Ethnicity	Recruitment Location	Diagnosis	Urgent Care Services Accessed
HN001	4	Male	27	Security guard	White, British	North, secondary care	Periapical periodontitis	Secondary Care DEC; Medical ED; NHS 111
HN003	1	Male	47	Taxi driver	White, British	North, secondary care	Periapical periodontitis	Secondary Care DEC
HN008	3	Male	38	Project manager	White, British	North, secondary care	Periapical periodontitis	Secondary Care DEC
HN011	4	Male	59	Civil servant	White, British	North, secondary care	Irreversible pulpitis, periapical periodontitis	Primary Care GDP; Secondary Care DEC
HN020	5	Female	60	Home maker	White, British	North, secondary care	Perio-endo lesion	Secondary Care DEC; GMP
HN023	9	Female	56	Home maker	White, British	North, secondary care	Periapical periodontitis	Secondary Care DEC
HN024	3	Female	19	Home maker	White, British	North, secondary care	Irreversible pulpitis, periapical periodontitis	Secondary Care DEC; GMP; NHS 111
HN025	1	Male	27	Retail	White, British	North, secondary care	Irreversible pulpitis, periapical periodontitis	Secondary Care DEC; NHS 111
HN026	2	Female	48	Nurse	White, British	North, secondary care	Periapical periodontitis	Primary Care GDP; Secondary Care DEC
HN028	4	Female	57	Senior carer	White, British	North, secondary care	Perio-endo lesion	Primary Care GDP; Secondary Care DEC
HN031	5	Female	24	Auxiliary nurse	White, British	North, secondary care	Periapical periodontitis	Primary Care GDP; Secondary Care DEC
PN001	1	Female	52	Carer	White, Irish	North, primary care	Perio-endo lesion	Primary Care GDP
HN032	4	Female	23	Engagement worker	White, British	North, secondary care	Periapical periodontitis	Primary Care GDP; Secondary Care DEC
HS001	2	Male	47	Construction worker	Black, Caribbean	South, secondary care	Periapical periodontitis	Primary Care GDP; Secondary Care DEC
HS002	2	Male	62	Ambulance preparation	Black, African	South, secondary care	Periapical periodontitis, perio-endo lesion	Primary Care GDP; Secondary Care DEC
HS003	9	Female	45	Data analyst (currently unemployed)	Black, Caribbean	South, secondary care	Periapical periodontitis	Primary Care GDP; Secondary Care DEC

 Table 5.1: Study sample characteristics of the adult problem-orientated attenders recruited.

A wealth and depth of data were collected from the participant interviews showing a complexity in the care pathways and decision-making associated with problem-orientated dental attendance. To clearly present the data patient pathways through urgent dental care are briefly summarised first. These care pathways were largely influenced by individuals' experiences and perspectives of urgent dental care and these are then discussed in depth. The combination of their care pathways and experiences formed a conceptual model which is then explained. Illustrative quotes are given throughout the data and discussion.

# 5.4.2 Patient care pathways

Care pathways through urgent care were complex with different services being consulted both for one, and across multiple, ADP experiences. A summary of illustrative quotes for the themes associated with care pathways are given in Table 5.2 and the care pathways are shown in Figure 5.3. Examples of how a sample of participants moved through these care pathways is given in Appendix I. Care pathways were intricately linked to experiences of care and are therefore discussed in depth in the following section.

Participants were aware they could try and seek urgent care in a primary care dental practice however access problems were reported. These could be a true barrier when appointments were either not available, or not available in a timely manner in relation to experiencing acute dental pain (ADP), which has been reported elsewhere (Pau, Croucher and Marcenes, 2000). Access could also be a perceived rather than true barrier.

When primary care was accessed negative experiences and dissatisfaction with the service was reported. In direct relation to chosen care pathways a common experience was that immediate treatment was not available in primary care. These negative experiences led participants to either move around different primary care dental practices when experiencing ADP or to seek care from secondary care dental emergency clinics (DECs) instead, which has been reported in urgent dental care patients previously (Pau, Croucher and Marcenes, 2000).

Reasons for initial care-seeking from DECs were related to the access barriers mentioned above, individuals' knowledge of the service, influences from others and affordability of dental care. Affordability of care was either a true or perceived barrier.

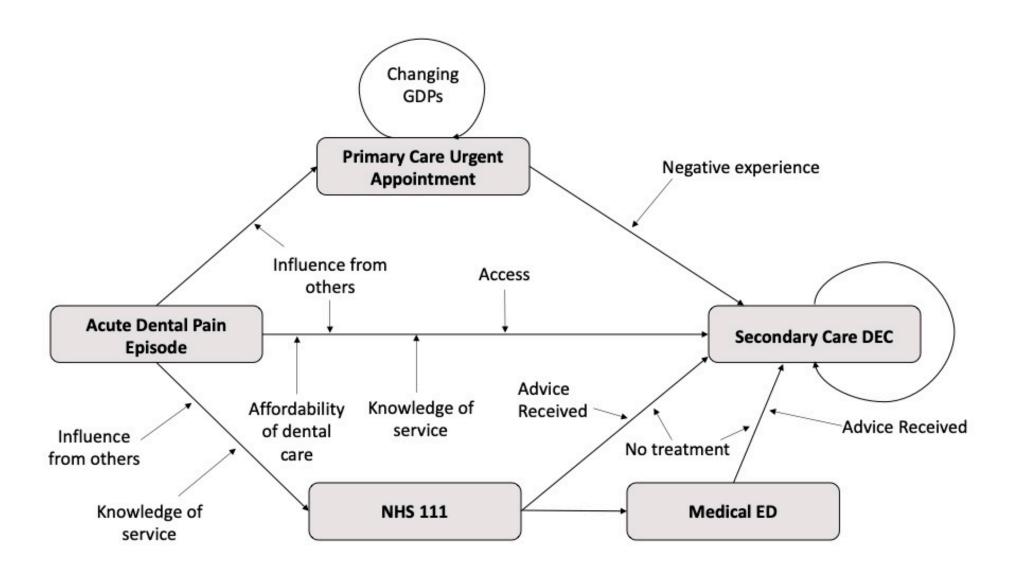
Influences from others played a significant role in deciding to seek care as well as where to seek care across all pathways to urgent dental care.

Where NHS 111 was accessed, the outcome was either advice to attend DEC, or referral to a medical ED. As no dental treatment was available at medical EDs, the advice given from ED doctors was to attend DEC. Two participants reported seeing a GMP for dental problems, however on exploration these were not urgent care attendances for ADP and therefore were not included in Figure 5.3, the details of these attendances are explored later in this chapter.

Once participants had attended a DEC, positive experiences and immediate availability (as opposed to no or delayed treatment elsewhere) acted as strong reinforcement of this care-seeking behavioural pattern and made it more likely to continue over time, with repeated DEC attendances and avoidance of primary care reported.

Theme	Representative Quote
Access	"I rang around a couple of dentists but they weren't able to fit me inI think
	it was because I wasn't registered with them and they were very, very
	busy and they didn't have any appointments available for about ten to
	fourteen days." Male, 59-years-old.
	"I've tried to get appointments but they said two weeks waiting or phone
	every day to see if there's a cancellation, and when you're in pain you can't be doing that, you need to be seen to straight away." Female, 60-years-old.
Advice	"I went up to the [ED department, hospital name redacted] They gave us
Received	[sic, me] antibiotics and said if the pain gets worse or you start being sick go
IXECCIVEU	straight to the A&E and then if you can wait go to the dental hospital and
	they would take it out." Male, 27-years-old.
Influences	"My family told us [sic, me] to ring [dental practice for emergency
from Others	appointment]." Female, 19-years-old.
Knowledge of	"I've just always known that it's [DEC] been here. I think being from
Service	Newcastle everyone knows that there's always the dental hospital." Male,
	38-years-old.
Negative	"I went by the NHS route. They told me I have to wait for an x-ray and I
Experience	had to go to hospital for an x-ray and wait two weeks for the results whether
A 66 1 1 1114 6	or not to pull my tooth out. So it's not very nice." Female, 45-years-old.
Affordability of	"Just for the money as well really. I couldn't really afford to go to the dentist
Dental Care	and pay for it." Female, 24-years-old.
No Treatment	"Last year I slipped and I hit my face and I saw an emergency private dentist I rang 1-1-1 Put us [me] into contact with the nearest
	emergency dentist and booked an appointment for us That was actually
	tragic. It was a complete waste of my time, money and effort. I went. He
	looked in my mouth and he went yeah you need to see your GP and then
	charged us [sic, me] 26 quid. I went to the dental hospital and they
	Cleaned it out. The next day I was perfectly fine." Male, 27-years-old.
Repeat DEC	"They actually help with pain whereas a normal dentist fobs you off they
attendance	just try and pass it off rather than do something about my problemThey
	actually don't judge based on appearance or what you've been through.
	Theyask you if you suffer with anxieties and fears and stuff." Female, 19-
	years-old.
Changing	"That's the four places that I changed just to see how people [dentists]
GDPs	improves themselves." Male, 62-years-old.

**Table 5.2:** Illustrative quotes for the themes associated specifically with urgent dental care pathways. Care pathways were intricately linked with experiences of care and the themes related to these are presented and discussed in depth in the following section.



**Figure 5.3:** Care pathways through urgent care for ADP showing the complexity of interactions and influencing factors between and within each part of the pathway shown.

# 5.4.3 Patient experiences and perspectives of urgent dental care

Throughout their care pathways, participants reflected and recalled a multitude of experiences and perspectives which closely linked to their decision about where and when to seek care, and the reasons for problem-orientated attendance. The overarching themes from the data related to a misunderstanding or lack of knowledge and the perceived characteristics of the attending dentist when they did seek dental care. Other themes also emerged and included: dental anxiety; affordability of dental care; impact of work; importance of oral health; self-management and impact of pain; influences from others. These will be discussed in the following section. Additional quotations by theme are given in Appendix J.

# Misunderstanding or lack of knowledge

Throughout the interviews participants demonstrated or shared feelings of confusion and misunderstanding regarding a wide range of dental topics. They either had a lack of knowledge, i.e. no knowledge or awareness, or showed misunderstanding, i.e. had knowledge which was incorrect. Examples of the distinction between these are shown in Table 5.3. The beliefs they held of oral health and provision of dental care were therefore inaccurate, often with misunderstandings and lack of knowledge interacting to create further misconceptions.

Theme Definition	Example
Lack of knowledge	"On the weekend, I haven't got a clue [how to see a dentist] All I
	would do is just to take a painkiller. That's the only option I'm
	thinking." Male, 62-years-old.
Misunderstanding	"When they advertise NHS patients accepted their treatment's
_	free." Male, 47-years-old.

**Table 5.3:** Examples of theme definitions for misunderstanding or lack of knowledge.

Subthemes relating to misunderstanding or lack of knowledge were: knowledge of dental care and diseases; dental charges; access; new knowledge.

#### Knowledge of dental care and diseases

Participants were often aware that they *should* seek regular dental care, however, did not understand why. A common misconception was that if ADP was not present then there would be no dental disease. This led participants to believe there was no need to see a dentist when pain free, which has been reported previously (Freidson and Feldman, 1958; Calnan, Dickinson and Manley, 1999; Gregory, Gibson and Robinson, 2007), as well as a lack of ADP being considered a sign of positive

perceived oral health (Atchison, Davidson and Nakazono, 1997). This belief could be recalled as far back as adolescence.

"I just didn't think it was something [dental check-ups] that I needed, and I just thought well I don't have any issues with my teeth, I don't have any pain so it's something that I don't need." Female, 23-years-old.

This belief was further compounded when participants believed they had a good oral hygiene regime and could not see any evidence of disease in their mouth on self-inspection.

"It's very uncommon ... to decide on your own ... to see the dentist to check if everything is in order... Only when you think that something wrong then you go... I cannot go to see the dentist when I know ... everything is fine. I didn't observe any wrong thing. I stay home and keep brushing my teeth as normal on a regular basis... For me there was no reason...to see a dentist because you're going to ask me why you are here for... I have to tell him that I'm not feeling well... I've got a hole on [sic, in] my teeth or wherever." Male, 62-years-old.

Participants did not understand dental diseases, and had misconceptions regarding dental caries and periodontal disease, their causes and prevention. This in turn led to the view that there was no need to seek regular care as there was nothing that could be done to prevent or stabilise disease once present.

"They just said I've got gum disease and I do brush my teeth and everything but I don't think it makes any difference, to be honest, because with the gum disease they just rot away I think." Female, 57-years-old.

Lack of knowledge or misunderstanding also contributed to repeat attendance for the same problem because participants misunderstood the nature of the treatment carried out, not realising it was temporary and that they needed to see a dentist for definitive treatment. This could be related to poor dentist communication and dentist characteristics which are discussed below.

"No they didn't actually [explain the need for definitive treatment], not the first time... They just said that it wasn't a permanent sort of thing but it should last a while." Female, 48-years-old.

Antibiotics were rarely wanted by participants for ADP, which is in keeping with previous studies (Anderson, 2004). There was, however, some confusion as to whether antibiotics were needed before any dental treatment could be successfully carried out. This belief was reported to be from previous dental emergency

attendances where antibiotics would be prescribed either by a non-dental professional, or by a dentist in primary care before being given a further appointment for definitive dental treatment.

"I know that [the primary care dentist] wouldn't do anything while it was so inflamed and sore... they need the infection out before they start doing my teeth...A lot of the time they've given us [sic, me] antibiotics and sent us away..." Female, 24-years-old.

Ethnographic research in primary dental care has found that patients attending for emergency care often have a strong desire for antibiotics (Thompson *et al.*, 2020) which is in contrast to the patients interviewed here. This could be explained by the majority of patients in this study being seen in secondary care where problemorientated attenders have learnt to expect definitive and better care compared to primary care and may therefore not believe they need antibiotics. Indeed, patients in this study who discussed a potential need for antibiotics all did so whilst reflecting on previous primary care experiences. In addition, in terms of service design in a teaching hospital, carrying out definitive dental treatment would be expected and be manageable. It may be, therefore, that there are differences in antibiotic prescribing rates in ADP between primary and secondary care.

A further misunderstanding related to regular dental attendance was by way of comparison to general healthcare-seeking whereby it wouldn't be expected to see your GMP for regular check-up appointments, instead waiting until there is a reason to attend. This has also been previously reported (Croucher and Sohanpal, 2006) and could relate to a general misunderstanding around health and healthcare use between services.

"Well, that's what the dentist is for isn't it? If you've got any [oral] problem, you visit the dentist and if you have any pain you visit a doctor." Male, 47-years-old.

A lack of understanding regarding dental disease and the need for regular check-ups is in keeping with the literature. As discussed in the literature review a common reason for not seeking dental care in both the ADHS and the GP Patient Survey was that there was a perception by the patient that no dental problems were present and there was therefore no need to see a dentist (Morris. *et al.*, 2011; NHS England, 2021). This therefore suggests that although the public may know they *should* see a dentist this does not necessarily translate into the desired attendance behaviour.

This may be partly due to a lack of knowledge underlying the belief that they should attend. This is also related to importance of oral health and is discussed further later.

Lack of knowledge or misunderstanding also resulted in delayed care-seeking behaviour for ADP due to a belief that toothache would subside within a few days therefore dental care would not be needed, which has been reported previously (Anderson and Thomas, 2003). This was due to previous experience of ADP whereby patients had pain for a short period of time before subsiding, and therefore believing the same would be true of all ADP.

"Because I know from doing it myself [ignoring the pain], if I had a broke tooth and the toothache would only hurt for about a week, two weeks, and then subside. And then it would reactivate several months later. So I used to just put up with the pain until I had to go." Male, 38-years-old.

During this period prior to care-seeking, self-management of ADP was important. Different medications were reported as being trialled in this period to see if they could manage the pain without the need for dental care. Similar behaviours are reported elsewhere (Finch *et al.*, 1988; Bedos *et al.*, 2004) and this is discussed further in the theme on self-management.

"I would leave it a couple of days and if it got worse, the pain, I would try my own ingredients first, like oil of clove, but if started getting worse I would probably if I can't get an appointment ... I would go to youse [sic; you i.e., DEC]." Female, 60-years-old.

This kind of behaviour could be recalled as far back as adolescence, with participants not understanding or fully appreciating why they should attend for regular appointments, regardless of whether they were childhood regular attenders or not. This lack of knowledge going into adolescence and young adulthood was a contributory factor to them either continuing as problem-orientated attenders, or ceasing regular dental care.

"I was really, really concerned when I went to the dentist [for check-ups] ...I just suddenly thought I'd been and they'd said everything's fine...And it just sort of faded into the background and then when I needed something done I would then go...I think it's when I was in my 20s there was always something else to do. ... that I wanted to do. ... I don't think I realised just exactly how important it was. I thought ... I'm going to have my teeth forever." Male, 59-years-old.

This transition period from being a child to an adolescent or young adult was an important period in determining dental attendance behaviours and is discussed later in relation to the conceptual model.

## **Dental charges**

Dental charges were often given as a reason for non-regular attendance. However, this was often a perceived barrier related to a lack of knowledge or misunderstanding regarding the cost of care. Most participants thought dental treatment would cost more than it does and therefore believed that they couldn't afford it. They often relied on knowledge passed on from friends or family, or from media coverage.

"I've always been told proper dentists are expensive. It's just the added expense and that I don't really want... I'm just going on what other people tell us, because I don't even know what a price is to the dentist will charge for what" Male, 47-years-old.

For those who reported an idea of how much dental treatment would cost, there was a lack of knowledge or misunderstanding about NHS dental bands (Appendix A), what they entailed and how you could pay for treatment.

"I know it's set prices for certain types of treatment but I think certain things beyond that aren't covered under the NHS. I think it's only certain treatments that are available." Male, 38-years-old.

Some had experience of paying for NHS dental care, however still reported a lack of knowledge or misunderstanding about NHS charges, what they had paid for and what they were entitled to for that charge.

"There was bits that confused us [sic, me] ... I can't remember exactly what the bands were, but I know ... the cap ... I needed ... that was the highest band which was the 250 odd pound one. And I know the lowest band was fillings and stuff. But what I didn't get... he didn't explain ... if you needed more than one filling was that in one price or was it you paid that one band price repeatedly... If I pay for the highest band do I then have to pay for a band one treatment as well?" Male, 27-years-old.

There was misunderstanding on what constituted NHS or private dentistry, some reported a belief that all NHS dental treatment was free, and that any dentistry that had to be paid for was private. This in turn led to misconceptions about access to NHS dental care and the belief that the only dental treatment available was private and therefore was expensive.

"I don't have a registered dentist... you always hear that there's no NHS dentists available... If you're not NHS the prices are probably more than I could afford because it is hundreds and thousands of pounds isn't it?" Male, 38-years-old.

In addition, there was confusion throughout the participants as to who, if anyone, was exempt from NHS dental charges, with a common belief that elderly patients were eligible for free dental treatment. In one case, the participant was eligible for free treatment due to being pregnant, however was not aware of this.

"I think it's people on benefits isn't it [who are exempt]? And old age pensioners, which is understandable". Female, 57-years-old.

The cost of dental care is often reported as a barrier to care-seeking in the literature. Within this theme the cost of care may be a perceived barrier rather than a true barrier (which is discussed later). This is also reported in ethnically minoritised groups with a lack of knowledge regarding dental charges, exemptions and what constitutes NHS or private dentistry resulting in problem-orientated dental attendance (Croucher and Sohanpal, 2006). Knowledge of dental charges as a theme has remained the same as reported in 1988 (Finch et al., 1988) despite dental contract reforms since then. In contrast, in 1988 it was reported that there was accurate awareness of who was eligible for free dental care, which was no longer found in this study. Indeed, since contract reforms in 2006 there has been a steady decrease in the number of patients accessing fee-exempt dental care (Shah and Wordley, 2021), which could reflect this lack of knowledge around who can access free dental care. This lack of awareness will be important to address to reduce oral health inequalities as patients who are exempt from NHS dental charges are likely to be from the most deprived areas and have the greatest burden of dental disease. It has been suggested that the demands of navigating bureaucracy associated with free dental care may compromise access for those who need it most (Harris, Pennington and Whitehead, 2017). Oral health literacy is likely to be of relevance in problemorientated dental attendance as low oral health literacy is associated with presence of ADP and use of emergency dental services (Batista, Lawrence and Sousa, 2017). Although specific levels of oral health literacy have not been examined in problemorientated dental attenders this theme on lack of knowledge or misunderstanding could indicate that it is of relevance in their care-seeking behaviour.

#### Access

Participants were not aware that out-of-hours dental services were available, which led to the belief that if you had ADP during the evening or weekend there was nothing that could be done, which resulted in delayed care-seeking behaviour.

"... I didn't think they [dentists] worked on a weekend..." Female, 52-years-old.

This belief has previously been reported by patients seeking emergency dental care in Wales (Anderson and Thomas, 2003), as well as by patients who have seen a GMP for dental problems (Cope *et al.*, 2018). This is also in keeping with the reported literature on out-of-hours dental care as discussed in the literature review, and clearly highlights the need for raised awareness of this service and how to access it within the general population.

#### New Knowledge

Knowledge was also related to participants' intention to begin to seek regular care. Some participants reported receiving new information about their current dental health, severity of, or information about dental disease during an urgent care attendance. This in turn made them realise the importance of regular dental care or gave the opportunity to reflect and realise that if they had attended for care sooner that the dental disease they had could have been prevented.

"The thing that helped us [sic, me] change my mind...I've always went back when there's been a problem, but this time the problem...[the person describes] could have been prevented if I had have took better care of myself...It was just like a revelation... And that sort of triggered off my emotions to think about what I was doing ...[normally] it's just been a case of get in... Oh yes, I see the problem. Click back. Whoosh. Right, okay, have a nice day." Male, 47-years-old.

This highlights the importance of the dentist giving clear information during an emergency appointment about the patient's oral health and any current oral diseases, which would also be in keeping with the Making Every Contact Count approach (Public Health England, 2016). Unfortunately, only a minority could recall being given information during their emergency appointment for them to reflect on it in this way and begin to consider changing their behaviour. This is also reported in the literature with patients who attend emergency dental services reporting a primary reason for attendance being reassurance and information about what is causing their pain (Anderson, 2004). Unfortunately, patients do not feel they understand their

dental problem better after seeing the emergency dentist and would like to be given more information (Anderson, Thomas and Phillips, 2005). Recent research has also shown that patients beginning to understand the importance of their oral health may help them overcome barriers to regular dental attendance (van der Zande et al., 2020). It should be noted that as this study did not include ethnographic methodology it is unknown as to whether this information was given to patients by the dentists, and they simply could not recall it following the appointment. This could be the case if information is given by the dentist before treatment is completed, when the impact of ADP, or dental anxiety may impact on their memory and attention. This requires further investigation as if this is the case it highlights the importance of appropriately timing information sharing during an emergency appointment. Nevertheless, knowledge appears to play a role in problem-orientated dental attendance, however in itself does not fully explain this pattern of visiting, and providing knowledge alone is unlikely to elicit long term behaviour change to regular dental attendance particularly in those from more deprived backgrounds (Harris, Pennington and Whitehead, 2017).

# <u>Dentist characteristics</u>

When participants accessed dental care, they reflected on the characteristics of the dentist they saw, with negative experiences reinforcing problem-orientated attendance, and positive experiences promoting the intention of regular care-seeking.

Specific dentist characteristics noted were negative attitudes towards problemorientated attenders, including a feeling of judgement or penalisation for their attendance pattern and a lack of empathy towards them or their situation. These negative characteristics can also result in patients seeking dental care from GMPs (Cope *et al.*, 2018).

"It's like if you've got more [dental] problems they get like rude with you... you should be doing this, you should be doing that when they have no idea of your background." Female, 19-years-old.

The importance of patients not feeling blamed by their dentist has been reported (Lahti *et al.*, 1995). Patients who have poor levels of oral health may feel stigmatized by this, which can make accessing care a more emotional experience (Harris, Pennington and Whitehead, 2017). This in turn may make them more susceptible to feeling blamed or judged by a dentist. This may also be further compounded if dentists label problem-orientated attenders as "bad' patients because of their oral

health and attendance habits as it creates a bigger gap between the patient and the dentist in terms of professional norms (Kelly and May, 1982).

When they did seek urgent dental care participants reported feeling uncomfortable due to the attending dentist's behaviour, which in turn made them not want to seek further dental care. Negative dentist attitudes such as these are known for decades as influencers towards continuing irregular attendance (Freidson and Feldman, 1958).

"[the dentist] absolutely terrified us [sic, me]. Every time I went in she's... really, really abrupt and shouted at us a lot, and I really didn't like it. She didn't make us feel comfortable or... I just wanted to run... I would rather have been in pain than go and see her to be honest... Or try and pull the thing [tooth] out myself". Female, 52-years-old.

This caused avoidance of care-seeking until ADP could no longer be tolerated, and the need to look for different dentists in different locations for urgent dental care.

"I changed...because I was not feeling at my ease... So when the person don't feel comfortable all you're going to do is just to change. That's what I did..." Male, 62-years-old.

There was a distrust of dentists which was related to previous experiences and those of family and friends. This was exaggerated when the need to pay for dental care was also taken into consideration.

"... [it] kind of makes us not want to go ... it's not paying that bothers us, I'll pay whatever ... obviously they're doing a job ... But ... a lot of dentists just don't care. They're just like... I'll have my money now thanks, see you later. ... I don't think all of them are like that. But a lot of them... are quite rude and just want paid." Male, 27-years-old.

This sense of distrust relating to payment was also reported when participants reflected on the transition from free NHS dental care as a child to the requirement to pay, similar to data from adolescent focus groups in New Zealand (Fitzgerald *et al.*, 2004).

"All the way through school we had ... a six month check-up van ... I had perfect teeth according to them... a couple of months after I left school and went for my check-up ... I needed my two front teeth capped. I needed four fillings ... that sort of put us off a bit because I thought hang on a minute, six months ago I had perfect teeth. How all of a sudden do I need four fillings and two caps?... [You] are just doing it for the money. So it sort of put [me] off." Male, 47-years-old.

When treatment was free, for example when seeing a dental student, these anxieties surrounding trust and payment were resolved. This may indicate that dentist characteristics are closely linked to dental charges with a higher priority placed on the dentist's professional role when paying for treatment. This contrasts with the rest of healthcare in the UK which is free and introduces the concept that dental patients are also "customers" (Male, 62-years-old) and therefore may have higher expectations for their care experience.

"I'd rather go to the dental hospital where I know even though they're a student..., they're learning and they care. It's not about money for them" Male, 27-years-old.

Dentists were largely considered as either being good or bad based on these perceived characteristics, and in line with the wider literature it was accepted that not all dentists would be bad, (Molin and Seeman, 1970; Finch *et al.*, 1988). Participants would discuss the difficultly in trying to find a "good dentist" who would possess positive characteristics in contrast to their own experiences which is also a reason why people do not seek regular dental care (Freidson and Feldman, 1958; Finch *et al.*, 1988).

"you hear that many different stories from different people, you don't know which dentists are good or which ones are bad ... Just like people pulling teeth out when the anaesthetic hasn't kicked in properly, and one of my friends, he said he went in for a tooth to be extracted and he pulled the wrong one out." Male, 47-years-old.

Mistrust of dentists, or fear of them making a mistake as in the previous quote can contribute to avoidance of dental care (Kleinknecht, Klepac and Alexander, 1973) and thereby has a reinforcing effect on irregular dental attendance (Freidson and Feldman, 1958). Lack of trust in the dentist has also been shown to be associated with poorer oral health related quality of life in older adults (Muirhead, Marcenes and Wright, 2014). As discussed in the literature review, mistrust of dentists can be considered a subtype of dental anxiety, this is discussed further in the following theme.

Experiences of dentist characteristics considered to be negative were largely confined to experiences seeking urgent treatment in primary care. This in turn led to repeated attendance at secondary care and avoidance of primary care.

"At the dental hospital everyone who I've seen has been absolutely amazing. The atmosphere is totally different [to primary care]... They're

so friendly. They ... sit and talk to you...explain everything.... They just spoke different to me.... They can't do enough to help you. And they made us feel ... confident...made us feel comfortable, relaxed. I couldn't believe it how they could be so different." Female, 57-years-old.

Experiences of negative dentist characteristics could be recalled as far back as childhood and were related to development of dental anxiety as an adult, which is discussed further in the following theme.

Positive dentist characteristics were related to participants' intentions to change their behaviour similar to other recent UK reports (Harris, Pennington and Whitehead, 2017). Qualities such as being emphatic, taking time to reassure and understand their concerns or worries resulted in participants considering attending for regular care. A barrier that remained was how to find a dentist who possessed these qualities outside of secondary care.

"If I had a dentist that I trusted... I would attend all of the appointments... So if I can find a dentist that I can trust then it would be great. ... somebody who would understand the way I felt about dentists and would take just that little bit more time... little bit more ... sympathetic to the way that I felt about dentists...I've been two or three times to the emergency unit for a dental issue. It would be great if you [sic, I] could go back there." Male, 59-years-old.

It should be noted that this study did not involve ethnographic methods and the actual dentist-patient interaction was therefore not observed. Dentist attitudes towards treating problem-orientated attenders has not been researched, however Canadian dentists report feelings of frustration and occasionally anger towards patients from the most deprived backgrounds who often attend only when in pain (Bedos *et al.*, 2013). This could suggest that the dentist-patient relationship is compromised, and clearly warrants further exploration and research given that the way the patient was made to feel did influence their subsequent attendance behaviour. Indeed, people's experiences of dental care are connected and reinforced by perceived dentist characteristics (Harris, Pennington and Whitehead, 2017). This means that each negative experience will build upon the previous creating a bigger barrier to care, whereas a good experience lowers this barrier.

#### Dental anxiety

Dental anxiety was reported as being a barrier to regular dental care-seeking behaviour however this was not widely reported and it was never an exclusive reason for problem-orientated dental attendance, which is in keeping with ethnographic research in this patient group (van der Zande *et al.*, 2020). This theme linked closely with dentist characteristics with participant dental anxiety developing as a result of negative childhood or adolescent dental experiences, and then leading to avoidance of regular dental care.

"I had a really bad experience when ...I was a child... [the dentist] was drilling the tooth, I jumped and he said what's wrong, and I said oh it's very, very sore...he just sort of shrugged it off ... he went oh just grin and bear it ... he started drilling again...I moved and he cut the inside of my mouth with the drill... I've been [dentally anxious] all my life, ever since... he always smelled of cigarette smoke and coffee... He was a big man as well... And he just sort of got stuck in and he just did what he had to do." Male, 59-years-old.

Dental anxiety also played a role in delayed care-seeking, with participants trying to manage ADP on their own, only attending when their pain reached a certain severity or they could no longer cope. At this point the impact of ADP on their life would enable them to overcome their anxiety and seek care.

"...it's just like basically waiting till the last minute [to seek dental care] till it is desperation time..." Female, 52-years-old.

Participants' dental anxiety also led to them feeling a burden, this was used as a further reason not to attend for planned dental care and instead only attend walk-in services where treatment could be accessed immediately when needed.

"...half the time I'm thinking well if the fear builds up and on the day I can't go then I'm wasting people's time and other people could have that appointment..." Female, 56-years-old.

Negative dental experiences as a child are widely reported as causing dental anxiety and dental avoidance in adulthood (Berggren and Meynert, 1984; Crawford, Hawker and Lennon, 1997; Liddell and Locker, 2000; Thomson *et al.*, 2009; Oliveria *et al.*, 2017), and the professional behaviour of the dentist, particularly in relation to communication, appears to be an important factor influencing development of dental anxiety (Bernstein, Kleinknecht and Alexander, 1979; Fico and Lagoe, 2018). There is therefore clearly an important link between dentist characteristics and dental anxiety. Perceived dentist attitudes by patients who are dentally anxious have been reported, with negative attitudes impacting on dental anxiety and the decision not to seek future dental care (Molin and Seeman, 1970; Berggren and Meynert, 1984; Gragoll *et al.*, 2021). Dentists who are perceived as being understanding and calm and friendly are considered desirable by patients who avoid dental care due to dental

anxiety. Conversely, dentists who are considered to be critical of the patient, distant and inconsiderate and lack empathy are deemed to be undesirable characteristics (Berggren and Meynert, 1984; Fico and Lagoe, 2018; Gragoll *et al.*, 2021). Furthermore, patients report dental anxiety as a result of feeling that dentists don't care for them, berate them or for not preparing them psychologically for treatment (Molin and Seeman, 1970). Some of these studies were, however, carried out 30-40 years ago and since then a greater onus has been placed on dental professional behaviour in undergraduate teaching (General Dental Council, 2015) so professional behaviour may have changed since then. Indeed, the age of some of the participants could reflect experiences at the time these studies were carried out. However, younger participants also reported similar experiences with perceived dental attitudes and dental anxiety, therefore this is likely to still be of relevance.

Linking dental anxiety to dentist characteristics may indicate that the dentist needs to be aware of how the patient perceives the way they deliver bad news, such as teeth having dental disease and requiring treatment, to patients who are problemorientated attenders. These patients may perceive a difficult conversation such as this as the dentist being critical or judgemental, which in turn may then act as barrier to them returning for treatment. Dentist-patient interactions between different patient groups may be important to research further using ethnographic work to observe verbal and non-verbal communication skills and how the patient perceives the dentist and the information given to inform future education of dentists.

Participants again contrasted their experiences between primary and secondary care but in relation to management of their anxiety. This difference in experience made participants more confident in seeking dental care in relation to their dental anxiety, however not within primary care.

"I had a nasty experience at a dental practice and I think that sort of put me off going ...[but at DEC] It was very, very positive.... I expected to be very, very anxious but the dentist that I saw was very, very good. I told him about my [past negative] experiences and he totally put me at ease. There was a very professional humour... I just felt as though he knew exactly what he was talking about. I just felt very confident in him. So it was a very positive experience... Even though I had a tooth out... I think I would rather stay with the dental hospital...I think it's still back to the good experiences that I've had. And I think if you find something that's good I think you'd rather stay with it." Female, 56-years-old.

Similar to above, positive dental experiences therefore may help to overcome barriers associated with dental anxiety, however if these experiences are confined to secondary care this will not necessarily facilitate urgent or routine care-seeking in primary care. This is similar to a previous study where patients with dental anxiety informally met a dentist through a support group and reported they would be happy to continue to see that dentist for care after establishing a good relationship with them, but would be reluctant to seek care elsewhere (Crawford, Hawker and Lennon, 1997). Promoting positive dental experiences and dentist characteristics are therefore of upmost importance in those with dental anxiety. Crucially, however, consideration needs to be given as to how these experiences can be transferred and maintained outside of secondary care, or with any change in dentist.

As dental anxiety was not reported as being a sole reason for problem-orientated attendance by participants it may be that dental anxiety plays a more predominant role in patients who avoid dental care altogether. These patients may present to non-dental providers such as GMPs when experiencing ADP and therefore may not have been recruited and this is a limitation to the study findings. It could be argued however, that this patient group would form a separate subgroup of problem-orientated attenders, or indeed dental non-attenders or avoiders, in which case they may have entirely different experiences and perspectives of ADP and dental care and may require different interventions to encourage regular dental care.

Dental anxiety is likely to be an important barrier to consider in problem-orientated attendance, however it is not an overarching barrier to care in all patients, and when present it links closely with other themes discussed. To note is the close link with dentist characteristics and mistrust of dentists which highlights the "Seattle System" of dental anxiety discussed in the literature review (Milgrom, Weinstein and Heaton, 2009). In this system mistrust of dentists is considered a specific subgroup of dental anxiety, however patients with this would not self-report anxiety, instead displacing their worries onto the dentist as a professional. If this is the case, then this specific subgroup of dental anxiety may be important to consider in problem-orientated attendance. Interestingly, the best management strategy for this subgroup is providing extensive information and placing emphasis on the patient's role in decision-making (Armfield and Heaton, 2013), which links back to the theme on lack of knowledge and misunderstanding. It may be that this patient group is not gaining the information and knowledge they need in an urgent care appointment to overcome

this specific form of dental anxiety, which turn increases their mistrust in dentists creating a bigger barrier to future care-seeking.

Nevertheless, even taking the potential for this subgroup into account, dental anxiety was not a sole barrier to dental care-seeking, which is in keeping with other qualitative studies including problem-orientated attenders which also found dental anxiety to be a barrier, but not in its own right and often linked closely to other barriers (Finch *et al.*, 1988; van der Zande *et al.*, 2020). In addition, anxiety is a barrier which patients appear to be able to overcome when other barriers are removed.

# Affordability of dental care

Dental charges were reported as being an actual barrier to care as well as being a perceived barrier as discussed above in relation to lack of knowledge.

Where dental charges were a true barrier to care the cost of treatment had to be balanced against other priorities or expenses.

"I would only go to the dentist if I needed to go because I can't afford the prices that they charge, because I've got other things to pay for... I would go but I would have to like not pay something else ... like a bill or something." Female, 60-years-old.

The cost of dental care had to be justified before it could be considered worth paying for. This meant that more expensive treatments could not be justified. Interestingly, although dental check-ups are a lower cost, the frequency of attending and therefore payment was discussed as being a barrier, particularly when the benefit was not understood which links back to the earlier theme on misunderstanding/lack of knowledge. When ADP was present the cost of treatment could be rationalised and therefore was no longer a barrier. Willingness and ability to pay for dental care is also a reason why patients seek dental care from GMPs (Cope *et al.*, 2018), and this would also be in keeping with reports of older adults being willing to pay less for preventive compared to curative dental care (Mittal *et al.*, 2021).

"I just go when I have an issue... I don't want to spend that much on check-ups at the dentist so I just go when I have an issue... Ultimately it's something that I can't afford ... I struggle with the idea of paying for it... it's a lot of money and things like the crown ... I'm questioning whether or not to have it because it's going to be a large expense." Female, 23-years-old.

Beliefs that dental care should be free also played a role in decision-making to seek care on a problem-orientated basis.

"I live on my own. I pay all my own bills. I pay for everything on my own and it's a lot of money to pull out your wages ... I don't want to go and pay for it unless I'm in pain.... I work for the NHS as well and I feel like why should I pay for to go and get my teeth checked when I'm working for the NHS as well." Female, 57-years-old.

Dental charges were also given as a barrier to maintaining regular dental attendance as they transitioned from adolescence into young adulthood with the requirement to start to pay for treatment. This was not the only factor playing part in changing their attendance pattern however and would often relate back to a lack of knowledge regarding the need for regular dental care.

"I think I would have gone more while I was at university had I not been put off by the cost of it. Just the prospect of paying £20 every time for the appointment just kind of put me off as well [as not understanding the importance of attending]." Female, 23-years-old.

Exemptions from dental charges were raised, and although this was an area participants had a lack of knowledge or misunderstanding about, concerns were raised about how fair current exemptions are.

"I don't know how much it costs ... but I think the prices are pretty steep. But if you've got to pay it then you've got to pay it haven't you? Because to get one of my teeth fixed it's going to cost us a quarter of my wage whereas I could just walk in tomorrow, hand in my notice, sign on two days later and get it done for free ... I don't agree with that at all. I work 45 to 54 hours a week whereas people who just do nothing... I understand people are in hard situations. But I don't think it's fair that people who do nothing don't have to do anything for their treatment. I don't see how that's fair." Male, 27-years-old.

The offer of free treatment had a potential impact on behaviour change and there was general agreement that preventive care, including check-ups, should be free to encourage attendance. This has been reported elsewhere with urgent dental care attenders reporting that reduced dental fees would be most likely to influence a change in their attendance behaviour (Haji Moris *et al.*, 2017). This could be demonstrated in some participants when they reflected on a period when they were exempt from dental charges and as result changed their behaviour.

"The only time I went on a regular basis was when my husband was unemployed and we got it free...I went pretty regular because you don't

mind when it's free. It's when you start having to pay. When I was pregnant I got it free as well." Female, 60-years-old.

This was not true of all participants however, some had periods where they were eligible for free dental treatment, but this had not been enough to enable them to change their behaviour. In addition, although free treatment was considered to be a benefit of attending secondary care it was not considered to be enough on its own to encourage regular care-seeking where other barriers would also need addressing.

"If [dental treatment was free and] it was obvious how to go and see or have an appointment [I'd go]." Male, 38-years-old.

Cost as an actual barrier to dental care is known (Hill et al., 2013), however similar to this study it is often closely linked to confusion or lack of knowledge of dental charges (Finch et al., 1988; Croucher and Sohanpal, 2006; Harris, Pennington and Whitehead, 2017; Cope et al., 2018; van der Zande et al., 2020) and is an important consideration in relation to problem-orientated dental attendance. It is rarely a sole barrier to care however, and therefore simply providing free dental care on its own is unlikely to elicit the desired behaviour change to regular dental attendance. This may be partly demonstrated in the SAIL dataset (Chapter 4) whereby the introduction of free dental check-ups in Wales did not appear to have an obvious effect on GMP attendances for ADP. In addition, introducing free dental check-ups in Scotland did result in an increase in utilisation of dental care, however this varied across patient groups and included those who accessed private dental care and those who would have been exempt from dental charges anyway (Ikenwilo, 2013). This may suggest that behaviour change was not just a result of the change in dental charges, and could be a result of increased awareness and knowledge as a result of dissemination of the policy change.

#### Work

Working hours were reported to be a barrier to accessing care in terms of being able to organise an appointment, particularly for those who worked long hours or shift patterns. Problems with access to care on non-working days increased this barrier further.

"I work full time and I do extra as well ... so probably just time and getting the appointments and things, you know...sometimes I try to book in on my days off [but] they haven't got appointments." Female, 48-years-old.

Work being reported as a barrier to regular dental care has been reported previously (Finch *et al.*, 1988; Harris, Pennington and Whitehead, 2017; van der Zande *et al.*, 2020), particularly in relation to the practicalities of appointment making around working hours. Being unable to access dental care around work also leads to patients seeking dental care from GMPs where access is considered to be better by patients (Cope *et al.*, 2018). Regular dental attenders are described as being able to reorder their lifestyles in order to access care (Gibson *et al.*, 2000), this therefore may not be an opportunity that problem-orientated attenders have, particularly in relation to work and in those from more deprived backgrounds (Harris, Pennington and Whitehead, 2017).

In this study, specific issues around zero-hours contracts were raised and how these can impact on both oral health as a priority around a chaotic working life, but also how taking time off has the additional effect of not being paid, which in turn adds an extra barrier to dental care-seeking.

"... you know when you have to leave at six to get to work and by the time you reach home it's seven, eight o'clock in the night again... you don't really have no time ... Because if you miss a day you don't get pay...But if I could see the dentist every day I will ... to make sure my mouth is good health. But ... I've got family to take care of. I've got kids. So I'm on zero hour contract. If I don't work I don't get pay [sic]." Male, 47-years-old.

This may indicate that particular contractual arrangements, such as zero-hours contracts, may have the potential to increase oral health inequalities, however further suitably designed research would be needed to address this.

As discussed above, participants would access urgent care at DECs due to problems with access in primary care. This attendance pattern had an effect on their working life due to the length of time assessment and treatment would take, however the availability of immediate treatment compensated for this. The impact of work also led to delay in seeking care as participants had to weigh up the decision of whether to take a day off work, with associated financial implications, or instead continue to suffer with ADP until they had an opportunity to attend outside of working hours.

"Because I obviously couldn't get appointment so I've rang the dental hospital, went in there early morning... so I've lost a full day's pay ... to get my teeth sorted." Female, 57-years-old.

When participants delayed care-seeking rather than take a day off work they discussed the impact of having other priorities as well as the need to work, find time to seek dental care and pay, in which case their ADP was seen as a lower priority.

"..the pain [is] bearable but it's getting worse... because I'm off work today I...go to the dentist ...[otherwise] I would have to book a day off work... I went to the dentist on Friday ... they said to me oh £62 to take your teeth out...because I was feeling so much pain I was making up my mind to pay ... but they give me appointment and I couldn't wait ... I get pay on a Friday... to pay the money and get the pain gone, yeah it's something that you have to do... But ... my daughter called me ...[and asked] "can I get £50?" ... I got £70 and my teeth was £60... I give the money to my daughter because she just got a young kid." Male, 47-years-old.

Delaying care-seeking and having to cope with increasing ADP severity led to a negative impact on ability to work. This in turn could lead participants to decide to seek care.

"Got laid off because of it [dental pain]. Because I'm a temp contract. So they laid me off because of it. It really has impacted my career." Female, 45-years-old.

Delayed care-seeking is often seen in problem-orientated dental attenders which can have an impact on their quality of life (Currie, Stone and Durham, 2015) as well as put them at risk of adverse events as discussed in the literature review. It is therefore important to understand why care-seeking is delayed so behaviour change to seek care at an earlier stage can be encouraged. A previous cross-sectional study at a DEC found that over one-third of patients had taken time off work to attend (Currie, Stone and Durham, 2015), which would be in keeping with the barrier of work seen here. However, as delayed care-seeking was also a result of the other themes discussed, the need to work and the maintenance of employment is unlikely to be a sole reason for this.

As work was associated with both problem-orientated dental attendance and delayed care-seeking governmental guidance covering time off work could be changed. At present individual employers dictate whether employees are allowed time off work to visit the dentist and there is no legal right for employees to have time off work for medical appointments (Citizens advice, 2019), if this was changed to classify a dental appointment as mandatory then this could remove this barrier.

# Influences from others

Influences from others, particularly family members, played an important role in all aspects of care-seeking in problem-orientated attendance, including decision to seek care (and no longer delay care), and where to seek care. It was largely a phenomenon reported by male participants with the influencing family member being the opposite gender.

"My girlfriend [made me attend]... Because I was trying to hide it [dental swelling] by growing a beard." Male, 27-years-old.

Family influence was recalled as far back as childhood, being an important factor in whether or not participants saw a dentist as a child before they transitioned to independence, which has been reported elsewhere (Crawford and Lennon, 1992; Kettle *et al.*, 2019).

"I used to see the dentist a lot for my regular check-ups and things...[because] my Mam took us." Female, 24-years-old.

In addition to family, others could also influence decision-making and attendance habits, including friends and the media. Dental professionals who attended schools also played a role in childhood dental care-seeking. Following regular childhood attendance participants could recall that as soon as the parental influence was lost or faded, they stopped attending.

"I didn't stop going straight [away] ... because I still was registered...I still had to go ... because I had braces fitted. But I really didn't look forward to appointments. I was really concerned about them... my mother took us [sic, me] and she says don't worry I'll be there... but as soon as I didn't have to then it was occasionally when I went to see the dentist." Male, 59-years-old.

The age reported for this transition ranged from 9-years-old to late twenties. Some participants related the change in attendance behaviour to the move from school to working life, or from college to university. This change in dental attendance behaviour during adolescence is documented in the literature, with a decrease in attendance noted with increasing age in adolescent patients (Finch *et al.*, 1988; Honkala *et al.*, 1997; Skaret *et al.*, 1998; Fägerstad, Windahl and Arnrup, 2016; Leary and Do, 2019) which continues into early adulthood (Okunseri *et al.*, 2013b). Adolescents acknowledge that looking after their teeth and attending a dentist is easy whilst they have the support of their parents, school and free treatment, however

report an awareness their oral health behaviours will change in the future (Fitzgerald et al., 2004; Hall-Scullin et al., 2015). This is discussed in more detail in the following chapters.

Parental influence also determined whether participants were irregular dental attenders as children which is again in keeping with the literature (Crawford and Lennon, 1992; Kettle *et al.*, 2019). These participants could relate their irregular dental attendance to their parents also having the same attendance pattern.

"I can only really vaguely remember going to the dentist when I was younger... I remember going but I know when I was growing up my parents would never like take us. It wouldn't be regularly. I know that much." Male, 27-years-old.

However, on occasion participants could recall their parents having different attendance habits, therefore parental attendance habits may not necessarily transfer to their children. Reasons for parents not taking their children to the dentist were outside the scope of the current study, however reported reasons in the literature include: family sociodemographic characteristics; parents' perceptions and attitudes; provider level factors (Badri et al., 2014). Sociodemographic factors include level of parental education, and economic and marital status, with parents who have a lower level of education or income being less likely to take their child for regular preventive dental visits. Parental perceptions and attitudes influence their child's attendance pattern through: lack of knowledge regarding the importance of childhood dental health; difficulty prioritising dental appointments; negative experiences when they do take their children to the dentist or when they attend themselves; lack of trust in dentists and the dental healthcare system; lack of confidence in convincing their children to attend (Hallberg et al., 2008; Badri et al., 2014). Provider level factors include: dentist communication, skills, access and low level of respect for patients accessing public dental services over private (Badri et al., 2014). These are similar themes to those which emerged explaining adult problem-orientated attendance and may therefore be important across the life course.

#### Importance of Oral Health

Participants reported that oral health was important and reasons for this were largely related to appearance, with concerns particularly relating to how others may judge them.

"... people with teeth look healthier...I think certainly in work... if I was walking around with missing teeth ... I would probably not be given the same respect as I would if I have a full set of teeth..." Female, 48-years-old.

Other reasons included function. In relation to the theme on lack of knowledge or misunderstanding, participants would discuss oral health being related to ADP, and a lack of pain indicating good oral health. Equally they believed oral health was important to avoid experiencing ADP.

"Because it's less pain...if you've healthy mouth you've not got any pain, you don't have to worry about your tooth then and you can eat properly." Male, 47-years-old.

Some participants began to discuss other reasons why oral health may be important and how this may relate to regular dental attendance, however they acknowledged having a lack of depth of understanding.

"[Oral health is important as] it can lead to other complications...There's things that dentists check for that normally don't get checked for...I don't know the details... A small problem with your mouth that could be easily dealt with by a dentist can lead to more complicated medical problems...I think people can get oral cancers and what have you...But other than that I don't really know. I just know that it happens." Male, 38-years-old.

This could indicate that problem-orientated attenders believe oral health is important on a superficial level. However, this belief alone isn't enough to outweigh the barriers to attendance (van der Zande et al., 2020). In addition, this could reflect the differences in decision-making processes related to immediate and long term gains and consequences of behaviours (Schiebener and Brand, 2015; Mueller et al., 2017). For problem-orientated attenders the immediate gains and consequences of attending only when in pain outweigh the potential long term gains of regular attendance which they have not directly experienced, for example preventing dental disease (similar to the situation where someone carries on smoking because of the immediate gain depsite being aware of the long term risk of smoking related diseases). Interventions which aim to simply promote importance of oral health may therefore not produce the benefit expected of them. The link between knowledge and importance of oral health may be important to consider as understanding the importance of oral health may in turn increase the perceived need for dental care, which has been found to be a facilitator for behaviour change towards regular dental attendance (Finch et al., 1988).

# Self-management and Impact of Pain

This theme covered two sub-themes: the impact ADP had on everyday life, and self-management strategies the participants used when suffering with ADP. The two subthemes were linked to explain delayed care-seeking and the eventual decision to seek care.

## **Self-Management Strategies**

Whilst suffering with ADP various self-management strategies were reported by the participants. These ranged from analgesia, to "old wives tales" (Female, 19 years [urban myth]), attempted self-extraction of teeth, or attempts to ignore the pain. For many it was failure of their self-management techniques which led to them to decide to seek dental care.

Over-the-counter analgesics such as paracetamol and ibuprofen were routinely used by participants, and often as a first line of self-management (Cohen *et al.*, 2009b).

"I was just taking paracetamol and ibuprofen [for] about three month until I got sorted out." Male, 27-years-old.

When these didn't provide sufficient pain relief participants would trial other forms of over-the-counter analgesics. These included different analgesics such as aspirin, but importantly also different brands of paracetamol or ibuprofen which the participants believed to be different analgesics to those they were already taking.

"I'm taking constant pain relief for it. I've been taking paracetamol for well, a few year now. But if the pain's like worse, the paracetamol don't relieve the pain, I take Anadin Extra [paracetamol, aspirin & caffeine]." Female, 57-years-old.

This links to the theme on lack of knowledge and misunderstanding and is important to acknowledge and may partly explain why problem-orientated dental attenders are at risk of unintentional analgesic overdose as discussed in the literature review. This may indicate that interventions are needed around analgesic use for ADP beyond the current restrictions that are in place in relation to the number of packets that can be bought (Committee on Safety of Medicines, 1997), particularly given very few participants sought advice from a pharmacist for their ADP.

"It was just this really intense throbbing. It was unlike anything else. It's probably like a 10 on the pain scale and I was trying to put ice and all sorts on it and I made myself ill because I was trying to take so many pain killers. I couldn't sit still for the pain. I was physically rocking

backwards and forwards. It was really, really painful...I was taking paracetamol and ibuprofen, aspirin, basically anything that I could try and numb it and I ended up taking probably too many and I was being sick. So I couldn't keep them down, they weren't really working." Female, 23-years-old.

This does, however, raise the importance of ensuring that dental professionals enquire specifically about analgesic use during their pain history during an urgent care attendance as patients may not be forthcoming in the amount of analgesics taken, particularly when they are unaware that certain brands of analgesics are the same medication.

In addition to over-the-counter pain relief, participants also borrowed prescription medication from other family members or friends to try and relieve the pain which has been reported in the US (Cohen *et al.*, 2009b).

"I've just been taking paracetamol and codeine and going to sleep because I cannot deal with the pain when I'm awake...I've been taking them every four hours...[I've] Probably not no, actually no, definitely not [followed the recommended dose]...And [it] hasn't been prescribed for me. I've borrowed it off ... my mam." Female, 24-years-old.

This again has patient safety issues if problem-orientated attenders are frequently taking medication which is not prescribed for them.

Aside from management with analgesics another common self-management strategy was a change in diet to avoid chewing on the painful tooth.

"I changed my diet to eat softer foods to make it less likely that things would interfere with my, or create pain in my tooth." Male, 38-years-old.

Once these methods had been trialled and failed to manage the pain, participants would resort to trying other remedies. These included use of cold water, hot compresses, and methods described as "old wives tales".

"[I tried] Everything. Normal medication. All the old wives tales.... Salty water. Ambesol [topical anaesthetic and antiseptic]. Paracetamol. Ibuprofen. Hot compress." Female, 19-years-old.

Various dental products would also be trialled, however often inappropriately, believing that they may help with ADP, which again links to the theme on lack of knowledge or misunderstanding.

"I flushed out with TCP. And I also bought like a Cortisol [Corsodyl, chlorhexidine mouthwash], something like that. I think Cortisol. I'll try anything but nothing worked." Female, 45-years-old.

A further self-management strategy was self-extraction, or auto-extraction (Altom and DiAngelis, 1989) of the offending tooth, which has been reported previously in problem-orientated attenders in the US (Gilbert, Duncan and Earls, 1998). The reasons for attempting this related to a combination of: failure of oral analgesia; the impact of the pain on everyday life; methods to avoid or delay dental care-seeking.

"I'll tell you the truth I did try to take it out myself but I couldn't fully crack it to loosen it... I have on several occasions removed my own teeth... I work on the taxis... on a busy Friday or Saturday night I haven't got time for pain. So I will just get a pair of pliers and pull them out... It was painful at first but it got easier the more I took out... I have been known to hit one with a hammer, I positioned a screwdriver in where I'd seen where the tooth was cracked and hit the screwdriver with a hammer to take the pain away." Male, 47-years-old.

As well as self-extraction, other attempts at dental treatment were trialled before deciding to seek professional dental care.

"I tried cracking my tooth because I thought that it was the wisdom tooth at the back pushing down. And I tried popping that with a pin." Male, 27-years-old.

Self-management of ADP rather than attending for urgent dental care was often normalised by participants and was considered part of everyday life.

"I would kind of just get on with it...it's what you do isn't it? You just get on with it, go to work, continue as normal." Male, 27-years-old.

Knowledge of these different self-management techniques was from various sources, including: family and friends; the internet; previous learnt experience.

"I was just so much in pain... like other people say oh try this, try that...Family members have just said oh try this it worked for me." Female, 60-years-old.

A further reason given for attempted self-management rather than seeking professional care was the belief that urgent dental care services were already overstretched and if they sought care then others may not be able to who may need treatment more.

"I feel if I can sort this myself then somebody else can have that seat to be seen [who are] more worse off than me. And I always feel I don't like to trouble people unless I really have to." Male, 47-years-old.

# Impact of ADP

Failure of self-management strategies was a reason for deciding to seek dental care, often in combination with the severity and impact of ADP on their quality of life, which is in keeping with reported literature (Crawford, Hawker and Lennon, 1997; Pau, Croucher and Marcenes, 2000; Anderson and Thomas, 2003).

"I was crying because it was so painful ... it got worse so that's why I went in to the dental hospital the next day early in the morning." Female, 57-years-old.

For participants who were dentally anxious the severity of the pain reached a level which exceeded their dental anxiety making them decide to seek care.

"It was really bad pain because I have a fear of dentists... I couldn't sleep with it or anything and I thought well my fear has to just go out the window, because it was so bad." Female, 56-years-old.

The experience of toothache and the impact it had on quality of life was a facilitator for some participants to discuss the potential of attending for regular dental care in an attempt to avoid the same experience in the future.

"I've just getten [sic, become] so fed up of being in pain when I've got the toothache... it just stops us doing anything, and it makes us horrible and grouchy with people...that's not who I want to be." Female, 52years-old.

The severity of dental infections, including the need for hospital admission was another reason given for deciding to change attendance behaviour.

"I don't really want to go through what I went through again...Just going in hospital... I think it scared us [sic, me] a bit." Male, 27-years-old.

The impact of ADP on quality of life and the associated planned behaviour change to seek regular dental care has been reported elsewhere, however this new behaviour goal is often short-lived (Gibson *et al.*, 2000). This may imply that although pain can be a facilitator for behaviour change it may not be enough to elicit long term change therefore, other barriers and facilitators will need to be addressed to achieve this. Participants were not followed up in this study therefore it is unknown as to whether

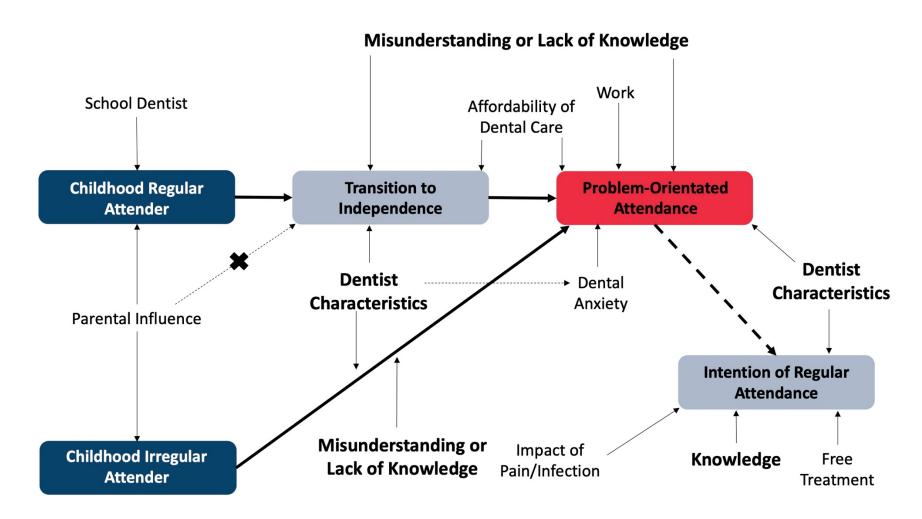
they did change their behaviour as planned, and if they did if it was maintained or not.

# **Summary**

Throughout the interviews multiple themes emerged for all participants related to reasons for their problem-orientated attendance pattern, which were similar to those previously reported prior to dental contract reforms (Finch et al., 1988). These themes frequently linked together, overlapped and compounded one another. This is in keeping with research carried out at the same time to the present study but elsewhere in the UK, where the authors found similar themes for urgent dental care attendance, but highlighted the complexities surrounding the interlinking of themes resulting in a web of causation (van der Zande et al., 2020). It is therefore important to bear in mind that addressing one of the themes discussed is unlikely to result in behaviour change and multiple themes will need to be targeted. Dental attendance patterns across the life course are also dynamic (Finch et al., 1988; Gibson et al., 2000) and this was apparent during interviews with participants reporting periods of regular attendance in addition to problem-orientated attendance, and the reasons for changes in attendance patterns varying at different time points. Problem-orientated attendance is therefore complex and the reasons for it should not be considered in isolation, instead they should be regarded as interlinking and dynamic throughout a person's life. This is demonstrated in the following section by use of a conceptual model.

# 5.4.4 Conceptual model of problem-orientated dental attendance

By examining the themes discussed above, participant care pathways, recall of childhood experiences and potential factors encouraging regular care-seeking a conceptual model was formulated. This models the pathways a patient goes through from childhood to adulthood to become a problem-orientated attender, through to factors which may correspond to an intention to change behaviour to regular attendance. The model is shown in Figure 5.4 and explained below. Examples of how a sample of participants moved through this conceptual model are shown in Appendix K.



**Figure 5.4:** Conceptual model of problem-orientated dental attendance.

Participants were either regular or irregular dental attenders as children, and they could recall the reasons for this being related largely to parental influence, as well as presence of a school dentist. For those who were regular attenders in childhood they progressed into a phase of transition to independence and during this they could recall gradually stopping regular dental care. The reasons for this change related to the loss of influence from their parents and misunderstanding or lack of knowledge, coupled with negative experiences with dentists and the need to begin to pay for dental treatment. They became problem-orientated attenders once they started suffering with ADP as result of dental non-attendance. For childhood irregular attenders, they continued the same attendance pattern into adulthood largely due to misunderstanding and lack of knowledge, as well as negative childhood dental experiences deterring them from the want to seek care. Negative dentist characteristics as a child across both pathways resulted in dental anxiety as an adult. Once established as adult problem-orientated attenders the themes discussed above would act as barriers to regular dental care and facilitators for continued problemorientated attendance.

All participants were interviewed following an urgent care attendance, and therefore their long-term behaviour in relation to dental care-seeking could not be explored. Some participants, however, did indicate intention to seek regular dental care. The reasons given for this potential change in behaviour related to experience of positive dentist characteristics, receipt of new knowledge, the long-term impact of ADP or the seriousness of a dental infection, or the possibility of receiving free dental care.

The conceptual model demonstrates the complexities involved with problemorientated dental attendance and how reasons for attendance can fluctuate over the
life course. It has been reported previously that encouraging regular dental
attendance over and above problem-orientated attendance involves a complex
network of factors, and simply addressing one is unlikely to result in long term
sustained behaviour change (Tash, O'Shea and Cohen, 1969; Finch *et al.*, 1988),
and in addition to the present study this has also been confirmed elsewhere more
recently (van der Zande *et al.*, 2020). This indicates that any interventions targeted
at problem-orientated attendance will need to be complex. As shown in the model
the overarching themes related to all pathways were misunderstanding and lack of
knowledge, and dentist characteristics. These may, therefore, be the most important

themes to consider in intervention development. The model in relation to intervention development and the subsequent next steps are discussed at the end of the chapter.

# 5.4.5 Links to dental GMP attendances (Chapter 4)

The reasons why patients visit a GMP for dental problems include a large component of lack of knowledge or misunderstanding (Cope et al., 2018), similar to the theme identified in this qualitative study. Lack of knowledge in relation to GMP attendances includes: misconceptions about symptoms; scope of practice of GMPs and GDPs; no perceived need for regular dental care and inability to access urgent dental care when needed; no knowledge of the availability of urgent dental care; lack of knowledge and transparency of dental charges (Cope et al., 2018). Similar themes were identified here showing parallels in the reasons both for GMP dental careseeking and problem-orientated attendance. In addition, a further reason given for seeking care from a GMP rather than a GDP was dissatisfaction with previous dental care, with the most damaging effect on a dentist-patient relationship being patients who felt they were not respected or treated with dignity by their GDP previously, and therefore sought care from a GMP instead (Cope et al., 2018). This therefore links closely with dentist characteristics, showing that this can both discourage regular dental attendance, encourage repeated problem-orientated dental attendance, and result in care-seeking from non-dental providers.

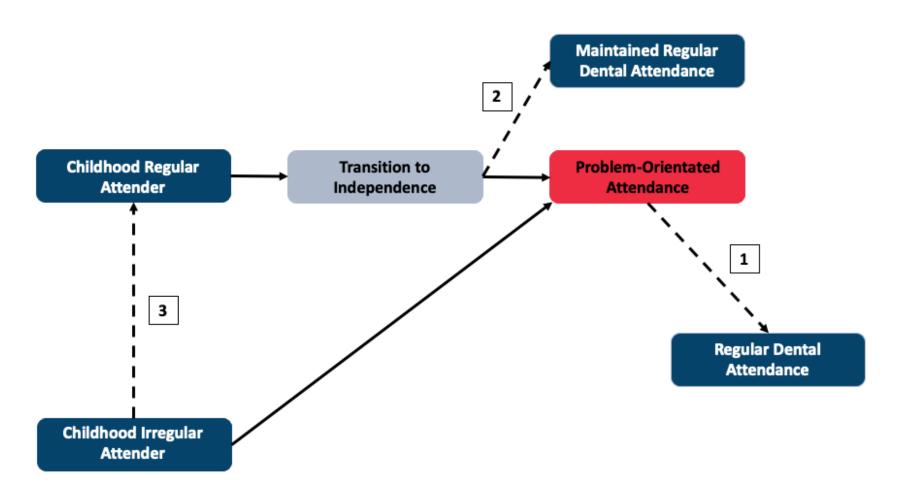
Seeking care from a GMP for dental problems may not be appropriate as GMPs are limited in the treatment they can give and report a lack of confidence in treating dental complaints. In addition to this, GMPs largely do not want to treat dental patients, with reported attitudes being to "grin and bear it", feelings of exasperation, an abuse of the system, waste of resources, and feelings of animosity towards dental consultations (Cope et al., 2015). These feelings of frustration from GMPs may therefore parallel the dentist characteristics theme discussed here. This could indicate that negative attitudes towards seeing problem-orientated dental attenders are apparent to patients during both dental and medical consultations. This would, in turn, reinforce their beliefs of previous negative healthcare experiences, increase their feeling of being a burden on healthcare professionals and the NHS, and then further reinforce their behaviour of only seeking care when they cannot tolerate their ADP any longer. Therefore, this may indicate that part of the solution to problem-oriented attendance may include healthcare professional interventions, which may be targeted at both GDPs and GMPs.

The patients interviewed in this study reported not seeking urgent dental care from GMPs because they knew they could offer little in the way of dental treatment. Two patients did report previous experiences of asking dental advice from their GMP. One reported only mentioning ADP because they were seeing the GMP about other medical problems, and not valuing the advice received. The other sought dental care from their GMP as an avoidance strategy believing they had a post-operative infection, therefore knowing their GMP would be limited to providing an antibiotic prescription, whereas a GDP may have wanted to carry out further dental treatment, such as cleaning of the infected socket. This therefore raises the possibility that patients who are frequent urgent dental care users, such as those recruited here, have sufficient health literacy knowledge to know not to seek urgent care from a GMP. Instead, patients who do seek dental care from a GMP may do so because of poor dental access, the wish to avoid dental care due to anxiety or dental phobia, or may be attending for other medical reasons and then mention their dental problems. Findings from a US study have shown that patients who attend a GMP for dental problems attend largely due to these reasons and only expect temporary treatment such as analgesics or antibiotics, and are aware that they will eventually need to see a GDP for definitive dental treatment (Cohen et al., 2009c). If this is the case, then separate interventions would likely be needed to target patients who choose to attend a GMP over and above a GDP.

# 5.4.6 Impact of qualitative findings on intervention development and limitations of study

From the conceptual model of problem-orientated attendance produced, there are three key time points that an intervention for problem-orientated attendance could target (Figure 5.5):

- 1. Encouraging established problem-orientated attenders to change their behaviour to become regular dental attenders.
- 2. Encouraging childhood <u>regular</u> attenders to maintain this attendance pattern as they transition to independence thereby preventing problem-orientated attendance.
- 3. Encouraging childhood <u>irregular</u> dental attenders to become regular dental attenders and in addition maintain this attendance pattern into adulthood.



**Figure 5.5:** Potential targets for an intervention aimed at problem-orientated attendance. (1) Encourage regular dental attendance in established problem-orientated attenders. (2) Maintain regular dental attendance in current childhood regular dental attenders as they transition into independence. (3) Encourage regular dental attendance in irregular childhood attenders.

Following this work package, the decision had to be made about which target to focus on for the final co-design study. Studies elsewhere in the UK were currently exploring interventions to encourage established problem-orientated attenders to become regular dental attenders (Harris, 2018), therefore efforts could have potentially been duplicated without time available to evaluate outcomes of any interventions developed. Ethnographic work from this group has also highlighted that barriers to preventive dental care in problem-orientated attenders accumulate over time (van der Zande et al., 2020), this may indicate that interventions earlier in life would be of benefit. In addition, there is a large national campaign addressing the need for parents to take young children to the dentist for regular care (British Society of Paediatric Dentistry, 2017), and even though early results show this campaign to be successful if the children attending do not maintain the behaviour following the transition to independence then problem-orientated attendance will still result. It was therefore decided to focus on developing an intervention targeted at adolescents and young adults that would aim to maintain their current regular dental attendance pattern, thereby preventing the change to problem-orientated attendance.

The decision about where to focus the intervention was also discussed with the study's PPI panel, and they were in agreement that the intervention co-design should focus on the transition to independence period. In addition, because of the level of lack of knowledge and misunderstanding demonstrated in this study, they believed dissemination of this to the public was important. As a result, an animation was co-created with the panel, further details on this are given in Appendix L.

One limitation of the study was that the reasons for change in attendance pattern during the transition to independence were based on participant recall and therefore could be subject to recall bias. For this reason, a further additional study was carried out for triangulation, this is presented in the following chapter (Chapter 6).

There are some further limitations to this study which will potentially affect generalisability. Firstly, non-English speakers were excluded, which means that this group of patients may have different experiences and perspectives of barriers and facilitators to care-seeking than discussed. However, previous qualitative work in this patient group reported similar themes to those found in this study (Croucher and Sohanpal, 2006). Secondly, participants were recruited from urban locations, and as shown in the SAIL dataset and NHS BSA data analysis (Appendix G) residing in a rural location is a predictor of repeated urgent care attendance, both in primary care

and at GMPs. Due to the epidemiology analysis not being complete prior to the end of this qualitative study the significance of recruiting from rural locations was not realised and as such patients were not actively recruited from rural locations. This means their experiences may not have been captured in this study and therefore may not be represented. Finally, although some patients discussed their experiences of private dental care, recruitment was only carried out in NHS recruitment sites, therefore experiences of problem-orientated attenders who access private urgent dental care may be underrepresented.

# 5.5 Summary

The reasons for problem-orientated attendance are multifactorial, interlinking and complex, however overarching themes relate to lack of knowledge and misunderstanding, and dentist characteristics. The transition to independence from childhood appears to be an important period where dental attendance patterns can change and targeting interventions at this could prevent problem-orientated attendance in adulthood. To explore this transition period a further qualitative study was carried out with adolescents and is presented in the following chapter.

# Chapter 6. Factors Affecting Regular Dental Attendance: Examining the Transition to Independence

#### 6.1 Introduction

The perceived importance of visiting a dentist regularly appears to decrease throughout adolescence and into young adulthood (Broadbent, Thomson and Poulton, 2006), with frequency of dental attendances decreasing from as early as 9-years of age (Hawley, Holloway and Davies, 1996), up to the transition from school to employment (Finch *et al.*, 1988). This change in dental attendance behaviour is also demonstrated in the CDHS and ADHS data, with 81% of 12- and 15-year-olds attending for a dental check-up (Tsakos *et al.*, 2015), dropping to 51% in 16- to 24-year-olds with 42% self-reporting that they attend less often than they did five years ago (Morris. *et al.*, 2011). Other more recent longitudinal studies also report the same trend (Okunseri *et al.*, 2013b; Fägerstad, Windahl and Arnrup, 2016; Leary and Do, 2019).

Whilst there is a wealth of research on children and adolescents' oral health behaviours (for example oral hygiene and diet) there is little on decision-making around current and future dental care-seeking (Badri *et al.*, 2014), particularly within the UK (Hall-Scullin *et al.*, 2015) with the majority of recent research taking place in Scandinavian countries. Previous research in this area has highlighted potential barriers to include: lack of knowledge or perceived importance of oral health and care-seeking; perceived or actual cost of care; negative experiences and dental anxiety (Craft, Croucher and Bowstead, 1980; Blinkhorn, Hastings and Leathar, 1983; Hawley and Holloway, 1992; Ostberg *et al.*, 2002; Fitzgerald *et al.*, 2004; Dodd *et al.*, 2014; Hall-Scullin *et al.*, 2015; Murray, Densie and Morgan, 2015; Fägerstad *et al.*, 2019). In addition, disruption in lifestyle as adolescents transition into young adults alongside the need to begin to take responsibility and engage in their own oral health and dental appointments can be a reason for change in attendance habits (Blinkhorn, Hastings and Leathar, 1983; Fägerstad *et al.*, 2019).

It is widely acknowledged that health behaviours will change throughout the life course but this key transition period from childhood to adolescence and into young adulthood is critical because of increasing autonomy and independence, as well as changes in social influences and the environment (Spear and Kulbok, 2004). As discussed in the preceding chapter this transition period could be a key time to develop and implement an intervention encouraging continued regular preventive

care-seeking in this target audience, in turn preventing adult problem-orientated attendance. In order to develop an intervention which is likely to be successful and acceptable it is important to fully understand the problem the intervention aims to address (Currie *et al.*, 2022c), this study was therefore carried out to explore adolescents' opinions and provide evidence in support, or otherwise, to the adult qualitative work already conducted.

# 6.2 Objective

1. To explore barriers and facilitators contributing to adolescents' decision of preventive dental care attendance as they transition to independence.

#### 6.3 Methods

# 6.3.1 Study design

This study used qualitative research methods in order to understand and explore adolescents' experience of dental care, and their understanding of NHS dentistry and dental disease.

# 6.3.2 Ethical approval

Ethical approval was obtained from Newcastle University Ethics Committee (Ref 1846/15318/2019).

#### 6.3.3 Sampling procedures

A purposive, convenience sample was used by recruiting from schools which had a wide range of catchment areas and demographics to capture a range of participants across different backgrounds. This sampling strategy was used to allow a depth and breadth of experiences to be gained, whilst maintaining a straightforward sampling strategy for the schools to use which did not exclude adolescents who wished to share their experiences or views based upon their background or dental attendance behaviour.

Sociodemographic status was considered using English IMD, and during recruitment participants' residential postcodes were recorded to allow calculation of this.

Additional demographic details captured included: age; gender; current self-reported attendance pattern (regular/irregular/non-attender).

Inclusion criteria were:

Participants 14-years-old and above

Exclusion criteria were:

- Those who were unable to converse and understand complex constructs in English
- Individuals younger than 14-years-old
- Individuals older than 18-years-old

Participants were aged 14- to 18-years-old as previous literature identified that by the age of 14-years-old adolescents have started to make their own decisions regarding dental attendance (Hawley and Holloway, 1992). The upper age limit was set to 18-years to match the age that pupils in England are required to continue in full or part time education (Education and Skills Act, 2008).

#### 6.3.4 Qualitative data collection

For this study focus groups were used to allow interaction between participants, enabling them to hear experiences and opinions of others, reflect and add to discussion. The focus groups were carried out within the school's registration or tutor groups with participants who felt comfortable talking about their experiences with each other. The groups were arranged by the group's teacher with input from the participants. They were also given the option of having individual interviews if they would rather not discuss their experiences with peers present, however no participants opted for this. Focus groups were conducted by myself.

A semi-structured topic guide was developed and checked by supervisors experienced in qualitative research (JD, VAS), as well as an external collaborator experienced in qualitative research with adolescents (ZM). The content of the topic guide was based on the previous guide from interviews with adult problem-orientated attenders with modifications from existing literature, and was reviewed and refined following each focus group. The final topic guide is shown in Appendix M.

The first two focus groups were carried out face-to-face in March 2020 prior to the COVID-19 lockdown in England. There was then a subsequent delay whilst schools were closed (Coronavirus Act, 2020). Following schools re-opening recruitment recommenced in October 2020 and the 2<sup>nd</sup> two focus groups were completed in November 2020 using Zoom (Zoom Video Communications, Inc. (2020) Version 5.4.7.) due to a risk assessment by the University allowing remote research only.

The mean duration of the focus groups was 39 minutes (+/- SD 17) minutes. All the focus groups were recorded using a digital voice recorder (Sony ICD-SX2000) and the files anonymised by group ID. The focus groups were transcribed verbatim by a

transcription company, with files transferred using a secure university drop-off system in password protected and encrypted files. Transcribed files were checked for accuracy by myself.

# 6.3.5 Participant recruitment

Participant recruitment was carried out from March 2020 to November 2020, with a period of delay during this due to the COVID-19 pandemic and subsequent school closures. Recruitment was from one registration/tutor group per year group of interest (year 9 to year 12) across the two schools. The registration/tutor group was selected by the school to reflect the widest range of demographics (e.g. gender, education level, free school meals). Letters about the study with an information sheet were sent home to all parents/guardians of the children in the selected registration/tutor groups (Appendix N). Parent/guardians had two weeks from receiving the letter to opt out of the study. Following this period, children whose parents had not opted out were screened for exclusion/inclusion criteria by the teacher and then given a standardised description of the study. Those who were interested in taking part were approached and given a participant information sheet (Appendix N) and the opportunity to ask any questions. Had further recruitment been required within a year group then a second registration/tutor group would have been invited to participate in the same manner.

Participants who wished to take part were required to sign a consent form (Appendix N). Consent procedures were as follows:

- Participants 14-years and older who were considered Gillick/Fraser
   Competent (House of Lords, 1986) were able to sign their own consent form.
- Those under 16-years-old where Gillick/Fraser competence could not be confirmed required parental/legal guardian consent, and the participant signed an assent form.

All participants were given a £20 gift voucher for their time in the study, which was sent via email following completion of the focus groups.

#### 6.3.6 Recruitment locations

Recruitment was from two schools in the North-East of England, both of which had a wide catchment area and served a range of demographics (Table 6.1). Participants over 16-years-old were recruited from the sixth form college (an educational

institution allowing pupils to study for advanced school level qualifications) attached to the 2<sup>nd</sup> school.

	School 1	School 2	England Average
School type	Community	Academy	
Pupils receiving free school meals	37%	23%	28%
Pupils staying in education	79%	85%	87%
Pupils in apprenticeships	8%	4%	4%
Pupils in employment	4%	4%	4%
Pupils not employed or in further education	9%	7%	5%

**Table 6.1:** Demographics of the schools participants were recruited from for the adolescent qualitative study alongside the English average for comparison (UK Government, 2021a).

# 6.3.7 Study sample

As per the previous qualitative study, recruitment was carried out until data saturation was reached, with an initial sample size estimated at 15 to 35 participants. Following an iterative, inductive data collection and analysis process, data saturation was reached after 4 focus groups (n=32) across all the study locations.

#### 6.3.8 Qualitative data analysis

As for the previous qualitative study, data analysis was iterative, using an inductive thematic analysis with frameworks to help to organise and sort the data (Silverman, 2016). This analysis helped to drive the development of a conceptual model. The steps involved in each stage were described in the previous chapter and included: open coding; axial coding; framework analysis. The coding framework was inputted into NVivo software (NVivo qualitative data analysis software; QSR International Pty Ltd. Version 11, 2016), and thematic frameworks were created using Excel spreadsheets (Microsoft office professional plus 2016, USA). The conceptual model was built up within PowerPoint (Microsoft office professional plus 2016, USA), with each focus group added onto the model in subsequent slides, so that the development could be tracked and refined. The final conceptual model, with associated themes and verbatim quotations were reviewed by the supervisory team (SS, VAS, JD), as well as by internal and external collaborators (CE, ZM, PB, LJH).

A secondary analysis was also carried out mapping the themes generated to the Theoretical Domains Framework (TDF) (Michie *et al.*, 2005; Cane, O'Connor and Michie, 2012). This mapping exercise was done to allow examination and

understanding of barriers and facilitators related to decision-making mapped to behavioural determinants to inform future intervention development. The TDF was developed to encompass a broad range of psychological theories and constructs of behaviour change so these can be easily identified by researchers. The second refined and validated version of the TDF was used to map to (Cane, O'Connor and Michie, 2012). It includes 14 domains and 84 theoretical constructs (summarised later in this chapter).

The final coding framework was used to map the codes to the relevant domains of the TDF. Focus group transcripts were also reviewed and recoded according the TDF to ensure that all behavioural and decision-making processes were identified and mapped across. This was reviewed by a supervisor with significant experience in the TDF (VAS).

#### 6.4 Data and Discussion

## 6.4.1 Summary

The summary characteristics of the participants are shown in Table 6.2. All participants were self-reported current regular dental attenders.

ID	Age	Gender	IMD Decile
BEL1	14	Female	1
BEL2	14	Female	4
BEL3	15	Female	7
BEL4	15	Female	10
BEL5	15	Female	3
BEL6	15	Female	4
BEL7	14	Female	9
BEL8	15	Female	2
BEL9	15	Male	3
BEL10	14	Male	5
BEL11	15	Male	5
BEL12	15	Female	5
BEL13	15	Female	1
BEL14	15	Male	10
BEL15	14	Male	1
BEL16	14	Female	3
PAR1	15	Female	5
PAR2	15	Female	6
PAR3	15	Female	3
PAR4	16	Female	8
PAR5	15	Male	2
PAR6	15	Female	3
PAR7	16	Female	5
PAR8	16	Male	10
PAR9	16	Female	2
PAR10	16	Female	3
PAR11	16	Female	7
PAR12	17	Female	3
PAR13	16	Female	8
PAR14	16	Female	8
PAR15	16	Male	4
PAR16	17	Male	2

**Table 6.2:** Study sample characteristics of the adolescent recruited to the qualitative study.

Five main themes emerged from the focus groups: knowledge; dentist characteristics; dental anxiety; affordability of dental care; transition from school.

Themes often linked together and interacted, which is demonstrated in the conceptual model following presentation of the themes. A brief summary of concepts mapped to the TDF is given at the end of the chapter and summarised in Table 6.3. As per the previous chapter, representative quotes are given throughout the data and discussion. Additional representative quotes are provided in Appendix O.

#### 6.4.2 Thematic analysis

#### **Knowledge**

This theme covers the knowledge of the adolescents in relation to their dental care and oral health.

The participants acknowledged that they had little, or very superficial knowledge about dentistry and their oral health, and one of the reasons they seek care is to see a professional who has this knowledge to pass on, as well as confirm and reassure them that their teeth are healthy, consistent with findings elsewhere (Craft, Croucher and Bowstead, 1980; Blinkhorn, Hastings and Leathar, 1983; Fägerstad *et al.*, 2019).

"PAR2: The thing is ... I don't really ... know masses about ... stuff that go wrong with your teeth...Like I don't think I've been told anything. PAR3: ...that's why I go to the dentist because I just genuinely have no idea ...What like the signs are...I bet no one knows about their teeth. PAR5: Yeah, apart from the dentist.

PAR2: ... that's the only time I ever think about my teeth... that's the only time I'm ever really told stuff...[there's] barely any learning about it in like Year 3."

Other participants were unsure why they saw a dentist for check-ups. In keeping with the adults interviewed, they compared dental care-seeking to GMP care-seeking and were unsure why there is difference in required attendance behaviour, a finding consistent with that in the 1980's (Craft, Croucher and Bowstead, 1980). This difference in healthcare systems and expected attendance behaviour may be something that healthcare professionals assume patients understand. Given that this misunderstanding exists from adolescence through to adulthood, and currently reinforces problem-orientated attendance patterns, intentional explanation and discussion may be required by healthcare professionals to ensure that the difference is understood and related to expected attendance behaviour.

Participants discussed the importance of seeing a dentist whilst they were growing up in relation to changes in their dentition, wanting reassurance that they would have "nice" (BEL6) teeth once they were adults.

"BEL3: ...we're all growing so...you want to know that it's happened properly. So when you're older you've not... got like a half a mouth of teeth and then half a mouth of like none.

BEL6: ... you're in that awkward bit between being a kid and an adult and you're like I kind of want my teeth to be nice as an adult...We're kind of like setting ourselves up to have good teeth."

They had superficial knowledge about what a dentist does at a check-up, often only being aware that the dentist checked for decay and oral hygiene.

"BEL7: Just to make sure you're doing everything right, and you're brushing your teeth right and not missing anything.
BEL1: Yeah, because they're the professionals, they know."

Participants were not aware that dentists checked for other diseases, such as periodontal disease or oral cancer. One participant was aware that the dentist did examine soft tissues but didn't know why. This lack of knowledge regarding periodontal and soft tissue diseases remains unchanged from earlier research (Blinkhorn, Hastings and Leathar, 1983; Hawley and Holloway, 1992).

"PAR2: I don't know. I feel like they don't talk about my tongue. [Laughter].

PAR2: I know it sounds weird but ... I feel like they do look at it but it's like I've never been told anything [about it]."

Similar to the adult problem-orientated attenders and other studies (Hawley and Holloway, 1992; Dodd *et al.*, 2014; Hall-Scullin *et al.*, 2015) participants thought good oral hygiene was protective against dental diseases, as such being unsure why they would need to see a dentist regularly. This was compounded when good oral hygiene was being confirmed repeatedly by the dentist. This could therefore contribute to the reason why adult problem-orientated attenders believe that there is no need to see a dentist if they are pain free and believe they have good oral hygiene. Indeed, adolescents who are irregular dental attenders also report the same belief (Murray, Densie and Morgan, 2015).

"BEL5: I feel like that's [not seeing a dentist regularly] kind of because you get all of these different ... toothpastes now...people just end up relying on them... oh it's fine, I have this funny toothpaste that will fix it... when you go to the dentist ... [they are] promoting them so then you're like so why am I coming here if that toothpaste can do it all."

There was agreement that oral health was considered important, however participants struggled to explain why. The majority only considered it important in relation to appearance, which is consistent with other studies in this age group (Craft, Croucher and Bowstead, 1980; Blinkhorn, Hastings and Leathar, 1983; Hawley and Holloway, 1992; Fitzgerald *et al.*, 2004; Stokes, Ashcroft and Platt, 2006; Dodd *et al.*, 2014; Fägerstad *et al.*, 2019). Only a minority could explain the potential implications of poor oral health in relation to function, perhaps as a reflection on the limited

experience they had of ADP and dental disease. General health was deemed to be more important than oral health and was considered distinct from whole body health.

"PAR3: I'd be more scared if ... like a health-related thing than having teeth [related problems] ...cancer is more scary than like tooth decay"

The concept that oral health is distinct from general health was also found in adult problem-orientated attenders, and has been reported elsewhere by adolescents (Craft, Croucher and Bowstead, 1980; Stokes, Ashcroft and Platt, 2006), although some are aware of a superficial link between the two (Hall-Scullin *et al.*, 2015). These beliefs in adult problem-orientated attenders may therefore originate in adolescence or younger and could be addressed at a younger age.

Despite attending for regular check-ups with a dentist, participants reported that their knowledge generally did not improve. This related closely to the perceived characteristics of the dentist and is discussed further in the following theme.

"PAR3: But I don't know what I'm doing right. Like I don't know what my teeth are...like I've got no clue about my teeth still."

Participants wanted dentists to tell them more about their oral health and future dental care. They reported dentists either not giving advice or praising and reassuring them but not feeling this was specific enough information. The need for specific, tailored oral health advice in adolescents has already been reported (Hall-Scullin *et al.*, 2015). A lack of communication between dentists and orthodontists was also raised as a contributing factor.

"I: The last time you saw a dentist did they give you any advice or information?

All: No.

PAR3: ...keep on doing what you're doing or whatever.

PAR2: ...there might have been something wrong but it was just so insignificant that to them it didn't really matter. But it might matter in the long run... it's just like yeah, your teeth are fine, go.

PAR3: I think they should give more advice...whenever I go [they're] like keep on doing what you're doing, but... I don't really know what I'm doing so I think ... give more...

PAR1: Information.

PAR5: I ... feel like I'm expecting more information and then I'm not... the orthodontist [will] say the dentist will speak to you about this, and the dentist will say the orthodontist will...so I feel like I'm going out without...that I've still got questions...

PAR3: Oh I always find that."

They wanted more information when something was noted as potentially being a problem and felt that dentists would sometimes omit giving them information because of their age. They believed that if people their age had a better understanding and more knowledge about dental care and what happens at a check-up and during dental treatment, they'd be more likely to seek regular care.

"PAR12: ... they could be reassured if they like know what's going to happen and they'd be more likely to go... Inform you about the possible treatments that might happen."

Participants discussed the impact of a lack of knowledge on feelings of dental anxiety. It was agreed that more information should be given by dentists on future treatment needed, but it was important for this to be tailored to the individual, otherwise could contribute to missed future appointments (Morgan *et al.*, 2016; Fägerstad *et al.*, 2019).

"PAR2: ... for your next appointment knowing you knew what happened [at the check-up]... and ...finding out what happens next time ... if you are consistently being told more information... that will help with the anticipation... So you know what to expect...
PAR3: I just like getting it over and done with, I do."

Participants also didn't know the cost of dental care, or expected it would cost more than it does, this is covered further in the theme on affordability of dental care.

Adolescents' lack of knowledge about dental care has been reported elsewhere (Craft, Croucher and Bowstead, 1980; Hall-Scullin *et al.*, 2015), however there are conflicting findings within the literature, indeed another study in UK adolescents concluded that they have good knowledge (Stokes, Ashcroft and Platt, 2006). This may be due to a focus more on oral health behaviours such as toothbrushing and diet, which participants in this study were aware of, rather than exploring depth of knowledge. For example, participants were aware of behaviours they *should* be doing, but were not aware of *why*. Superficial knowledge about oral health and dental care may not therefore be sufficient for them to deem dental care-seeking as important when making their own dental care decisions.

This theme relating to lack of knowledge or misunderstanding is consistent with that found in adult problem-orientated attenders, therefore this lack of knowledge may begin at an early age and potentially be linked to dentist characteristics as discussed below. If knowledge can be imparted during adolescence this may be retained

during transition into independence and therefore influence future decision-making surrounding dental care.

# **Dentist Characteristics**

This theme covers the perceived characteristics of dentists, which were either deemed positive or negative by the participants. Positive characteristics were associated with a better dentist-patient relationship, better knowledge and understanding, reduced dental anxiety and the want to continue regular dental care. Negative dentist characteristics resulted in a poorer relationship, lack of or incorrect knowledge, negative experiences, and anxiety. This theme linked closely with that of dental anxiety and is discussed further later.

The importance of seeing the same dentist was reported. Those who saw the same dentist reported a better experience and relationship, consistent with other studies (Skaret *et al.*, 1999; Fägerstad *et al.*, 2019). Indeed, continuity of care has been highlighted as an important priority for reducing oral health inequalities in children and adolescents (Watt *et al.*, 2019).

"PAR2: I've got the same dentist since I was little... so sort of sense of comfort with that I suppose... it like feels like they know you. PAR4: Yeah. I've had the same dentist for like as long as I can remember ...like I'm not scared when I go to the dentist."

Those who had seen different dentists discussed their experiences and the differences between good and bad dentists.

"BEL6: ... ["bad dentists"] just try get the job done as soon as they can. BEL2: ...Even though they all get taught the same stuff and go on the same courses and everything, like they all do it different. BEL2: Sometimes you go in and you get sunglasses for the light and other times you just have to be blinded for a few minutes."

Participants reported feeling left out of conversations, and that the dentist would speak to their parents but not engage with them. This was given as a reason why they didn't receive the knowledge they wanted from the appointment, often feeling that they were leaving the appointment being unable to ask the dentist questions.

"PAR4: I think it's important to feel like you're included... because you know if you find out after you think well why wasn't I like asked about this... they haven't done anything wrong but it would be nice to be sort of included in the discussion of it....

PAR2: Yeah... they sort of talk about it ... they forget you're there... the only reason they actually speak to you is like at the end if they give you free toothpaste."

This resulted in participants having dental treatment but being unaware it was going to happen or what the treatment was. This relates to the previous theme on knowledge, and also resulted in dental anxiety.

"PAR5: I didn't even know they were going to do that [fissure sealant], it was like weird not being told ...I think they told my mam but I had no idea.

PAR1: I hate when they do that

All: Yeah.

PAR5: You don't know til afterwards..."

As well as feeling left out of conversations, negative dentist characteristics which were reported included: feeling like the dentist didn't care; not making them feel comfortable; being patronising, critical, shaming them or being condescending. Similar dental professional behaviours have been reported as barriers to careseeking in adolescents (Fitzgerald *et al.*, 2004; Fägerstad *et al.*, 2019), and causing fear-related behaviours in children and adolescents (Zhou *et al.*, 2010; Morgan *et al.*, 2016).

"BEL5: I felt like my old dentist ...would get sick of us when, do you know when you would try to speak and they were like why is she opening her mouth. Shut up. You know what I mean?"

The dentist's use of dental terminology or jargon such as saying "a lot of technical stuff to the other person that's there" (BEL6) also left participants feeling left out and was identified as a negative characteristic, this has also been reported in adults (Calladine, Currie and Penlington, 2022).

The majority of participants had experience of seeing an orthodontist and compared their relationships between the different dental professionals. The want or need for orthodontic treatment was also given as a reason why they seek regular dental care at their age. This reason for dental care-seeking in adolescents has also been reported in the rural US (Dodd *et al.*, 2014) and may indicate that a potential site for intervention delivery could be within the orthodontic clinic. They often preferred their orthodontist as they had a more positive experience with them and could see a visible change in their teeth as a result of their treatment, whereas they didn't value what their dentist did other than either note areas of good or poor oral hygiene. Those who reported a good relationship with their dentist had a broader

understanding and appreciated the role of the dentist more. The fact that the majority of participants had experience of orthodontic treatment highlights that they were all current regular dental attenders, and a similar theme may not be found with non-attenders in this age group and would warrant further qualitative work with this group.

"BEL7: He [orthodontist] knows everything about us [sic, me] and he's like ... you're on track, that's really good... he says reassuring things to me whereas ... the dentist they're like ... that's wrong and that's wrong...

BEL3: ... I feel like I appreciate the dentist more because they have to find the issues where like... the orthodontist they already know it's this certain tooth that's got to go this way."

Studies elsewhere have identified the dentist's professional role as a barrier to careseeking in adolescents, particularly in relation to communication and professional
skills (Badri *et al.*, 2014; Fägerstad *et al.*, 2019). Numerous studies within the wider
healthcare literature have also highlighted the importance of adolescents being
involved in discussions and decision-making about their healthcare (Jordan *et al.*,
2018), for this to be possible it is essential that health professionals have good
communication skills and create a strong professional-patient relationship (Garanito
and Zaher-Rutherford, 2019). Furthermore, adolescents who report being satisfied
with healthcare appointments are more likely to return for subsequent appointments
(Litt and Cuskey, 1984).

In a similar way to the adult qualitative study, it should be highlighted that these dentist characteristics discussed are those perceived by the participants as no ethnographic methods were involved. However, given that there were similar experiences reported by both the adult problem-orientated attenders and the adolescents it is clear that dentist characteristics play an important role in decision-making around dental care-seeking.

### Dental Anxiety

This theme relates to issues associated with dental anxiety that participants discussed. Dental anxiety was commonly linked to negative dentist characteristics, with previous negative experiences causing anxiety about future appointments. It was also agreed that dental anxiety would be a reason why people their age avoided seeing the dentist, which would be consistent with the literature (Murray, Densie and Morgan, 2015; Fägerstad, Windahl and Arnrup, 2016) and prevalence rates of dental

anxiety being between 7.1% and 19.5% for adolescents (Klingberg and Broberg, 2007).

"I: Can you think of any reasons why people your age might decide not to go and see a dentist?

BEL6: Fear...There's a lot of people scared of dentists. All: Yeah."

Participants reported feeling anxious before seeing a dentist even though they attended regularly and had minimal experience of invasive dental treatment. Anxieties related to the discomfort of having dental instruments in the mouth were raised and particular anxieties were discussed about the discomfort of dental radiographs, which has been reported by other adolescents (Fägerstad *et al.*, 2019). This may be a reflection of their limited experience of invasive dental treatment for comparison, but also highlights the importance of dentists being aware of potential anxieties related to routine procedures carried out during check-up appointments and the need for careful patient management during these which could be easily overlooked.

Anxiety was linked to the dentist characteristics, with the dentist either being able to induce more anxiety or relieve it depending on what they did during previous appointments, consistent with the literature on childhood and adolescent dental anxiety (Morgan *et al.*, 2016).

"PAR1: I was quite nervous... I had a normal check-up and he says you have to come back ... to get a filling. I was like really like [anxious] when they're doing it...he was debating whether to put the anaesthetic in and he was like I'm just going to drill... if you feel any pain put your hand up...he's drilling and I'm thinking I'm ready to put my hand up because the pain's coming, so I was quite ready to pee in my pants for that one... because I was expecting a big like jolt of pain. [Laughter]

PAR5: They [dentists] make a lot of people scared going to the dentist as well because I know I'm terrified...but I think my dentist is really nice...I don't know if she like talks to me whilst I was there, so she kind of made me feel a bit more at ease.

PAR3: Yeah, same."

Not knowing or understanding what was going to happen at appointments was reported to cause anxiety, again consistent with previous reports (Morgan *et al.*, 2016). This would interact with other issues that would cause dental anxiety, such as having an injection and heighten anxiety further. They also reflected that adolescents don't like to admit if they don't understand what the dentist was saying,

and how this could then increase anxiety further. This has also been reported elsewhere and could be due to unequal power relationships between the young patient and dentist making the patient feel they are unable to ask questions (Morgan *et al.*, 2016). This highlights this complex relationship between the themes on dentist characteristics, knowledge and dental anxiety.

"PAR10: ...a lot of people don't like it because ...literally there's someone with their hands in your mouth for like up to twenty minutes. And you don't know what's going to happen and especially at our age we tend to just agree, so like they'll say I'm going to do this and you won't know what they mean but most of the time ... you just agree without knowing ... So then like that's putting people on edge ...it's restricted breathing ... and like getting injections in your mouth and stuff like that and then just past traumatic experiences like putting people off."

The "stigma" (PAR15) associated with dentists was widely discussed in terms of how dentists are perceived by the public and the negative image associated with them causing dental anxiety. Participants recognised that in reality not all dentists would behave as per the perceived "evil" (PAR10) image, however it's often assumed by society. This perceived image was often related back to media sources, or family and friends. They believed that this would have an impact on people their age deciding whether to seek dental care, consistent with other studies (Fägerstad, Windahl and Arnrup, 2016; Fägerstad *et al.*, 2019), and the impact of these negative "dentist stories" has been reported elsewhere (Dodd *et al.*, 2014). Having a good experience with a dentist was seen as a way of overcoming this perceived negative image, however having a bad experience would reinforce it. The role of family, peers and the media again played a role in how participants felt about dental appointments.

"PAR2: ... you're always given like horror stories about dentists... my dad doesn't like the dentist so ... that is passed down... like the dentist is a bad place to be.

PAR5: ... I think if people have a positive experience...they aren't afraid of the dentist ... we go in and come out and they forget about it... to actually be anxious ... they have to remember all the negative parts, and so that's what people have passed on to them."

Interestingly, previous qualitative research with dentally anxious children and adolescents found that patients were more worried about what the dentist thought of them, rather than their perceived negative view of the dentist (Morgan *et al.*, 2016). Given that not all participants in this study reported having dental anxiety, this could indicate that these concerns are specific to children and adolescents with dental

anxiety, and the perceived dentist identity is of more relevance and concern to the wider population.

Negative dental experiences in childhood have been shown to lead to the development of dental anxiety in adulthood (Oliveria *et al.*, 2017) and avoidance of dental care in adolescence (Fägerstad *et al.*, 2019). Indeed, the adults interviewed who reported dental anxiety could recall associated negative childhood experiences. For this reason, it is imperative that childhood dental experiences are as positive as possible. The data here suggest simple solutions which may help, such as the dentist making sure the adolescent patient knows what treatment is going to be carried out and what to expect, as well as being aware that patients of this age group may not feel they can highlight when they don't understand something. An intervention, based on cognitive behavioural therapy, has also been developed aimed at dental anxiety in children and adolescents (Porritt *et al.*, 2017), as this is implemented wider within the UK this may address barriers specifically with dental anxiety. This intervention is currently aimed at children up to 16-years-old and could be considered as a basis for retrofitting an intervention for older adolescents and adults in the future.

The themes of dentist characteristics and dental anxiety closely linked and overlapped, with negative dentist characteristics leading to anxiety, and positive characteristics helping to overcome it, therefore interventions targeting dental professional (communication) skills could be of relevance. The media and other social influences clearly also play a role in dental anxiety and the perceived identity of the dentist by way of negative stories. Interventions could therefore use the opposite of these by portraying positive stories relating to dental experiences or the dentist identity.

### Affordability of Dental Care

This theme related to the cost of dental care as a factor in participants' decision-making around future care-seeking. All participants were receiving free dental treatment at the time of the focus groups, however, the prospect of having to pay for treatment in the future was given as a reason for them not planning or wanting to continue to seek regular care. Interestingly, the fact that care was currently free was given as a reason for them to attend regularly now so they can make the most of the

free treatment, which has also been reported in Swedish adolescents (Fägerstad *et al.*, 2019).

"BEL10: It's free but you have to pay once you go past a certain age so you make the most of it now...[I'd] Still go [when I'm older] but not as regular...Because you have to pay..."

Dental charges were reported to be a barrier to future care-seeking due to concerns over the value for money and the ability to pay as a young adult who may be either in higher education or starting a new job.

"PAR4: It's a lot of pressure to put on someone that age whose like just started in like an apprenticeship or like a job ... because they're still kids and stuff and they still get stressed and all that."

In addition, the regularity of the payment was also given as a reason for participants to stop seeking care as often as they currently were, which was also reported by the adult problem-orientated attenders. This could be linked back to the theme on knowledge whereby participants potentially didn't understand the benefits of a check-up and therefore couldn't justify the cost. The majority also didn't know the cost of dental treatment and some assumed that it would be more expensive than it actually is, consistent with findings from earlier qualitative research in the UK and internationally (Craft, Croucher and Bowstead, 1980; Ostberg *et al.*, 2002; Murray, Densie and Morgan, 2015).

"BEL11: It's expensive when you're going like every six month.

BEL13: For what they do it's expensive. If you get a check-up they don't do much. All they do is just look about with the mirror."

Participants were also aware that their parents didn't attend a dentist regularly due to the cost and they thought that would also influence their future decision-making, this has also reported by New Zealand adolescents (Fitzgerald *et al.*, 2004).

When asked for their opinions on paying for dental treatment the participants were often divided, however they largely agreed that check-ups should be free, consistent with the opinions of adult problem-orientated attenders. This may again relate back to knowledge of what happens during a dental check-up and the value that they believe this is worth. Health economics research has not been carried out in this cohort, and it would be interesting to see what their willingness to pay for a dental check-up and/or treatment is and if this changes if their knowledge and understanding of dentistry improves.

"BEL1:I think if it's just a check-up and you don't need anything done then it should be free, but like if they have to do...a filling or something then it should need to be charged. But like just for a check-up just to look at your teeth and be like yeah, you're fine... for only five minutes...then you shouldn't really need to pay for that. [All: heads nodding]."

Participants discussed the potential for dental charges currently increasing oral health inequalities, being aware that those who most need dental treatment were also those who were most likely to be unable to afford it. This was given as an argument to reduce the cost of dental care.

"BEL13: But it's like people are just expected to pay and they can't. So like it's a disadvantage for poorer people.

BEL9:...It's less accessible by everyone with the higher prices, so if the prices were lower then more people would go and a lot more people would have healthy teeth and stuff."

In keeping with adult problem-orientated attenders participants were either confused or had no knowledge about current exemptions from dental charges, which relates to the first theme on knowledge. However, once given this information, they didn't agree with the exemption for higher education and felt that it could be improved. They again reflected on inequalities in relation to this.

"PAR3: So like full-time education's ... free but if you're in a bad household there's less chance you'll be in full-time education and then that means you've got to pay for a dentist and that doesn't make much sense

PAR1: It's impossible.

PAR5: ... like a lot of people the only reason they wouldn't go to the dentist is because they didn't have money. But at eighteen if they didn't have money then I feel like the whole cycle of like not going to the dentist just starts a lot earlier."

As all participants were under 18-years-old, they were all receiving free dental treatment at the time of the focus groups, however the introduction of dental charges in the near future was a clear barrier to continued care-seeking for a large proportion. This has been reported as a future barrier in adolescents in the UK in the 1980's (Craft, Croucher and Bowstead, 1980), in Swedish and New Zealand adolescents (Fitzgerald *et al.*, 2004; Ostberg *et al.*, 2010; Fägerstad *et al.*, 2019) and a current barrier in those living in rural areas in the US (Dodd *et al.*, 2014) where dental treatment needs to be paid for an at earlier age, and they have the added costs of significant time and travel to access care. The decision-making process around

whether participants would ultimately decide to pay for dental care is discussed further later in the chapter.

### Transition from School

The transition from school appeared to be a key time point for the participants when they predicted they might change their current dental attendance behaviour. This has been reported previously in Scottish adolescents, with lifestyle changes leading to disruption, an inability to cope and subsequently routine dental attendance becoming less important (Blinkhorn, Hastings and Leathar, 1983). It is also during this period that adolescents need to begin to engage in self-management of their own oral health and dental care-seeking and lack of responsibility for their own oral health is considered a barrier to future care-seeking (Fägerstad *et al.*, 2019).

Whilst they were at school three reasons were given as to why they regularly attended a dentist: parental influence, orthodontic treatment (discussed above) and social norms. Once they left school two subthemes emerged as potential future barriers to care-seeking: lacking skills for appointment making and balancing and conflicting priorities.

### **Parental Influence**

An immediate response from participants when asked why they currently see a dentist was that their parents made them go. If this influence was no longer present, they weren't sure if they would attend regularly.

"PAR2:...the reason I go [to the dentist] is because of my mum...They're [parents] just like oh that's what you're doing today.

PAR3: That's what parents are for, aren't they?

PAR2: ... yeah, depends on your parents.

[All: Agreement]

PAR5 ... my parents say I have to, but if they gave me the choice...my

immediate reaction would be no... I'd not even think about it.

PAR3: Yeah. Don't realise the importance of it.

Participants also reflected on the experience of seeing a dentist with their parents and family and reported this making it a positive experience. They discussed social interactions with the dentist being more challenging if their parents or family weren't in attendance, also reported elsewhere (Fägerstad *et al.*, 2019). This could relate to dentist characteristics and their experiences to date, for example feeling left out of conversations, meaning they don't have the opportunity to develop communication skills with the dental team when they feel supported by their parents or family.

Interestingly, in earlier UK qualitative work adolescents reported seeking dental care with family as being a barrier to care-seeking due to feelings of embarrassment to be seen out with their families (Hawley and Holloway, 1992). This could represent the increasing period of adolescence reported, whereby adolescents now enter puberty earlier but take on independent adult roles later (Worthman and Trang, 2018), therefore relying on parents for some social interactions at an older age. Indeed, the upper age range of adolescence has been suggested to now be up to 24-years-old (Sawyer *et al.*, 2018) so it is perhaps not surprising that adolescents in the age group of this study still appreciate parental support.

"BEL5: ... it's normally like a family gathering when we go...then there would just be you, like you'd miss the...like the chats that you have ... and then, you know, what I mean?
BEL6: Which can be awkward and quiet because you need your mum to start the conversation."

Parental influence as a reason for regular dental attendance in childhood is reported throughout the literature (Crawford and Lennon, 1992; Hall-Scullin *et al.*, 2015; Kettle *et al.*, 2019), particularly when parents are also regular attenders (Attwood, West and Blinkhorn, 1993; Kinirons and McCabe, 1995; Scott *et al.*, 2002). This was also reported by the adult problem-orientated attenders, however equally parental influence was also a reason for irregular childhood attendance. As all participants in this study were regular attenders it was not possible to explore this further and may require further qualitative work specifically with irregular child/adolescent attenders.

Within the wider healthcare literature it has been demonstrated that adolescents are more likely to attend healthcare appointments when made by their parents, with this being the strongest predictor of appointment compliance (Irwin Jr, Millstein and Shafer, 1981). Combined with the delay in adolescents taking on independent adult roles (Worthman and Trang, 2018) this could be more important now than when this study was carried out. Current legislature indicates that adolescents over 16-years-old can consent for their own dental treatment (The Health and Social Care Act 2008 (Regulated Activities) Regulations, 2014), which coincides with this initial transition from school period. At this point dental professionals may assume that parents are no longer needed at appointments and similarly, parents may feel they no longer need to accompany their child. However, if loss of parental influence is a barrier to continued care-seeking as suggested by these data it may be important for parents to continue supporting adolescents in dental attendance until an older age when they

feel able to attend alone. Indeed, the end of adolescence is extremely difficult to define as it varies between individuals and it cannot be easily measured by a physical outcome, instead involving both a new social role and having the associated knowledge, skills and social competence (Dahl et al., 2018). The concept that adolescents need to begin to take responsibility for their dental care-seeking when they leave school (Fägerstad et al., 2019) may therefore be premature and it may not be appropriate to assign an age to this. In addition, interpreting this as "lack of responsibility" may be an oversimplification given the complexities of barriers faced. Instead, this lack of *engagement* may be a consequence of insurmountable barriers which adolescents feel unable to cope with without the necessary environmental context and resources to support them. It may, therefore, be more important for dental professionals, parents/carers and the adolescent patient to have ongoing conversation and reflection on when they may be ready for this transition. An important aspect to consider in this interaction, however, is the importance of respecting adolescents' increasing sensitivity to status and autonomy and the importance of them being supported to make their own decisions (Dahl et al., 2018). Indeed, interventions targeted at adolescents often fail because they imply that the adolescent is unable to make the correct choice without adult expertise (Yeager, Dahl and Dweck, 2018), therefore a carefully balanced approach is need to ensure parental influence and support is maintained until the right time, alongside consideration for the social and developmental changes they are experiencing. The participants in this study were under 18-years-old and it would be interesting to see if a similar theme is identified in young adults when further environmental changes and barriers may exist, such as a move to university or away from the parental home.

In terms of intervention development, as parental influence is likely to be potential facilitator for children attending the dentist regularly, and loss of this influence then becomes a key time point when dental visiting behaviour may change interventions could be targeted at two times: (1) when parental influence is lost, or (2) in the period prior to this to ensure regular dental visiting is maintained once adolescents become independent. Future research could also consider interventions targeted at parents to ensure children are taken to the dentist regularly to prevent problem-orientated attendance originating in childhood as per the previous chapter.

### **Social Norms**

Participants also reported attending a dentist because that was the normal thing to do at their age. Some participants were surprised to find that people their age wouldn't see a dentist regularly.

"PAR1: I didn't realise that people like didn't, especially our age, don't go to the dentist like regularly."

Social norms as a reason for seeking dental care has been reported by other adolescent groups (Stokes, Ashcroft and Platt, 2006; Hall-Scullin *et al.*, 2015), as well as for other adolescent behaviours (Maxwell, 2002). Interestingly, adult problem-orientated attenders did not report social norms as a reason for regular childhood attendance. This could be due to recall bias or could potentially indicate a shift in social norms with more children seeking regular dental care.

One group compared adults who they knew to be problem-orientated attenders to their regular attendance pattern and found this attendance behaviour surprising and "weird" (PAR4). However, as a group they then rationalised this behaviour against the cost of dental care which they had previously decided would be a future barrier to their own care-seeking.

"PAR4: Someone I know in my family, he just goes like whenever there's a problem...Which I find really weird.

PAR3: Yeah, same as my dad...

PAR5: Yeah, that's what my dad does.

[All: General agreement]

PAR4: He's like he's got a tooth with a hole in it.

PAR2: But that just seems odd.

PAR3: But do you have to pay for check-ups as an adult.

PAR5: Yeah. My dad pays, yeah I think so.

PAR4: Oh well I was wondering why...I mean like the money thing...

PAR2: ...makes sense to hear about the money thing but then it's still a

bit odd...

[All: General agreement]"

Indeed, the quote above highlights that this patient group do have strong opinions on complex issues of health and are potentially motivated to maintain their oral health more than their parents. However, given the findings of the adult qualitative study and epidemiological studies such as the CDHS and ADHS as highlighted in the introduction, there may be a change in their motivation as they transition into adulthood and subsequently become problem-orientated attenders. Of course, this could also be a cohort effect and highlight changes in adolescent's opinions and motivations around oral health. Future work could involve following adolescents up over time as they transition into adulthood to monitor changes in their attendance

patterns, with associated qualitative work to understand the changes in barriers as they present in real time. Although it is unknown whether the adolescents in this study will change their attendance behaviour as they transition, they did highlight some barriers that they could already see emerging which they thought may stop them attending despite their current motivation, these are discussed below.

### **Appointment Making**

Once parental influence was lost, participants were aware that they could make their own decisions about whether they would continue to seek care. One barrier to seeking care which was consistently reported was the need to make their own dental appointments once their parents no longer did this for them. This was also linked to their transition from school to working life or higher education. Reasons for concerns about making appointments related to: the social interaction required; the need to complete "complicated" (PAR3) paperwork; and needing to organise a time they were available to attend. For many this was a potential reason for them no longer accessing regular dental care.

"PAR3: What do you have to do [to make an appointment]?

PAR5: ...it's like really awkward and complicated...does your mam have to sign something?

PAR3: But like I've always gone with my mam.

PAR4: Like making the appointment, it's like pressure.

PAR2: ...when I have to start making my own appointments or when I have to start signing for stuff myself I wish I'd been like told before like,

this is what's going to go on. It's actually fine, don't panic.

PAR3: I've seen like some of the forms...some of the questions I'm like

they are a bit complicated...

PAR1: It's like an exam"

Participants also related the concerns over appointment making to changes in environment when they'd potentially need to find a new dentist as well as make an appointment, for example moving away to university.

Appointment making as a barrier to care-seeking in this age group has not been reported elsewhere, indeed earlier studies have found children as young as 12years-old to have started to make their own decisions around dental care-seeking (Hawley and Holloway, 1992) and around one-third of 15-17 year-olds make their own dental appointments (Craven, Blinkhorn and Schou, 1994). Instead, barriers related to appointment making included remembering to make and attend appointments (Hawley and Holloway, 1992). These studies were, however, carried out over twenty years ago and this may suggest a delay in adolescents' autonomy with more reliance on parents for appointment making until an older age than previously reported. Development of autonomy is a complex process with a number of internal and external influences, one being the environment and how supportive it feels (Spear and Kulbok, 2004), therefore if adolescents feel unsupported when seeking dental care (as the dentist characteristics theme suggests) this may hinder development of autonomy in terms of their dental decisions making them feel unable to access care independently. A further explanation for this change could be due to change in the skills of adolescents over the past three decades which are required to make an appointment. For example, participants reported feeling unable to communicate with the dental team to make an appointment, this could be due to concerns relating to dentist characteristics, communication skills or a combination of the two. An intervention could therefore include components related to appointment making, for example by teaching skills required, or by creating a supportive environment to make an appointment. The paperwork that requires completing could also be demystified and made more accessible for younger people or explained whilst they have the support of their parents.

### **Balancing and Conflicting Priorities**

Participants reflected on changes that would occur when they left school, and that other priorities may emerge and take precedent over dental appointments, which has been reported in Swedish adolescents (Fägerstad *et al.*, 2019). One barrier they identified was the need to start paying for dental treatment as discussed above. In terms of conflicting priorities, the cost of care was weighed up against their perceived importance of oral health compared to the perceived benefit of seeing a dentist, other life priorities and the potential cost of other things they'd need to pay for once they left school.

"PAR16: ... my parent's background is imprinted on my opinions of the cost of it [dental care]. So I'm prepared to grow up and know that I'll not have that much like money and stuff ... [dental care] it's not necessary... it's that expensive it's not worth putting that money into it.

PAR10: ... the money that would like go into paying for the dentist, I might be like in a situation ... oh I've got this amount of money and I could spend it on one thing or on the dentist... do I want to spend it on something more important or more necessary? Because...I've not benefitted like after the dentist so I want to pay for something that I feel would benefit us [sic, me] more...

PAR13: ... there's just like support off your parents too which you stop getting so you wouldn't go, like advice on money and telling you to go, and like making the appointments and stuff.

PAR14: Just the cost, like it's just not massively important to like pay that amount."

Again, the balance of the importance of oral health was compared to the importance of general health and was given as a reason why oral health is less important and therefore could not justify the need to pay to see a dentist. Potential problems with oral health were seen as easier to fix, possibly on your own without needing to see a dentist. If this belief originates in adolescence, then it's perhaps unsurprising that adult problem-orientated attenders will regularly attempt self-management of their ADP before seeking dental care. This would also be in keeping with reports that adolescents would prioritise seeking care from a doctor over a dentist (Fägerstad *et al.*, 2019).

"PAR3: If I had a like lump I'd probably think it's cancer...if my teeth like discoloured I probably wouldn't even know...

PAR1: Yeah, like you'd just buy some teeth whitening toothpaste.

All: Yeah

PAR1: Or use like salt water.

PAR2: ... And that's a balance. It's ... like medical stuff, I think that's so much more important and ... But then if you look at your teeth you sort of overlook it and like I'll be fine.

PAR3: Yeah. I would."

A further change in priorities related to the need to start further or higher education or employment. They reported that it was easy to attend the dentist whilst at school as they could take time off, but weren't sure how easy it would be in comparison once they'd left. Difficulty getting time off work for dental appointments has been reported by young adults recently starting work (Hawley and Holloway, 1992), as well as by the adult problem-orientated attenders, so this concern may translate into an actual future barrier.

This balance between priorities when leaving school has been reported by other adolescents (Hall-Scullin *et al.*, 2015) as well as the process of weighing up the positives and negatives when deciding whether or not to seek dental care (Stokes, Ashcroft and Platt, 2006) and pay for treatment (Fägerstad *et al.*, 2019). In addition, the perceived importance of regular dental visiting appears to decrease from adolescence into young adulthood (Broadbent, Thomson and Poulton, 2006), when other priorities such as being with friends, buying clothes or leisure activities are considered more important than seeking dental care (Fägerstad, Windahl and

Arnrup, 2016). Coupled with the other barriers discussed such as lack of knowledge and negative experiences with dentists through adolescence, this highlights the complex decision-making process young adults will go through when they must begin to pay for dental care. It is therefore important that adolescents have full and correct knowledge, as well as positive dental experiences when making these decisions to facilitate future decisions for dental care-seeking. Given the data presented, introducing dental charges at 18-years-old in England may not be the most appropriate timepoint, and as highlighted by the participants the current exemption criteria may be widening oral health inequalities. This should be taken into consideration in future dental policy changes. Indeed, dental care in Scotland has recently been made free of charge to those 18- to 25-years of age for this reason (Scottish Government Primary Care Directorate, 2021) and dental check-ups in Wales have been free to those under 25-years-old for several years (National Health Service, 2006). The effect of these policy changes should be closely evaluated as they could serve as further evidence for the need for change in England. Unfortunately, the data in this study and from the SAIL dataset analysis (Chapter 4) would suggest that simply removing dental charges is unlikely to cause behaviour change on its own, however it would remove one barrier in what is a complex process.

### 6.4.3 Conceptual model

By examining the themes discussed above a conceptual model was formulated. This models the barriers and facilitators that shape the decision-making process adolescents go through as they become independent and make their own decisions about dental care-seeking. The model is shown in Figure 5.4 and explained below.

The superficial reasons for children attending the dentist regularly relate to parental influence, social norms and the need or want for orthodontic treatment. In addition, they acknowledge that they have little knowledge or understanding of dentistry and oral health and therefore want to gain knowledge and reassurance from a dentist. Further reasons for regular attendance relate to having a dentist they have a good relationship with (positive dentist characteristics), which makes them more likely to want to return for regular care. If they have a good dentist-patient relationship, they receive the knowledge and reassurance they want which encourages them to continue to seek regular care. In contrast to this, if they see a dentist that they

consider to have negative characteristics there are two possible outcomes explained within the current study:

- 1. They do not receive the reassurance and knowledge they want leading to lack of knowledge or misunderstanding about dentistry and oral health.
- 2. Development of dental anxiety.

Both above outcomes are then potential barriers to future dental care-seeking as they transition into independence. In addition, as they begin to make their own decisions about dental care-seeking they need to be able to weigh up balancing and conflicting priorities in relation to: how important they consider oral health to be; other life priorities at that time; the need to begin to pay for dental care. Misunderstanding and lack of knowledge around dentistry and oral health will then feed into this decision-making process if they don't understand the importance of oral health or have the knowledge of the cost of dental care.

Once parental influence is lost this becomes a barrier to seeking care, but in addition and allied to this there is substantial anxiety over the need to the make dental appointments without parental support.

A key time point for these changes to begin was reported as being around the transition from school into further or higher education or employment. For example, the need to begin to pay for dental care commences at 18-years-old (or 19-years-old in full time education) and those in the focus groups reported that they felt parental influence would also be lost at this point as well as other life priorities beginning to take precedence or change. This is therefore a key time point for potential behaviour change and therefore intervention, however this transition to independence may span over a longer time period than just this time point and may vary between individuals given the evidence within the literature for a widened period of adolescence up to the mid-twenties (Sawyer *et al.*, 2018).

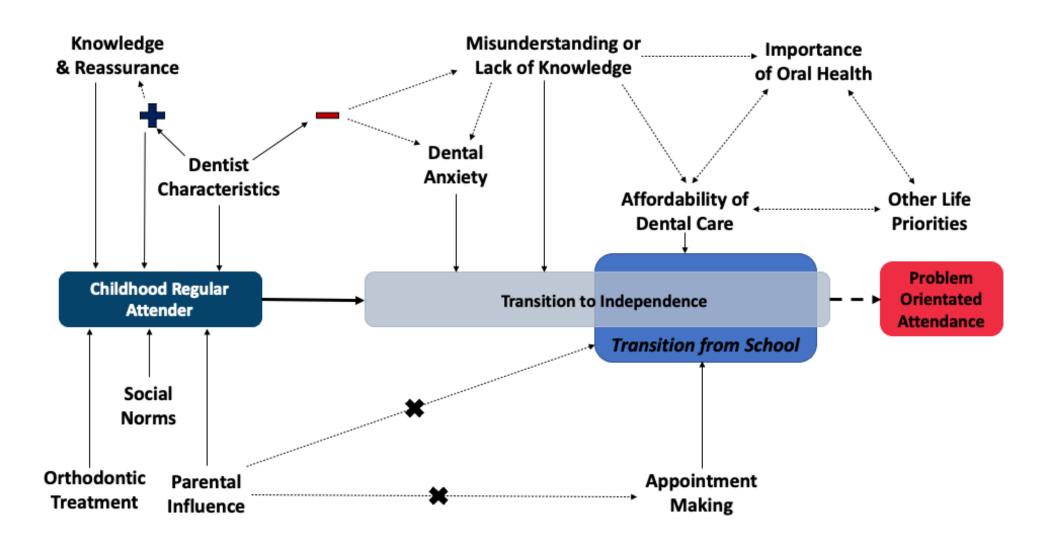


Figure 6.1: Conceptual model of adolescents' barriers, facilitators and decision-making surrounding future dental care-seeking.

# 6.4.4 Mapping to Theoretical Domains Framework

A secondary analysis of the themes and focus groups was performed using the TDF. This is summarised in Table 6.3, with TDF domains highlighted in the quotations given above. The complexity behind the decision-making process, the barriers and facilitators for future dental care-seeking, is summarised in Figure 6.2 showing the links between TDF domains.

Domain	Definition	Theoretical Constructs	Explanation
1. Knowledge	An awareness of the existence of something.	Need/want for knowledge	Participants would seek regular dental care with the aim of receiving knowledge and reassurance about dentistry and their oral health. When this was not received this could create barriers to future careseeking related to lack of knowledge or misunderstanding surrounding oral health and diseases, dentistry as a healthcare system (including associated future charges, how to find a dentist, make an appointment and complete the required paperwork), the reasons to seek regular care. When knowledge was received this would facilitate future regular care-seeking. Participants expressed the wish for knowledge regarding (future) dental treatment to help them overcome barriers to careseeking, and when this was not received could result in dental anxiety.  Participants believed they lacked certain skills to be able to seek dental care independently. These related particularly to finding a dentist and making an appointment, as well as being able to attend for dental care alone. Specific skills included communication skills with the dental team and organisation skills to arrange an appointment.  The dentist's professional role could impact on participants current and future dental care-seeking by either being perceived as positive (e.g. continuity of care, included in conversations and decision-making) or negative (e.g. feeling left out of conversations, patronising or condescending). Positive characteristics would facilitate current and future dental care-seeking, whereas negative characteristics would be a barrier to future careseeking. Dentists were acknowledged as being professionals and therefore had the knowledge and
		Receipt of knowledge	
		Oral health and diseases	
		Knowledge of dental system	
		Reasons to seek regular dental care	
		Dental treatment	
2. Skills	An ability or proficiency acquired through practice.	How to find a dentist and make an appointment	
		Communication	
		Organisation	
3. Social/Professional Role and Identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting.	Dentist characteristics	
		Source of knowledge/information	

		Perceived dentist image	information that participants wanted, however this was not always received. The perceived identity of dentists within society was considered to be negative, which could cause anxiety around careseeking. Participants who were also receiving orthodontic treatment acknowledged differences in the perceived professional role between their dentist and orthodontist and therefore could compare and contrast positive or negative characteristics between the two. Equally, participants who had experiences of seeing different dentists could compare positive and negative characteristics.
		Perceived dentist role	
4. Beliefs about Capabilities	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use.	Acceptance of lack of own dental knowledge	Participants recognised that they lacked knowledge about their own oral or dental health and dentistry and gave this is a reason for wanting to seek care from a dental professional, however when this was not received this would impact future barriers to careseeking. They also believed that good oral hygiene and use of certain toothpastes promoted by dentists would be protective of dental diseases and questioned whether they needed to see a dentist regularly, particularly when the dentist reported they had good oral hygiene. They also believed that dental problems would be easy to fix on their own.
		Perceived competence in management of dental disease	
5. Optimism	The confidence that things will happen for the best or that desired goals will be attained.	Perceived competence in management of dental disease	Participants believed that good oral hygiene or certain toothpastes as promoted by dentists would be protective of dental diseases and they therefore did not need to see a dentist. They also believed that dental problems would be easy to fix on their own.
6. Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation.	Importance of oral health	Participants acknowledged that oral health was important but only on a superficial level, this would therefore create conflicting priorities when deciding
		Oral health in comparison to whole body health	whether or not to seek dental care in the future. Oral health was seen as distinct from whole body health and not considered as important.

7. Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus.	Knowledge as a facilitator	Participants would see a dentist to gain knowledge, if this was received this would facilitate/reinforce future care-seeking. Positive dentist characteristics and continuity of care would also facilitate and reinforce future care-seeking. Participants were dependent on parents to make and take them to dental appointments, when this influence was lost behaviour change to non-regular attendance was considered. Participants would seek regular dental care if they wanted, or were having, orthodontic treatment.  Dentistry was compared to whole body health and other health care-seeking and was considered less important due to differences in healthcare systems.
		Dentist characteristics	
		Continuity of care	
		Reliance on parents	
		Orthodontics as a facilitator	
		Experience with dentistry in comparison to other health care systems	
8. Intentions	A conscious decision to perform a behaviour or a resolve to act in a certain way	Introduction of dental charges	Participants showed intention to change their behaviour and stop seeking regular dental care once they were required to pay for dental care. Whilst dental treatment was free this was seen as a motivator to attend. In addition, the desire or need to have orthodontic treatment was seen as motivation to seek regular dental care.
		Need/want for orthodontic treatment	
9. Goals	Mental representations of outcomes or end states that an individual wants to achieve.	"Nice" adult teeth	A goal of regular care-seeking as a child or adolescent was to have "nice" teeth as an adult. In addition, participants would seek dental care in order to receive knowledge and reassurance from a professional.
		Need/want for knowledge and reassurance	
10. Memory, Attention and Decision Processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives.	Affordability of dental care and value for money	Participants considered the future cost of dental care to be a barrier to regular care-seeking, particularly related to the perceived value for money for a dental check-up. This was further compounded by participants believing preventive behaviours (such a good oral hygiene and using certain toothpastes)

		Balancing and conflicting priorities	would protect them against dental disease and seeing a dentist would add no further value. Future dental charges also created conflicting priorities for participants, whereby they'd need to be able to prioritise paying for dental care over other life priorities and against the perceived (lower) importance of oral health.
11. Environmental Context and Resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour.	Affordability of dental care	The future cost of dental care was seen as a potential barrier to regular dental care-seeking. Participants also reported seeking dental care during school to be easy but believed future working
		Transition from school	environments would make accessing dental care more challenging once they left school. Leaving school and moving away from home was also seen a barrier to care-seeking due to the potential need to change dentists. Participants would seek regular
		Orthodontic treatment as a facilitator	dental care because of the relationship between being referred for orthodontic care by a dentist, and the need for continuing regular care whilst undergoing active orthodontic treatment.
12. Social Influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours.	Parental influence	A reason for regular dental care-seeking was that parents would make participants' dental appointments and take them. A further reason for regular care-seeking as a child or adolescent was
		Social norms	that it was the expected behaviour (social norms). Family, peers and the media influenced the perceived identity of dentists portraying them as
		Wider family and peer influences	being negative which was considered a barrier to care-seeking and could create anxiety when seeking care. In addition, older family members not seeking regular dental care due to the perceived
		Media influence	unaffordability of care made participants question whether they would be able to afford dental care in the future.
13. Emotion	A complex reaction pattern, involving experiential, behavioural,	Dental anxiety	Dental anxiety was a barrier to care-seeking. Positive or negative experiences with a dentist could

	and physiological elements, by which the individual attempts to deal with a personally significant event or matter.	Dentist characteristics	initiate development of dental anxiety and influence future decisions about care-seeking. Anxiety was also reported in relation to dental care as a system, with the need to make an appointment and pay for dental treatment being reported as causing
		Anxiety related to the dental system	
		Communication with the dental team	substantial anxiety over future care-seeking. Anxiety was also reported in relation to communicating with the dental team.
14. Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions.	No themes map to this domain.	

**Table 6.3:** TDF Coding Framework with the psychological definitions and mapped theoretical constructs. (Definitions from Michie et al., 2005; Cane, O'Connor and Michie, 2012).

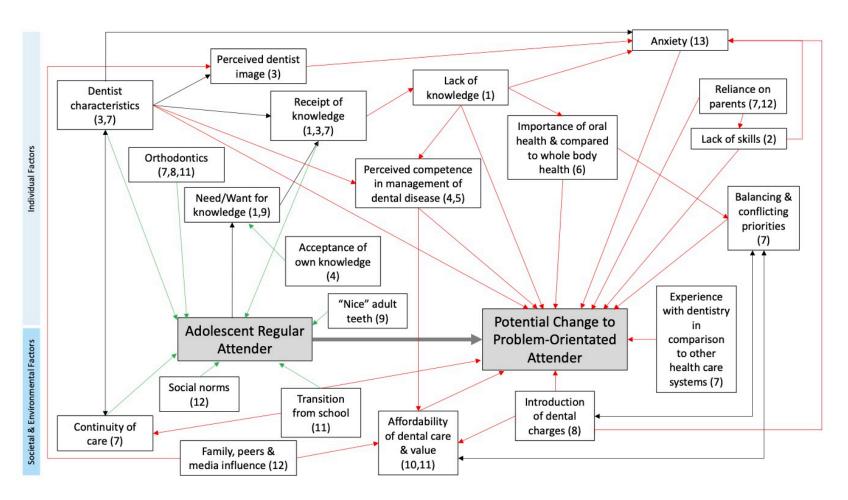


Figure 6.2: A summary of the TDF in relation to potential change from regular attendance to problem-orientated attendance. Green arrows indicate a positive influence on behaviour (e.g., regular dental attendance), red arrows indicate a negative influence on behaviour (e.g., change to problem-orientated attendance), and black arrows indicate an influence which can be either positive or negative depending on the context. TDF domains are indicated by the bracketed numbers: (1) Knowledge, (2) Skills, (3) Social/Professional Role and Identity, (4) Beliefs about Capabilities, (5) Optimism, (6) Beliefs about Consequences, (7) Reinforcement, (8) Intentions, (9) Goals, (10) Memory, Attention and Decision Processes, (11) Environmental Context and Resources, (12) Social Influences, (13) Emotion, (14) Behavioural Regulation.

# 6.4.5 Impact of qualitative findings on intervention development and limitations of study

The focus groups with adolescents allowed for triangulation with the adult qualitative study to confirm recalled ideas about the transition to independence period as well as add further breadth and depth to the data. The reasons for potential change to problem-orientated attendance during this transition period appear to be more complex than recalled by the adults interviewed. The overarching barriers to continued regular attendance include: dentist characteristics; lack of knowledge or misunderstanding; dental anxiety; dental charges and affordability of care; appointment making; perceived importance of oral health. In addition, a key time period for behaviour change and therefore potential intervention is during the transition from school to higher education or employment. Again, it should be noted that targeting just one of these barriers in intervention development is unlikely to result in behaviour change (Michie, van Stralen and West, 2011), therefore a complex intervention will more than likely be required.

There are several findings from this work package which can be taken into the intervention development phase. There is clear lack of knowledge and misunderstanding during adolescence which appears to be maintained into adulthood and then contributes to continued problem-orientated attendance. If this knowledge can be gained during adolescence then problem-orientated attendance may be avoided, for example if the importance of dental health is understood, alongside the cost of dental care and the benefits of regular dental check-ups then when dental charges are introduced young adults may be more willing to pay for dental care. Linked to this is the concept of oral health being separate and less important than whole body health, and if adolescents were aware of the links between the two then oral health may be considered more important. In addition to knowledge, there is also lack of skills within adolescents to facilitate their continued dental attendance, for example skills required to make their own dental appointments. Any intervention designed could therefore incorporate an element of knowledge and skills.

Although not all participants reported dental anxiety, this appears to be barrier to care-seeking once parental influence is lost. Lack of knowledge and misunderstanding can also contribute to this, as can negative dentist characteristics. An intervention could therefore involve an element of support for dental anxiety,

however this may not be of relevance for all adolescents and the intervention should therefore not focus solely on this.

Dentist characteristics can be either a facilitator for maintained regular dental attendance when positive, or a barrier when negative. In addition, dentists and the wider dental team have the ability to pass on knowledge and skills required by adolescents to encourage their continued regular attendance, as well as influence the development of dental anxiety. An intervention could, therefore, be targeted at dental professionals instead of, or as well as, adolescents. However, a limitation to this approach is that dental professionals have not been involved in the qualitative study and ethnography has not been carried out. As a result, the dentist characteristics discussed here are those perceived by adolescents and adults, and the intricacies of the dentists behaviour and communication to create these feelings are unknown. If an intervention was to be designed targeting dental professionals, it would be of benefit to study the dentist-patient interaction and relationship further to ensure the intervention designed would be acceptable to dental professionals as well as result in the desired professional behaviour change. Again, addressing dentist characteristics alone may be unlikely to result in patient behaviour change given the number and complexity of barriers that exist. A professional intervention may therefore need to run in parallel with a patient or public targeted intervention.

Focus groups highlighted that one reason children and adolescents seek dental care is because of the need or want for orthodontic treatment, and this appears to be a priority for this age group. In addition, those undergoing orthodontic treatment reported a good relationship with their orthodontist, often better than that with their dentist. This could therefore be a future site for intervention delivery. A limitation to this, however, is that not all adolescents will receive orthodontic treatment. In addition, given that those in the least deprived areas are almost twice as likely to have orthodontic treatment than those in most deprived areas (Ravaghi *et al.*, 2019) this would have the potential to increase oral health inequalities.

The transition from school is a key time point for behaviour change in relation to dental care-seeking. Participants saw this as being the time period when parental influence would be lost, and there would be key changes in their environment such as a move to a new area for university or work. This time period, or prior to this, could, therefore, be the ideal time to deliver an intervention and this should be considered during the development process.

Finally, the introduction of dental charges at 18-years-old is a clear barrier to continued care-seeking, it should therefore be considered if this is the appropriate age to introduce these. Current exemptions may also be widening oral health inequalities in young adults and these may also require revision. Both of these suggested changes, however, would require policy change and are unlikely to result in behaviour change alone if other barriers discussed are not overcome.

There are some limitations to the qualitative work carried out. Firstly, the sample contained a higher proportion of female participants. Given that some studies show adolescent males to be more likely to miss or cancel appointments (Fägerstad, Windahl and Arnrup, 2016) some barriers or facilitators relevant to males may have been missed. There is conflicting evidence, however, regarding this (Fägerstad, Windahl and Arnrup, 2016), with one recent UK study finding no difference, although hypothesising that this could be due to male participants conforming to peer expectations in single gender focus groups (Hall-Scullin *et al.*, 2015). Even though there were fewer males in this study, focus groups were with mixed genders therefore this should not be the case. This was however taken into account in the following intervention co-design work by ensuring there was increased recruitment of male participants to validate the themes that emerged here. This is discussed in more detail in the following chapter.

Similar to the adult qualitative study adolescents from rural areas were not recruited. This may mean that additional barriers or facilitators for this group may have been missed and will require further research, particularly given there is some evidence that adolescents in rural areas are more likely to miss or cancel dental appointments (Fägerstad, Windahl and Arnrup, 2016). There is some existing evidence however, that rural adolescents report similar barriers to their counterparts in urban areas but with the addition of dental access as a barrier (Dodd *et al.*, 2014). This could mean that any intervention developed may still be of benefit to those in rural areas but may require additional policy change to increase access. This is something that should be carefully considered during implementation and evaluation of the intervention.

Finally, all the adolescents recruited were self-reported regular dental attenders, as such the experiences and opinions of irregular or non-attenders in adolescence were not captured. Given that the aim of the intervention is to promote *continued* regular care-seeking in adolescents and young adults this should not affect the intervention development process, however future qualitative work is needed with this patient

group to explore their barriers to care-seeking. During the intervention development process it may be possible to design an intervention which has active components relevant to irregular or non-attenders based on the experiences of adult problem-orientated attenders, the current literature and patient involvement, however careful evaluation will be needed in this patient group during implementation to determine if a further intervention is needed.

A strength of this study is the range of relative deprivations included in the sample. Previous qualitative work with adolescents has focused on recruitment in particular levels of deprivation, this study therefore highlights barriers to care-seeking which are of relevance to all adolescents across relative deprivation levels.

# 6.5 Conclusion from Both Qualitative Studies

A summary of the findings of both qualitative studies combined into one conceptual model is shown in Figure 6.3. As demonstrated the reasons for the transition from regular childhood dental attendance into adult problem-orientated attendance and the subsequent maintenance of this behaviour are complex. They are multifactorial and interlinking, some of which are relevant across the pathway from childhood into adulthood. These include: dentist characteristics; lack of knowledge or misunderstanding; dental anxiety; dental charges and affordability of care. Any interventions designed to target problem-orientated attendance therefore need to be designed as complex interventions targeting as many of the barriers discussed as possible. The following chapter presents the co-design process used to develop an intervention targeted at adolescents and young adults with the aim of preventing problem-orientated attendance.

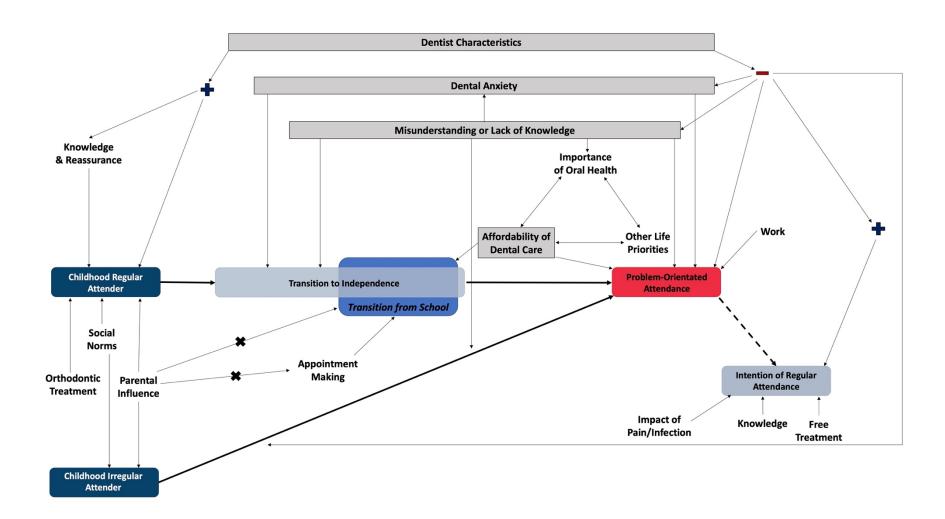


Figure 6.3: Summary conceptual model of problem-orientated attendance including the transition to independence.

# Chapter 7. Co-Designing an Intervention to Prevent Problem-Orientated Dental Attendance

### 7.1 Introduction

The qualitative research presented so far in this thesis has highlighted that adults who are established problem-orientated dental attenders report being regular childhood attenders, before transitioning to problem-orientated attendance during adolescence. This finding is also confirmed in cross-sectional large population and longitudinal studies (Morris. *et al.*, 2011; Okunseri *et al.*, 2013b; Tsakos *et al.*, 2015; Fägerstad *et al.*, 2019; Leary and Do, 2019). In addition, the previous chapter demonstrated that adolescents face multiple barriers to continued dental careseeking as they make a transition to independence and young adulthood.

A large UK campaign is addressing the need for parents to take young children to the dentist for regular care (British Society of Paediatric Dentistry, 2017). Even though early results show this to be successful (Holland C., 2019) if these children then transition to problem-orientated attendance following adolescence, the campaign will not achieve desirable lifelong behaviour change. An intervention targeted at adolescents and young adults to encourage regular dental care-seeking as they make the transition to independence could therefore prevent problem-orientated attendance.

During intervention development it is important to involve relevant stakeholders. Using a co-design approach means that the intervention is grounded in the patients' experiences as well as service contextual constraints, rather than dictated by "professional expertise". This ultimately means that the final intervention is more likely to be acceptable and result in the targeted health behaviour change (Currie *et al.*, 2022c). Importantly, this approach also aligns with the recently published consensus statement on future directions for the behavioural and social sciences in oral health (McNeil *et al.*, 2022). This penultimate chapter describes an intervention co-design process to begin to develop an intervention to prevent problem-orientated dental attendance.

# 7.2 Objectives

1. To further explore barriers and facilitators to regular preventive dental careseeking in adolescents and young adults.

- 2. To co-design an intervention and produce a design brief ready for development of materials and interface.
- 3. To mock-up and de-risk the intervention design.

### 7.3 Methods and Results

### 7.3.1 Theoretical basis of intervention development

An intervention can be defined as a purposeful effort targeting a person or population to create change via a hypothesised or known mechanism of action (Currie *et al.*, 2022c). Interventions can be targeted at different levels from policy and community to individual. The intervention development process encompasses designing and planning an intervention through to feasibility, piloting or evaluation (Skivington *et al.*, 2021). This process is iterative, recursive and cyclical to achieve the optimum intervention (Craig *et al.*, 2008).

A range of different frameworks have been developed that can be used for intervention development (an example of a selection of these is provided in Table 7.1). For this thesis Evidence-Based Co-Design (O'Brien *et al.*, 2016) was selected because it is rooted in the evidence base (as depicted in Figure 7.1), uses relevant behaviour change and psychological theory and also incorporates co-design. This framework can therefore be considered as both a partnership *and* theory and evidence-based approach (O'Cathain *et al.*, 2019b). Employing a co-design (and therefore partnership) approach ensures that the intervention designed is likely to be acceptable and feasible and therefore reasonably likely to have a positive behavioural outcome. In addition, using a theory and evidence-based approach means that the intervention will be fully described in its theoretical basis aiding its design and evaluation so that it is clear how the intervention works (or fails) during evaluation. This in turn helps to optimise the intervention as it is developed, and helps it be tailored to differing contexts.

Another framework could equally have been selected, however it is important to note that although each has a different approach they all essentially converge onto the same key steps (Araújo-Soares *et al.*, 2019; Currie *et al.*, 2022c):

- 1. Understanding the behavioural issue and developing an intervention objective
- 2. Defining the core of the intervention
- 3. Developing materials and interface
- 4. Empirical optimisation

- 5. Outcome and process evaluation
- 6. Implementation

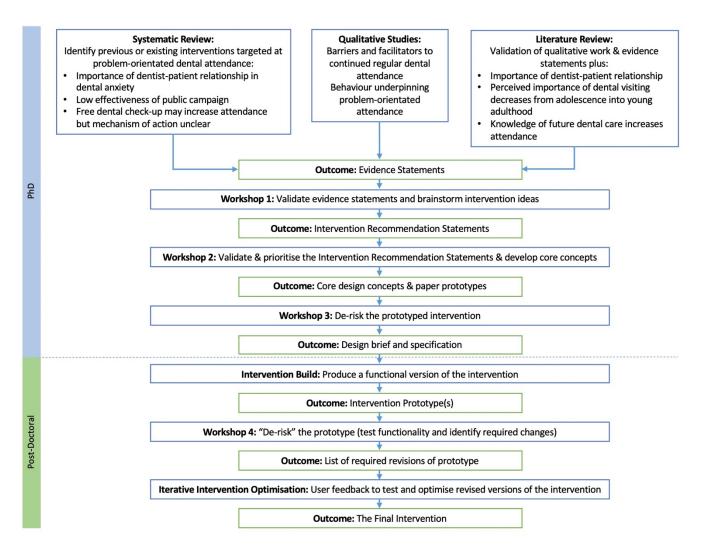
This means that frameworks can be used flexibly. Indeed, it is suggested that the these formal methods should not be followed in a linear "cookbook" fashion, but instead the intervention development team should make strategic decisions based on evidence and expert knowledge at each stage, considering the relevance of each to the specific intervention in its context (Araújo-Soares *et al.*, 2019). As an example, throughout this intervention development process, elements of the Behaviour Change Wheel (Table 7.1) (Michie, van Stralen and West, 2011) were also incorporated as the need arose (detailed throughout the chapter). This highlights the importance of transparency with reporting the intervention development process. Finally, at present little evidence exists to demonstrate which framework(s) would be considered superior (O'Cathain *et al.*, 2019a) and therefore selection of a framework should be based on what best suits the problem being addressed.

Framework	Purpose	Steps
Behaviour Change Wheel (Michie, van Stralen and West, 2011).	A tool which aids behaviour analysis, selection of mechanisms of action, design and selection of the intervention that can be used to change the identified mechanisms of action. It can also be used to match intervention functions and policy categories to behaviour influences.	<ol> <li>Defining the issue in behavioural terms, selecting the target behaviour, specifying the target behaviour and identifying what needs to change</li> <li>Identify intervention options using intervention functions and policy categories</li> <li>Identify the intervention content and implementation options by identifying behaviour change techniques (BCTs) and the mode of delivery</li> </ol>
Evidence-based co-design (O'Brien et al., 2016).	A systematic, sequential, co-design approach which integrates scientific evidence along with expert knowledge and stakeholder involvement.	<ol> <li>Integrate evidence from systematic reviews, qualitative research and other research to develop evidence statements</li> <li>Co-design workshops to validate the evidence statements and brainstorm intervention ideas to determine the intervention principles and core concepts</li> <li>Develop a design brief and intervention specification</li> <li>Intervention build to produce a functioning version</li> <li>Co-design workshop to de-risk the intervention</li> <li>Iterative intervention optimisation from user feedback to produce the final intervention</li> </ol>
MRC and NIHR Framework for the Development of Complex Interventions (Skivington et al., 2021)	A framework providing guidance on four stages of intervention development: development or identification of the intervention; feasibility; evaluation; implementation. At each stage six key questions should be considered before progressing to the next.	<ol> <li>How does the intervention interact with its context?</li> <li>What is the underpinning theory?</li> <li>How can diverse stakeholder perspectives be included?</li> <li>What are the key uncertainties?</li> <li>How can the intervention be refined?</li> <li>What are the comparative resource and outcome consequences of the intervention?</li> </ol>

Table 7.1: A selection of examples of intervention development frameworks available (Adapted from Araújo-Soares et al., 2019; Currie et al., 2022c).

# 7.3.2 Overview of study design

This study used evidence-based co-design methodology to build upon the results of the previously presented work. This uses an iterative, systematic, and sequential approach to design and develop an intervention. A series of workshops involving members of the research team, patients, other relevant stakeholders and expert opinion were utilised (Figure 7.1). This allowed a sequence of evidence validation, intervention ideas, prototyping, testing, analysing and optimizing the intervention(s) to a beta version (O'Brien et al., 2016). This iterative approach meant that after every stage of intervention design the research team analysed the outcome, which was then used for subsequent workshops. For this thesis, the intervention was developed up to the point of prototyping, whereby a design brief and intervention specification was produced as a final outcome. This will then be used to build the materials and interface during post-doctoral research to carry on with the intervention development process. Given that the outcome of each workshop was used as a subsequent input to the following workshop, which influenced methodology the methods and results of each workshop are presented sequentially.



**Figure 7.1:** A flowchart of the entire intervention co-design process (adapted from O'Brien et al., 2016). The aim of this doctoral thesis will be co-design up to the build of a functional version of the intervention.

# 7.3.3 Ethical approval

Ethical approval was obtained from Newcastle University Research Ethics Committee (Ref 2025/6404/2020).

### 7.3.4 Participant recruitment

Each workshop had representation from members of the public and primary care dentists, as well as other relevant stakeholders who were identified as development progressed.

### Public recruitment

The public representatives were a purposive sample consisting of adolescents and young adults. Inclusion criteria were:

- Aged 16-30 years-old (inclusive)
- Experience of seeking routine dental care, either being:
  - o Current regular dental attenders, or
  - A previous dental attender who had since transitioned to irregular or non-attendance.

### Exclusion criteria were:

- Those who were unable to converse and understand complex constructs in English
- Individuals younger than 16-years-old
- Individuals older than 30-years-old
- No experience of seeking routine dental care

Participants were required to be over 16-years-old as the previous qualitative study highlighted that those under this age were unlikely to have started to make their own decisions around dental care-seeking. The upper age limit was set at 30-years-old to ensure a wide age range of adolescents and young adults were included, and by this age it was agreed that participants would have fully transitioned to independence and be making their own dental care decisions. Participants were also required to have experience of seeking dental care due to: (1) the intervention's primary aim being to encourage *continued* dental care-seeking; (2) evidence from previous studies highlighting the importance of the dentist-patient relationship and participants therefore needing the ability to reflect on their experiences of this.

The study was advertised using a poster (Appendix P) via local schools and colleges, youth organisations, social media and online via Newcastle University Canvas (an online teaching and notification platform). In addition, for those over 18-years-old recruitment was also via VOICE, which is an large network of UK citizens interested in taking part in research (VOICE, 2022).

Interested participants were asked to self-refer to the study and were sent an electronic information sheet (Appendix P) and were screened for inclusion/exclusion criteria. Participants signed an online consent form (Appendix P). This was online to facilitate online recruitment and workshops given the ongoing COVID-19 pandemic limiting face-to-face contacts.

Recruitment was not carried out in NHS organisations due to: (1) the ongoing COVID-19 pandemic impacting attendance at healthcare services; and (2) participants being unlikely to be established problem-orientated dental attenders at the age of recruitment and therefore being unlikely to consult urgent care services.

Participant recruitment started on 1<sup>st</sup> December 2020 and was ongoing throughout the study period up to two weeks prior to the final workshop on 5<sup>th</sup> August 2021.

All patients were emailed a £100 gift voucher following each workshop to encompass the requirements for pre-reading and attendance at a two-hour workshop. In addition, participants were given a £5 gift voucher per workshop for use in local food shops to cover the expenses of refreshments.

Purposive sampling was used to ensure that a balance of genders were recruited (given the high proportion of females in the previous study) as well as a range of ages, sociodemographic status and dental attendance patterns. Sociodemographic status was considered using IMD as per the previous studies.

#### Primary care dentist recruitment

Dentists currently working in primary dental care were also recruited for all three workshops. The only inclusion criteria were they had to be registered with the General Dental Council and working in primary dental care.

Primary care dentists were recruited via local dental networks (non-NHS organisation) including the local Clinical Research Network, and the Northern Dental Practice Based Research Network. Interested participants were again asked to self-

refer to the study who were recruited in the same manner as the public representatives (information sheet and consent form given in Appendix P).

The recruitment period was the same as for public recruitment. All dentists were reimbursed for potential loss of earnings following the rate recommended by the British Dental Association Guild at £70 per hour (British Dental Association, 2020). They were also sent a £5 gift voucher to cover refreshment costs.

Purposive sampling was used for recruitment to ensure dentists working in dental practices serving a range of sociodemographic statuses were included. Sociodemographic status was again measured using IMD for the dental practice postcode.

## 7.3.5 Overview of workshops

Workshops were all two hours in duration with at least one comfort break scheduled. Due to the ongoing COVID-19 pandemic the workshops were held online using Zoom conferencing software (Zoom Video Communications, Inc. (2020) Version 5.4.7.). Due to the virtual nature of the workshops and some participants being adolescents all workshops were kept to a maximum of two hours in duration. To aid the shortened workshop duration participants were sent pre-reading two weeks before all workshops to provide background information and encourage reflection. Between workshops participants were actively encouraged to email ideas and suggestions to myself to include in the ongoing analysis. All workshop materials were reviewed by the user-researcher to ensure the language was appropriate and understandable.

All workshops were led by myself and a user-researcher who was a member of the study's PPI/E (patient and public involvement/engagement) panel (EK). Large group discussions were held in the main Zoom room, and small group work was carried out in breakout rooms (Figure 7.2). The small group work was led by facilitators. Where possible a back-up facilitator was also present in case of technological problems.

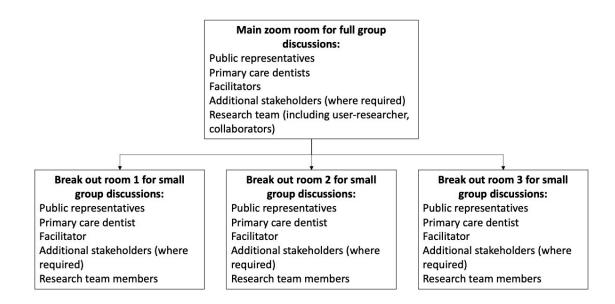


Figure 7.2 Overview of workshop format in Zoom.

Members of the research team and relevant collaborators were present throughout the workshop series. Due to the workshops being virtual the number of participants were kept to a minimum, therefore the research team had multiple roles including: observer, scribe, Zoom host as well as relevant expert input to group discussions. To manage any technological issues with Zoom the participants were given a contact telephone number for myself. Immediately prior to all workshops there was a team meeting, and immediately following each workshop there was a team debrief.

Prior to all workshops, facilitator training sessions were carried out to provide guidance on the background and aims of each workshop, exercises to be carried out, and anticipated outputs. Prior to the training the facilitators were asked to anonymously score their confidence in facilitating the workshop on a scale from 1 (not confident) to 10 (very confident). The mean score for the group improved following training from 5 to 8. For all workshops the facilitators were also given a handbook detailing any relevant evidence base and the exercises to carry out.

All workshops and breakout rooms were recorded. Following each workshop, the recordings were anonymised and professionally transcribed verbatim. Workshop transcripts, notes and diagrams produced during exercises were used in a thematic analysis. Frameworks were used to help organise and examine themes. Intervention components were mapped to the TDF and BCTs and were checked by a supervisor with extensive experience of using these (VAS).

# 7.3.6 Workshop 1

# Workshop Aim

The first workshop tested and validated evidence statements and used blue-sky thinking to brainstorm intervention ideas.

## **Participants**

Nine public representatives and three primary care dentists were involved with participants divided into three groups. Public representatives were separated into heterogenous groups to ensure representation of different ages, genders and dental care experiences in each group. The summary participant characteristics are shown in Table 7.2.

Study ID	Age	Gender	IMD Decile	Occupation	Dental Attendance Pattern	Workshop Group
P001	17	Male	6	Student (College)	Regular	1
P002	22	Male	9	Student (University)	Regular	
P003	26	Female	1	Finance Administration	Regular → Irregular	-
D001	56	Female	9	Dentist	N/A	
P004	17	Male	7	Student (College)	Regular	2
P005	23	Female	8	Student (University)	Regular → Irregular → Regular	
P006	19	Female	6	Student & Youth Worker	Regular	-
D002	39	Male	3	Dentist	N/A	
P007	21	Male	5	Student (University)	Regular	3
P008	21	Female	9	Student (University)	Regular → Irregular	
P009	16	Female	1	Student (School)	Regular	
D003	44	Male	3	Dentist	N/A	

**Table 7.2:** Summary participant characteristics for workshop 1.

In addition to the participants there were also three facilitators (AGR, CP, ZF), the user-researcher and the research team. The research team (JD, SJS, VAS, BA) were present as observers, as well as experts in their respective fields (academic dentists, health psychologist/intervention development, senior research methodologist with expertise in developmental science/intervention development).

#### <u>Procedures</u>

#### Prior to the workshop

Prior to the workshop the findings from a systematic review of previous interventions (See Appendix Q (Currie *et al.*, 2021)), a wider literature review on adolescent dental attendance and the findings from the previous qualitative studies were combined to form evidence statements (Figure 7.1). These evidence statements related to:

- Dentist characteristics
- Lack of knowledge/misunderstanding
- Dental anxiety
- Dental charges
- Appointment making
- Transition from school
- Importance of oral health.

The evidence statements were reviewed by research team members (VAS, BA, JD). An example is given in Figure 7.3, and the remainder are provided in Appendix R.

#### 1. DENTIST CHARACTERISTICS

DATA SOURCE: Qualitative study, Systematic Review & Literature Review

STATEMENT: Perceived characteristics of the dentist play a role in patients deciding whether or not to seek regular dental care. A positive dental experience related specifically to positive characteristics of the dentist was reported to encourage regular dental care seeking. Perceived negative dentist characteristics were associated with future dental attendance being less likely. This was reported in both adults and adolescents.

ADDITIONAL RELEVANT INFORMATION: Adult patients reported dentists creating feelings of judgement or penalisation and a lack of empathy as reasons for not attending regularly. Mistrust of dentists in relation to paying for treatment was also reported. Adolescents reported dentists being cold, disengaged and condescending as being negative characteristics, as well as feeling that they weren't included in conversations with the dentist and their parents/guardians about their oral health and treatment.

LINKS TO OTHER EVIDENCE STATEMENTS: This evidence statement links to the one on dental anxiety as the systematic review identified an intervention targeted at patients with dental anxiety which highlighted the importance of the dentist-patient relationship in those who are dentally anxious becoming regular attenders.

Note: These are dentist characteristics as perceived by patients and members of the public, dentists were not included or observed in these studies.

**Figure 7.3:** An example of an evidence statement used in the first workshop.

Prior to the workshop the participants were given pre-reading (Appendix S) containing the questions that were posed during group discussions and the evidence statements.

#### **During the workshop**

At the start of the workshop participants completed an icebreaker exercise, the aim being to introduce the participants and also bring the public representatives and dentists together at the same level of skill and knowledge. Details on the icebreaker are provided in Appendix T.

Following this there was a 10-minute audio-visual presentation on the research to date and the evidence statements by the user-researcher (EK) and myself. In small groups, participants then discussed their opinions and reflections on the evidence statements, aiming to prioritise them, being encouraged by the facilitators to think from the perspective of different roles, e.g. swapping from patient to dentist. As a large group the lists were compared with the aim of producing a final prioritised list. In small groups the participants were then encouraged to use blue sky thinking to generate intervention ideas based on the evidence statements. Blue sky thinking is a creative design process whereby participants are encouraged to generate ideas where there are no limits to consider. As a large group the intervention ideas were presented and discussed creating a thematic map of intervention ideas to take forward in the co-design process. Google Jamboards (Google, 2022) were used throughout the exercises to help facilitate and to allow all participants to interact simultaneously.

#### Analysis & Results

Two thematic analyses were completed from the workshop transcripts: (1) validation of the evidence statements and (2) intervention ideas.

#### **Evidence Statements**

During the workshop participants were asked to reflect on the evidence statements and share their opinions and experiences related to them. This allowed data collection for triangulation for the previous adolescent qualitative study as well as validation of the evidence statements. A summary of the analysis is given in Table 7.3 with illustrative quotes in Appendix U. All participants agreed with the evidence statements and accepted them as validated for the intervention development.

de ba de	legative dentist characteristics are a barrier to care-seeking, whereas positive lentist characteristics are a facilitator to continued care-seeking but only when other	Social/Professional Role & Identity;
ex	parriers don't exist. Positive characteristics will not necessarily outweigh negative lental experiences when they happen. Dentist characteristics may be more important as a child than later in life when they are able to reflect on negative experiences.	Memory, Attention & Decision Processes; Emotion
lin	ns young adults are paying for their experience of dental treatment there is a fine ne between their identity as a patient or a customer which may influence how they berceive the dentist when they start paying for treatment.	Memory, Attention & Decision Processes; Environmental Context & Resources
Lack of Knowledge	mportant to have knowledge both of dental care (e.g., when to go, what happens at check-up, why it's important to go) but also the dental system and how to navigate (e.g., cost of care, how to find or change dentists).	Knowledge
-   Sr	Skills are also important to consider alongside knowledge, e.g., skills associated with finding a dentist, organising time to attend, managing finances to pay.	Skills; Emotion
to de	Anxiety is wider than just dental anxiety, it also encompasses fear of bad news (e.g. both need extracting), paying for care and accessing and navigating a complex lental system.	Knowledge; Skills; Social/Professional Role & Identity; Environmental Context & Resources; Social Influences; Emotion
(e	Dental anxiety is a barrier but can be overcome when other barriers are addressed e.g., with knowledge, awareness of importance of oral health, with parental upport).	Knowledge; Skills; Beliefs about Consequences; Memory, Attention & Decision Processes; Social Influences; Emotion
	Affordability of dental care will be a barrier that fluctuates over the life course lepending on other competing demands and priorities.	Memory, Attention & Decision Processes; Environmental Context & Resources
_	mportance of link to lack of knowledge as dental charges are also a perceived parrier.	Knowledge; Emotion
Tr	he perceived value of a check-up.	Beliefs about Consequences; Memory, Attention & Decision Processes
Appointment Making	Need to teach knowledge, practicalities & skills needed to make an appointment.	Knowledge; Skills; Beliefs about Capabilities; Emotion
	A barrier beyond adolescence.	N/A
School CI	Requirement for parental support can go beyond transition from school.  Change in environment can lead to behaviour change related to a number of parriers.	Social influences Knowledge; Skills; Environmental Context & Resources; Social Influences

lunnautanas at Oval	Oral health as a priority will fluctuate over the life course.	Memory, Attention & Decision Processes; Environmental Context & Resources
Importance of Oral Health	Too young to get dental diseases.	Knowledge; Optimism; Beliefs about Consequences
	Oral health compared to whole body health.	Knowledge; Beliefs about
		Consequences

 Table 7.3: Summary of thematic analysis in relation to the evidence statement validation.

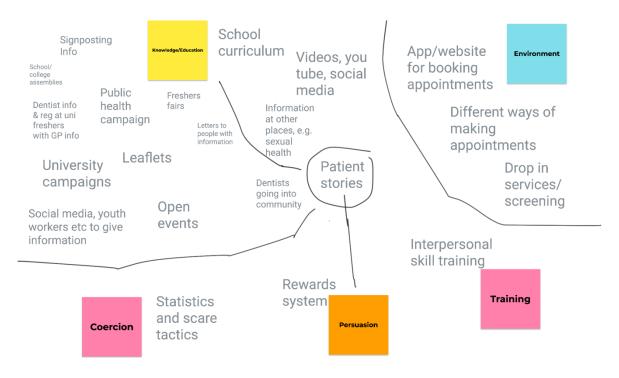
The consensus prioritised list of evidence statements for each group are shown in the final Google Jamboard in Figure 7.4. Due to the evidence statements being so intricately linked together the participants struggled to agree on a prioritised list. As a result, it was agreed that an intervention would need to target as many of the evidence statements as possible to achieve behaviour change. This meant that a complex intervention would most likely be required due to the number of components and range of behaviours that would be targeted (Skivington *et al.*, 2021).

Group 1	Group 2	Group 3	Final
Transition from school	Dentist Characteristics	Importance of oral health	
Appointment making	Lack of knowledge/ misunderstanding	Lack of knowledge/ misunderstanding	
Lack of knowledge/ misunderstanding	Importance of oral health	Appointment making	
Dental anxiety	Dental anxiety	Dental charges	8
Dentist Characteristics	Transition from school	Dental anxiety	
Importance of oral health	Dental charges	Transition from school	
Dental charges	Appointment making	Dentist Characteristics	

**Figure 7.4:** The final Google Jamboard showing each groups prioritised list of evidence statements.

#### Intervention Ideas

The thematic map generated during the workshop encompassing all groups intervention ideas is shown in Figure 7.5.



**Figure 7.5:** The thematic map created during the workshop encompassing all groups broad intervention ideas. Intervention ideas were organised into themes by intervention functions according to the Behaviour Change Wheel (Michie, Atkins and West, 2014).

Analysis of the intervention ideas revealed a series of recurring design ideas.

Quotations to reflect these are given in Appendix U. These included:

- Various forms of promotional campaigns, centralised leaflets or letters posted out to adolescents and young adults.
- Integration of teaching on dental care and associated barriers into the school setting and/or curriculum.
- Meeting dentists outside of the dental practice.
- Use of positive patient stories from dental care.
- Linking oral health to whole body health to increase the perceived importance of oral health.
- Incentivising adolescents and young adults for attending dental check-ups.
- Creating a new way to make dental appointments which would be more acceptable to adolescents and young adults.
- Training dentists to improve patient experiences.

#### **Outcomes**

As participants were unable to prioritise the evidence statements, a model was required for the following workshop to show how the evidence statements linked and related to behaviour change theory. This was required so that, as the intervention

was designed, the participants could ensure it mapped to as many of the evidence statements as possible. One of the most simple behaviour change models is the COM-B model (Michie, van Stralen and West, 2011). This model shows that if you want a person, or group of people, to carry out a particular behaviour (in this instance going to the dentist for a check-up) they need to have the Capability, the Opportunity and the Motivation to carry out the Behaviour (COM-B). Each component of the COM-B model links to the TDF (as shown in Appendix V) allowing creation of this model, shown in Figure 7.6. In summary, using the COM-B model, for adolescents and young adults to decide to seek dental care they must have:

- Physical Capability: the skills to find (or change) dentists and make a dental appointment (e.g., communication, organisation skills).
- Psychological Capability: knowledge about dental care and the dental care system (including why to seek regular dental care, what happens at dental appointments, the cost of dental care, and how oral health links to whole body health). They need to be able to balance the decision to attend a dental appointment against other life priorities which will change over time (e.g., leaving school, moving away from home, buying a house).
- Physical Opportunity: ability to pay for dental care and manage changes in their physical environment (e.g., find and access a dentist) and resources (e.g., payment for care) as they make key transitions, for example from school to university or employment.
- Social Opportunity: ability to make the decision to seek dental care when
  parental support is lost (e.g., when parents no longer make/attend
  appointments) and when they hear negative stories about dental care from
  friends, family or in the media.
- Reflective Motivation: ability to develop a positive relationship with a dentist or reflect on negative experiences and still decide to seek care, as well as believe that oral health is important.
- Automatic Motivation: ability to manage dental anxiety if present, and also manage other emotions surrounding dental care, including: anxieties over the cost of care; receiving bad news; making an appointment; changing dentists; access to dental care.

Based on the COM-B model an intervention is most likely to work if it targets all these components (Michie, van Stralen and West, 2011).

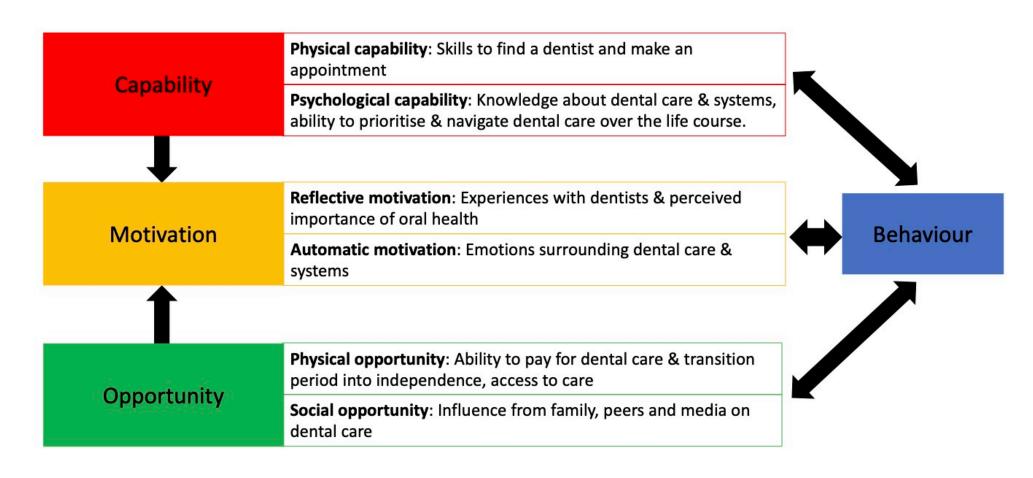


Figure 7.6: The COM-B model produced to show the behaviour change required for the intervention (adapted from Michie, van Stralen and West, 2011).

A final output of the first workshop was a list of intervention recommendation statements (IRS). These were based on the evidence statements and the broad intervention ideas the participants generated in the workshop. Each IRS included consideration against the APEASE (Affordability, Practicability, Effectiveness/Cost-Effectiveness, Acceptability, Side-effects/Safety and Equality) Criteria (Michie, Atkins and West, 2014). These criteria allow intervention developers to consider the effectiveness of interventions and were therefore used to help the participants prioritise which intervention ideas they wanted to design further. The IRS were checked by research team members (VAS, BA, JD) and relevant collaborators (PB, ZM, LJH). The IRS are summarised in Table 7.4 and an example is given in Figure 7.7 (the full list is given in Appendix W).

IRS	Intervention Aim	Rationale Summary
Promotional Campaign	The intervention should aim to increase knowledge and skills around attending a dentist.	A lack of knowledge and skills around attending a dentist plays a role in patients not seeking regular dental care. These include a lack of knowledge on why visiting a dentist regularly is important, what happens at dental appointments, the cost of dental care, importance of oral health and a deficiency or lack of confidence in the skills needed to find a dentist or make an appointment. If patients have knowledge and skills, it will improve their decision-making on whether to make and attend a dental appointment as they become independent and transition from school to further education and/or employment. They may also have reduced anxieties surrounding dental care, for example knowing how to book an appointment, what will happen and how much it will cost. A promotional campaign could be used to increase the knowledge and skills highlighted.
School Curriculum	The intervention should aim to increase knowledge and skills around attending a dentist by being integrated into school curricula.	This has the same rationale as the promotional campaign but involves a different delivery. Dental health has very recently been added to primary and secondary school curricula; however, this relates only to knowledge of dental health, benefits of good oral hygiene, flossing, healthy eating and regular check-ups and does not include specific skills around navigating dental systems, such as how to find a dentist and make an appointment. Additionally, it does not provide knowledge on what happens at dental appointments and the cost of dental care.
Meeting Dentists	The intervention should aim to increase knowledge and skills around attending a dentist and improve dentist-public relationships by dentists visiting schools or public places.	This has the same rationale as the promotional campaign and school curriculum, but in addition, if dentists delivered this teaching outside of the dental surgery this would provide the public with the opportunity to meet dentists in a less emotional setting and make an appointment.
Patient Stories	The intervention should aim to increase knowledge and skills around attending a dentist and decrease anxiety surrounding dental care using videos which share positive patient stories when engaging with dental care services.	This has the same rationale as the promotional campaign and school curriculum but in addition, if positive patient stories are shared this may help reduce anxiety surrounding the process of making an appointment and seeing a dentist.
Make Every Contact Count	The intervention should aim to increase the perceived importance of oral health by linking oral health to wholebody health.	The reported importance of oral health appears to decrease from adolescence into young adulthood, and in addition other life priorities start to take precedent over dental attendance. Oral health is often considered as being distinct from whole body health and therefore considered less important. In addition, there are clear links between oral health and whole-body health. If perceived importance of oral health can be increased this would play a role in patients deciding to seek regular dental care. This intervention could be based the current Make Every Contact Count (MECC) behaviour change

		approach (Varley and Murfin, 2014) which has been endorsed by organisations such as NHS England and Public Health England (Public Health England, 2016).
Reward System	The intervention should aim to increase regular dental attendance by offering a reward for continued attendance for check-ups.	As adolescents and young adults transition into independence and have to begin to pay for dental treatment they need to make the decision on their own whether to continue to seek regular dental care against other life priorities. If a reward was offered for continuing their regular attendance pattern this may incentivise them to continue to seek care.
Appointment System	The intervention should include a new system for making dental appointments which is more accessible to younger people.	Adolescents and young adults report anxiety surrounding appointment making, specifically in relation to in person or telephone communication, and in relation to the paperwork that needs completing at appointments.
Dentist Training	The intervention should include training for dentists on communication and other interpersonal skills.	The professional role of the dentist plays a part in patients deciding whether or not to seek regular dental care. A positive dental experience related specifically to positive characteristics of the dentist encourages regular dental care-seeking. Perceived negative dentist characteristics are associated with future dental attendances being less likely. Specific dentist characteristics reported as being negative include dentists creating feelings of judgement or penalisation, showing a lack of empathy, being cold, disengaged and condescending. In addition, adolescents report feeling left out of conversations between their parents/guardians and the dentist. If the dentist-patient relationship can be improved then patients may be more likely to continue seeking regular care. This may involve training for dentists in the form of postgraduate education or continuing professional development, and/or training of student dentists.

**Table 7.4:** A summary of the IRS generated from workshop 1 to facilitate intervention development in workshop 2.

#### TITLE: Promotional campaign

RECOMMENDATION: The intervention should aim to increase knowledge and skills around attending a dentist.

RATIONALE: A lack of knowledge and skills around attending a dentist plays a role in patients not seeking regular dental care. These include a lack of knowledge on why visiting a dentist regularly is important, what happens at dental appointments (including paperwork that needs completing), the potential cost of dental care, the importance of oral health and a deficiency or lack of confidence in the skills needed to find a dentist or make an appointment. If patients have this knowledge and these skills it will improve their decision making on whether to make and attend a dental appointment as they become independent from their parents and transition from school, to further education and/or employment. They may also have reduced anxieties surrounding dental care, for example knowing how to book an appointment, what will happen and how much it will cost.

ADDITIONAL DETAIL: This could be achieved using promotional materials such as leaflets or posters displayed in places such as education and healthcare settings, leisure centres, sports grounds, digital or social media campaigns or by individual letters or leaflets posted out to patient groups.

#### APEASE Criteria:

Affordability	Potential costs would include design and printing of promotional materials, postage for letters or leaflets, translation costs for non-English speakers. These costs would need to be scaled for delivery to all of the country. There will also be environmental costs associated with mass production of printed materials.
Practicability	Where the promotional materials are placed would need to be considered to ensure maximum exposure, for example education settings, cinemas, leisure centres and healthcare settings such as GP surgeries, A&E departments, pharmacies. These places would need to agree to take part and be happy to display the material. For materials to be posted out a centralised system is likely to be required which contains details on the patient groups targeted and their correct contact details, this will require access to GP records which will require ethical and data protection approvals to access which will be challenging. If this centralised system is chosen for distribution of materials it will most likely need to be NHS endorsed and carried out as a nationwide screening campaign rather than having a period of initial small scale trial.
Effectiveness & Cost- Effectiveness	A previous promotional campaign to increase dental attendance was largely ineffective for changing attendance behaviour of irregular dental attenders but did raise awareness of the need for a check-up <sup>1</sup> . Generally, use of promotional materials on their own can have a low potential for behaviour change, however may be effective when combined with other interventions. This intervention only targets one part of the COM-B model, however depending on the design of the intervention may also reduce anxiety surrounding dental care, and if knowledge and skills can be targeted from a younger age then these may be maintained into adulthood thereby potentially resulting in long term behaviour change.
Acceptability	Promotional materials are likely to be acceptable to the target audience, however adolescents and young people may not choose to read them in detail. It may also be difficult to teach skills, such as appointment booking, using written materials only.
Side- effects/Safety	This intervention would also target non-attenders and therefore have a positive side effect of encouraging them to seek dental care. It is unlikely there would be any negative side-effects, however the potential to increase inequalities needs to be considered (see equity).
Equity	The materials would need to be designed and displayed to be accessible by all otherwise they could increase inequalities, this would need to be considered in their design and placement, ensuring they were available in different languages and designed for people who may be unable to read.

Figure 7.7: An example of an IRS in full.

<sup>1</sup>Anderson R, Morgan J. Marketing dentistry: a pilot study in Dudley. Community Dent Health 1992;9 Suppl 1:1-220.

## 7.3.7 Workshop 2

#### Workshop Aim

To validate and prioritise the IRS and develop core concepts of the intervention(s).

#### **Participants**

During the first workshop it was noted that, due to their own experiences (including those of the dentists), participants struggled to reflect on experiences of people who did not attend university, therefore an extra three public representatives who had not gone to university were recruited. This workshop should have had twelve public representatives with three primary care dentists, however, three public representatives and one dentist didn't attend, therefore the final workshop consisted of nine public representatives and two dentists. One of the public representatives and the dentist were contactable following the workshop and provided individual feedback and reflections at a later date via Zoom. The summary participant characteristics are shown in Table 7.5.

Study ID	Age	Gender	IMD Decile	Occupation	Dental Attendance Pattern	Workshop Group
P001	17	Male	6	Student (College)	Regular	1
P002	22	Male	9	Student (University)	Regular	
P003	26	Female	1	Finance Administration	Regular → Irregular	
P010*	27	Female	1	Health care assistant	Regular → Irregular → Regular	
D001	56	Female	9	Dentist	N/A	
P004	17	Male	7	Student (College)	Regular	2
P005	23	Female	8	Student (University)	Regular → Irregular → Regular	
P011*	24	Male	3	Logistics management	Regular → Irregular	
P007	21	Male	5	Student (University)	Regular	3
P012*	24	Male	8	Hospitality	Regular → Irregular	
D003	44	Male	3	Dentist	N/A	
P006	19	Female	6	Student & Youth Worker	Regular	Contacted after
D002	39	Male	3	Dentist	N/A	workshop

**Table 7.5:** Summary participant characteristics for workshop 2. \*Indicates the newly recruited participants who did not attend university.

There were also three facilitators (AGR, CP, ZF), the user-researcher (EK) and the research team (CCC, JD, SJS, VAS, BA). In addition, a designer/graphic facilitator (MJ) was also present to:

- Provide expertise from a design perspective
- Facilitate intervention design and stimulate small group discussion
- Document discussions about potential interventions in narrative and pictorial forms

# **Procedures**

Participants were sent the COM-B model, IRS and an explanation of the APEASE criteria as pre-reading. The workshop began with a short presentation explaining these.

In small groups participants discussed the IRS in terms of the APEASE criteria in order to validate and prioritise them. The groups were allowed to combine IRS if they believed they would complement each other, being encouraged to consider any changes need to the APEASE criteria as a result. Following this, the whole group reached a consensus on which IRS to take forward in the design process.

In small groups the participants then began to design the intervention based on the prioritised statements. To ensure an equal amount of time was invested into each prioritised statement each group was given a single statement to focus on initially, before widening their discussions to involve the other statements. Throughout the small group discussions, the designer moved between groups to begin to map out the intervention as it was being designed, provide design feedback and stimulate discussion. At the end of the workshop the intervention designs were discussed as a large group and feedback obtained.

#### Analysis & Results

#### **Intervention Recommendation Statements**

All groups agreed with the APEASE criteria for each IRS. The prioritised IRS and final group consensus are given in Table 7.6. Supporting quotations are provided in Appendix U.

Group 1	Group 2	Group 3	Consensus
School Curriculum & Meeting Dentists	School Curriculum & Make Every Contact Count	Appointment System	Appointment System (with additional knowledge, skill & patient stories section)
Appointment System	Reward System	Promotional Campaign	School Curriculum incorporating Meeting Dentists & Patient Stories
Reward System	Appointment System	Patient Stories	Reward System (combined into the new appointment system)

**Table 7.6:** The prioritised IRS from each group and the final full group consensus.

All groups agreed that a new appointment system would be beneficial to help overcome barriers adolescents and young adults currently face. As a result, it was agreed that this should be part of the intervention. In addition, the participants felt that it would be important to incorporate some teaching on knowledge and skills within the appointment system to address additional barriers and increase the likelihood of behaviour change. Two groups prioritised the school curriculum and reward system and it was agreed to take these forwards. The promotional campaign was rejected after discussion as the participants believed that most adolescents and young adults would not engage with this. One group prioritised Making Every Contact Count as they believed teachers should promote oral health more regularly, however it was agreed this could be included in the school curriculum. All groups discussed the benefit and value of patient stories and agreed these should be combined and included as materials in the intervention. Public participants felt strongly about meeting dentists outside of the dental practice and believed that combining this with the school curriculum would increase the success of the intervention. Some practical difficulties associated with this were highlighted by the dentists, and it was agreed this would be included in the school curriculum design if practical and feasible. Finally, it was agreed that the reward system should be designed so that reward tracking could be incorporated into the appointment system.

The group agreed that each of the prioritised IRS could act as interventions in isolation, however believed that if they were developed in combination as a complex intervention they would target more parts of the COM-B model and therefore increase the success of the final intervention.

#### **Intervention Design**

A summary of the intervention design following workshop two is given in Table 7.7. Supporting quotations are given in Appendix U. An example of the pictorial representation of the discussion relating to the appointment making system is given in Appendix X showing how the groups began to link the different intervention components together.

Intervention	Aim	Materials Needed	Procedure, Provider & Delivery Mode	Link to Other Intervention Components
School Curriculum	Promote the importance of oral health and regular dental visiting (6, 7, 8, 9) including knowledge of:  Cost (1, 4, 10, 13)  How oral health links to whole body health (1, 6, 7)  What happens at a dental appointment (including paperwork) & during treatment (1, 3, 13)  Management of dental anxiety (1, 13, 14)  How to find a dentist (1)  And skills for:  Finding a dentist (2, 10)  Making an appointment (2, 13)  Communicating with the dental team (2, 3, 13)	Materials need to be co-designed with stakeholders, but they should be visual, engaging and ideally interactive and/or practical. Clinical images should be displayed as animations or cartoons. Should ideally be adaptable to use in different school settings (e.g. school assembly or small group teaching) and to use outside schools (such as youth centres) to ensure the intervention is delivered to as many people as possible.	Delivered in secondary schools to year 10/11 (14–16-year-olds), ideally by a member of the dental team. The team member should be engaging and passionate, and could include foundation dentists and/or dental students. Students should have the opportunity to ask questions. Could be delivered in person, or virtually.	The appointment making system and rewards system could be promoted/introduced in schools as part of this teaching.
Appointment Making	Develop an appointment making system which will be more accessible to young people, including the following features:  • Find a nearby dentist (1)  • Reviews of dentists (3, 10, 13)  • Make an appointment (8, 9)	Development and co-design of a smartphone application (app) and website. Both an app and website are needed to allow wider access (e.g., for those who don't have a smart phone, or don't have a computer). Both the app and website should look and function in a similar manner.	The website/app should be linked to relevant google searches and promoted on social media, by use of Make Every Contact Count (GMPs, sexual health clinics, pharmacies etc.) and with leaflets placed in community centres, leisure centres etc.  The provider would need identifying, but could be an NHS provider such as NHS digital.  The app should also direct the	The app/website can be introduced in the school curriculum. The rewards system can be incorporated into the website/app to track points rewards.

	<ul> <li>Link appointment to iCalendar (11)</li> <li>Direct the user on how to access urgent dental care if needed (1, 11)</li> <li>This should also include a "knowledge base" where further information and patient stories can be accessed (as per the school curriculum aims).</li> </ul>		user to the external website/app for NHS 111 for access to urgent dental care.	
Rewards System	Increase regular dental attendance by offering rewards for attendance for dental checkups (7, 8, 10, 11, 14).	Tracking of points and rewards would be built into the appointment making app/website.	The user earns points for every dental check-up they attend, as well as for interacting with the knowledge base in the app/website and leaving reviews for dentist following attendance. Points are then exchanged for rewards from brand partners.	This would be incorporated into the appointment making app/website. It could also be promoted in the school curriculum.

**Table 7.7:** A summary of the intervention design during workshop 2. Intervention aims are mapped to the TDF in parentheses: (1) Knowledge, (2) Skills, (3) Social/Professional Role and Identity, (4) Beliefs about Capabilities, (5) Optimism, (6) Beliefs about Consequences, (7) Reinforcement, (8) Intentions, (9) Goals, (10) Memory, Attention and Decision Processes, (11) Environmental Context and Resources, (12) Social Influences, (13) Emotion, (14) Behavioural Regulation.

During groups discussions, some aspirational aims were raised. These were considered aspirational due to potential design, logistical or data protection issues. These were acknowledged and documented to be discussed during the development of materials and interface post-doctoral. For completeness, these were:

- Link the appointment making website/app to the user's NHS data from the preexisting NHS app to reduce barriers associated with complexities of NHS dental charges paperwork.
- Inclusion of relevant paperwork for the dental appointment in the appointment making system (e.g., medical history forms) and transferring to the dental practice ahead of the appointment.
- Inclusion of other health behaviours in the reward system (e.g., smoking cessation, exercise, diet).

In addition to the above design details the participants discussed potential ideas for patient stories. These are summarised in Appendix Y mapped to BCTs they would target. As an example, one suggested patient story was the impact of not attending the dentist for check-ups leading to dental pain and the impact of this on everyday life. As a result, the person seeks urgent dental care for the pain and realises that it's not as daunting as it was assumed to be and that barriers can be overcome so they wished they'd attended earlier for prevention. This story would map to multiple BCTs, including: problem solving; instruction on how to perform a behaviour; information about health consequences; salience of consequences; anticipated regret; information about emotional consequences; demonstration of the behaviour; social comparison; information about others' approval; credible source; pros and cons; comparative imagining of future outcomes; framing/reframing; vicarious consequences.

Following discussion with the research team it was suggested that some of the stories (e.g., that mentioned above) could be interactive stories, whereby the user watches part of the story and then decides which path to take, therefore being able to see the outcomes of the decisions they make. Feedback on this idea was included in workshop three.

# **Outcomes**

A final summary of the core concepts of the intervention(s) and how they could link together following workshop 2 is given in Figure 7.8.

In the final workshop participants would be asked to consider the intervention design further to de-risk it and make necessary changes. To do this in a virtual setting a final outcome of the second workshop was to produce storyboards for the intervention, the aim being to aid participants in imagining how the intervention could work. Following the workshop, the designer produced these based on the observed discussions and intervention design, and an example is provided in Figure 7.9.

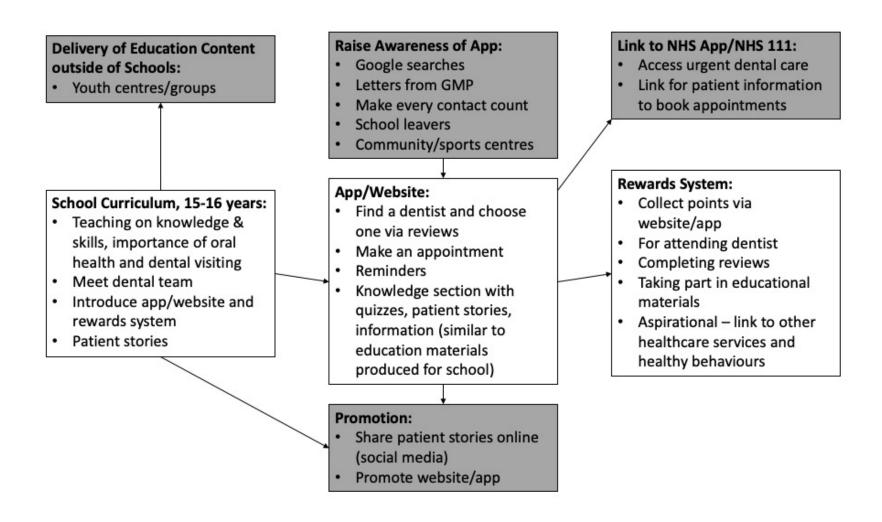
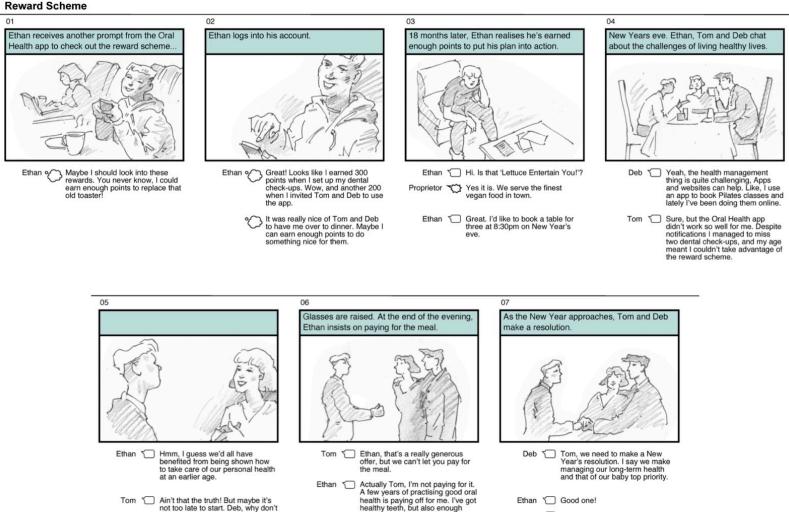


Figure 7.8: A summary of the core concepts of the intervention(s) and how they could link following workshop two.



points from the reward scheme to

pay for this meal with you guys.

Tom Agreed. I'll reinstall that app and

get right onto it dear :-)

Figure 7.9: An example of one of the storyboards produced as an output of workshop two.

Deb Ee, we're having a baby!

you tell Ethan our good news.

# 7.3.8 Workshop 3

#### Workshop Aim

To de-risk the prototyped intervention and make any required changes to the intervention design.

## **Participants**

Following the second workshop it was highlighted by the research team that participants in secondary school (and therefore end-users of the school-based intervention) were under-represented, therefore two further 16-year-olds were recruited. In addition, two extra stakeholders were recruited, one secondary school teacher and one foundation dentist (given the possibility was raised of foundation dentists or dental students being involved in delivery of the school-based intervention). This workshop therefore should have had twelve public representatives, unfortunately three dropped out on the day of the workshop. One of the participants gave feedback on the intervention following the workshop. Three dentists planned to attend, however one did not. The summary participant characteristics are shown in Table 7.8.

Study ID	Age	Gender	IMD Decile	Occupation	Dental Attendance Pattern	Workshop Group
P004	17	Male	7	Student (College)	Regular	1
P012	24	Male	8	Hospitality	Regular → Irregular	
P007	21	Male	5	Student (University)	Regular	
P010	27	Female	1	Health care assistant	Regular → Irregular → Regular	
P013*	16	Female	1	Student (School)	Regular	
D001	56	Female	9	Dentist	N/A	
D004*	28	Female	1	Foundation Dentist	N/A	
P003	26	Female	1	Finance Administration	Regular → Irregular	2
P011	24	Male	3	Logistics management	Regular → Irregular	
P005	23	Female	8	Student (University)	Regular → Irregular → Regular	
P014*	16	Male	6	Student (School)	Regular	
D003	44	Male	3	Dentist	N/A	
S001*	39	Female	6	Secondary School Teacher	N/A	Moved between groups
P006	19	Female	6	Student & Youth Worker	Regular	Contacted after workshop

**Table 7.8:** Summary participant characteristics for workshop 3. \*Indicates the newly recruited participants.

There were also two facilitators (ZF, GT), the user-researcher (EK), designer (MJ) and the research team (CCC, JD, SJS, VAS, BA). Two additional collaborators were also present (ZM, PB) with expertise dental public health, specifically relating to intervention development.

#### <u>Procedures</u>

As pre-reading the participants were sent details of the intervention design from workshop two, the storyboards and some questions so they could begin to reflect on the intervention design and de-risk it. In addition, they were sent examples of interactive stories which had previously been co-produced with young people.

During this workshop the participants worked in two groups to "walk through" the intervention design using the storyboards to generate discussion. Participants were asked to reflect on any parts of the intervention they thought may not achieve the

desired behaviour change, and what would need to change in the intervention design as a result. Following open discussion, the facilitators had specific design related questions for the group to discuss. Semi-structured topic guides were used to aid this (Appendix Z). Each group initially focussed on either the school curriculum or the appointment making system combined with the reward system. Halfway through the workshop the facilitators swapped groups so the other group could feedback on the remaining part(s) of the intervention. The facilitators were able to share feedback and changes from the previous group to help generate discussion and build upon ideas. The secondary school teacher remained in the school curriculum group throughout the workshop.

The workshop ended with full group debrief giving the participants chance to give any final feedback on the changes to the intervention design.

# Analysis & Results

Some potential issues with the intervention components were raised and solutions discussed. Quotations to support changes made are provided in Appendix U.

#### School Curriculum

The main potential problem with the school curriculum intervention was that students may not find it interesting and may not engage. It was emphasised that to make the content interesting the intervention should include a practical, interactive component. Interactive patient stories were seen as being beneficial and all participants were keen to include these in the intervention. The inclusion of the dental team in delivering the intervention was highlighted as being important. Without either a practical element, or a member of the dental team delivering it, participants were concerned that the intervention would fail. The secondary school teacher also agreed with this and highlighted the difference in teaching formats required for those of different educational levels in order to engage them. Students with a lower educational level respond better to outside speakers and practical exercises.

An additional concern raised by the teacher was the amount of time the intervention would take to deliver, with the potential for it being unfeasible or unacceptable to deliver if it was too long, as well as also impacting negatively on formal teaching time. It was therefore decided that the intervention be delivered in a short period of time, around 30-50 minutes, aiming to have maximum engagement and impact in that time. As a result, the decision was made to change the aim of the school-based

intervention and make it more focussed around introducing the app/website component of the intervention, as well as raising awareness of the importance of oral health through some short interactive, practical exercises. Ideas suggested for these included a short practical exercise handling dental instruments and/or materials (assuming the equipment was not anxiety provoking and safe) and use of the short interactive patient stories. These short exercises would be used to engage attention and raise interest in oral health, before introducing the app/website with the students given time to access this and begin to engage with it.

The dentists present expressed concerns over availability of dentists to cover all schools on an annual basis given the targets they face. One suggestion was that dental nurses and dentists from the community dental services who do not have the same targets as primary care dentists could deliver the intervention, however these services also have commitments to the patients they are commissioned to care for. Delivery by foundation dentists and dental students was, however, considered feasible and acceptable. One solution to the issues raised by dentists was to provide an incentive to the practice for the dental team to attend using flexible commissioning. In addition, if dental practices took part in the intervention, in turn, they may have patients wishing to book dental treatment with them, which could again form an incentive. Following this discussion, the dentists present were more amenable to delivering the intervention.

A final consideration raised was how the students would access the website/app component of the intervention in schools. The teacher highlighted that most students of this age group would have a smart phone, however, would not necessarily have internet access. In addition, use of mobile phones in school was a controversial area and could raise safeguarding issues. It was therefore decided that this teaching would need to be carried out with access to computers or tablets at the school, which the teacher believed would be possible.

#### **Appointment Making & Rewards System**

The appointment making system was considered to be highly beneficial by participants with only a few concerns raised. One potential issue raised was around access for those who do not have a smart phone, computer or internet access. This had previously been discussed with one of the participants who is also a youth worker with adolescents from the most deprived areas of the North-East of England.

Their feedback was that most adolescents would have a smart phone, however, would not all have internet access. Additionally, those from the most deprived areas would have access to internet and/or a computer at youth centres. The teacher in the group also confirmed this. This highlighted the importance of having the appointment system readily available in both an app and website format so as many people as possible can access it, as well as the importance of working with organisations such as youth centres. A further solution suggested was that mobile phone data be included as a potential reward within the rewards system.

The logistics of making a dental appointment within the new system were discussed. Public participants were very keen to make an appointment directly within the app/website, however the dentists present were concerned how this would fit with the variety of differing computer systems present in dental practices. One potential solution was to have the ability to select a dental practice and provide availability for an appointment in a message which would be sent to the practice to book an appointment in their own system and then confirm it on the app/website. This was considered acceptable by the participants assuming this could be communicated via the app/website and did not require a telephone conversation.

The ability for the user to leave reviews of the dental practice within the app/website was seen as being beneficial and acceptable by all participants. The dentists also highlighted the potential for this to cause positive "spill over" behaviour change (Michie, Atkins and West, 2014) in the dental team, which could indirectly target the barriers highlighted associated with dentist characteristics.

A final addition to the appointment making system was by comparison to currently available apps for NHS GMP practices in which you can look up your medical history as well as make appointments. A desirable addition to the app/website if feasible was the ability to look up your dental history, as well as active treatment plans and the cost associated.

In terms of the reward system initial concerns were raised over how it would be funded and the potential complexities associated with this. It was agreed that if the reward system was centralised and rewards were funded by brand partners this would be feasible. Comparisons were made to the current systems in place by government to incentivise young people to take up the COVID-19 vaccination (UK Government, 2021b). In addition, it was thought that brands may be willing to

become partners because of the positive reputation gain they would receive by promoting a health intervention, whilst only losing a small marginal gain by the reward offered.

A similar theme was raised as for the appointment system for those who do not have internet access. Similar solutions were discussed as above, with the additional suggestion that either the dental team should be able to access the rewards system to log dental attendances, or the rewards system could be linked to centralised records (e.g., NHS Business Service Authority data) to confirm attendance.

One of the concerns raised by the public representatives was the time it would take to gain enough points to be rewarded because if this takes too long motivation to use the app/website would be lost. One proposed solution to this was similar to that suggested in the prior workshop by including other health change behaviour goals they could be rewarded for. Suggestions included linking the app/website to other pre-existing apps which currently allow exercise tracking. Following discussion, it was agreed that use of the pre-existing NHS Live Well model could be used, with rewards potentially being gained for all healthy behaviours included Live Well, in addition to the oral health rewards. It was also suggested that additional points could be gained for continued and sustained behaviour change.

Participants discussed the age range that should be eligible for the reward system. It was agreed that everyone should be able to access the app/website to use the appointment making system and knowledge base, but it would be unfeasible for the whole population to be rewarded. It was agreed by all participants that the rewards should start around the transition from school to allow points to be accumulated whilst dental treatment is still free to build motivation. The end age was more difficult to define but was generally agreed to be mid to late twenties. It was agreed that this end age would allow time for young adults to leave university and/or be settled in employment with fewer conflicting priorities to contend with. In addition, by this time period it was hoped that the user would have built an understanding and appreciation for seeking regular dental care (as well as any other positive behaviour change), and as such have the internal motivation to attend once the external motivation of the rewards system was lost.

Participants discussed the potential to open the rewards system to other population groups who may be facing similar barriers but were not within the specified age

range, for example those in part-time or full-time education at an older age, or those from the most deprived areas. It was therefore agreed that in addition to the prespecified age range personal circumstances should also be taken into consideration.

A final point raised was the importance of linking the appointment system and rewards system to ensure that other barriers to attending (e.g., dental anxiety) can be overcome once an appointment is made.

Interestingly, when asked, participants highlighted a stronger preference and prioritisation for the appointment making system over the rewards system. This could indicate that the app/website may result in the desired behaviour change even without the addition of rewards for external motivation.

#### <u>Outcomes</u>

The outcome of workshop 3 included the de-risked and refined intervention design. The design is summarised according to relevant parts of the template for intervention description and replication (TIDieR) checklist in Table 7.9. Due to some potential design complexities both an aspirational and pragmatic design were created for the appointment making and rewards systems, both of these are presented and explained below in further detail below.

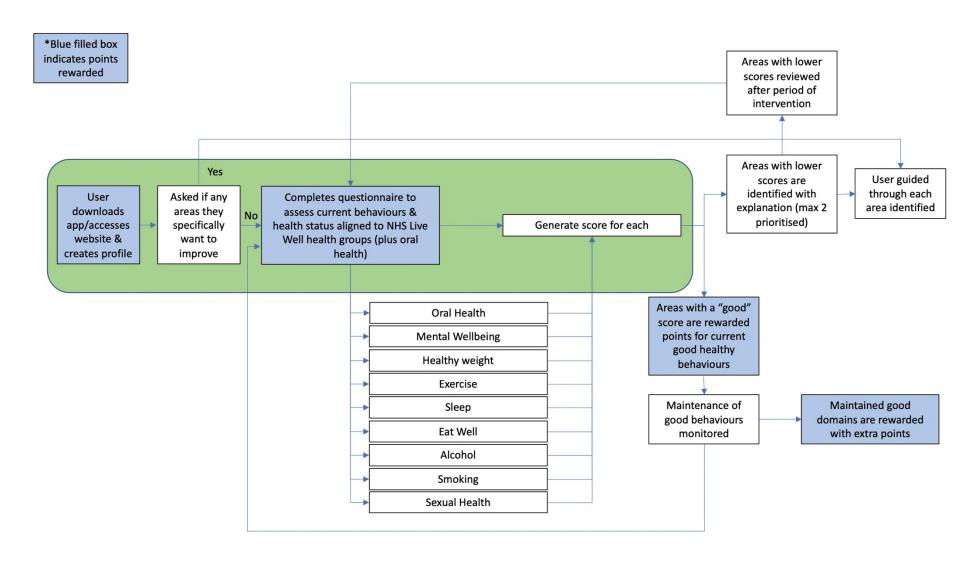
Intervention Component	Aim	Materials	Provider	Delivery Mode	Where	When and How
School Curriculum	Highlight the importance of oral health and the link with regular dental visiting, introduce the website/app and allow students time and resources to complete a profile and begin to engage with the reward system.	Dental materials and instruments that are safe for students to handle (e.g., impression material and objects to take impressions of). Short interactive videos and/or animations. Computer and internet access for the website/app.	Secondary school teachers and/or the dental team where feasible. Resource allocation maybe used for dental team members to prioritise schools in the most deprived areas. Additional providers may include youth workers.	A short (30 minute) lesson consisting of: (1) Practical exercise to engage attention, handling of dental materials and instruments (for example taking impressions of everyday objects); (2) Interactive patient story video for the students to watch individually; (3) Introduce the app/website and allow students time to create a profile and begin to engage and earn points; (4) question and answer session.	Delivered in secondary schools to year 11 (15–16-year-olds) to align with the age for introduction of the rewards system.	Delivered once per school year (with written information on the app/website provided for any pupils absent).
Appointment Making System	Provide an appointment making system that is accessible to young people.	A complementary app and website will need developing with stakeholder input. Interactive patient stories and reading material/brief interventions for knowledge base.	Ideally this will be centralised to an NHS organisation such as NHS Digital or NHS X.	An app and website which includes the following features: (1) Find a nearby dentist; (2) Reviews of dentists; (3) Make an appointment; (4) Link appointment to iCalendar; (5) Direct the user on how to access urgent dental care if needed; (6) Knowledge base with information and patient stories targeted at barriers to care-seeking; (7) User's dental history and active	App/Website, promoted in secondary schools. In addition it should be linked to relevant internet search engines, promoted on social media, in community centres, youth centres, leisure centres and by use of Make Every Contact	Continuous promotion and use by the enduser. Available to all the population.

				treatment plan (including preventive advice given) with estimated cost.	Count (GPs, sexual health clinics, pharmacies etc).	
Rewards System	Promote regular dental attendance (plus other positive health behaviour change) by offering a reward.	The app/website developed for the appointment system. Brand partners with a reward system to exchange collected points for rewards.	Ideally this will be centralised and linked to the appointment system therefore the same provider will be used.	The user earns points for: (1) engaging with the app/website (e.g., interacting with educational materials, leaving reviews of dentists); (2) positive behaviour change (e.g., attending a dental checkup); (3) sustained and continued positive behaviour change. Points can be exchanged for rewards from brand partners.	Via the appointment making App/Website.	Continuous promotion and use by the enduser. Available to young adults (16-years-old to mid/late twenties) and those matching free NHS dental treatment exemption criteria and/or in full/part time education.

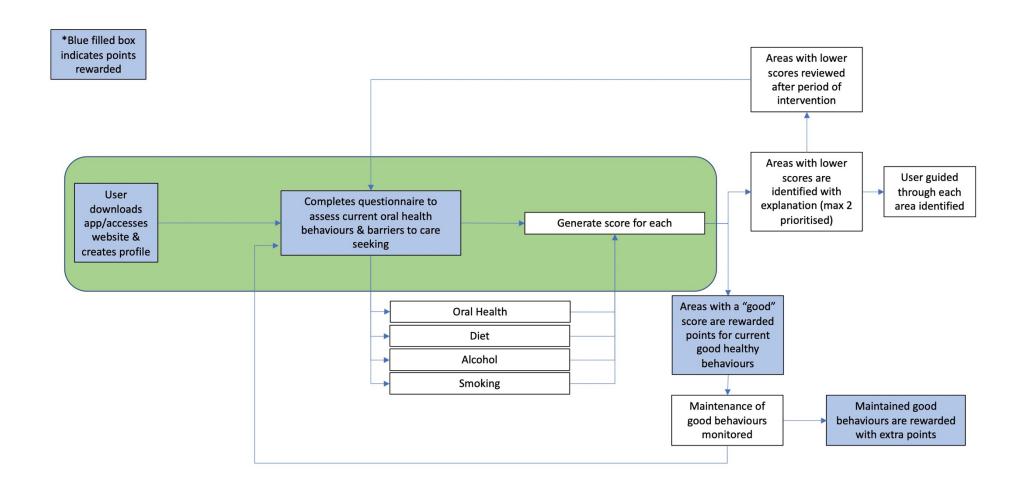
**Table 7.9:** Summary of the final intervention design aligned to the TIDieR checklist and guide (Hoffmann et al., 2014). Note the TIDieR domains on tailoring and intervention adherence and fidelity are not included as the intervention has not yet been evaluated.

The appointment making and reward system interventions will both be in the format of a website and smartphone app. Once the end-user accesses the website/app they will create a profile and be guided through a questionnaire to assess their current behaviour. In the aspirational design this will be assessed against the NHS Live Well areas as well as oral health (Figure 7.10), and the end-user will also be given the option to select any particular areas they want to focus on themselves. In the pragmatic design (Figure 7.11) the questionnaire will focus only on oral health and related behaviours. This questionnaire will identify and prioritise the behaviours the end-user should change to guide them to the relevant sections of the app/website. Within the school-based intervention, the students will be given access to a computer and time to create their profile and complete the questionnaire.

The end-user will be able to earn points for the reward system by creating a profile and completing the questionnaire. In addition, any current good behaviours identified by the questionnaire will be rewarded with points. These good behaviours will be monitored and continued behaviour will also be rewarded with additional points (Figure 7.11).



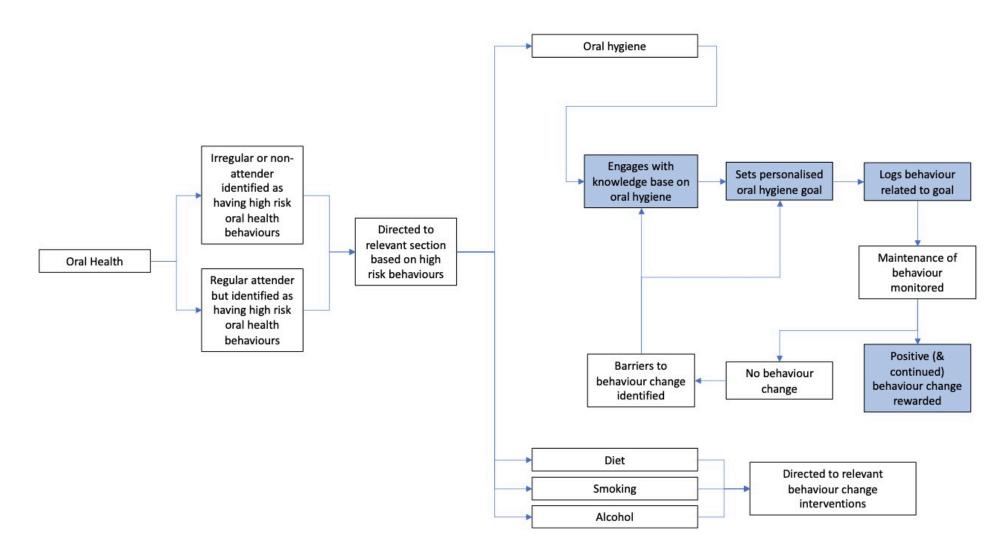
**Figure 7.10:** End-user profile creation and behaviour assessment in aspirational design. The green shaded box indicates the activities completed during the school-based intervention. Blue shaded boxes indicate activities which will be eligible for points in the reward system.



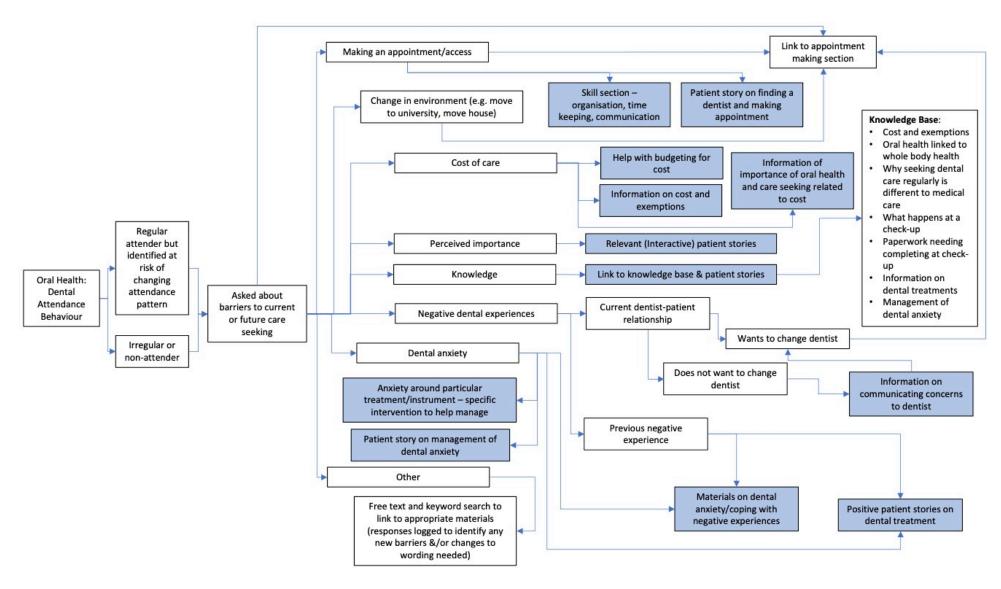
**Figure 7.11:** End-user profile creation and behaviour assessment in pragmatic design. The green shaded box indicates the activities completed during the school-based intervention. Blue shaded boxes indicate activities which will be eligible for points in the reward system.

The end-user will then be guided through educational material and interventions relevant to the areas identified. The materials specific to each of these will be developed in the post-doctoral period, and if the aspirational design is used, relevant collaborators with expertise in behaviour change in the differing areas will be sought. The literature can also be reviewed for any pre-existing interventions which have already been developed and trialled for each area which could be refined for use within the app/website. An example for oral health related to oral hygiene behaviours is provided in Figure 7.12. Given the focus of this thesis was on dental attendance a more in-depth overview of examples of materials and interventions related to this in provided in Figure 7.13.

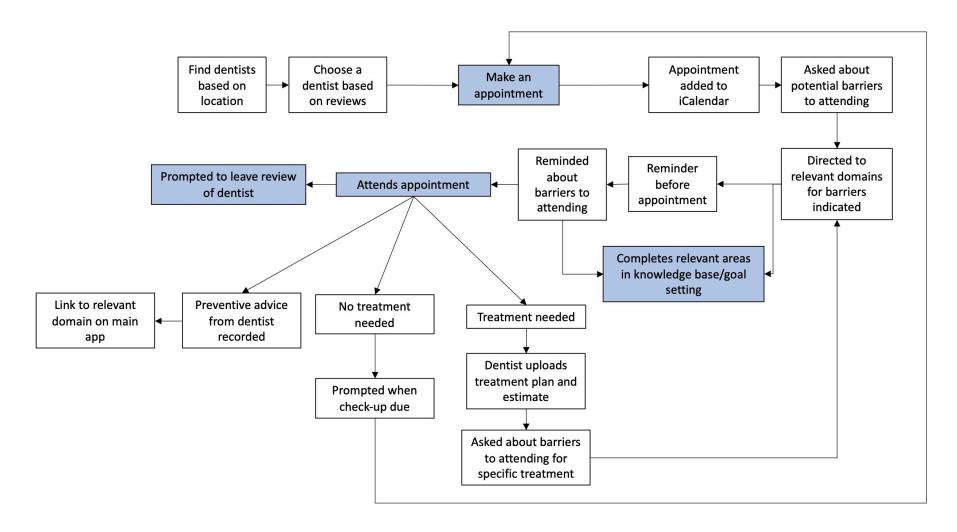
The final part of the app/website is the appointment making section. All end-users will be able to access this regardless of the areas identified as needing behaviour change. Two versions were again designed. The aspirational version (Figure 7.14) included: (1) immediate appointment booking within the app/website, and (2) ability for the dental team to interact with the app/website and upload treatment plans and prevention goals. The pragmatic version (Figure 7.15) includes a simplified appointment making system and the assumption that the dental team won't be able to upload patient treatment plans and prevention goals.



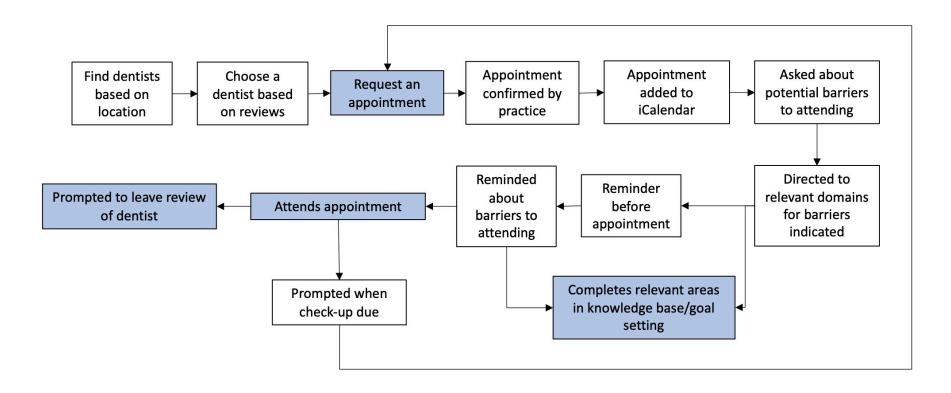
**Figure 7.12:** An example of the oral health section and how the end-user would be guided through relevant educational material and intervention. Blue shaded boxes indicate activities which will be eligible for points in the reward system.



**Figure 7.13:** An example of the dental attendance section and how the end-user would be guided through relevant materials. Blue shaded boxes indicate activities which will be eligible for points in the reward system.



**Figure 7.14:** Aspirational design for the appointment making system embedded within the app/website. Blue shaded boxes indicate activities which will be eligible for points in the reward system.



**Figure 7.15:** Pragmatic design for the appointment making system embedded within the app/website. Blue shaded boxes indicate activities which will be eligible for points in the reward system.

The final outcomes from workshop three are two logic models: (1) A logic model of change (Figure 7.16); (2) a dark logic model (Figure 7.17). The logic models are for the pragmatic design focussing solely on oral health and dental care-seeking behaviour change. Figure 7.18 shows the links between the intervention BCTs to the COM-B model.

### Inputs

One-off School-Based Intervention

### Website/App:

- Reward system
- Appointment making system
- Knowledge base
- · Patient stories

#### **Active Components**

- Problem-solving around barriers to dental care seeking & direction to solutions within the app/website
- Review behaviour goals within the app/website modify according to behaviour change
- Highlight <u>discrepancy between</u> <u>current behaviour and goal</u>
   within the app/website
- Self-monitoring of behaviour within the app/website
- Instruction of how to perform the behaviour in relation to skills required to attend a dental check-up
- Provide information about health consequences in relation to the importance of oral health and dental visiting
- 7. Anticipated regret via patient stories of not seeking dental care
- Demonstration of the behaviour, social comparison, information about others' approval & comparative imagining of future outcomes via patient stories
- Prompts/cues to remind of upcoming or due dental appointments
- 10. Material incentive/reward (behaviour) for engaging with the app/website and positively changing behaviour
- Reduce negative emotions surrounding dental care, including as a system and dental anxiety
- Restructuring the physical environment by creating a new way to make a dental appointment

### Determinants & Change Objectives

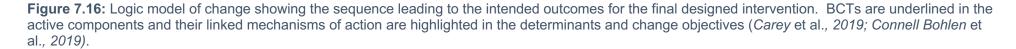
- Beliefs about capabilities to seek dental care
- Goal setting to change oral health and dental care seeking behaviour
- 3. Feedback on current oral health and dental care seeking behaviours
- Behavioural regulation on own oral health and dental care seeking behaviour
- 5. Knowledge & Skills on oral health and dental care seeking
- 6. The importance of oral health & dental care seeking in relation to knowledge, beliefs about consequences, perceived susceptibility/vulnerability & resulting intention to change behaviour
- 7. Social learning/imitation, norms & social norms of oral health and dental care seeking behaviours
- 8. Memory, attention & decision processes, behavioural cueing for future dental visiting
- Positive <u>reinforcement</u> of oral health and dental care seeking by use of incentives and rewards
- Reduced negative <u>emotion</u> around dental care seeking and navigation of dental systems
  - 11. Aiding appointment making via <u>environmental</u> <u>context & resources</u>

### **Outputs**

- 1. Seek & maintain regular dental care visiting
- Avoid change to problemorientated dental attendance behaviour
- 3. Improved oral health behaviours

### **Outcomes**

- 1. Prevention of dental disease
- 2. Reduced incidence of acute dental pain & potential sequalae
- 3. Reduced incidence of odontogenic infection & hospital admission
- Improved oral health related quality of life
- 5. Reduced healthcare costs



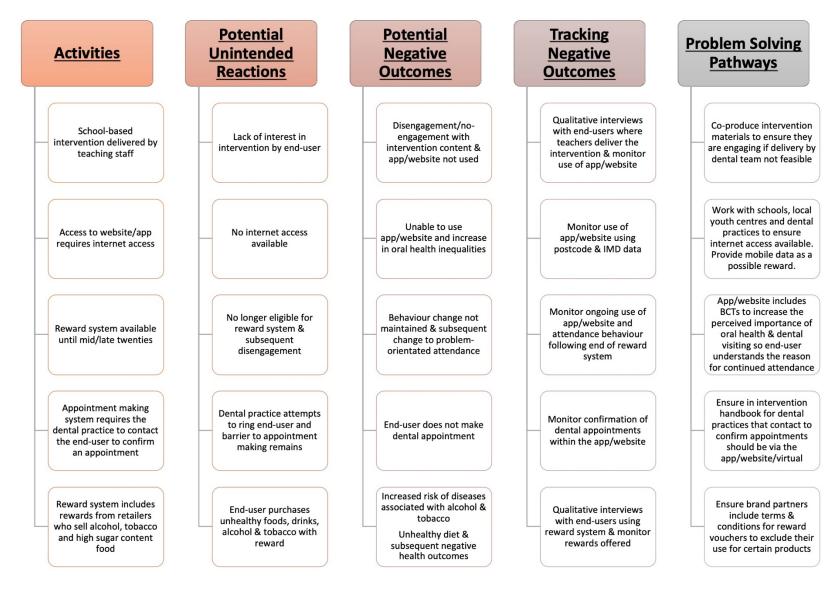


Figure 7.17: Dark logic model for final intervention design to show potential unintended negative outcomes and how these could be mitigated.

Canability	Physical capability: Skills to find a dentist and make an appointment	Instruction & demonstration on how to perform the behaviour	
Capability	Psychological capability: Knowledge about dental care and systems	Problem-solving, review behaviour goals, self-monitoring, health consequences	
		•	
Motivation	<b>Reflective motivation</b> : Experiences with dentists & perceived importance of oral health	Health consequences, anticipated regret, comparative imagining of future outcomes	Behaviour
	Automatic motivation: Emotions surrounding dental care & systems	Material incentive/reward, reduce negative emotions	Bellaviour
1			
Opportunity	Physical opportunity: Ability to pay for dental care & transition period into independence	Prompts/cues, restructuring the physical environment	
	<b>Social opportunity</b> : Influence from family, peers and media on dental care	Social comparison, information about others' approval	

Figure 7.18: The links between the intervention BCTs and the COM-B model produced (adapted from Michie, van Stralen and West, 2011).

### 7.4 Discussion and Next Steps

This evidence-based co-design approach allowed the development of an intervention to encourage regular dental attendance in adolescents and young adults to the point of development of materials and interface. The intervention is an e-Health complex intervention and consists of three parts: a school-based component; an app/website to facilitate appointment making and address other barriers to dental care-seeking; a reward system for positive behaviour change.

School-based interventions are widely used in health promotion, however can be challenging in mid-adolescence (13/14-years-old to 17-years-old) with multiple metaanalyses showing only weak benefits of traditional school-based interventions compared to children or younger adolescents (Yeager, Dahl and Dweck, 2018). Yeager et al. demonstrate that traditional interventions in middle adolescents fail because they do not show sensitivity to adolescents' increased need for social status and respect. Often being based largely on sharing knowledge via assemblies, lectures and homework. Interventions targeted at this age group should therefore take this sensitivity into consideration and support their feelings of autonomy. Nevertheless, school-based oral health promotion interventions have been shown to be effective in this age group, particularly when they include more than just a knowledge based component and are based on behaviour change theory (Tsai et al., 2020). The school-based part of this intervention would be in keeping with this and of importance may be the interactive patient videos. These could be a critical part in engaging adolescents' attention and promoting respect and autonomy by allowing them to engage in decision-making, allowing them to make the "wrong" decisions and seeing subsequent outcomes.

The second part of the intervention involves a new appointment making system available as an app/website, which will also include interventions to target potential barriers to care-seeking. Mobile health (mHealth) interventions are becoming increasingly popular, however few have been developed for dental and oral health. Of those developed their predominant focus is on oral hygiene behaviours or simple text message dental appointment reminders, however, they do show promising results including with adolescents (Badawy and Kuhns, 2017; Toniazzo *et al.*, 2019). The intervention developed here is a complex intervention in comparison to those reported to date. As such it has a wider aim and includes a diverse range of BCTs. Importantly, it has also been co-designed with adolescents using a theory driven

approach which other mHealth interventions in oral and dental health lack. Within adolescent health, mHealth interventions are being widely developed and trialled for sexual and reproductive health, including interventions on education, behaviour change communication and incentives with promising results reported (Feroz *et al.*, 2021). In addition, an appointment making app has been recently co-created for sexual and reproductive health (Brault *et al.*, 2021), this has not yet been trialled but will be important to follow for any potential lessons that can be learnt and transferred to this intervention.

The final component of the intervention includes a rewards system. This has both an incentive and reward BCT as the participants will be informed in advance about the reward if they change their behaviour (incentive) and will subsequently be rewarded when they do (reward). Incentive-based behaviour change interventions have been shown to be successful (Giles *et al.*, 2014), particularly in smoking cessation (Notley *et al.*, 2019). There is often concern that once the incentive is withdrawn the behaviour will not be maintained, however this is often not the case. For example in smoking cessation studies behaviour change is often maintained in long term follow-up (Notley *et al.*, 2019).

Despite their success, financial incentives can be controversial with conflicting opinions from the public (Giles *et al.*, 2015). They are largely acceptable if they are shown to be cost-effective, however, can be unsupported if not carefully designed and communicated. They can be unsupported due to concerns over: "gaming the system"; spending reward money on unhealthy behaviours; incentives being unfair to already healthy people; use of centralised funding being unjust and unfair. For these reasons, it will be important within the design of the app/website to ensure a robust method of confirming behaviours (such as attending a dental check-up), including terms and conditions on vouchers to ensure products such as alcohol and tobacco cannot be bought, and that current healthy behaviours at the start of the intervention are rewarded. In addition, use of brand partners and transparency in funding arrangements will be important.

Incentive-based interventions are also considered more acceptable if the scheme is available to a large group targeting population health (Giles *et al.*, 2015). Given this reward scheme will be available to all young people and those exempt from NHS dental charges a wide group will be targeted. If the aspirational design is also used a wide range of health behaviours will also be included therefore improving population

health. As this intervention was co-designed with members of the public who prioritised a rewards scheme and believed it to be acceptable these concerns over public acceptability have been largely addressed, however this will require continued evaluation during the remainder of the intervention development process. In addition, careful economic evaluation will be required to evaluate and demonstrate cost-effectiveness.

A framework to document interventions that include a financial incentive has been produced to ensure that they are fully described (Adams *et al.*, 2014). The reward framework for this intervention is shown in Appendix AA, alongside the current evidence base supporting the reward system design. This has been completed to date however as some information will be determined in the following stages of intervention development some domains cannot be fully reported and designed.

The final workshop highlighted potential design issues with the intervention. The majority of these were addressed within the workshop and subsequent design modifications, however some will need consideration in the future feasibility study.

Firstly, within the school-based intervention the long-term feasibility of dental members delivering this needs to be considered. One solution is to consider resource allocation and prioritise delivery from the dental team in schools from the most deprived areas. One outcome in the feasibility study will therefore need to be focussed on the number of dental team members available and willing to deliver the intervention. If feasible, their time will also need to be reimbursed therefore the use of flexible commissioning will need to be considered. Commissioners of dental services will need to be engaged with the research team in the future as they will be crucial to assess system-based feasibility and acceptability. If delivery by the dental team is not feasible then any subsequent impact on the effectiveness of the school-based intervention will need to considered.

A large component of the intervention involves use of an app/website. This raised the potential of excluding those who do not have access to a mobile phone or internet and the potential to increase oral health inequalities. This could be a potential barrier to uptake of the intervention and will require monitoring as the intervention is developed, implemented and evaluated. One solution was to include mobile phone data as a reward within the reward system, and this will need to be explored in the next stages of intervention development.

Given that dental appointment making is a barrier to care-seeking in adolescents an important part of this intervention is the ability to make a dental appointment within the app/website. This may, however, present some logistical challenges. There are currently a range of different computer based dental appointment systems available which are not standardised and linking the app/website to these could be a design challenge. This will be addressed as the intervention is built post-doctoral, but if this is not possible the participants agreed a potential solution to be a messaging system built into the app/website which allows them to request an appointment. The acceptability of this is likely to be an important outcome to consider for the feasibility study, ensuring that qualitative data are collected from both the end-user and the dental team on the functionality of the appointment making system.

One further benefit of the app/website is the potential for this to also be available to the wider population in the long term, not just adolescents and young adults. Indeed, many of the barriers to regular care-seeking identified by adult problem-orientated attenders may be overcome by using the app/website. For example, they expressed concerns over how to find a good dentist, which would be facilitated within the app/website by looking at reviews of dentists. The primary aim of the app/website will be for adolescents and young adults initially, however if successful could be extended, and if needed refined using further co-design, to include a wider range of people.

A final decision to make in the next stages of intervention development will be whether to develop the aspirational or pragmatic version. The aspirational design was prioritised in the co-design workshops by participants as it would allow endusers to accrue points quickly therefore providing motivation to use the app/website, and also achieve positive behaviour change across a range of important behaviours. In addition, by including other health behaviours it utilises the common risk factor approach, thereby increasing effectiveness and efficiency and reduces duplication of multiple separate interventions (Sheiham and Watt, 2000). Furthermore, it highlights how oral health impacts on general health helping to "bring the mouth back into the body" rather than being considered a distinct and less important aspect of overall health. Importantly, this approach aligns with the FDI World Dental Federation's Vision for 2030 by integrating oral health into general health (Glick *et al.*, 2021). This aspirational version will, however, present more design complexities for the intervention, as well as for future evaluation as more outcomes would need to be

recorded to evaluate effectiveness. One solution may be to initially develop and evaluate the pragmatic version, and if successful begin to add in extra health behaviours. It should be noted that the pragmatic version also includes a common risk factor approach by including behaviours such as smoking and alcohol use, therefore, as well as having direct oral health outcomes, it will also have an impact on other diseases.

Intervention development encompasses the process from the creation of the intervention through to evaluation and, if successful, implementation (Skivington *et al.*, 2021). This chapter therefore describes the first stage of intervention development up to the point of development of materials and interface. During post-doctoral research the intervention development process will continue. This will involve early economic modelling and seeking funding to build the intervention, involving end-user feedback (for example think aloud interviews for the app/website design) and co-design and co-creation of intervention materials. Following this a feasibility study with process evaluation will be required to address some of the uncertainties highlighted above, before further intervention refinement as required, and then a full-scale process evaluation.

### 7.4.1 Limitations of study

As highlighted above and through this thesis, when interventions are developed it is of upmost importance to ensure they do not widen pre-existing health inequalities. For this reason, the participants recruited for the co-design (and indeed for the other qualitative studies) were selected to ensure a range of sociodemographic backgrounds were included, ensuring those from the most deprived areas were represented. Participants were sampled using IMD decile, and as shown in the study characteristics tables the most deprived decile (1) was included in all studies. However, an IMD decile covers a wide range of deprivations, and as such it is possible that those living in the most deprived locations and therefore the most marginalised of society were not recruited. Indeed, when discussing the qualitative findings and co-design with the participant who was also a youth worker it was highlighted that the results of the studies would be relevant, however it is likely that additional barriers would exist for those with the most deprived socioeconomic backgrounds, particularly for those involved with recreational drug use and crime. This means that the intervention developed may not address all barriers for the most marginalised of society, and this will be something to closely evaluate as the

intervention is developed. In addition, to fully understand the barriers this group face and develop an intervention to overcome these it was felt that a separate research project may be required. This is a clear area for future research, and once the barriers are fully understood it may be possible to use the intervention designed here and refine it further, or indeed, a separate intervention may be required.

Another public group to consider are those living in rural areas. The SAIL databank analysis (Chapter 4) demonstrated that those living in rural areas were significantly more likely to seek dental care from a GMP, and unfortunately those living in rural areas were not recruited for the subsequent qualitative or co-design studies. As such, the intervention designed may not overcome all barriers that adolescents and young adults living in rural areas face. It will therefore be important to ensure the intervention is carefully evaluated in rural areas to observe any potential differences in outcomes. If this is the case, then further qualitative work may be required with this specific group and the intervention refined as required. In addition, a likely barrier for this particular patient group is access to dental care, this barrier will require policy change to be overcome and will need to be considered in addition to the intervention.

A further consideration in terms of the potential need for policy change is the barrier highlighted of affordability of dental care. The intervention designed does include BCTs to help with the transition to the requirement to pay for dental care, for example problem-solving to overcome conflicting barriers and priorities, and information on cost of dental treatment to reduce negative emotions associated with this. It does not, however, address the barrier of affordability of care in terms of resources. The research completed in this thesis highlights the barriers dental charges create both for adolescents and young adults, as well as problem-orientated attenders, and provides evidence for the need for policy change in terms of current dental contracts. Although this could not be incorporated into the intervention a separate policy brief will be produced highlighting the evidence generated in this thesis to inform the development of implementation of dental policy.

One evidence statement that was not directly addressed by the intervention was that of dentist characteristics. This was a strong theme in both the adult and adolescent qualitative work and was also deemed important by the co-design participants. This is another area which will require further research and is discussed further in the final chapter of this thesis.

A final limitation to the co-design work was the limitations posed by the COVID-19 pandemic. Prior to the pandemic, and this study, intervention co-design had not been carried out virtually. Carrying out workshops on Zoom (Zoom Video Communications, Inc. (2020) Version 5.4.7.) meant that they had to be significantly reduced in duration, and in addition participant numbers had to be limited to aid interaction in a virtual space. Each workshop aim was achieved in this virtual format, however one challenge encountered was the ability for participants to be creative in a virtual space without physical interaction. Future co-design in a virtual setting may therefore benefit from exploring new ways of encouraging creative thinking which are more accessible. Limitation of participant numbers also meant that during some workshops when participant availability changed at short notice some groups were smaller than planned and did not have a dentist representative. This was overcome on the day by asking a member of the research team with previous experience of working in primary dental care to share their views, and these were explored following the workshop with the dentist who was unable to attend. In future studies, even though participant numbers need to be limited, it may be beneficial to recruit extra stakeholders to account for potential short notice drop out. It should be highlighted, however, that there were also some strengths to carrying out the codesign virtually. Participants from outside the North-East of England could be recruited without the need to travel, and collaborators and research team members could also join from a distance. Not only did this allow opinions and experiences from outside the immediate area to be shared, it also reduced the carbon footprint associated with the study.

### 7.5 Conclusion

In conclusion, this evidence-based co-design approach allowed creation and design of an intervention to encourage adolescents and young adults to seek regular dental care as they transition to independence, thereby preventing problem-orientated attendance. The intervention development process incorporated evidence from previous studies, the wider literature and theoretical basis of behaviour change to design an intervention grounded in the public and stakeholder experiences and opinions. In addition, the intervention was de-risked and refined to ensure it is likely to be feasible and acceptable. Next steps will include building and designing the materials and interface and a feasibility study.

### Chapter 8. Conclusions, Implications, and Future Research

### 8.1 Thesis Conclusions

This thesis aimed to build an understanding of problem-orientated dental attendance, and associated care pathways. This understanding was then used to facilitate the development of an intervention to reduce problem-orientated attendance.

Attendances at Welsh GMPs for dental problems were explored over a 44-year period. This was the first study to explore GMP attendances for specific ADP diagnoses which patients acknowledge GDPs are best placed to treat, as well as exploring variables for deprivation, rurality and appointment outcome. Changes in attendance rates were noted over the study period, which appeared to coincide with some key policy change dates. Overall, dental attendance rates at GMPs appeared to be decreasing, however just over 10% of patients were repeat attenders. Predictors of repeat attendance included living in an urban and deprived area, or rural area, as well as being prescribed an antibiotic or no referral as an appointment outcome.

The reasons that emerged from the qualitative data collected in this thesis for starting and maintaining problem-orientated attendance were complex and multifactorial. They also linked to patient choice of attendance location and associated care pathways. The transition from adolescence into independence was a key period for this behaviour change to become a problem-orientated attender. Some barriers and facilitators which contributed to decision-making around problem-orientated attendance spanned both adolescence and adulthood. These key, overarching themes included: lack of knowledge or misunderstanding; dentist characteristics; dental anxiety; dental charges and affordability of care. These themes interacted and could compound one another, creating a complex network of barriers and facilitators explaining the transition to, and maintenance of, problem-orientated dental attendance.

Using the understanding developed from the qualitative data and based on evidence and theory, an intervention was co-designed with relevant stakeholders. This intervention aims to encourage adolescents to continue to seek regular dental care as they transition into independence, therefore seeking to reduce problem-orientated dental attendance. The intervention consists of an e-health complex intervention which addresses the key barriers to care-seeking. It is designed in line with the TDF and behaviour change theory to encourage and motivate attendance through the use

of incentives and rewards. To maximise its impact, it was developed in a way that it can be introduced to adolescents during a short school-based educational session. The intervention has been developed and de-risked up to the point of development of materials and interface. Crucially, this intervention has been developed involving stakeholders from the start, as well as using a theoretical framework, meaning that the intervention is likely to be acceptable and have a positive behavioural change, and therefore aligns to the recently published Consensus Statement on Future Directions for the Behavioural and Social Sciences in Oral Health (McNeil *et al.*, 2022).

### 8.2 Next Steps for Intervention Development

During post-doctoral research, funding will be sought to design and build the app/website and associated materials (e.g., the interactive patient stories). This will involve some further co-design work, including think aloud interviews from stakeholders as they use the intervention to aid further refinement and co-design. The materials built into the app/website will also be co-designed to ensure they are acceptable and likely to result in the desired behaviour change. Economic modelling will also be required to begin to consider cost-effectiveness of the intervention. Following this the intervention will be taken into a feasibility study, before final process evaluation, and if successful, implementation.

This thesis also demonstrated areas of policy which are barriers to regular dental care-seeking, including age of introduction of dental charges, actual affordability of care, dental exemptions and access in rural areas. A policy brief will be produced to highlight these to policy makers in an attempt to influence future policy decisions.

### 8.3 Implications for Clinical Practice

The findings from this thesis have some immediate clinical implications. Given that the dentist can either create a barrier to, or facilitate, future care-seeking, their interaction with adolescents and established problem-orientated attenders should be reflected upon.

With adolescents, it is recommended that dentists ensure they actively include the patient in discussions about their oral health and treatment planning. They should be supported and empowered to take part in decision-making, enabling them to begin to take ownership of their oral health. The dental team should also keep in mind that adolescents may not feel able to ask questions or highlight when they don't

understand something. As a result, the dentist should dedicate time during an appointment to specifically ask the patient if they have any questions or would like anything discussed or clarified further. Priority should also be given to continuity of care with the same dentist to allow a strong dentist-patient relationship to be established, with ongoing conversations between the dentist, patient and parents/carers to establish when the adolescent is confident to begin care-seeking independently. During this period, whilst the adolescent patient has parental support, the dental team could introduce the patient to the paperwork they need to complete in the future, as well as provide knowledge on future dental charges. The dental team should also be conscious of how scheduling appointments can be a barrier, being mindful of the anxiety adolescents face with this. Again, during this transition period when the patient has parental support the dental team could encourage the adolescent to begin to organise their own appointments.

For adult problem-orientated attenders, the dental team should be aware of the complexities of the barriers these patients face to regular care-seeking and the potential for delayed care-seeking. Therefore, when a problem-orientated attender makes the decision to seek care, they are likely to have exhausted all means of selfmanagement as well as overcome a multitude of barriers. For this reason, it is imperative that the health professional and wider team ensure they show an empathetic patient-centred approach to their management. Ideally, time should be taken to explore the barriers faced and how they may be overcome, particularly if they relate to something which could be easily addressed during the urgent care appointment, such as misunderstanding or lack of knowledge. Importantly, information on current oral health, disease and treatment needs should be delivered in a manner showing empathy to the complexities of barriers faced, as well as at a time when information can be retained and reflected upon, for example following treatment completion. This should include information on all disease present, not just that related to the patient's presenting complaint, given that this patient group can hold the belief that a lack of dental pain indicates a lack of dental disease. Finally, when problem-orientated attenders do present for urgent dental care, the dentist should ensure they enquire specifically about analgesia use given the potential for inadvertent overdose.

### 8.4 Future Research

This thesis has identified several areas for future research.

In terms of dental GMP attendance, given that just over 10% of patients were repeat attenders, an intervention could be developed specifically to reduce repeat attendance. This could include an intervention targeted at GMPs to change antibiotic prescription and referral behaviour. Further qualitative work could also be carried out with dental patients seeking GMP treatment to establish specific patient groups who attend here (e.g., rural areas with access problems, dental anxiety/phobia) and reasons for attendance, with specific intervention co-design targeted at these. GMP attendance rates were reducing overall, however the potential impact of COVID-19 and subsequent impact on dental access must also be considered. This could justify a further natural experiment in the form of a repeat study of a similar nature to establish any changes in attendance rates.

In terms of care pathways for ADP the adult qualitative data suggested that problemorientated attenders can seek care from multiple health care providers and will repeat attend to secondary care DECs. The reasons behind these care pathways related largely to patient experience, access, and affordability of care. Clearly these care pathways can be streamlined, with patients ideally presenting to, and accessing, urgent dental care services in a timely manner and receiving appropriate treatment to relieve their pain on the first attendance. This is a further area for future study and co-design of services could be considered to ensure that patients "get the right care, at the right time, in the right place" (NHS England, 2014).

Dentist characteristics was an overarching theme throughout the qualitative and codesign studies and is not directly targeted in the current intervention design. The
actual dentist-patient encounter and relationship was not observed in the qualitative
aspect of this thesis, and this certainly warrants further investigation given the
substantial barrier to care created. Ethnographic research in both urgent and routine
dental care could be used to observe the dentist-patient relationship and any
differences between regular and problem-orientated dental attenders, including both
verbal and non-verbal communication. It would also be of benefit to carry out
ethnography with adolescent dental appointments, to triangulate the findings reported
by this patient group. The results could then be used to inform intervention
development targeted at dental professionals, to encourage both regular dental careseeking during the transition to independence period, and a change from problemorientated to regular dental attendance.

A further area of research could be within health economics considering adolescents' and young adults' willingness to pay for dental interventions or programs. This thesis highlighted that introduction of dental charges at 18- or 19-years-old initiates a complex decision-making process around the need and ability to pay for treatment. This also appears to relate to their perceived value of a dental check-up and how important they consider oral health to be. Willingness to pay experiments could therefore be used to establish: (1) what adolescents and young adults would pay for a dental check-up (2) how their knowledge and perceived importance of oral health influences this value. This in turn could influence future intervention development and/or policy.

Finally, as addressed in the limitations throughout the previous chapters, some specific patient groups were not included, or may be underrepresented in this thesis. Non-English speakers were excluded, and as highlighted in the literature review, language barriers are a known barrier to dental care-seeking. Patients who live in rural areas were shown to be more likely to seek GMP dental care, and they may also face additional barriers (such as access) which require consideration. The most marginalised groups, such as those from the most highly deprived areas may also not have been included. Further qualitative work is therefore needed with these groups to understand the barriers they face, as well as further co-design to address these and initiate relevant change(s).

### **Appendix A. NHS Dental Charges Summary**

In England, NHS dentistry in primary care is one of the healthcare services patients have to pay a contribution for, along with prescriptions and opticians. The cost of treatment is determined using a banding system, whereby the patient pays for whichever band covers the most expensive part of the treatment they need (Table A.1). For example, if a patient has a treatment plan which includes a filling, they will pay a band 2 cost, and this will include all treatment, including any band 1 treatments. For each band the GDP earns a set number of Units of Dental Activity (UDAs). Each GDP has a UDA target to meet on an annual basis, and their salary is based on the number of UDAs they complete.

Band	Treatments Included	Patient Cost	Number of UDAs
Emergency Dental Treatment	Emergency care in dental practice, including examination and diagnosis and urgent treatment required as determined by the GDP (e.g., temporary dressing, filling, pulpectomy, extraction)	£23.80	1.2
Band 1	Examination, diagnosis, radiographs, preventive advice, scale and polish (if clinically needed), fluoride varnish, fissure sealants.	£23.80	1
Band 2	Fillings, root canal treatment, tooth extractions.	£65.20	3
Band 3	Crowns, bridges, dentures and any other dental treatment requiring laboratory work.	£282.80	12

**Table A.1:** Summary of NHS Dental Charges (National Health Service, 2005). Patient cost correct at time of thesis submission.

Some patient groups are exempt from NHS dental charges, these include patients:

- Under 18-years-old, or under 19 and in full-time education
- Pregnant or had a baby in the last 12 months
- Having treatment in an NHS hospital, or treatment by a hospital dentist (e.g., in DECs)
- Receiving low income benefits, or aged under 20 and a dependant of someone receiving these. Low income benefits include:
  - Income support
  - Income-related employment and support allowance
  - o Income-based jobseeker's allowance
  - Pension credit guarantee credit
  - Universal credit (in some circumstances)

### Appendix B. Read Codes and Keyword Search for SAIL (Chapter 4)

Read Code	Read Code Description
1912	Toothache
J020	Pulpitis
J0200	Pulpal abscess
J024	Acute apical periodontitis
1914	Dental swelling
J0250	Dental abscess
J0251	Dentoalveolar abscess
J0332	Paradental abscess
J083	Oral cellulitis and abscess
75112	Surgical removal of wisdom tooth
J0331	Acute pericoronitis
J0340	Chronic pericoronitis
1913	Bad teeth/caries
J010	Dental caries
J01y1	Sensitive tooth dentine
J03	Gingival/periodontal disease
J065	Alveolitis of jaw
J080	Stomatitis
S8363	Broken tooth injury
191	Tooth symptoms
J05y	Other specified dental disorder
J052	Dental diseases/conditions

**Table B.1:** List of Read codes included in SAIL data search for dental GMP attendances (Chapter 4).

Keyword search included: dental; tooth; dental pain; orofacial pain; pulpitis; pulpal pain; symptomatic apical periodontitis; apical periodontitis; facial pain; toothache; tooth ache; tooth pain; dental abscess; tooth abscess; periradicular abscess; dentoalveolar abscess; alveolar abscess; apical abscess; facial swelling; facial cellulitis; oral swelling; extra oral swelling; swelling of face; pericoronitis; infection following extraction; infected socket; dry socket; oral infection; oropharyngeal infection; dental infection; chronic dental pain; jaw pain; jaw ache; temporomandibular disorder; temporomandibular joint dysfunction; temporomandibular joint; TMD; TMJD; dental caries; caries; tooth decay; periodontal disease; gum disease; gum infection; ANUG; NUG; pyorrhoea; oral ulceration; recurrent aphthous stomatitis; mouth ulcers; Ludwig's angina; oral cellulitis; facial trauma.

NB – "oral" was not included as a keyword on advice of the SAIL analysis team as it captured too many non-dental events, such as "medication taken orally".

### Appendix C. Summary of PDP Analysis in SAIL Dataset (Chapter 4)

Over the 44-year period studied there were 468,827 Read codes associated with persistent orofacial pain, these accounted for 468,137 patient attendances. The overall attendance rate was 4.22 (95% CI 4.21-4.42) patient attendances per 1000 patient-years. Patient attendances increased from 1990 to 2006 and then remained at a relatively stable attendance rate (Figure C.1).

Patients were most commonly female (71.66%) and the mean patient age was 39-(SD 19) years-old. Patients were more commonly from urban areas (65.92%) and relatively evenly distributed between WIMD quintiles (Table C.1; X2 (4df, n=468,137)=32.39, p=0.996).

WIMD Quintile	No. Patients	%	
1	96,285	20.57	
2	89,722	19.17	
3	96,167	20.54	
4	87,777	18.75	
5	98,186	20.97	

Table C.1: WIMD quintile breakdown for persistent orofacial pain attendances at Welsh GMPs.

The majority of patients attended with a diagnosis of migraine (63.70%, 2.69 (95% CI 2.68-2.70) attendances per 1000 patient-years), followed by TMD (12.33%, 0.52 (95% CI 0.52-0.52) attendances per 1000 patient-years). Female patients consistently attended more frequently with all diagnoses. Almost one-third (n=92,192, 30.54%) of patients attended more than once with a persistent pain diagnosis. 47,769 patients (15.83%) attended more than once within a 12-month period.

There were 20,103 referrals associated with persistent pain diagnoses, and almost half (47.94%) of patients referred were referred more than once. Using logistic regression analysis female patients were more likely to be referred compared to male patients (OR 1.23, 95% CI 1.17-1.29, p<0.0001). Residing in a rural location was also predictive of being referred (OR 1.17, 95% CI 1.12-1.22, p<0.0001). The odds of being referred varied across WIMD quintiles with those in the least deprived quintile having the greatest odds of being referred (OR 1.39; 95% CI 1.29-1.48).

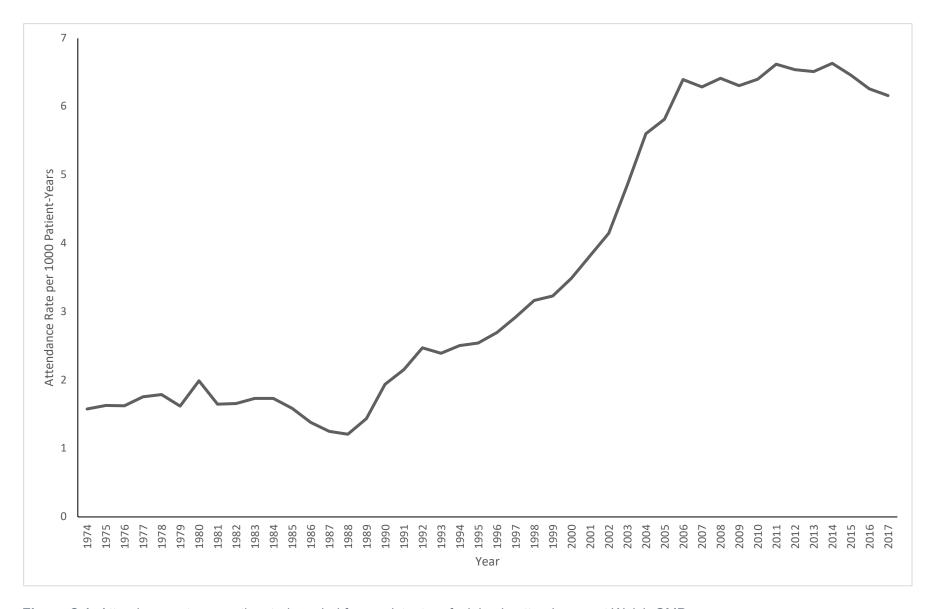


Figure C.1: Attendance rates over the study period for persistent orofacial pain attendances at Welsh GMPs.

## Appendix D. Publication from the SAIL Analysis on Dental Attendances at Welsh GMPs

This paper was published in the Journal of Dental Research (Currie *et al.*, 2022a) which summarises the analysis on attendance rates over time and predictors of repeat attendance.

Research Reports: Clinical

# Dental Attendances to General Medical Practitioners in Wales: A 44 Year-Analysis

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#### **Abstract**

One-third of the UK population is composed of problem-oriented dental attenders, seeking dental care only when they have acute dental pain or problems. Patients seek urgent dental care from a range of health care professionals, including general medical practitioners. This study aimed to identify trends in dental attendance at Welsh medical practices over a 44-y period, specifically in relation to dental policy change and factors associated with repeat attendance. A retrospective observational study was completed via the nationwide Secure Anonymised Information Linkage (SAIL) Databank of visits to general medical practice in Wales. Read codes associated with dental diagnoses were extracted for patients attending their general medical practitioner between 1974 and 2017. Data were analyzed with descriptive statistics and univariate and multivariable logistic regression. Over the 44-y period, there were 439,361 dental Read codes, accounting for 288,147 patient attendances. The overall attendance rate was 2.60 attendances per 1,000 patient-years (95% CI, 2.59 to 2.61). The attendance rate was negligible through 1987 but increased sharply to 5.0per 1,000 patient-years in 2006 (95% CI, 4.94 to 5.09) before almost halving to 2.6 per 1,000 in 2017 (95% CI, 2.53 to 2.63) to a pattern that coincided with changes to National Health Service policies. Overall 26,312 patients were repeat attenders and were associated with living in an area classified as urban and deprived (odds ratio [OR], 1.22; 95% CI, 1.19 to 1.25; P<0.0001) or rural (OR, 0.84; 95% CI, 0.83 to 0.85; P<0.0001). Repeat attendance was associated with greater odds of having received an antibiotic prescription (OR, 2.53; 95% Cl, 2.50 to 2.56; P<0.0001) but lower odds of having been referred to another service (OR, 0.75; 95% CI, 0.70 to 0.81; P<0.0001). Welsh patients' reliance on medical care for dental problems was influenced by social deprivation and health policy. This indicates that future interventions to discourage dental attendance at medical practitioners should be targeted at those in the most deprived urban areas or rural areas. In addition, health policy may influence attendance rates positively and negatively and should be considered in the future when decisions related to policy change are made.

Keywords: dental care, primary health care, toothache, antibacterial agents, epidemiology, public health

### Introduction

One-third of UK adults do not seek routine dental care, instead attending only with acute dental pain or dental problems (Morris et al. 2011; Steele et al. 2011). This attendance pattern is not exclusive to the United Kingdom, with global estimates suggesting that just over half of dental patients see a dentist for preventive or regular dental care (Reda et al. 2018). Patients with acute dental pain present to a range of health care providers in addition to dentists (general dental practitioners [GDPs]): hospital emergency departments (Currie et al. 2017), pharmacists (Cohen, Bonito, et al. 2009), and general medical practitioners (GMPs; Anderson et al. 1999; Cope et al. 2016). Attendance at practitioners other than GDPs may not be the most appropriate place for patients to seek dental care, with operative dental treatment not being available resulting in potentially inappropriate antibiotic prescriptions, direct, indirect, and opportunity costs, as well as additional burden on health care services (Cope, Wood, et al. 2018).

Patients may prefer to seek care dental care from a GMP rather than a dentist for various reasons: interpretation of

symptoms, perceptions of GMP scope of practice, comparative ease of navigating medical and dental systems, previous dental experiences, and willingness and ability to pay for treatment (Bell et al. 2008; Cope et al. 2015; Cope, Butt, and Chestnutt 2018; Cope, Wood, et al. 2018). GMP guidance and legislation within the United Kingdom highlights that presenting to GMPs

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A supplemental appendix to this article is available online.

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### Appendix E. Topic Guide for Adult Qualitative Study (Chapter 5)

The final topic guide is shown below, highlighted questions and probes were added as interviews progressed to explore emerging themes.

- 1. How would you describe the current health of your teeth and mouth as it is now? Explore:
  - Frequency of dental pain
  - Do you consider dental health important?
  - What do they consider good oral health to be?
- 2. How would you describe your general health? Explore:
  - How they prioritise their general health does this align with their dental health
  - If they need medical care who would they see for: sore throat, ear ache, stomach upset (i.e. complaints generally best managed in primary care)
  - Do they see a difference between their doctor and dentist?
  - Can they access GP appointments when needed?
  - Would they go to their GP with a dental problem? Why (not)?
- 3. Could you tell me a little bit about why you attended the emergency dentist? Explore:
  - Reason for attendance symptoms, and why on this particular day?
  - Duration of symptoms & impact on life
- 4. How did you try and manage your toothache before this appointment? (For example, did you talk to or see anyone else about your toothache before this appointment?) Explore:
  - Who have you seen?
  - Why did you decide to go there?
  - In the past for other dental problems who have you seen? Explore these experiences.
  - Any self-management techniques:
    - What? And why (over seeking dental care)?
    - How did they learn about these?
    - What medications? Where from? Stuck to recommended dose?
    - Did failure influence decision to seek care?
- 5. How did you find your appointment with the emergency dentist? Explore:
  - What treatment was carried out?
  - Treatment options discussed and which treatment carried out, why? Did they expect to get antibiotics?
  - Can you tell me what the dentist advised about any follow up care?
  - Were they told about disease process/prevention? Any new knowledge received which influences future decisions?
  - Did they have a full dental exam or specific to pain?
  - If they had did it make a difference to care pathway?
- 6. Following your appointment today can you tell me about your future plans in respect of your teeth? Explore:
  - What are your plans regarding seeing the dentist in the future?
  - Why will you/won't you? (i.e. has something at this appointment made them change their mind about seeing a dentist on a regular basis?)
  - What will you do if any further symptoms or pain?
  - Is there anything that would encourage you to see a dentist on a regular basis?

- Where do they see their dental health in the future? Do they want to improve it or happy as they are?
- Awareness of the reasons for seeking regular care?
- Is work an impact? Shift patterns, zero hours contracts etc?
- 7. Could you tell me a little bit about your experiences of the dentist over the past few years? Explore:
  - Any anxieties/phobias/bad experiences
  - Any of these experiences influence why attending emergency/not regular attender
  - Barriers/facilitators
  - (If previously were a regular attender, what happened to change their attendance pattern)
  - Experiences as a child, and as transitioned into adolescence and young adulthood probe for any changes in attendance habits and why.
  - Can you describe the relationships you've had with dentists in the past?
     Probe:
    - Specific negative or positive characteristics?
    - Can they trust dentists?
    - Problems with attitudes/mistrust?
    - Do these influence their care-seeking behaviour?
  - Difference between primary and secondary care?
- 8. How do you go about looking for a dentist?
  - In hours vs out of hours
  - NHS vs private
  - Barriers and facilitators
  - Opening hours, are dentists open late at night or weekends? Have they tried to access at these times? Does opening hours have an influence on them attending, does it relate to their working hours?
- 9. What would you do if you had toothache on an evening or weekend and needed treatment? Explore:
  - Awareness of our of hours dentistry/NHS 111
- 10. What are your thoughts and experiences of paying for dental treatment? Explore:
  - Their opinion on the cost and system do they understand the banding system? How much does dental treatment cost? Where have they gained this information from?
  - Are they aware of exemptions?
  - NHS vs private
  - Is cost a barrier? Perceived or actual?

### Appendix F. Recruitment Poster, Participant Information Sheet & **Consent Form for Adult Qualitative Study (Chapter 5)**

Recruitment Poster

# **Have You Needed Emergency Treatment** for Toothache?



We are looking for volunteers to help us understand what people do when they have toothache and don't have a dentist they see regularly.

You may be eligible if you:

- Are able to converse in English
- Are over 16 years of age
- Have had two episodes of toothache in the past 18 months for which you had to seek emergency care

Participation involves an interview with a researcher, lasting no longer than one hour, which can be either over the phone or in person.

As a thank you for participating you will be given a £20 gift voucher.

Prof Justin Durham, Chief Investigator Miss Charlotte Currie, PhD Student

School of Dental Sciences, Newcastle University

**NHS Foundation Trust** 

For more information please call 0191 208 8247

or email charlotte.currie@newcastle.ac.uk



The Newcastle upon Tyne Hospitals **NHS** 



### Participant Information Sheet





## Understanding **RE**peat **A**ttender**s** for emergency care **N**ot continuing care: REAsoN study

Chief Investigator: Dr Justin Durham

Research Student: Charlotte Currie

### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends, relatives and GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### What is the purpose of the study?

In this study we would like to explore the reasons why patients visit and use the emergency services for dental problems, rather than see a local dentist for routine regular check-up appointments.

### Why have I been chosen?

You have been asked to take part in the study as you have attended for an emergency appointment with a dentist in pain or you have contacted the research team identifying yourself as being a potential participant. We are interested in the reasons why you do not see a dentist for check-up appointments and what you do when you experience dental pain. Approximately 30 people will be interviewed, in both the North and South of England.

### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

### What will happen to me if I take part? What do I have to do?

If you choose to take part in this study then you will be interviewed by one of our researchers. This interview can either take place in person, or at a pre-arranged time which is convenient for yourself over the telephone. The interview is unlikely to last any longer than one hour. If you would rather be interviewed face to face at a later date then this can also be arranged if requested and the interview will be held in a private room at one of the institutes participating in the study. Before the interview the research team will ask you to sign a consent form, if you are being interviewed the same day as signing your consent form, then the research team will contact you 24 hours after the interview to confirm that you are still happy for your interview to be used in the study. During the interview you will be asked questions about the reasons you chose to attend the emergency dentist today, what happened during the appointment, what your future plans are to see a dentist, and about your previous experiences visiting a dentist.

If you do participate any information you provide will be treated as highly confidential and will not be shared with other individuals or organisations outside the research team.

The interviews will be recorded and then anonymously transcribed (written down) word for word by a professional transcription company. Some of the word for word quotations may be used in presentations, publications or a press release of the research, however they will be anonymised.

All study records will be the responsibility of the chief investigator. The paper transcriptions will be stored in a locked cabinet. At the end of the study the documentation records consistent with the local NHS R&D policy (JRO-SOP12) will be securely archived in a facility in the Faculty of Medical Sciences and held for a period of five years.

The research team may wish to contact you in the future about involvement in further research following this project. They may also wish to contact you to take part in a press interview following publication of this research. These are optional and if you do not want to be contacted in the future then please let the research team know and indicate this in the appropriate box when you sign the consent form.

### What are the possible disadvantages of taking part?

You will be asked to take part in an interview that may last up to an hour, however the date and time of this interview can be arranged to suit you. If preferred you can be interviewed face to face, however this may involve travelling to the interview, for which your travel expenses will be given.

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

By taking part you will be helping to explain why patients see their dentist for emergency dental appointments rather than regular routine dental treatment. If dentists understand the reason why patients do this we may be able to change the services offered so you can avoid having to use the emergency services.

### What will happen to the results of the study?

If requested the results of the study will be available for you to read once completed.

### What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. If you have a complaint please contact Dr Justin Durham at Newcastle Dental School, Level 5, Framlington Place, Newcastle NE2 4BW.

If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (0191 208 8247).

### Further information and contact details

If there is anything that is not clear in this information sheet and/or should you wish to make further contact, please find the contact details for the investigators and the Patient Advice and Liaison Service (PALS) below:

Contact details for investigators:

Dr Justin Durham
Level 5 C/O Restorative Secretaries
School of Dental Sciences
Framlington Place
Newcastle University
Newcastle Upon Tyne
NE2 4BW
0191 2227828

Miss Charlotte Currie Level 4 C/O CDH Secretaries School of Dental Sciences Framlington Place Newcastle University Newcastle Upon Tyne NE2 4BW 0191 2088247

The Patient Advice and Liaison Service (PALS):

Freepost: RLTC-SGHH-EGXJ North of Tyne PALS The Old Stables Grey's Yard Morpeth NE61 1QD

Freephone: 0800 0320202 Test: 01670511098

Email: northofthetynepals@nhct.nhs.uk

Thank you for taking the time to read this information sheet and considering taking part in the study.

The patient should be able to retain a copy of this sheet and also given a copy of the signed consent form if they chose to take part.





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		4 04/09/2017	
Participant Identification Nun		.,.,	
Name of Researcher:			
Consent Form		Please i	nitial bo
	opportunity to conside	nation sheet (04/09/2017, version 12) for er the information, ask questions and have	
I understand that my participa without giving reason, withou		that I am free to withdraw at any time affected.	
		dy, the data collected up to this point will nless I withdraw within 24 hours of the	
quotations may be used in wr	itten documents, oral <sub>l</sub>	hat anonymous, verbatim (direct) presentations or published scientific name in these documents to maintain my	
happy for anonymised verbat	im (direct) quotes to be e to see if I would like	be interested in this project and I am e used in press releases and for the to be interviewed together with the	
		scribed by a private transcription company nvolvement will remain confidential.	
will be looked at by the resear regulatory authorities or from	rch team, and may also the NHS Trust, where these individuals to h	otes and data collected during the study, to be looked at by individuals from it is relevant to my taking part in this ave access to my records. I understand that	
I am interested in future resea	arch studies and give p	ermission to be contacted.	
I agree to take part in the abo	ve study.		
Name of participant	 Date	Signature	

### Appendix G. NHS BSA Data Analysis (Chapter 5)

The below paper was published in the British Dental Journal (Currie *et al.*, 2022b), this was carried out for triangulation of the adult qualitative study in relation to the low numbers of repeat emergency dental attendances in primary dental care.

**OPEN | VERIFIABLE CPD PAPER** 

**RESEARCH** 

# Urgent dental care use in the North East and Cumbria: predicting repeat attendance

Charlotte Currie, \*1,2 Simon Stone, 1,2 Mark Pearce, 3 David Landes 4 and Justin Durham 1,2

### **Key points**

Predictors of being a repeat attender for urgent and emergency dental care included being a woman and living in the most deprived and rural areas of the North East and Cumbria.

Over a six-year period (2013–2019), the number of one-off urgent and emergency dental care attenders to primary care in the North East and Cumbria decreased before beginning to increase.

Over the same period, the number of repeat urgent and emergency dental care attenders to primary care in the North East and Cumbria decreased before stabilising.

#### **Abstract**

**Introduction** Around one-third of the UK population are 'problem-orientated dental attenders', only seeking care when suffering with dental pain and often on a repeated basis to secondary care. Little is known about attendance in primary care. The aim here was to examine the period prevalence of repeat urgent care attenders and establish predictors of repeat attendance in primary care.

**Methods** Data on urgent and emergency dental care attendances in primary dental care in the North East and Cumbria were analysed from 2013–2019. Variables included: patient sex; ten-year age band; lower super output area; and Index of Multiple Deprivation. Period prevalence was calculated and data were considered year by year to identify trends in attendances. Analysis was with descriptive statistics and predictors of repeat attendance were identified using logistic regression modelling.

**Results** Over the six-year period, there were 601,432 attendances for urgent primary dental care, equating to a period prevalence of 2.76% for the geographic population studied. In total, 16.15% of attendances were repeat attendances (period prevalence 0.45%) and predictors included being a woman and residence in deprived and rural areas. All urgent care attendances decreased over the six-year period, with one-off attendances beginning to increase again in 2019, while repeat attendances stabilised.

**Conclusion** Interventions to encourage regular dental attendances should be targeted at patients from the most deprived and rural areas of the North East and Cumbria; however, a decrease in repeat attendance was noted in these areas.

### Introduction

Just under 10% of the dentate population in England, Wales and Northern Ireland report experiencing acute dental pain¹ which is known to have a significant impact on everyday life.²-³ Despite this, almost one-third of the UK population are so called 'problem-orientated attenders',¹-4.5 only seeking care when they have acute dental pain or problems, often waiting over two months before doing so. 6.7.8 As well

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as affecting their quality of life, this also puts them at risk of serious adverse events such as  $unintentional\ paracetamol\ overdose^{9,10,11,12,13,14}$ and life-threatening infections.  $^{15,16,17,18}\ As$ problem-orientated attenders only seek care when they have acute dental pain, they frequently use drop-in services in secondary care, often on a repeated basis and for the same problem,3,19 as well as presenting to other healthcare professionals including hospital (medical) emergency departments, 20,21,22 general medical practitioners23,24 and other allied health professionals. 25,26,27,28 They will also seek urgent or emergency dental treatment with primary care general dental practitioners; however, little is known about the rates or predictors of repeat attendance in primary care. It is important that research is carried out to understand problem-orientated dental attendance so that interventions can be developed to encourage regular dental attendance and part of this understanding

must include where these patients attend, to ensure that any interventions are sited in the appropriate places.

The North East and Cumbria covers a population of just under three million people, with a slight predominance of women at 51%.29 The North East of England has a slightly different demographic to that of Cumbria, with Cumbria having a generally older population and more rural areas.30 Access to dental services also varies between the North East and Cumbria, with 2-4% of North East residents reporting being unable to access dental care, compared to 8% of Cumbria.31 A further 12% of those responding to the National GP Survey stated that they did not try to access care because they thought that they would not be able to get an appointment.31 In addition, previous commissioning reports have shown that Cumbria has higher utilisation rates of urgent dental care services than the

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# Appendix H. Secondary Analysis of Adult Qualitative Study Using the Theoretical Domains Framework (Chapter 5)

#### Methods

A secondary analysis was carried out mapping the themes generated to the Theoretical Domains Framework (TDF) (Michie *et al.*, 2005; Cane, O'Connor and Michie, 2012). This mapping exercise was done to allow examination and understanding of participants' problem-orientated behaviour and decision-making processes mapped to behavioural determinants to inform future intervention development.

The TDF was developed to encompass a broad range of psychological theories and constructs of behaviour change so these can be easily identified by researchers. The second refined and validated version of the TDF was used to map to (Cane, O'Connor and Michie, 2012). It includes 14 domains and 84 theoretical constructs shown in Table H.1.

The final coding framework was used to map the codes to the relevant domains of the TDF. Interview transcripts were also reviewed and recoded according the TDF to ensure that all behavioural and decision-making processes were identified and mapped across. This was initially done with five transcripts jointly between the myself and a supervisor with significant experience in the TDF (VAS), I then reviewed all remaining transcripts.

#### Results

The analysis is summarised along with the domain definitions in Table H.1, and represented diagrammatically in Figure H.1 and Figure H.2. This mapping process allows identification of behaviour change theory driven factors in relation to specific aspects of problem-orientated attendance, for example what influences delayed careseeking or the intention to seek regular dental care. These can be used in intervention development in the future.

Theoretical Domain	Definition	Themes	Explanation
	An awareness of the existence of something.	Experiential knowledge	
		Dental access	
		Dental disease and treatment	Participants had experiential knowledge related to
Knowledge		NHS dentistry and charges	previous experiences, this knowledge was not always correct and led to misunderstanding which acted as a barrier to regular dental care-seeking. They also had lack of knowledge related to dental access, dental diseases and the appropriate treatment required (including self-management and use of analgesics), NHS dentistry (what is entails,
		Reasons to seek regular dental care	the cost, differences to other healthcare such as GMP) and reasons to seek regular dental care. When participants received new knowledge about their oral health or dental disease they showed the intention to begin seeking regular dental care.
		New knowledge	
Skills	An ability or proficiency acquired through practice.	How to find a dentist	Participants lacked the skills to be able to access regular dental care, particularly in relation to organisation around work and other life priorities, and finding a dentist that possessed the

		How to access care	characteristics they deemed as positive. They had skills in self-management of ADP, and when these failed they would decide to seek care.
		Inability to solve own pain/infection	
		Dentist characteristics	The experience with a dentist could act as a barrier or facilitator to dental care-seeking. A positive dental encounter made participants show the intention of regular care-seeking, whereas negative
Social/Professional disp Role and Identity indiv	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting.	Different observations made on professional characteristics of dental professionals based in primary and secondary care	encounters were a barrier. Differences in dentist characteristics were noted between primary and secondary care and influenced decision-making in where to seek care. Participants would move around dental practices to try and find a dentist who had the positive characteristics they desired, and failure with this led to repeated urgent care attendances in secondary care.
Beliefs about Capabilities	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use.	Perceived competence in management of dental pain and disease	Dental care-seeking was delayed due to participants' belief that they could manage their own dental pain (i.e. through oral analgesics), or that the pain would subside without dental treatment. In addition, participants held the belief that lack of dental pain meant they did not need to seek dental care, particularly if they could not see any obvious disease and considered themselves as having good oral hygiene behaviours.
Optimism	The confidence that things will happen for the best or that	Perceived competence in management of dental pain and disease	Dental care-seeking was delayed due to participants' belief that they could manage their own dental pain, or that the pain would subside without
Optimoni	desired goals will be attained.	Long term retention of teeth	dental treatment. During adolescence and young adulthood participants could recall dental attendance being a low priority due to the belief that

			they would always have their teeth and wouldn't need to worry about dental disease.	
Beliefs about Consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation.	Consequences in self- management of ADP	Consequences (often failure) in own self- management of ADP would result in the decision t seek urgent dental care. Participants believed ora health was important but only had superficial	
		Importance of oral health	understanding of why (related to a lack of knowledge). Care-seeking would be delayed due to the concerns over being a burden on NHS dental care and the consequences this could have on others.	
		Being a burden		
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or	Care experience	Positive experiences at secondary care resulted in repeated urgent dental care attendances here and avoidance of primary care. Dentistry was compared	
	contingency, between the response and a given stimulus.	Experience with dentistry in comparison to other health care professionals and systems	to whole body health and other healthcare seeking and was considered less important because of differences in the healthcare systems.	
Intentions	A conscious decision to perform a behaviour or a resolve to act in a	Motivation	A lack of motivation to acquire the skills or knowledge to seek regular dental care was given as a reason for maintained problem-orientated dental attendance.	
	certain way	Impact of ADP/Infection	Once participants understood or experienced the consequences of ADP/infection they showed the intention to seek regular dental care.	

Goals	Mental representations of outcomes or end states that an individual wants to achieve.	Intention of regular dental attendance	Participants showed the intention to be regular dental attenders when or if barriers to regular careseeking were removed.
Memory, Attention and Decision Processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives.	Balancing and choosing priorities	Once self-management of ADP failed, or pain intensified beyond the ability to cope participants would make the decision to seek dental care. In order to seek care participants had to be able to balance and choose between other priorities, and presence of ADP could outweigh other priorities and barriers to care. This decision-making process also fed into decision-making on where to seek care. Participants previous negative experiences with dentists in primary care would lead to them repeatedly changing dentists to see if their experience improved, this often led to them having a good experience in secondary care and choosing to
		Changing dentists	repeat attend there rather than primary care.
		School dentist	Changes in either the environment or recourses
	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour.	Free dental treatment	Changes in either the environment or resources could result in change in care-seeking behaviour to either decide to access urgent care or intention to
Environmental Context and Resources		Access to dental care	attend for regular care (for example when cost was no longer a barrier). Resources (or lack thereof)
		Work	could also cause delayed care-seeking and act as a barrier to regular preventive care-seeking.  Participants noted a difference in experience
		Costs	between primary and secondary care which could be explained by differences in service available
		Differences between primary and secondary care experiences	resources and constraints.

Social Influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours.	Family influences	Family influence played a role in deciding to seek	
		Media influence	urgent dental care, delaying care-seeking (when needing to prioritise), self-management of ADP and attendance pattern as child. Social norms influenced dental attendance patterns as a child. The media could influence perceived knowledge on access to services and cost of care.	
Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant event or matter.	Anxiety	The emotions associated with dental anxiety were a	
		Experiences with a dentist	barrier to care-seeking. Experiences with a dentist could evoke either positive or negative emotions and acted as a barrier or facilitator to care-seeking. The negative emotions associated with ADP or	
		Impact of ADP/infection	infection led to the decision to seek urgent dental care and intention of regular care-seeking.	
Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions.	Self-monitoring of ADP	Participants would attempt to self-manage their own ADP and would self-monitor their own pain levels in relation to self-management techniques they trialled. Once their ADP could not be self-managed they	
		Change in attendance behaviour during transition to independence	would decide to seek care. As participants transitioned to independence they would break the habit of regular dental care and transition into problem-orientated dental attenders.	

**Table H.1:** TDF Coding Framework with the psychological definitions and mapped theoretical constructs for the qualitative study with adult problem-orientated attenders. (Definitions from Michie et al., 2005; Cane, O'Connor and Michie, 2012).

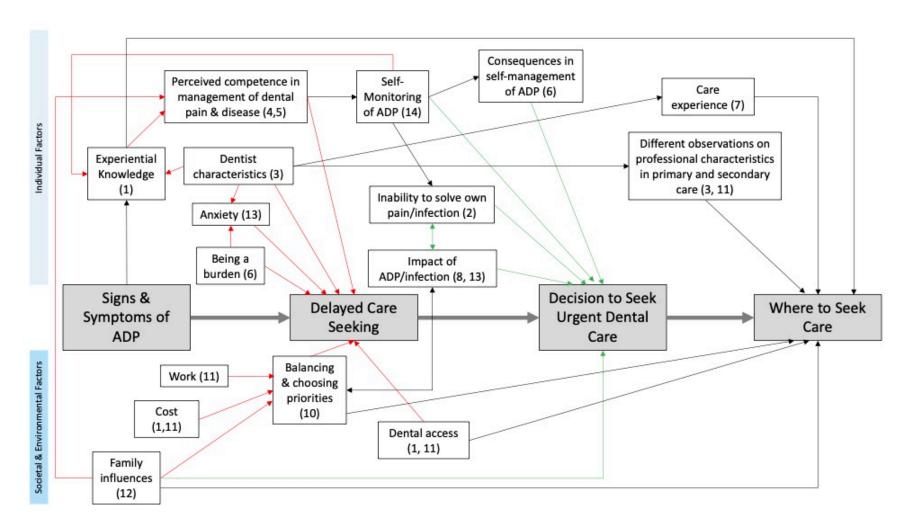


Figure H.1: A summary of the TDF in relation to delayed care-seeking, decision-making to seek urgent dental care and where to seek care. Green arrows indicate a positive influence on behaviour (e.g., the decision to seek care), red arrows indicate a negative influence on behaviour (e.g., the decision to delay care-seeking), and black arrows indicate an influence which can be either positive or negative depending on the context. TDF domains are indicated by the parentheses: (1) Knowledge, (2) Skills, (3) Social/Professional Role and Identity, (4) Beliefs about Capabilities, (5) Optimism, (6) Beliefs about Consequences, (7) Reinforcement, (8) Intentions, (9) Goals, (10) Memory, Attention and Decision Processes, (11) Environmental Context and Resources, (12) Social Influences, (13) Emotion, (14) Behavioural Regulation.

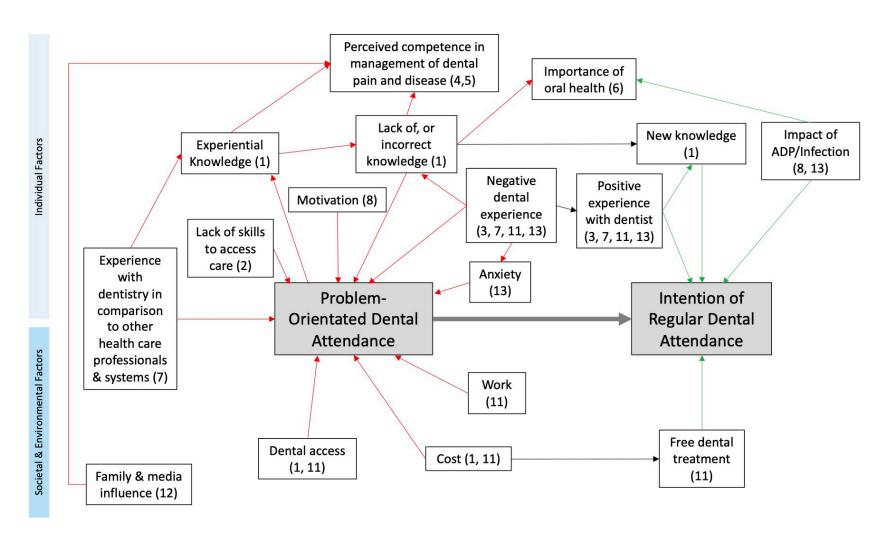
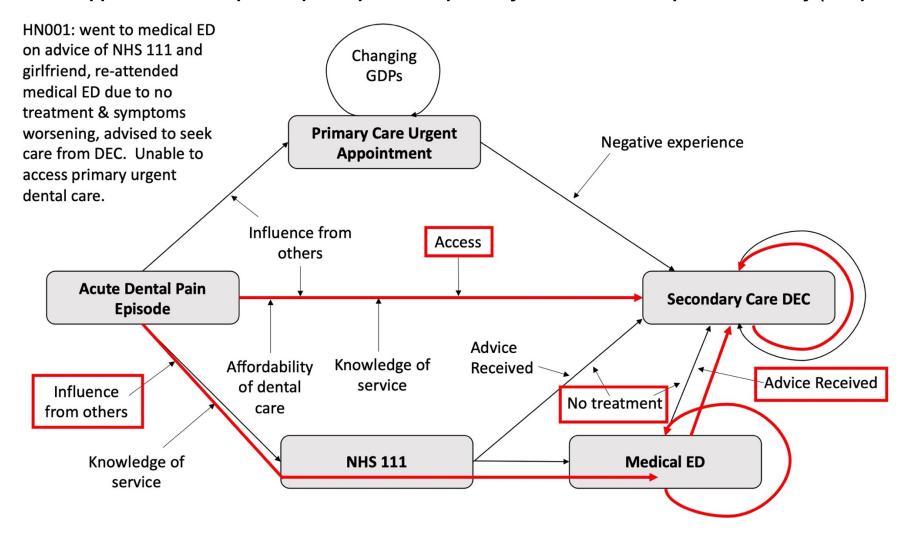


Figure H.2: A summary of the TDF in relation to problem-orientated attendance behaviour and intention for behaviour change. Green arrows indicate a positive influence on behaviour (e.g., encourages regular attendance), red arrows indicate a negative influence on b behaviour (e.g., encourages problem-orientated attendance). TDF domains are indicated by parentheses: (1) Knowledge, (2) Skills, (3) Social/Professional Role and Identity, (4) Beliefs about Capabilities, (5) Optimism, (6) Beliefs about Consequences, (7) Reinforcement, (8) Intentions, (9) Goals, (10) Memory, Attention and Decision Processes, (11) Environmental Context and Resources, (12) Social Influences, (13) Emotion, (14) Behavioural Regulation.

## Appendix I. Examples of participant care pathways from the adult qualitative study (Chapter 5)



**Figure I.1:** An example of participant HN001's urgent care pathways from the adult qualitative study.

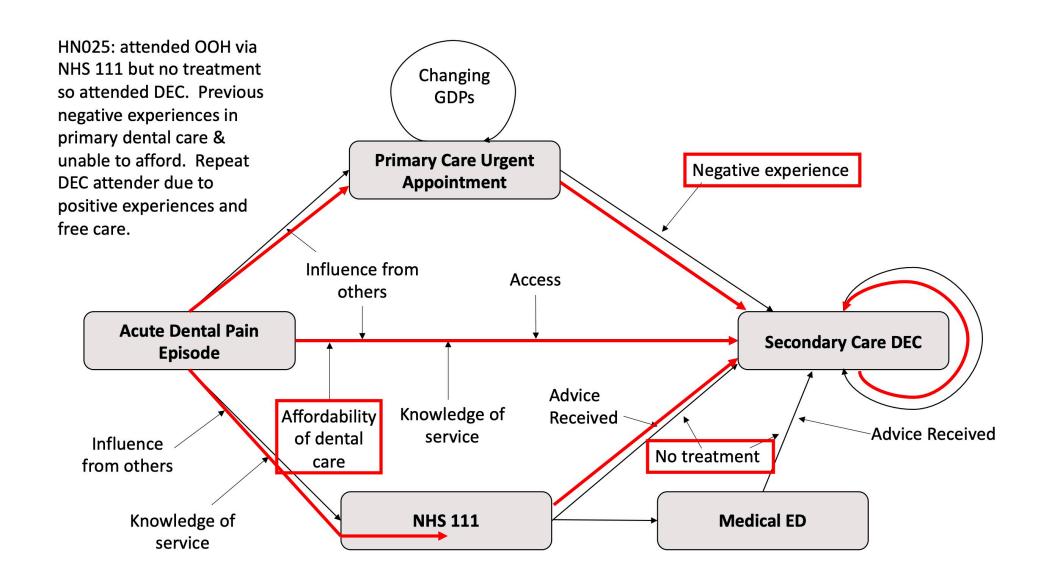


Figure I.2: An example of participant HN025's urgent care pathways from the adult qualitative study.

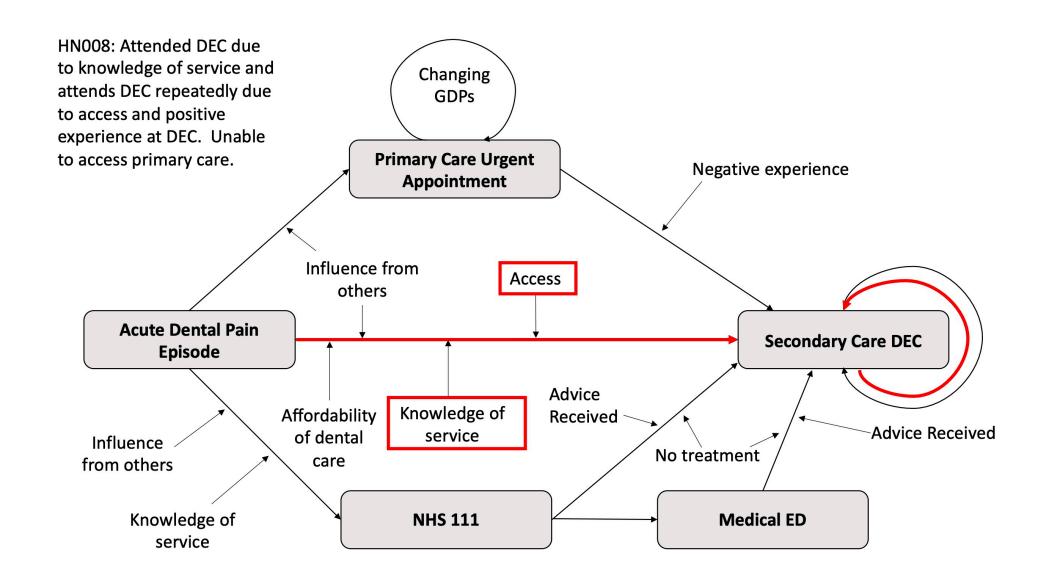


Figure I.3: An example of participant HN008's urgent care pathways from the adult qualitative study.

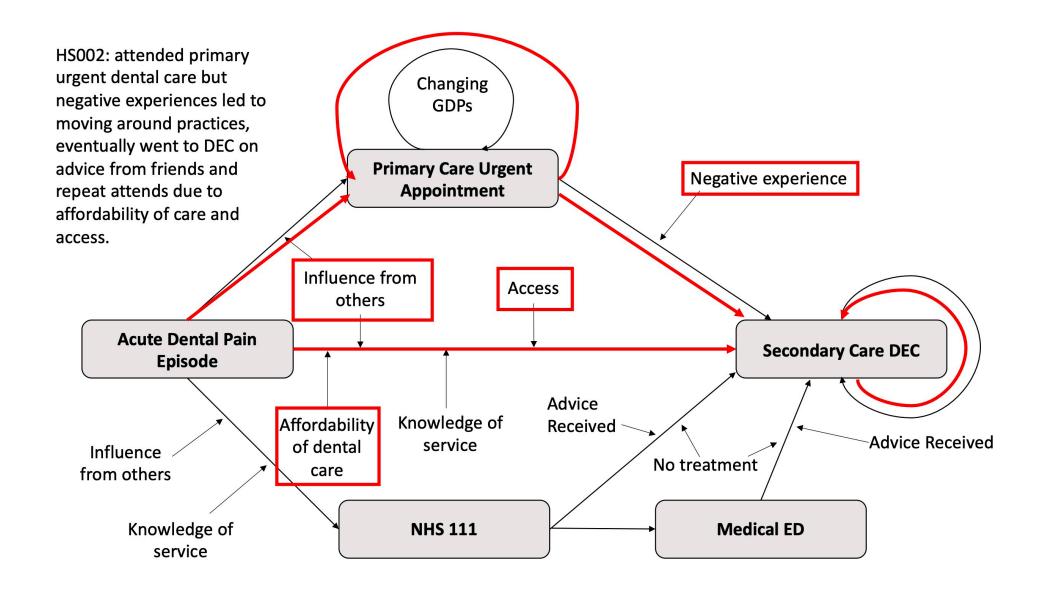


Figure I.4: An example of participant HS002's care pathways from the adult qualitative study.

# Appendix J. Additional Quotes from Adult Qualitative Study (Chapter 5)

Theme	Further Illustrative Quotations
Lack of Knowledge/ Misunderstanding	"But then I never had no pain or anything bother with my teeth up to that [age]. So it's just it [going to see a dentist] didn't seem necessary to me." PN001.
	"I probably [had toothache for] about two or three days and I thought oh it might just subside, and it didn't, it just got worse and worse to the point where I just couldn't bear it." HN023.
	"I think once my mam was no longer responsible for my [dental] appointments and what have you I just didn't have any, didn't look into it. And my mam probably told us [me] that I had an appointment, but once I was 16, 17, 18 I was like well it doesn't matter." HN008.
	"And I'd love to get my teeth in clean and tested and get them filled and get thembut I seen some figure in it and I see like two thousand pound2800. I don't know what it is but prices is there and I caught my eye by the prices because even if I want to do them stuff to my tooth I couldn't afford it so I just never look at it." HS001
	"Once I've left [DEC] the problem's gone so its' not necessary anymore [to see a dentist]" HN008.
	"I just when I've been in the waiting room I've just seen different categories where it's just like three different prices and I wouldn't have a clue to say if I had to go and get my tooth done and it did cost us £250 whether they would let you pay in three instalments or anything. I just don't know anything about that." HN026.
	"you've got pay for private NHS would be free there is some in NHS where you've got to pay some stuff[the banding system is for ] both I think" PN001.
	"I think it's at a reduced price if you're NHS, but I think it varies from dentist to dentist". HN008.
	"For me, when you are going just for observation, like the first time when I went there to tell them that I'm feeling a pain they didn't do anything. They just gave me an application form to fill, to put my insurance number and all those things, they charged me £21 and they gave me an appointment when they do a clearing, like a clean, they clean my teeth. That's what they done and they charged me £59. For me, charging such amount is when maybe they're taking off mythey're doing a very heavy job, not only seeing a customer, giving him a paper thing too to know where he lives, his date of birth and all blah, blah and to pay £21 I think is not relevant he just opened the mouth and they said here, come this day and blah, blah To be honest I don't know how they work out the cost. If they're charging the right amount, £59, maybe they would have charged only maybe £25. I haven't got a clue why they're charging from £21 just for the first visit when you go and tell them what's going wrong. They charge you £21 and then it's double or can be more than that." HS002.
	"I would suffer [with the toothache]. The last one [toothache] was over the weekend and I suffered until the Wednesday." HN020.  "I'd probably wait until the dental hospital was open [if I had toothache on weekend] because I wouldn't know where else to get
	any help. So just painkillers and wait." HN008.
	"I would just manage [dental pain] until the weekday and then go and get them sorted out then." HN011.  "Oh my God, I hope that don't happen [toothache at the weekend] because I don't know what to doI would just stick to painkillerthat's the only way, only option for someone that have pain over the weekend". HS001.
	"I didn't realise how bad they were and maybes if I had went sooner they could have saved my teeth." HN031.

#### **Dentist Characteristics**

"I've tried to get an appointment and it's just like I said, two weeks waiting and phone every day for a cancellation. But if you're in extreme pain that day and you've got to see somebody because you're so, you know, the pain's unbearable, you've got to try to just ease that pain... But all I'm getting is because I'm not a regular customer, like a regular patient, going every six month or whatever, I don't think they want to deal with you if you're not a regular... I think we are penalised...I feel like we're being penalised if you don't go regularly. They stick to the regulars and if you're not a regular I don't think...they so penalise you saying you have to wait two weeks. That's my opinion. That's how I feel." HN020.

"The way the dentist spoke to us ...he was quite abrupt ... I felt a bit uncomfortable... It was just his attitude and obviously his tone of his voice the way he wasn't very nice... I don't want to go back to the dentist because I just felt so uncomfortable." HN028.

"I took my son to a couple of his dental appointments and I found his dentist to be quite brusque so I wasn't...because my wife said well why don't you just go to the same one as [son's name redacted], but I didn't like the way that he sort of talked. So and that's one of the things is finding a dentist who's going to understand what my worries are. So I know it sounds stupid at my age being worried of the dentist but it's just something that I've got to work through." HN011.

...probably [go back to] the dental hospital. I had a really good experience there..." HN031.

"the differences [between primary and secondary care], like I said, the way you welcome the customer, the way you treat the customer. So myself I can feel that if they're doing it professionally or if it's not really, really what I'm expecting...I prefer to pay here [DEC] than my dentist..." HS002.

"They were better than my dentist in explaining things. Like they explained what was happening, why it was happening, what they were going to do. It was really good actually for me to know exactly what they were doing and why they were doing it...I think I just at the dentist you just go in and they just...I don't really feel like they're that interactive with me, like they don't really explain what's going on...I struggle to understand really what they're talking about...but I think at the dental hospital, because they had to talk it through with supervisors and they had to talk it through between each other they kind of included me in that so it was just more of an open discussion, there was more talk about what was going on. I think they were more reassuring. They were just talking to me in general and keeping me calm and I just thought it was a bit more positive." HN032.

"When I was young and I needed a filling it was at the dentist I had, [dentist name redacted] decided it would be a good idea when he was drilling my tooth to drill into my gum. And when I tried to stop him he told us [me] to stop being a baby." PN001. "I must have been about eight or nine, bearing in mind I'm 56 now, and I'd gone to the dentist and evidently I needed a filling and this particular dentist, there was no anaesthesia at all and he was drilling and drilling and drilling and obviously caught the nerve and I shrieked, and he actually slapped me, said not to be stupid and carried on drilling, and there was blood everywhere and it was just an awful experience. The pain was just unbelievable. And I was just screaming." HN023.

"Just their politeness [at DEC], the way they go on with you now. I think it's just really good at how they say to you and that and explain what they're going to do and also the last time I went to my dentist she took the tooth out and she scraped my gum and it was bleeding, the bottom gum. The dentists who are practicing are much better than our own, my own, dentist." HN020.

#### **Dental Anxiety**

"I'm terrified of dentists so I tend to only go if I need something done." HN011.

"I would see them when I'm in pain really. I'm scared of drills...So a medium pain and I'd go and see them, yeah." HS003.

"I went in [for urgent care], they did the work and there was other stuff that they said right, you'll need to come back and have a check-up and see a hygienist and some other stuff, but I didn't go back for the second appointment because I was petrified."

HN011.

"I would only go if it was absolutely necessary...I would make appointments for check-ups and when it came to the day I couldn't go because I would get so anxious... I would get up...knowing I had to go and I would be physically sick because I would get into such a state... I just couldn't go... Sometimes I would be able to go but then I've actually been sick in the dentist's surgery." HN023.

"I remember having to have nearly...well I had all my back teeth out. So I can remember that. So I think after that I think I was a little bit frightened to go to the dentist because that went on for ages." HN026.

"I would quite happily be tret by any of the people that I saw yesterday. I'll be perfectly happy to go back because it felt like they understood what you were going through. And they were really, when they were talking to you, they were talking to you and just reassuring you and advising you what they were doing." HN011.

"Well, it was scary [as a child] but you know...I were really scared of dentists...but here [DEC] I never have no problem...I don't have no problem with anything what's going to make me better...I don't have any fear once I know the thing is good for me, and if I'm having pain and it's going to help me I'm going to do it" HS001.

# Affordability of Dental Care

"If I have to go only to my regular dentist that choice that I said I have to go and pay. But again I have to make sure that I've got enough money to do it because I'm not happy with my salary. They pay me £8 an hour for the job I do during the night. They pay not only me, us, all of us, £8. It's not enough to working from 10 to 8 o'clock. Ten p.m. to 8 o'clock £8. I have to pay my rent. I have to go and pay £59 for the teeth. No sometime I prefer to stay home only take tablet and then I don't have a choice. And I think it's not really good for us as a patient. It's not really good that the fact is." HS002.

"With me working full time I have to pay for my dentists appointments. And with us just finding out that my girlfriend's pregnant I haven't had the money to consistently go to a dentist. So I can't pay for it because to save money I kind of try to ignore it and it just got worse." HN025.

"...just for the money as well really. I couldn't really afford any to go to my dentist and pay for it... It was just like a constant throbbing pain. I had been putting it off for a few weeks because I just couldn't afford it" HN031.

"I'm a full-time carer. I get income support and other benefits...[if I had to pay] I wouldn't be able to afford it..." PN001. "I would just pay the £60 and get the teeth out, get the pain out,... [when not in pain] you have to have the money spare to do that [check-ups], and at the moment I don't have that." HS001.

"I find it frustrating when there's people who have got...who don't work and things and they just go to the dentist and get everything done and then there's people who do work and don't go to the dentist because they can't pay for it." HN031. "I'm fine about it [paying for treatment], to be honest, because I think that eventually probably the National Health Service could wind up where there are quite a few areas where you're going to have to pay for the treatment. So I am fine to pay for it, it's not a thing because obviously the National Health Service is under pressure because of financial restraint. I'm a civil servant so we're pretty much in the same sort of boat financially, so it's something. If it was just maintenance type of work then possibly yeah that should be free, but anything cosmetic then yeah, I agree, it should be paid for." HN011.

"I just feel ... we don't pay to go and see the GP and probably your dental health is just as important as every other bit of health that you go and see the GP for. So I don't understand how it's different." HN031.

	"I think I'm going to end up having false teethit's very expensive to get your teeth out and false teeth put in, I'm going to haveI'll put the money away now for me and my husband if we need false teeth because at the minute we're just barely living off his wage". HN020.
Work	"It was an agenda problem I had a problem at home where the people have to come and change my tap in my bathroom and another day my daughter ask me, because we were on holiday period for the kids, so I have to keep the kid because she had an appointment somewhere, so I couldn't come here because of the agenda. The agenda was busy for me, that's why Now, yeah. I said definitely I have to come, so I came just from work because I do night shift. From work I didn't go home, I came straight away as they said you have to get there before eight o'clock if you want to be seen. So when I finish my work straight away I jump on the 468 that took me here." HS002.
	"[it was a] time factor, work factor, pain factor [decision to seek care] work on the taxis and on a busy shift I haven't got
	time for pain…" HS003 "It was a convenient day for work. I was able to get the day off without too much trouble. And at first I thought it might be okay, but it had got more and more painful as the days went on." HN008.
Influence from Others	"My mum made us [see a dentist] Otherwise I'd be honest I wouldn't have went." PN001.
	"I can't remember not seeing a dentist when I was little my mam did always make sure that we saw a dentist. Both in school, because we sometimes saw them there I remember seeing dentists all the way through my childhood, but then once I wasn't a child then I didn't really see a dentist." HN008.
	"I'd ask friends where they go [to see a dentist]." HN031
	"I think I'm just too lazy I don't feel motivated to try and find out if there is a local NHS dentist. So I think I just kind of take what I see in the media is there's none." HN008.
	"Well I was taken by my parents so I used to attend all of the appointments regularly and I didn't feel too bad about them, to be honest." HN011.
	"Just when I had problems my mam would take meThey [parents] just went when they had problems, so then ended up getting false teeth." HN020.
	"My dad was absolutely terrified didn't actually go to see a dentist until I think he would have been about 65 my mam used to go and see our dentist regular yeah." HN026.  "[my partner told me] go and see a dentist". HN008.
	"I was never really forced to go when I was youngerI was never taken for regular check-ups by my parentsI just didn't see it as being a thing I've just never really went." HN025.
	"I was recommended by someone who knows here, because since I was living in the UK since 1994 I never heard about this service here that you can come here, they can receive you free of charge. That the first time I heard about that in 2019 only. Someone told me I think it's good for you to go to King's College [dental emergency department]". HS002.  "It's just like other people say oh try this, try that [self-management method]. So I try see which one was better." HN020.
Importance of Oral Health	"Obviously you need your teeth. But it's not even like just an aspect of needing your teeth, it's more like I don't know, it just kind of like pushed on people, doesn't it, to have perfect teeth and stuff and to fit in. I don't know, it's pushed on everyone. You always hear stuff about obviously there's no offence, like women but it's always deemed in media that women get things pushed on them about how they're supposed to look and that but people don't realise this affects men as well, especially with

my teeth, and I think other men deal with that on a more aesthetically type of place. For a man it's how they look but obviously you need your teeth for eating, speaking." HN025

"it's very important. Otherwise you will lose all your teeth and you eventually have dentures on your teeth. It's not very nice is it?... Then people do judge you by your teeth. They do. You live in a society where everything's all about image. Since social media has started everyone's obsessed with their image. So it does make a difference in my view." HS003

"without healthy teeth you can't eat, it would impact on more or less everything if you can't smile or if your teeth look awful. It could really have quite a large impact on your life." HN023

"People with teeth look healthier, if you've got missing teeth you don't look at healthy". HN008.

#### Self-Management and Impact of Pain

"I just use Sensodyne toothpaste and if I get any pain I use oil of clove or Anbesol." HN020.

"...quite regularly [have toothache]...I'll avoid eating really cold ice cream or having a hot cup of coffee...". HN008.

"I did once. But the tooth was very, very loose and I managed to get it out. I just kept wiggling it and twisting it and it come out. It was one of my front ones. My other front one that's missing. [I did it] Because I just didn't want to go and see that other dentist." PN001.

"I didn't really [know how to do it at first]. I just I know from past extractions when they [dentists] twist it they listen for the crack, and when it cracks it pulls out. So I used to just twist them with the pliers until I heard the crack." HN003.

"I've got a friend that she's working but she's on very minimum wage and she had to pay for her dental treatment and she couldn't afford to go. And she was in agony for months. And she just had to keep trying to loosen the tooth, loosen the tooth, loosen the tooth all and in the end she asked me to get it out for her." PN001.

"I also went online. I either went to google or YouTube, they giving you a remedies [on] how to kill the pain...Telling you to...both things they tell you, just to flush your mouth with cold water, for some person said use our Listerine, it helped. Helped a lot. Listerine." HS003.

"...[the toothache] did disturb my sleep, waking up and being in pain and taking painkillers through the night to try and deal with it..." HN008.

"I suffer a lot of toothache. I know what generally works." PN001.

"Well I was really extremely tired because I wasn't sleeping because of the pain, and I've got children to look after and I was in pain looking after children and I was taking paracetamol and trying to get sorted myself but I didn't, it got worse." HN020. "A lot of the time I just couldn't do anything because of the pain. Just like doping myself up with painkillers and just sitting around or lying around because I couldn't do anything because of the pain. And it wouldn't be just my teeth, it would be causing massive headaches and that." PN001.

"It was the pain. It got to the point where it was just so bad and constant. I have quite a high pain threshold so that's how I was able to ignore it for eight months, but over those eight months it got progressively worse to the point where I felt like I was constantly doing 9 rounds with Mike Tyson." HN025.

"I've got pain for say five weeks now...Oh, it's [toothache] very like it's...you just can't explain it. Too hurtful. Can't explain. When it comes on can't think, can't...you can't do nothing at all. It's like your body just numb." HS001.

"As it was getting worse I knew I had to come and get it looked at. But I think if I had left it any longer I would have got to the point where it would have a larger impact on day to day life." HN008.

"To be honest over everything I've said, like over the pain I've been in for the past couple of months I'm just that's been enough for me. This is it now. I'm getting everything sorted now...It's getting too much. The pain is getting too much. Her, bless her, having to sit and listen to us whinge, that's not fair on her. I just want to get it all sorted then once it's sorted its out the way instead of it just being left and getting progressively worse." HN025.

"I always feel like I don't want to trouble people unless I really have to...it's just the way I am, I don't like to be a burden..."
HS003.

"There's other people who are in pain who might not get a ticket because I'd went over a bit of jaw ache when I've been in pain for eight months." HN025.

"Well I spoke to my workmate like oh I can't eat because I got toothache and this and that but it don't stop me from going eat all day... But I've got toothache before in the past and that like couldn't sleep nor nothing." HS001.

# Appendix K. Examples of Participants in Relation to Conceptual Model of Problem-Orientated Attendance (Chapter 5).

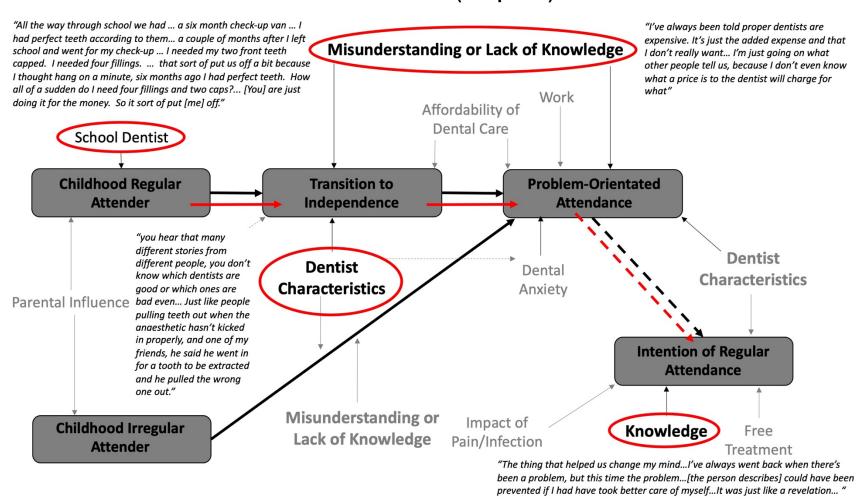


Figure K.1: An example of participant HN003 in relation to the conceptual model of problem-orientated dental attendance.

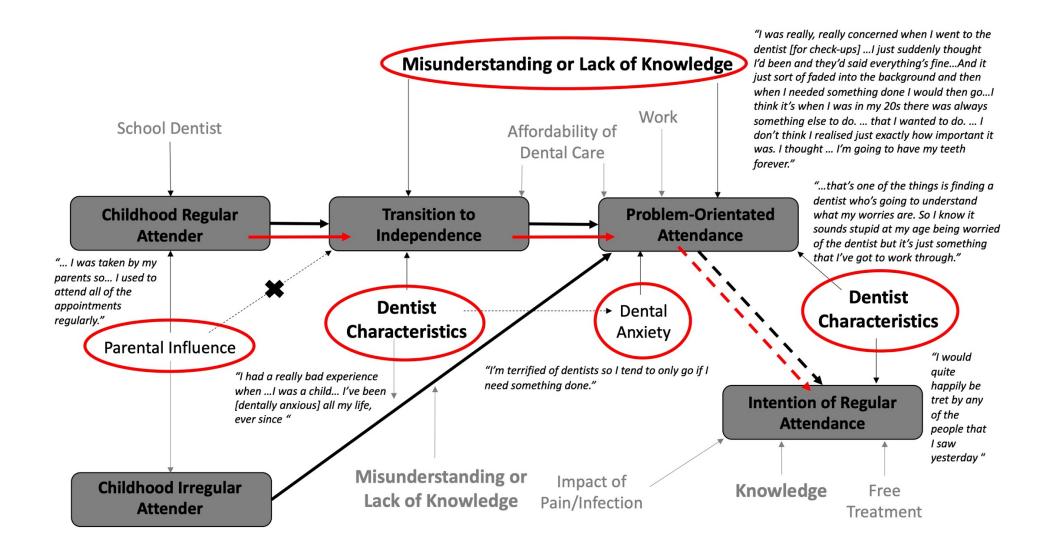
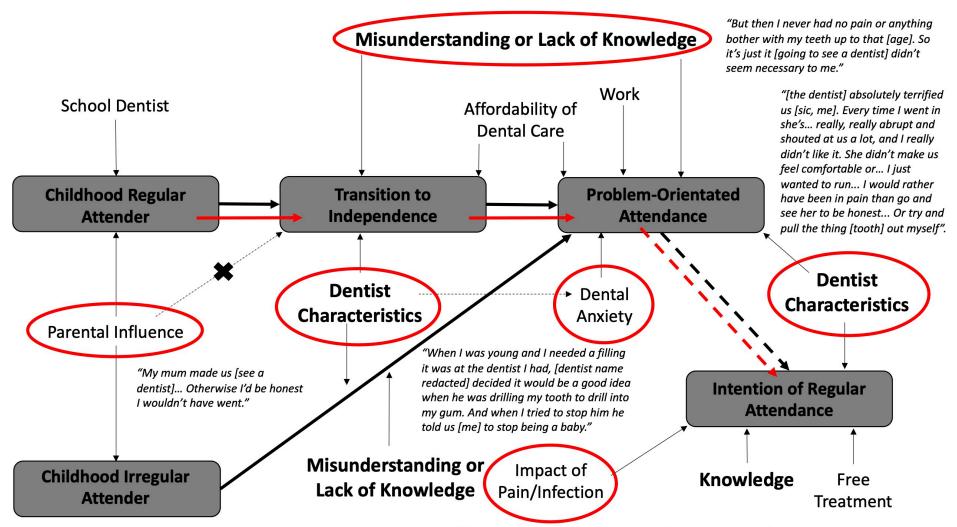


Figure K.2: An example of participant HN011 in relation to the conceptual model of problem-orientated dental attendance.



"I've just getten [sic, become] so fed up of being in pain when I've got the toothache... it just stops us doing anything, and it makes us horrible and grouchy with people...that's not who I want to be."

Figure K.3: An example of participant PN001 in relation to the conceptual model of problem-orientated dental attendance.

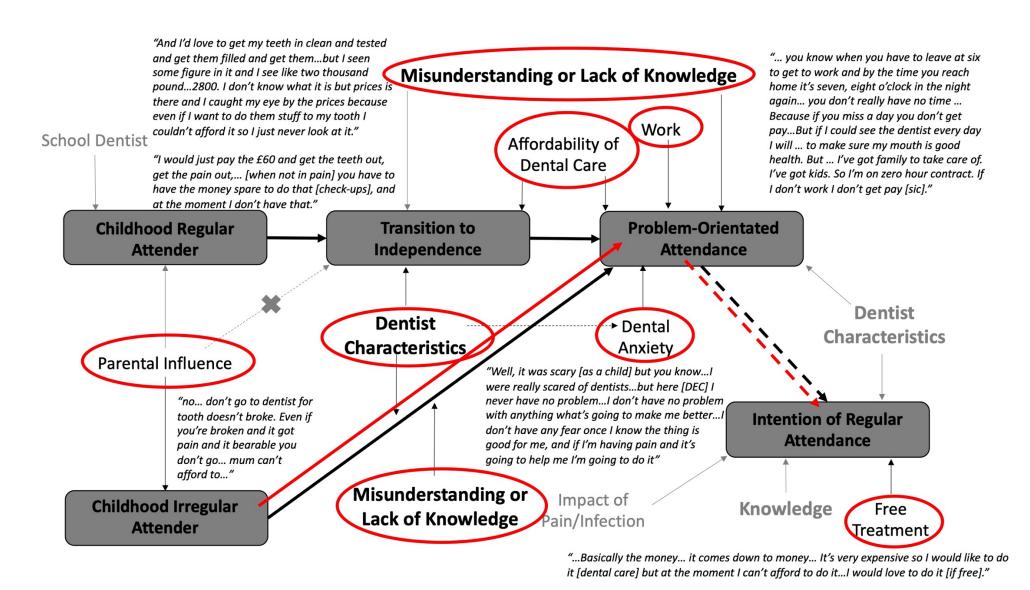


Figure K.4: An example of participant HS001 in relation to the conceptual model of problem-orientated dental attendance.

# Appendix L. Co-Creation of Animation with PPI/E to Target the Theme on Lack of Knowledge/Misunderstanding (Chapter 5)

As part of this PhD project a patient and public (PPI/E) panel of problem-orientated dental attenders was formed, they provided input to the ongoing research and dissemination plan. Due to the obvious need for public education regarding dental care and dental diseases it was suggested by the panel that an animation would be helpful to debunk the common myths about dental care and toothache. To ensure that this animation was well received and understood it was co-created with the PPI/E panel. Additional funding for this was received from the Newcastle University Faculty of Medical Sciences Celebrating Excellence in PPI/E award, with additional funding from the Tilly Hale award provided for the most outstanding application.

The qualitative research (Chapter 5) identified that problem-orientated dental attenders showed a lack of knowledge about the need for regular dental care, and had misunderstandings regarding dental charges, dental diseases and how to access dental care. In addition, it appeared that when patients were given information about dental disease or care, they reported considering attending for regular care. Common myths associated with dental care and toothache emerged from the qualitative work, therefore it was decided to use these to structure the animation. This media form was selected due to the target audience being largely young adults (18 to late 30s) from the more deprived areas of the UK, and it was felt by the panel that an animation would be most likely to attract and engage their attention, as well as deliver the educational material in a clear and informative way.

A series of seven panel meetings and activities were used to co-create the animation. Following each stage of animation design a panel meeting was held to feedback any changes required to the animation company. The following stages were used:

- Identify myths associated with dental care and disease from the qualitative research
- 2. Prioritising exercise for the order of the myths in the animation
- 3. Develop and refine a voiceover script for the animation
- 4. Select design of animation and review storyboard
- 5. Review and feedback of the animatic (this included the timing of the animation, voiceover and final design features)

- 6. Review and feedback on animation version one
- 7. Final animation viewing

Different dissemination avenues have been, and will be, utilised to maximise exposure of the target audience to the animation. The panel suggested that social media be widely used to share the animation to the target audience, including use of Facebook, Instagram, Twitter and YouTube. In addition, to ensure the widest possible reach of the animation to the public and the target audience key stakeholders have agreed to share the animation via their patient education channels and social media. These stakeholders to date include the British Dental Association, Oral Health Foundation and NHS 111. The animation will also be played in NHS Durham and Darlington NHS Foundation Trust Accident & Emergency and outpatient departments. Approvals are also being sought to allow use of the animation in pharmacies, GP surgeries, job centres and local colleges and universities. To date the animation has not yet been released due to the ongoing COVID-19 pandemic and the associated change in patient pathways and impact on primary dental care services. It is envisaged that the animation will be released and used as part of the press release for the research study when published post-doctoral, at this point it will be reviewed and edited as required to ensure it still aligns with any changes to primary dental care as a result of the pandemic.

To view the animation, scan the QR code below:



### Appendix M. Topic Guide for Adolescent Qualitative Study (Chapter

6)

The final topic guide is shown below, highlighted questions and probes were added as interviews progressed to explore emerging themes.

#### **Establishment of ground rules**

- No right or wrong answers; we just want to find out what you think
- Confidentiality information collected during the study is confidential and access will be restricted to our research team. Some of your comments may be included in a report on the study or in articles for scientific journals, but these will not use your real name or any other information that could be used to identify you.
- Some people your age go to the dentist regularly (and by "regularly," we mean every 6 months to a year), and some go less regularly. You (meaning the whole group, not an individual person) don't need to tell us how often you go to the dentist if you don't want to. You may go regularly but know people who don't. Any information you may want to share about why people your age do or don't go to the dentist would be very helpful for us
- The conversation will be recorded; however, nobody will be able to identify you from that recording other than me.
- Any questions?

#### TURN ON AUDIO RECORDER and inform participants the recorder is now on.

#### Questions

- I'd like you to all think back to the last time you saw a dentist, whenever that was. What kind of things happened at that appointment?
  - Explore what happened, e.g. check-up or treatment and their understanding of what happened, e.g. if they had a check-up what was the dentist doing or looking for? (probe, any knowledge on periodontal disease, oral cancer screening?)
  - Explore any advice or information given to them by the dentist, e.g. when are they going back, oral hygiene/diet advice etc (Probe, was there anything they wanted/expected to find out from their dentist but didn't? Did they understand what the dentist told them? Were they involved in decision-making/discussions?)
  - Explore <u>why</u> they went
- How did you feel last time you were at a dentist?
  - What did they think about the dentist and how they treated them, was there anything particularly good or bad? Is there anything the dentist could have done differently?
- Can you remember any other times you've seen a dentist? What happened then, was it the same as what you've just told me?
  - Explore same areas as above, was it different, how? Why? Which experience was better and why?
  - Can they remember when they started a seeing a dentist (e.g. can't remember not going or started at an age they can remember)

- Have their attendance patterns always been the same? Any move from regular to irregular and vice versa? Explore what may have initiated the change.
- Who takes you to see the dentist when you go? Do they also see a dentist?
  - Explore patterns of attending in their family, do they all go or just the children?
  - Explore any opinions or experiences of dentistry that may have been passed on from family members
  - o Influences from siblings, parents, and grandparents to consider
  - Who makes your dental appointments? Have you made your own appointments before? Explore this as a (future) barrier.
  - o How will they feel in the future attending without parents/family?
- Why do people your age go and see a dentist? Or why may people your age decide not to go and see a dentist?
  - Explore why they think you see a dentist for check-ups
  - o Is it different between adults and children?
  - Awareness of checking for caries, periodontal disease, oral cancer
  - Is it important? Why? Do they think oral health is important and why?
- Is there anything you think may make people your age more likely to see a dentist?
  - Probe how do people their age perceive dentists (their image/"stigma")? Where does this perceived image come from (friends/family/media?)
- Thinking about the future what are your plans when you leave school?
   Are you going to college or into work etc?
  - o What are their plans about seeing a dentist after this change? Why?
  - Is this transition an important time for them to potentially change their behaviour? Why?
  - Explore any barriers that emerge
- People your age don't pay to see a dentist, but most adults have to pay.
   What do you know about paying for dental treatment?
  - Explore if they are aware of when they have to start paying
  - o Will payment affect their decision to seek care?
  - Are they aware of any of the current costs for different treatments?
  - o What do they think different treatments should cost?

# Appendix N. Parental letter, Participant Information Sheets, Consent and Assent Forms for Adolescent Qualitative Study (Chapter 6)

#### Letter to parents/guardians



Dear parent/legal guardian,

Best wishes,

The school your child is attending has agreed to take part in a research project organised by Newcastle University. The research is looking at the experiences of teenagers when visiting a dentist. The results of the study will be used to help improve the experiences of teenagers in relation to dental care.

An information sheet on this study is included with this letter. If you and your child wish to take part they would be asked to attend a group discussion with a researcher from Newcastle University, during which they would be asked about their experiences of seeing dentists. The researcher has a full clear Disclosure and Barring Service check. The group discussions will take part in the school, in form groups and will take approximately one hour. If your child would like to take part but would rather not discuss their experiences in a group setting then an individual interview with the researcher can be arranged instead.

Please take time to read the enclosed information sheet. If you, or your child, would rather that your child <u>not</u> take part in this study then please complete and return the slip at the bottom of this letter to the school by [INSERT DATE]. If you would like any further information then please contact the school who will ask the research team to contact you directly.

Charlotte Currie		
(Researcher at Newcastle University)		
Name of child:		
I do not want my child to take part in the o	dental research study fror	n Newcastle University.
Parent Signature:	Date:	



# Investigating Problem-Orientated Patient Pathways: Toothache to Treatment

Examining the Transition to Independence in Relation to Dental Attendance

Chief Investigator: Dr Simon Stone Research Student: Charlotte Currie

#### **Parent Information Sheet**

Your child is being invited to take part in some research. Before you and your child decide if you want to take part, it is important for all of you to understand why the research is being done and what they will have to do. Please take time to read this information sheet carefully and discuss it with your child. You can also discuss it with friends or the school if you wish. Ask the research team if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like your child to take part.

#### What is the purpose of the research?

In this research we would like to find out more about teenagers' experiences of seeing a dentist.

#### Why has my child been chosen?

Your child has been asked to take part as they attend one of the schools who have agreed to help with recruitment for this study. We are interested in what happened and how they felt when they last saw a dentist and on any other occasions they can remember seeing a dentist. We are also interested in what they know about dentistry and what their plans are about seeing a dentist again when they get older and leave school.

#### Do they have to take part?

It is up to you and your child to decide whether or not to take part. If you do decide for your child to take part you will be given this information sheet to keep and your child will be asked to sign a consent form. Once they have signed the consent form, you and your child are still free to decide not to take part at any time and you do not need to give a reason.

#### What will happen to them if they take part? What do they have to do?

If you and your child choose to take part then your child will have a group discussion with a researcher about their experiences seeing a dentist. This will be done with

other students in their form group who they feel comfortable having a group discussion with. The researcher has a clear disclosure and barring service (DBS) check and works for Newcastle University. This group discussion will be done at their school and at a time arranged by their teachers make sure it doesn't affect their normal school classes or school work. It will last for about one hour. During the group discussion they will be asked questions about what has happened when they've seen a dentist, how they felt and any other thoughts they have about dentists and what they think they'll do in the future about seeing a dentist.

If they do participate, any information they provide will be treated as highly confidential and will not be shared with other individuals or organisations outside the research team. The group discussion will be recorded and then anonymously transcribed (written down without any of the students' names) word for word by a professional transcription company. Some of the word for word quotations may be used in presentations, publications or a press release of the research, however they will be anonymised so no one knows who said it.

The research team may wish to speak to you and your child in the future about taking part in more research following this project. They may also wish to contact you and your child to take part in a press interview following publication of the research. These are optional, and if you do not want to be contacted in the future then please let the research team know and indicate this in the appropriate box when you sign the consent form.

All study records will be the responsibility of the chief investigator. The paper transcriptions will be stored in a locked cabinet. At the end of the study the documentation records consistent with the local policy will be securely archived in a facility in the Faculty of Medical Sciences and held for a period of five years.

#### What are the possible disadvantages of taking part?

Your child will be asked to take part in a group discussion that may last up to an hour, however the time of this will be arranged so it doesn't affect any of their school classes. Some people do not like to talk about their experiences in seeing a dentist. If there are any questions your child would not like to answer, they can tell the researcher they do not want to answer.

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

By taking part, your child's answers will help researchers develop ways to improve other teenagers' experiences of seeing a dentist. They will also be given a £20 shopping voucher to say thank you for taking part.

#### What will happen to the results of the study?

The results of the study will be given to the school without any students' names included and combined with the results from other schools so you can find out what happened.

#### What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. If you, or your parents, have a complaint please contact Charlotte Currie or Dr Simon Stone at Newcastle Dental School, Framlington Place, Newcastle NE2 4BW.

If you have a concern about any part of the study, you should ask to speak with the researchers who will do their best to answer your questions (0191 208 8247).

#### Further information and contact details

If there is anything that is not clear in this information sheet, and/or should you wish to make further contact, please find the contact details for the investigators below.

Contact details for investigators:

Dr Simon Stone Miss Charlotte Currie
School of Dental Sciences School of Dental Sciences

Framlington Place Framlington Place
Newcastle University Newcastle Upon Tyne Framlington Place
Newcastle University Newcastle Upon Tyne

**NE2 4BW**0191 2088515 **NE2 4BW**0191 2088247

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Thank you for taking the time to read this information sheet and considering taking part in the study.

The participant should be able to retain a copy of this sheet and also given a copy of the signed consent form if they chose to take part.



# Investigating Problem-Orientated Patient Pathways: Toothache to Treatment

Examining the Transition to Independence in Relation to Dental Attendance

Chief Investigator: Dr Simon Stone Research Student: Charlotte Currie

## **Participant Information Sheet**

You are being invited to take part in some research. Before you decide if you want to take part it is important for you to understand why the research is being done and what you will have to do. Please take time to read this information carefully and discuss it with your parents and friends. You could also ask your teacher if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### What is the purpose of the research?

In this research we would like to find out more about teenagers' experiences of seeing a dentist.

#### Why have I been chosen?

You have been asked to take part as your school has agreed to help find teenagers to take part in this study. We are interested in what happened when you last saw a dentist and how you felt, as well as any other times you can remember seeing a dentist. We are also interested in what you know about dentistry and what your plans are about seeing a dentist again once you've left school.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part and you sign the consent form you are still free to decide not to take part at any time and you do not need to give a reason.

#### What will happen to me if I take part? What do I have to do?

If you choose to take part then you will have a group discussion with a researcher about your experiences seeing a dentist. This will be done with other students in your form group who you are happy having a discussion with. This group discussion will be done at your school and at a time arranged by your teachers and the research team to make sure it doesn't affect your normal school classes or school work. It will

last for about one hour. During the group discussion you will be asked questions about what has happened when you've seen a dentist, how you felt and any other thoughts you have about dentists. You will also be asked what you think you'll do in the future about seeing a dentist once you've left school. Any questions the researcher asks you and the group will not have a right or wrong answer, and if you don't understand the questions the researcher can help explain them. If you don't want to answer any of the questions that is also ok. You can let the researcher know that you would rather not answer that question at any time.

If you do take part in this study, any information you give will be treated as highly confidential, this means that no one else will know what you've said outside of the group discussion and the research team. The group discussion will be recorded and then anonymously transcribed (written down without your name being included) word for word by a professional company. Some of the word for word quotations may be used in presentations, publications or a press release of the research, however they will be anonymised so no one knows who said it.

The research team may wish to speak to you in the future about taking part in more research following this project. They may also wish to contact you to take part in an interview with the press (for examples the news reporters or journalists) when they publish the research. These are optional and if you do not want to be contacted in the future then please let the research team know and indicate this in the appropriate box when you sign the consent form. The research team will help you with this if you would like.

All the study's paperwork and information will be the responsibility of the chief investigator. All paperwork will be stored in a locked cabinet. At the end of the study, the study's paperwork and information will be kept in a secure location at Newcastle University in the Faculty of Medical Sciences for a period of five years.

#### What are the possible disadvantages of taking part?

You will be asked to take part in a group discussion that may last up to an hour, however the time of this will be arranged so it doesn't affect any of your school classes. Some people do not like to talk about their experiences in seeing a dentist. If there are any questions you would not like to answer, you can tell the researcher you do not want to answer.

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

By taking part, your answers will help researchers develop ways of helping to improve other teenagers' experiences of seeing a dentist. You will also be given a £20 shopping voucher to say thank you for taking part.

#### What will happen to the results of the study?

The results of the study will be given to your school without your name, and combined with results from other schools so you can find out what happened.

#### What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. If you, or your parents, have a complaint please contact Charlotte Currie or Dr Simon Stone at Newcastle Dental School, Framlington Place, Newcastle NE2 4BW.

If you have a concern about any part of the study, you should ask to speak with the researchers who will do their best to answer your questions (0191 208 8247).

#### Further information and contact details

If there is anything that is not clear in this information sheet, and/or should you wish to make further contact, please find the contact details for the investigators below.

Contact details for investigators:

Dr Simon Stone Miss Charlotte Currie
School of Dental Sciences School of Dental Sciences

Framlington Place Framlington Place
Newcastle University Newcastle Upon Tyne Framlington Place
Newcastle Upon Tyne

**NE2 4BW**0191 2088515 **NE2 4BW**0191 2088247

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Thank you for taking the time to read this information sheet and considering taking part in the study.

The participant should be able to retain a copy of this sheet and also given a copy of the signed consent form if they chose to take part.



## **Investigating Problem-Orientated Patient Pathways: Toothache to Treatment**

Examining the Transition to Independence in Relation to Dental Attendance

Participant Identification Nu	mber:		
Name of Researcher:		Pleas	se initial boxes
I confirm that I have read an Version 1) for this study and information, ask questions a	d I have had the opportu	nity to consider the	
I understand that my particil at any time without giving re			
I understand that if I wish to to this point will be included withdraw within 24 hours of	in the analysis of the re		
I agree to the group discuss verbatim (direct) quotations presentations or published s identified by name in these	may be used in written scientific papers. I unde	documents, oral rrstand that I will not be	
I understand that the media project and I am happy for a in press releases and for the like to be interviewed togeth occasion arise.	anonymised verbatim (di e research team to appr	rect) quotes to be used oach me to see if I would	
I understand that the data was transcription company and sinvolvement will remain con	securely stored by the re	• •	
I am interested in future res contacted.	earch studies and give բ	permission to be	
I agree to take part in the al	pove study.		
Name of participant	Date	Signature	
Researcher	 Date	 Signature	



## **Investigating Problem-Orientated Patient Pathways: Toothache to Treatment**

Examining the Transition to Independence in Relation to Dental Attendance

#### **Participant Identification Number:**

Name of Researcher:		Ple	ease initial boxes	
I confirm that I have read and understand the information sheet (25/11/19, Version 1) for this study and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.				
•	time without giving	voluntary and that they are reason, without their or my		
collected up to this poir	nt will be included in	draw from the study, the data the analysis of the research ars of the group discussion.		
I agree to the group dis anonymous, verbatim ( documents, oral preser understand that my chil documents to maintain	direct) quotations matations or published will not be identifi	ay be used in written I scientific papers. I		
project and I am happy used in press releases	for anonymised ver and for the research be interviewed toge	ic might be interested in this batim (direct) quotes to be team to approach me to se ether with the Researchers		
	and securely stored	usly transcribed by a private by the researcher and that r	ny	
I am interested in future contacted.	e research studies a	nd give permission to be		
I agree to my child takir	ng part in the above	study.		
Name of participant	 Date	 Parent Signature		
· ·	Date	Child Signature		
Researcher	 Date	Signature	<del></del>	



## **Investigating Problem-Orientated Patient Pathways: Toothache to Treatment**

Examining the Transition to Independence in Relation to Dental Attendance

Participant Identification Number:		
Name of Researcher:		
Child to circle all they agree with:		
Do you understand what this project is about?		Yes/No
Have you asked all the questions you want?		Yes/No
Have you had your questions answered in a way yo	u understand?	Yes/No
Are you happy to take part?		Yes/No
If any of the answers are 'no' or you don't want to a lift you do want to take part, you can write your name.  Date:		e!
The researcher who explained this project to you n	eeds to sign too:	
Print name:		
Sign:		
Date:		
Thank you for your help.		

# Appendix O. Additional Quotes from Adolescent Qualitative Study (Chapter 6).

Theme	Additional Quotes with TDF domains in bold
Knowledge	"PAR1: I don't know [why I see a dentist].
	PAR2: Yeah
	PAR4:it's like a normal thing to do really
	PAR5: but you don't see the doctors so often so, like
	PAR4: Yeah."
	"BEL3: They just check your teeth.
	I: What are they checking your teeth for?
	BEL4: To see if they're damaged or have, what do you call them?
	BEL2: Fillings.
	BEL4: Fillings, yeah."
	"I: So a few of you mentioned then that you had check-ups. What kind of things happen as part of a check-up?
	BEL8: See if your teeth are healthy.
	BEL9: Make sure you brush them right.
	I: Anyone else?
	BEL11: See if there's anything wrong.
	I: What kind of things might be wrong with your teeth?
	R11: Holes.
	I: So what do you think a dentist is doing when you have a check-up?Do you think you know what a dentist is doing?
	BEL8: No.
	I: No? I can see lots of head shaking Do you think you need to know what a dentist is doing?
	All: Yeah.
	I: But you don't feel like you do at the minute?
	BEL11: No."
	"BEL13: But like now you have all the toothpaste to do it for you. So
	BEL9: Yeah, you don't need to go [to the dentist] with that toothpaste.
	BEL10: Yeah. So if you've got the toothpaste then you don't need to."
	"PAR3:I wish they'd like say more if your teeth are like bad instead of not saying and then telling you, you need to come in to get your teeth removed or something.
	PAR2: Yeah.

PAR1: Yeah.

PAR3: Like if they see something a bit dodgy ... I wish they'd just like straight up be like...

PAR2: ... they sort of like sugar coat it... I had to get... like a layer on the top of my molars ... a protective layer but I think it was because ... the inside of my tooth was wrong, but they didn't say that, they just said we're just going to do this for protection as if it was like we wouldn't understand or something."

"I: Are you happy that you know what the dentist is doing and why they're doing that?

PAR3: I don't really know what they're doing.

PAR1: Not sure, yeah.

PAR1: Yeah. I don't understand that.

PAR2: Yeah, and they'll be saying like one nurse will be like E3 or something.

PAR5: Yeah."

I: If you were told what was going to be happening at each appointment that would make you feel better.

All: Yeah.

PAR1: Yes.

PAR3: Sometimes, I don't know. If it's something really bad I'd worry like all the time

PAR4: Yeah. I don't ...

PAR3: And if there were, say they were going to give me a filling or something ... I think I'd be more scared. Because I think sometimes, I think it just depends on the person really."

### Dentist Characteristics

"BEL2: What I don't like about dentists is like every time that you go you get a different person. I always get a different person. I'm like what's going on."

"BEL6: My dentist doesn't really give very good advice. But we went on this trip a while ago called the medicine and dentistry one, and they gave us these purple tablets to see where you don't brush your teeth, and I learnt more then than I have going to the dentist."

"PAR1: I've changed dentists like a few years ago... I was a bit nervous to start with because I had been seeing him for like eight years something then you change and it's quite scary."

"PAR11: When I got moulds taken I was really like scared... I didn't really know what was going to happen because the lady wasn't very good at explaining ... she didn't tell us [sic, me] what was going to happen, so I didn't know that she was going to shove like a massive mould in my mouth...She said it to my mum but then she never actually told me... I was just sat in the chair and couldn't hear what they were saying to each other... she had like one of the face masks on... I couldn't even really understand what she was telling me. I couldn't breathe properly...That's like freaks me out a bit about going now.

PAR13: I think mine didn't actually explain what was about to happen and all of a sudden it was like when she explained it the little explanations she gave us, she just didn't made it very, very clear I was like trying to not move and she had to do it again and again.

Like I could have the stuff up my nose and she basically went but let's not explain what's happened, just tell us [sic, me] she can't mess it up. She couldn't have added any more stress to it, which made me more like hyperventilate and I was just like stopped breathing..."

"PAR3: Because I think they always like if my brother brushes his teeth better than me they always like say something

PAR2: Oh they do that, yeah.

PAR5: They compare. Yeah.

PAR4: They shame you.

PAR2: Yeah, they shame you compared to the other people in the room. I had a tea stain on the back of my teeth the last time we went and he wouldn't let it go.

PAR3: Yeah.

PAR2: Yeah.

PAR1: It looks like everyone gets stressed.

PAR3: Like I didn't know why my brother did it better. Like I would have rather have been able to like…like if they tell me what he's done better is probably some incentive to do better, but how do you brush your teeth better?

I: Yeah. So if he'd explained why your brother was better than you then...

PAR3: Yeah."

"BEL6: They say a lot of technical stuff to the other person that's there...

BEL2: Oh yeah.

BEL3: Yeah, like the numbers...

BEL6: What are they even saying?

BEL3: I know, but on top of that ... they're saying nice things about your teeth as well. Like oh you still have a lot of baby teeth, you must have took care of them well... Like they do have all these technical words but they speak to you as if they've known you forever. They're nice about it."

"BEL3: I kind of enjoy being there because well it sound like really bad but my dentist is so relatable. When I got my roots removed she had that Everybody's Talking About Julie, the musical soundtrack, on in the background, so I was just jamming to that so she like makes it very relaxed for when you're there so like it makes it enjoyable rather than .aahhh hands in my mouth."

"BEL7: I like the orthodontist better than an actual...than a normal dentist.

I: And why is that?

BEL7: Because I get the same orthodontist every time. Like for everything.

*I:* So the fact you see the same person is important?

BEL7: Yeah."

"BEL1: Yeah, and most of us need braces anyway so you have to go to a dentist to get referred...I like the orthodontist better because I can see the improvement whereas with the dentist they kind of just go yeah, you've brushed your teeth, that's fine. BEL3: I know but you wouldn't have seen the improvement if it wasn't for your normal dentist."

"BEL3: I had to get my premolars taken out so that I could get more braces and as the dentist were doing the thing I had a different dentist and as she was doing...as she was talking my teeth like yeah, like, she was like oh by the way if something goes wrong and the tooth breaks we might have to like get you in a surgery, you know, like traumatised. So that was the most traumatising experience of my life. And yeah, that's about it."

### **Dental Anxiety**

"I: What should dentists do?

BEL10: Just talk to you. Just like talk to you like a normal person.

BEL12: And tell you what you're getting done.

BEL13: Yeah.

BEL10: And just make you feel comfortable."

"I: So the last time you were at a dentist how did you feel?

PAR3: Scared...

PAR2: Yeah. I was really anxious."

"PAR2: The thing is it's like I think you're like ...like I remember reading that book Demon Dentist ...

[Talking over one another].

PAR2: Something like that is like you're given it as a kid and it just sort of freaks you out. You go in and still expect someone to pull your teeth out and make a chair out of them."

"I: Is there anything that could be done which would make people your age more likely to go and see a dentist?

PAR15: I'd get rid of the stigma around them...

I: So what type of a stigma do you think dentists have?

PAR9: Because they're dentists.

PAR10: Yeh, they're just dentists.

PAR11: That's exactly it, just dentists.

PAR10: It's just what people think about dentists, like evil.

PAR15: Yeah... Evil. Like loads of like barbershop dentists who's killed people in the past.

PAR10: Yeah. They need to stop making horror films where dentists are involved in them, because that's never going to end well. That just really like no dentist realistically is going to say give you a filling and actually saw your mouth in half, like no. But they need to stop making films that stuff like that happens because it's just irrational, but still causes fear."

PAR3: ... if people have a bad experience with the dentist then that ...carries forward and ... they don't like the dentist because they're scared the same thing will happen again...

PAR2: ... It's like nothing's ever gone horribly wrong with my teeth ...the dentist is fine, like I don't mind going, but then it's like always before you go you do think that's the stuff other people have said."

"BEL3: [I'm anxious about] The funny x-ray. Do you know what when he put like the big clamp in your mouth and then they walk outside.

BEL2: Oh yeah. And it proper hurts.

BEL3: Yeah.

BEL2: Because it digs right into the side of your cheek.

BEL3: Yeah. It digs right into your cheeks.

BEL2: And they're like oh close your mouth, put your teeth together and you can't.

BEL3: Uh-huh. And then these...they were using an adult one in your mouth and not too big in for a fit. They're like oh it's safe, it's safe and they run three miles away then they come back. It's like oh it's all good.

BEL1: The last time I got an x-ray I had a cold and she told me not to move when I really needed to cough, and then she had to take the same x-ray like five times because the machines were slow. So I really needed to cough and she just kept on going don't move and then running out the room. I was like but I need to move to cough.

BEL4: Yeah.

BEL5: My dentist is really nice about that because I had like a bad cough. She was real nice about it and she's like OK, so ready. It's like it's a mission to get it done as quickly as she can before I like end up coughing it up."

"BEL7: When I was like little my brother said that dentists were evil, that's when I started being afraid of them from about four, I think, and when I went to the dentist they genuinely had to drag me in to the cabinet thingy and I wouldn't let them, because my baby teeth were falling out and I wouldn't let them pull it out so I was crying and I had to run in the hallway and they pretended as if they were washing my teeth and that's how they got my tooth out."

"PAR 10: The worst was like when you get the little x-ray thing you've got to bite down really hard..."

"I: Was there anything in particular that happened that made you feel more anxious that day?

PAR16: So I don't know, I think it was just because like it's something new and that I'm not a hundred per cent sure what's going to happen. I wasn't a hundred per cent sure on it. Like that's what provoked my anxiety so I was that's like not scarred me but that has...that make me more wary when I go to the dentist.

I: OK. So, you didn't really know what was going to happen and that was what was making you worried. PAR16: Yeah."

### Affordability of Dental Care

"BEL7: It can just put some people off from it because that's the problem with most adults in my family, they're like well I'm not paying for that."

"I: OK. What about everyone else? Do you think the fact that you're going to have to pay in the future might stop you going?

BEL6: It just depends where life takes you really.

BEL2: Yeah.

BEL6: It will depend how struggling, how much you're struggling with money and how expensive it is.

BEL3: Yeah, I feel like it would be a reason for why I would see them less regularly.

BEL2: Yeah."

"I: Do you know how much you have to pay at the minute to see a dentist?

BEL6: No.

BEL1: I'd say sixty pound.

*I:* Do you know what that's for?

BEL1: Just a check-up.

BEL7: Sure it's about £25 for a check-up.

BEL3: Are you sure?

[BEL7 Shrugs shoulders]"

"I: ...people your age don't have to pay to see a dentist at the minute, but most adults do have to pay. What do you know about paying for dental treatment or what do you think about it?

BEL13: It's expensive...My mum went on last week or something and she has to get a new tooth or something and it's like £600.

I: Right. Do you think you should have to pay?

BEL13: Nah.

BEL9: Yeah.

BEL14: Or like lower prices.

BEL10: Yeah, in some respects because you cannot just have everything for free because it's not how it works really.

BEL13: But it's like people are just expected to pay and they can't.

BEL10: Yeah.

I: Do you think a lot of it's to do with price then would you say?

BEL13: Uh-hm.

I: OK. So do you all know how much you have to pay at the minute for something like a check-up then?

BEL12: What, as an adult? Not sure...

BEL13: Say 20?....I'm not sure... I don't know.

BEL10: Twenty to 30 aye.

BEL12: £100 plus."

PAR5: And it's too expensive.

PAR3: Yeah. And like the money thing, like paying for a check-up. Like, it's probably not [that important].

"PAR4: Basically I don't have any money, like. Not that you can't go, it's just that well not that you won't go, it's that you can't because you're focusing on like eating and drinking, like.

PAR5: But then... it's like I don't know, do you have to get like dental insurance and stuff like that. It's like that's still a lot of money to pay out for just in case.

PAR3: Oh yeah, yeah.

PAR5: I feel like if it's for university, for example, and money's really tight then I'd be like well these are the things I need on money and stuff for and they'll be like necessary everyday things that go there and then if I'm OK then these things will be next important and then maybe a check-up.

PAR3: Yeah."

"I: What do you know about having to pay for dental treatment?

PAR3: It's expensive ...

PAR4: I think it's, is it twenty-five quid?

PAR5: Oh I can't remember.

PAR4: No, if anything's wrong you've got to pay like quite a lot more

PAR3: Oh yeah, yeah, yeah.

PAR2: Obviously, I thought the check-up was like forty guid or something.

PAR3: Because if I paid for a check-up and found out something was wrong I'd have to pay like a thousand pounds..."

"PAR10: I just think it's like a bit unfair that like say you don't choose to uni and you choose to like go get a job and then you have to start paying straight away there's so much other things to pay for...

PAR13: Depends on your situation...

PAR11: Yeah. Depends on like the financial situation. If it's not practical to spend that money on the dentist then I won't..."

# Transition from School

"I: What about when you get a bit older, what do you think you're going to do?

BEL1: I would go.

BEL6: You'll not go, not when you're older though.

BEL5: I think I'll still go but ...I wouldn't go regularly ... I think I would extend the amount of time that I have between. So like now I have six months. Maybe when I'm older I'll have once a year, like every year. I don't know...

BEL1: I would still go because it's like all this work I would want to make it, like I said, correct.

BEL2: Yeah. I'd still go but how long I have in between I don't know.

BEL7: I wouldn't go as often... Because you keep busy because you've got more stuff to do.

BEL4: I mean I'd still go regularly something like that...but I think it would be difficult as an adult because like my grandma takes me because my dad can't fit in with work because normally the open spaces are during the day and it's difficult to get time off work so...

BEL3: I think I would still want to go but obviously if we end up moving to go into a university then ... you've got that pressure of setting up a new one... so I feel like I would be a bit apprehensive of going...I don't know what they're like.

BEL4: Especially in a new place ... And you're unfamiliar with the area.

BEL6: Then as you get older and you're encouraged to be more independent...So then you kind of feel obliged to do it yourself...It's a bit difficult when you don't know how to do it...Like when you don't know how to make an appointment or what to say and it's a bit intimidating when they're like well what am I supposed to do. I don't know what to do.

All: Yeah."

"BEL5: I feel like the adults in my family don't go regularly. Like they just don't go. Except for my mam, but that was because she's got false teeth.

I: OK. And the others don't go?

BEL5: No.

*I:* Would they go if they had toothache or something like that?

BEL5: No. They wouldn't... Like my brother when he was about 17 he chipped his tooth by like skateboarding into a sign by accident and he hasn't been to the dentist for that, and it's like his front two teeth.

I: OK. What about everyone else's families?

BEL4: My dad's a bit terrified of dentists, but he still goes.

BEL5: My mam's side of the family goes, but I don't get my...I don't think my dad goes.

*I:* Do you know why not?

BEL5: I don't really talk about it..."

"BEL13: My mum just said you're going to the dentist on Monday."

"I: What about you all said that your parents take you to see the dentist. Do they also see a dentist as well? All: Yeah.

BEL9: My dad doesn't. I: He doesn't...My dad doesn't go because he hasn't been in years and he's too scared in case he gets wrong... Or has to spend loads of money to get it done.

I: OK. Everyone else's parents go?

BEL16: Yeah.

BEL10: Yeah.

I: OK. Have any of them ever said anything to you about what they think of dentists or anything like that?

BEL10: My dad's scared... Because he had to get loads of stuff done because his teeth were bad."

"PAR3: Because of my parents I've always been going for like regular visits and appointments"

PAR2: I think I'd try and do it so that I didn't have to change my dentist [if going to university] in that like when I saw him it linked to when I was back home....And then I could like go with my mum still.

PAR3: It wouldn't feel that important at that point in life.

PAR4: Yeah. That is how it feels.

PAR3: Yeah.

PAR5: Yeah. I'm probably like going to university and if I was away from home then I'd like maybe keep it at home, my dentist at home, for a bit and then once I'd transitioned into university I'd move dentists as well. Like it wouldn't be the first thing I change ...

I: OK. And what about when you start your apprenticeship? Are you going to carry on seeing a dentist or?

PAR1: Oh I'm going to make sure. Yeah. You know, you eat every day. If you have a pain in your tooth I'd be straight to the dentist. I'd ring them on that night and be like I've got a pain and then they'd be like, I don't know, because they'd probably say like is it constant and then check the next two days it's still there of course I need to go and sort it out and be like late...

I: So you'd go if you had pain?

PAR1: Yeah."

"BEL6: It's a bit difficult when you don't know how to do it [make an appointment].

BEL3: Yeah.

BEL2: Yeah.

BEL6: Like when you don't know how to make an appointment or what to say and it's a bit intimidating when they're like well what am I supposed to do. I don't know what to do.

I: So you think that would make it harder. You wouldn't know how to make an appointment.

BEL6: Yeah.

*I:* Is there anything you think that would make that easier for you?

BEL6: I don't know."

"BEL9: But sometimes, and as well when you're making an appointment and you're off for six months and then they give you a date and you're about to say yeah, and then they start listing other dates at different times and you're like which one do I choose?"

PAR9: I'd definitely have to have someone tell us like exactly what they say [making a dental appointment] because I just wouldn't know what to say on the phone. I'd just be like aah... I'd need my mum sit right next to me and tell us what to say...

PAR10: If I knew like what to say and I had to go...

PAR12: Yeah. I'm the same. Like I hate speaking on the phone."

"PAR11: Just if you don't have time [to go to the dentist], like if you've got a job where you can't get time off to go...it's quite easy to get time off now to go...I'd just miss a lesson..."

# Appendix P. Recruitment Poster, Participant Information Sheets & Online Consent Forms for Intervention Co-Design (Chapter 7)





# Investigating Problem-Orientated Patient Pathways: Toothache to Treatment

Chief Investigator: Prof V Araujo Soares

Research Student: Charlotte Currie

### **Participant Information Sheet**

You are being invited to take part in research. Before you decide if you want to take part, it is important for you to understand why the research is being done and what you will have to do. Please take time to read this information sheet. You can also discuss it with friends or family if you wish. Ask the research team if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

### What is the purpose of the research?

In this research we would like your support to design an intervention which would encourage young people to continue to see a dentist for regular dental check-ups as they transition to early adulthood.

### Why have I been chosen?

You have been asked to take part as you are currently a regular dental attender or have previously been a regular dental attender and you are in the age range the intervention we would like to design will be targeted at.

### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign an online consent form. Once you have signed the consent form, you are still free to decide not to take part at any time and you do not need to give a reason.

### What will happen if I take part? What do I have to do?

If you choose to take part, then you will be invited to attend a maximum of three workshops with other people a similar age to you as well as with dental care practitioners and potential designers. These workshops will either be at Newcastle University or they will be online via Zoom. Zoom is free to download online video conferencing software, if you have not used this before a member of the research team will be able to provide you with the information to download it and on how to use it. Prior to the workshops you will be sent a link to join

the Zoom workshop. During the workshop you will work in small groups to help design what you think would be a good intervention for someone your age to encourage them to see a dentist on a regular basis. The workshops will last no longer than 3 hours and there will be regular breaks throughout. Each workshop will be approximately 2-3 months apart and you'll be given the dates of these in advance. Some of the workshops may have some short pre reading for you to do to help prepare for the workshop.

If you do participate, any information you provide will be treated as highly confidential and will not be shared with other individuals or organisations outside the research team. The workshops will be recorded and then anonymously transcribed (written down without any names) word for word by a professional transcription company. Some of the word for word quotations may be used in presentations, publications or a press release of the research, however they will be anonymised, so no one knows who said it.

The research team may wish to speak to you in the future about taking part in more research following this project. They may also wish to contact you to take part in a press interview following publication of the research. These are optional, and if you do not want to be contacted in the future then please let the research team know and indicate this in the appropriate box when you sign the consent form.

All study records will be the responsibility of the chief investigator. The paper transcriptions will be stored in a locked cabinet. At the end of the study the documentation records consistent with local rules will be securely archived in a facility in the Faculty of Medical Sciences and held for a period of five years.

#### What are the possible disadvantages of taking part?

You will be asked to take part in a series of workshops that may last up to 3 hours, however there will be regular breaks throughout this.

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

By taking part, you will help develop an intervention that people your age will be more likely to accept and use than one that is designed by researchers on their own. You will also be given a £100 shopping voucher for each workshop you attend to say thank you for taking the time to take part.

### What will happen to the results of the study?

An intervention will be developed, and you will be able to see the intervention (or interventions) that are designed at the third workshop.

### What if there is a problem?

Any complaints you may have about the study will be addressed. If you have a complaint please contact Charlotte Currie at Newcastle Dental School, Framlington Place, Newcastle NE2 4BW.

If you have a concern about any part of the study, you should ask to speak with the researchers who will do their best to answer your questions (0191 208 8247).

#### Further information and contact details

If there is anything that is not clear in this information sheet, and/or should you wish to make further contact, please find the contact details for the investigators below.

Contact details for investigators:
Miss Charlotte Currie
School of Dental Sciences
Framlington Place
Newcastle University
Newcastle Upon Tyne
NE2 4BW
0191 2088247

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Thank you for taking the time to read this information sheet and considering taking part in the study.



# Investigating Problem-Orientated Patient Pathways: Toothache to Treatment

Chief Investigator: Prof V Araujo Soares

Research Student: Charlotte Currie

### **Dentist Participant Information Sheet**

You are being invited to take part in research. Before you decide if you want to take part, it is important for you to understand why the research is being done and what you will have to do. Please take time to read this information sheet. You can also discuss it with friends or family if you wish. Ask the research team if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

### What is the purpose of the research?

In this research we would like your support to design an intervention which would encourage young people to continue to see a dentist for regular dental check-ups as they transition to early adulthood.

### Why have I been chosen?

You have been asked to take part as you currently deliver dental or orthodontic care to people in the age range this intervention will be targeted at.

### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign an online consent form. Once you have signed the consent form, you are still free to decide not to take part at any time and you do not need to give a reason.

### What will happen if I take part? What do I have to do?

If you choose to take part then you will be invited to attend a maximum of three workshops with young adults representing dental service users, as well as potential designers. The young adults will have experience of seeing a dentist for check-up appointments, however may have decided to stop seeking care recently. These workshops will either be at Newcastle University or they will be online via Zoom. Zoom is free to download online video conferencing software, if you have not used this before a member of the research team will be able to provide you with the information to download it and on how to use it. Prior to

the workshops you will be sent a link to join the Zoom workshop. During the workshop you will work in small groups to help design what you think would be a good intervention for a young adult to encourage them to see a dentist on a regular basis. As dentists treating patients of this age group your input to the development of this will be vital to ensure it is likely to be accepted by other dental professionals. The workshops will last no longer than 3 hours and there will be regular breaks throughout. Each workshop will be approximately 2 - 3 months apart, and you'll be given the dates of these in advance. Some of the workshops may have some short pre reading for you to do to help prepare for the workshop.

If you do participate, any information you provide will be treated as highly confidential and will not be shared with other individuals or organisations outside the research team. The workshops will be recorded and then anonymously transcribed (written down without any names) word for word by a professional transcription company. Some of the word for word quotations may be used in presentations, publications or a press release of the research, however they will be anonymised, so no one knows who said it.

The research team may wish to speak to you in the future about taking part in more research following this project. They may also wish to contact you to take part in a press interview following publication of the research. These are optional, and if you do not want to be contacted in the future then please let the research team know and indicate this in the appropriate box when you sign the consent form.

All study records will be the responsibility of the chief investigator. The paper transcriptions will be stored in a locked cabinet. At the end of the study the documentation records consistent with local rules will be securely archived in a facility in the Faculty of Medical Sciences and held for a period of five years.

### What are the possible disadvantages of taking part?

You will be asked to take part in a series of workshops that may last up to 3 hours, however there will be regular breaks throughout this. These workshops may be scheduled when you would normally be seeing patients, however you will be reimbursed for any loss of earnings at the British Dental Association's Guild rate of £70 per hour. Payment will be made, via a BACS transfer, within 1 calendar month of the workshop. A UK citizen right to work check will be carried out. It is the responsibility of the participant to ensure they comply with regulations regarding tax and benefit. For more information please visit <a href="https://www.gov.uk/hmrc-internal-manuals/employment-income-manual/eim71105">https://www.gov.uk/hmrc-internal-manuals/employment-income-manual/eim71105</a>

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

By taking part, you will help develop an intervention that young people will be more likely to accept and use than one that is designed by researchers on their own. This in turn will encourage young people to attend for routine dental check-ups where they can receive preventative care, rather than stop attending and develop dental disease.

### What will happen to the results of the study?

An intervention will be developed, and you will be able to see the intervention (or interventions) that are designed at the third workshop.

### What if there is a problem?

Any complaints you may have about the study will be addressed. If you have a complaint please contact Charlotte Currie at Newcastle Dental School, Framlington Place, Newcastle NE2 4BW.

If you have a concern about any part of the study, you should ask to speak with the researchers who will do their best to answer your questions (0191 208 8247).

### Further information and contact details

If there is anything that is not clear in this information sheet, and/or should you wish to make further contact, please find the contact details for the investigators below.

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Miss Charlotte Currie
School of Dental Sciences
Framlington Place
Newcastle University
Newcastle Upon Tyne
NE2 4BW
0191 2088247

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Thank you for taking the time to read this information sheet and considering taking part in the study.

# Co-Design Consent Form Patient/Public

Page 1: Page 1			
Study Title: Investigating Problem Orientated Patient Pathways: Toothache to Treatment - Intervention Co-Design			
Contact Details: Miss Charlotte Currie			
E-mail: charlotte.currie@newcastle.ac.uk			
Address: Newcastle Dental School, Level 4, Framlington Place, Newcastle, United Kingdom, NE2 4BW			
Please follow the below link to read our information sheet for this study before you complete the consent form.			
https://static.onlinesurveys.ac.uk/media/account/124/survey/677250/question/codesign_participant_informat.pdf			
Please can you provide the following information:  1. Name: * Required			
Traine. Tregance			
2. Email address: * Required			
1/5			

3. Confirm email address: * Required		
(Please note the above email address you provide is where your gift voucher will be sent to following the workshops.)		
4. Age: * Required		
5. Gender: *Required		
6. Home postcode: * Required		
Thank you for reading the information sheet about our research project. If you would like to take part, please read and sign this form. Please check the boxes to indicate if you agree or disagree with the following statements (please note you must agree with all statements except those highlighted as optional to be able to take part in the study):		
7. I confirm that I have read and understand the information sheet for this study and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. * Required		

2/5

← Agree	C Disagree
	rticipation is voluntary and that I am free to withdraw at any vithout my legal rights being affected. * Required
C Agree	C Disagree
	h to withdraw from the study, the data collected up to this analysis of the research project unless I withdraw within 24 equired
C Agree	c Disagree
(direct) quotations may be us	p being audio recorded, and that anonymous, verbatim sed in written documents, oral presentations or published nd that I will not be identified by name in these documents to Required
← Agree	C Disagree
I am happy for anonymised withe research team to approach	nedia and wider public might be interested in this project and verbatim (direct) quotes to be used in press releases and for ch me to see if I would like to be interviewed together with h an occasion arise. <i>Optional</i>

12. I understand that the data will be anonymously transcribed by a private transcription company and securely stored by the researcher and that my involvement will remain confidential. * Required				
C Agree	C Disagree			
13. I am interested in future Optional	e research studies and give permission to be contacted.			
∩ Agree	↑ Disagree			
14. I agree to take part in the	ne above study. * Required			
C Agree	○ Disagree			
15. Finally, can you please confirm whether you would like to participate in this study. If you select YES you are providing an electronic signature to consent to taking part in this study. If you select NO then your details will be deleted and you can click 'finish' to exit the form. * Required				
C Yes				

# Co-Design Consent Form - Dentist

# Page 1: Page 1 Study Title: Investigating Problem Orientated Patient Pathways: Toothache to Treatment - Intervention Co-Design Contact Details: Miss Charlotte Currie E-mail: charlotte.currie@newcastle.ac.uk Address: Newcastle Dental School, Level 4, Framlington Place, Newcastle, United Kingdom, NE2 4BW Please follow the below link to read our information sheet for this study before you complete the consent form. https://static.onlinesurveys.ac.uk/media/account/124/survey/677211/question/codesign\_dentist\_information\_.pdf Please can you provide the following information: 1. Name: \* Required 2. Email address: \* Required

3. Confirm email address: * Required		
4. Age:		
5. Practice postcode:		
Thank you for reading the information sheet about our research project. If you would like to take part, please read and sign this form. Please check the boxes to indicate if you agree or disagree with the following statements (please note you must agree with all statements except those highlighted as optional to be able to take part in the study):		
6. I confirm that I have read and understand the information sheet for this study and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. *Required		
C Agree C Disagree		
7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason, without my legal rights being affected. * Required		
2/5		

C Agree	○ Disagree			
	if I wish to withdraw from the study, the data collected up to this in the analysis of the research project unless I withdraw within 24 b. *Required			
C Agree	○ Disagree			
quotations may be us	kshop being audio recorded, and that anonymous, verbatim (directed in written documents, oral presentations or published scientific that I will not be identified by name in these documents to maintain quired			
C Agree	○ Disagree			
10. I understand that the media and wider public might be interested in this project and I am happy for anonymised verbatim (direct) quotes to be used in press releases and for the research team to approach me to see if I would like to be interviewed together with the Researchers should such an occasion arise. <i>Optional</i>				
C Agree	○ Disagree			
11. I understand that the data will be anonymously transcribed by a private transcription company and securely stored by the researcher and that my involvement will remain confidential. * Required				
C Agree	○ Disagree			

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12. I am interested in future Optional	research studies and give permission to be contacted.				
C Agree	○ Disagree				
13. I agree to take part in th	e above study. * Required				
C Agree	○ Disagree				
14. Finally, can you please confirm whether you would like to participate in this study. If you select YES you are providing an electronic signature to consent to taking part in this study. If you select NO then your details will be deleted and you can click 'finish' to exit the form. * Required					
C Yes					

## Appendix Q. Systematic Review Completed for Intervention Co-Design (Chapter 7)

This systematic review was published in the Journal of Oral Rehabilitation (Currie *et al.*, 2021) to inform the intervention co-design.



### Appendix R. Evidence Statements for the Intervention Co-Design (Chapter 7)

Almost one third of the UK are "problem-orientated dental attenders", these being people who are irregular attenders at a dentist, only seeking care when having dental pain or problems, rather than attending for regular preventative care (i.e. check-up appointments). The research team has carried out qualitative work<sup>1</sup> with those attending the dentist only when with symptoms (interviews with 16 patients) and found the reasons for this behaviour. These reasons are complex. Adults who only attend the dentist when they are in pain often reported being regular childhood attenders, before changing during adolescence and young adulthood. Further qualitative work was therefore carried out with adolescents (focus groups with 32 people). A systematic review<sup>2</sup> was also carried out to find any previous interventions that have been developed to encourage regular dental attendance in those who only seek care when experiencing pain, which identified four interventions. The results from all of these studies combined with existing research literature on dental attendance behaviour forms the basis of the below evidence statements. It is important to note that the reasons for these changes in dental attendance behaviour observed from childhood to adulthood are multifactorial and therefore targeting one evidence statement only is very unlikely to support change from problem-orientated attendance to a more regular and preventive one.

Below we present the evidence statements that we have gathered from the research conducted by our team as well as from a literature review of research conducted in this area. Each evidence statement has a summarised name which will be referred to during the co-design workshops. For each statement the data source is provided along with any additional relevant information.

<sup>1</sup> Qualitative research involves interviewing patients about their experiences and opinions and looking for recurring ideas or patterns to explain a research question.

A systematic review involves searching through all previous research which has been done in a particular area and combining it to answer a specific research question.

### 1. DENTIST CHARACTERISTICS

DATA SOURCE: Qualitative study, Systematic Review & Literature Review

STATEMENT: Perceived characteristics of the dentist play a role in patients deciding whether or not to seek regular dental care. A positive dental experience related specifically to positive characteristics of the dentist was reported to encourage regular dental care-seeking. Perceived negative dentist characteristics were associated with future dental attendance being less likely. This was reported in both adults and adolescents.

ADDITIONAL RELEVANT INFORMATION: Adult patients reported dentists creating feelings of judgement or penalisation and a lack of empathy as reasons for not attending regularly. Mistrust of dentists in relation to paying for treatment was also reported. Adolescents reported dentists being cold, disengaged and condescending as being negative characteristics, as well as feeling that they weren't included in conversations with the dentist and their parents/guardians about their oral health and treatment.

LINKS TO OTHER EVIDENCE STATEMENTS: This evidence statement links to the one on dental anxiety as the systematic review identified an intervention targeted at patients with dental anxiety which highlighted the importance of the dentist-patient relationship in those who are dentally anxious becoming regular attenders.

Note: These are dentist characteristics as perceived by patients and members of the public, dentists were not included or observed in these studies.

### 2. LACK OF KNOWLEDGE/MISUNDERSTANDING

DATA SOURCE: Qualitative study, Systematic Review & Literature Review

STATEMENT: A lack of knowledge or misunderstanding around dental care and NHS dentistry plays a role in patients (both adult and adolescent) not seeking regular dental care.

ADDITIONAL RELEVANT INFORMATION: Adolescents can have superficial knowledge about dental care, for example they know that they should brush their teeth twice a day and see a dentist every 6 months, but do not fully understand why. Instead, they rely on dentists to provide information and reassurance at appointments, however this is not always received. This results in a lack of knowledge as they move into early adulthood and impacts on their future decisions around whether to see a dentist or not. The belief that visiting a dentist is important also decreases from adolescence into young adulthood. Specifically, this lack of knowledge seems to relate to: dental diseases; importance of regular dental care; NHS dental charges; access to dental care. In addition, having knowledge of what will happen at future dental appointments increases the likelihood of patients attending, this was evident from the literature and also from a discharge counselling intervention which decreased repeat urgent care attendance (however this study did not look at future regular dental attendance). The systematic review also identified a study which used a generic advertising campaign to try and

increase attendance for dental check-up appointments across a town, this had no effect on those who were irregular dental attenders as it did not increase their awareness of need for a dental check-up.

LINKS TO OTHER EVIDENCE STATEMENTS: This also relates to the evidence statement on dentist characteristics with adolescents highlighting the importance of them feeling included in conversations so they are able to gain the knowledge they require and ask any questions they may have of the dentist.

### 3. DENTAL ANXIETY

DATA SOURCE: Qualitative study, Systematic Review & Literature Review

STATEMENT: Dental anxiety was reported to cause irregular dental attendance in adults. Adolescents report attending a dentist regularly even though they are anxious due to parental and family influence.

ADDITIONAL RELEVANT INFORMATION: Dental anxiety in both adults and adolescents was often related to negative childhood dental experiences. Influence from family, childhood peers and media sources were also reported to cause feelings of dental anxiety in adolescents. The systematic review identified an intervention targeted at adults with dental anxiety who were irregular dental attenders. This found that attendance at a dental anxiety clinic increased regular dental attendance, however it was largely the improved dentist-patient relationship which caused this change and those who were unable to see the dentist who delivered the intervention were less likely to become regular attenders as a result.

LINKS TO OTHER EVIDENCE STATEMENTS: This also relates to the evidence statement on dentist characteristics as negative dentist characteristics tended to reinforce dental anxiety and reduce the likelihood of future attendance, whereas positive dentist characteristics would provide some reduction in dental anxiety and increase the likelihood of future attendance.

### 4. DENTAL CHARGES

DATA SOURCE: Qualitative study, Systematic Review & Literature Review

STATEMENT: The cost of dental care was reported to be a barrier to seeking regular dental care in adults, and a likely future barrier for adolescents once they had to start paying for treatment.

ADDITIONAL RELEVANT INFORMATION: There were mixed feelings as to whether dental care should have to be paid for, in particular for check-up appointments. The systematic review identified a change in dental policy in Scotland where free dental check-ups were offered causing an increase in people attending, however the increase was seen across all patient groups including those who wouldn't have paid for dental treatment prior to the change, and also those attending (and paying) for private dental check-ups. Therefore the change may not have been solely related to a change in payment and may have also been due to an increase in awareness of dental check-ups.

LINKS TO OTHER EVIDENCE STATEMENTS: This also relates to the evidence statement on lack of knowledge and misunderstanding as the cost of dental care was often given as a reason for non-attendance when participants were unaware of how much dental treatment costs or assumed it costs more than it does.

### 5. APPOINTMENT MAKING

DATA SOURCE: Qualitative study

STATEMENT: Adolescent patients reported specific anxiety and lack of knowledge regarding making a dental appointment on their own without their parents or family.

ADDITIONAL RELEVANT INFORMATION: Specific anxieties related to the conversation to make an appointment either in person or on the telephone, and in relation to the paperwork that needs completing at appointments.

LINKS TO OTHER EVIDENCE STATEMENTS: This also links to the statement on lack of knowledge or misunderstanding as adolescents reported not understanding how to make an appointment, the associated dental paperwork, what it is for and how to complete it.

### 6. TRANSITION FROM SCHOOL

DATA SOURCE: Qualitative study & Literature Review

STATEMENT: The move from school to further education or working life appeared to be an important time point for adolescents to change their dental attendance behaviour. This was reported in both adolescents and also in adults reflecting back on their life.

ADDITIONAL RELEVANT INFORMATION: Adolescents acknowledge that looking after their teeth is easy whilst they have support of their parents, school and free treatment. Reasons for this transition period being important related to a loss of parental/family influence, need to start paying for treatment, having to attend appointments alone and moving away from home to a new city.

LINKS TO OTHER EVIDENCE STATEMENTS: This links to the evidence statement on knowledge and importance of oral health as the belief that visiting a dentist is important decreases from adolescence into young adulthood. It also links to the statement on dental anxiety as once parental influence to attend is lost those who are dentally anxious may no longer attend.

### 7. IMPORTANCE OF ORAL HEALTH

DATA SOURCE: Qualitative study & Literature Review

STATEMENT: The reported importance of oral health appears to decrease from adolescence into young adulthood, and in addition other life priorities start to take precedent (are seen as more important) over dental attendance.

ADDITIONAL RELEVANT INFORMATION: N/A.

LINKS TO OTHER EVIDENCE STATEMENTS: The perceived importance of oral health links closely to the evidence statement on lack of knowledge and misunderstanding if adolescents and young adults do not understand dental diseases and the importance of regular dental care, and also to dentist characteristics if adolescents feel they are not included in conversations and therefore don't gain the knowledge they require or expect. It also links closely to the evidence statements on dental anxiety, dental charges and appointment making as these barriers may not be overcome if the importance of oral health does not outweigh them. As the importance of oral health decreases from adolescence into young adulthood this also closely links to the statement on the transition period.

# Appendix S. Example of Participant Pre-Reading for Co-Design Workshop 1 (Chapter 7)



# Investigating Problem-Orientated Patient Pathways: Toothache to Treatment

### **Intervention Co-Design**

**Workshop 1 Participant Pre-Reading** 

Workshop Date: Thursday 4th February 2.30-4.30pm

### **Zoom Details:**

https://newcastleuniversity.zoom.us/j/87902790482

Meeting ID: 879 0279 0482 Meeting Passcode: 889584

### **Workshop Plan:**

2.30-2.35pm: Introduction

2.35-2.50pm: Small group introduction and icebreaker exercise

2.50-3.00pm: Evidence statement presentation

3.00-3.25pm: Small group work - Evidence statement exercise

3.25-3.30pm: Break

3.30-3.40pm: Full group evidence statement prioritisation

3.40-4.05pm: Small group work - Intervention ideas exercise

4.05-4.10pm: Break

4.10-4.25pm: Full group intervention ideas

4.25-4.30pm: Close and next steps

### Please have this pre reading to hand during the workshop for reference.

### **Workshop Summary**

Research has found that children who see a dentist on a regular basis often stop seeing a dentist regularly once they transition into adolescence and young adulthood. This can then lead to the development of dental diseases, such a tooth decay and gum disease which eventually cause pain and infection and the need for emergency dental treatment. The aim of this series of workshops is therefore to develop an intervention which will encourage young people to continue to see a dentist for regular check-up appointments as they transition into young adulthood. For these workshops we are focussing on attendance at a regular high street dentist <u>not</u> an orthodontist.

During the first workshop you will work in small groups to carry out exercises to begin to design the intervention. These small group exercises will be led by a member of the research team (known as a facilitator) with another member of the research team observing and making notes. Following each small group exercise the facilitator will feed back the outcome of your exercise to the rest of the group, and as a larger group you will then work together to combine the small group outcomes into one final outcome. The exercises you will be doing are summarised below, please take the time to read through them, familiarise yourself with the content and begin to gather your own thoughts and make notes ready for the workshop. There are no right or wrong answers to any of the exercises, we encourage you to carry these out based on your own experiences and opinions as well as the information you will be given throughout.

Please also have this pre reading to hand during the workshop for reference.

#### **Icebreaker Exercise**

This is a very short exercise to allow you to meet the other people in your small group. During this exercise you will be asked the following questions and asked to answer one by one, you may be asked to explain your answer:

- What are your expectations and hopes from this workshop?
- How would you describe a "model dentist"?
- How would you describe a "model patient"?

### **Evidence Statement Exercise**

For this exercise you will be reviewing the evidence statements which have been provided as an appendix to this document.

In the first part of this exercise we will ask you for your opinions on the evidence statements. For each statement please think about whether you agree, disagree or want to change it in anyway. In addition are there any extra statements you think should be added?

For the second part of the exercise you will be asked to put the evidence statements in order of priority from which you think are most to least important to consider when developing this intervention. We will encourage you to consider this from your own perspective as well as the perspective of other people, for example from the perspective of both patients and dentists. Please take some time to think about what order you think these should be in before the workshop.

To do this exercise online we'll be using a Google Jamboard which you will all be able to access and use at the same time. So you are familiar with this and how it works there is a short video tutorial for you to watch at:

https://campus.recap.ncl.ac.uk/Panopto/Pages/Viewer.aspx?id=a68fd01d-8695-41cd-b007-aca9010e4cb9

There is also a training Jamboard for you to experiment with. Please feel free to use this to introduce yourself to each other before the workshop, it is available at:

https://jamboard.google.com/d/1E4r7zJmCRT3LEKxIve6yZEBOCp1jPjtyhU4pdWWPEWU/edit?usp=sharing

### Intervention Ideas Exercise

In this final exercise you will begin to generate ideas for the intervention. Please note at this stage we are not expecting to produce a final detailed intervention, we are simply trying to understand what form the intervention may take at a later stage.

You will use the prioritised list of evidence statements to begin to think about broad intervention ideas which may target them. You will be asked to group together similar ideas and prioritise them as you go. These ideas will then be fed back to the whole group and the ideas prioritised to decide which to take forward into the next workshop.

To help prioritise the intervention ideas you will be encouraged to think about the intervention ideas against the following APEASE criteria:

### o Is it affordable to do?

- Is it **practical**? For example will it require the use of highly trained people to deliver or can it be delivered easily in day to day life or by routine dentists?
- Will it be effective? And will it be cost effective? Effective relates to how well you think the intervention will work, whereas cost effective considers the ratio of how much it will cost to deliver it against how effective it will be. This is something you will want to consider if you have a few intervention ideas as ideally you'd want to select the intervention that will have the biggest effect for the lowest cost.
- Will it be acceptable to everyone involved? For example something which may be seen as acceptable to patients may not be seen as acceptable by dentists or policy makers and vice versa. For an intervention to be successful it needs to be acceptable by everyone who will be involved in it.
- Will there be any potential **side effects** or any safety considerations to make?
   Or will there by any unintended consequences of it?
- Will it promote equality between different groups of people? Or will it increase differences in between groups of people from different backgrounds?

# Appendix T. Icebreaker Exercise for Co-Design Workshop (Chapter 7)

The facilitator posed questions to the group and asked each participant to provide a response in turn. The participants were encouraged to expand on answers given and the facilitators were allowed to use relevant probing questions to encourage this. They also encouraged the other participants to reflect on the answers given and respond where appropriate. The following questions were asked:

- What are your expectations and hopes from this workshop?
- How would you describe a "model dentist"?
- How would you describe a "model patient"?

Their answers were used in thematic analysis and the facilitators were able to use them where appropriate to help engage group discussion in later exercises.

### Appendix U. Representative Quotations from Co-Design Workshops (Chapter 7)

### Workshop 1

### Evidence Statement Validation

Evidence Statement	Participant Reflections	Example Quotation
Dentist Characteristics	Negative dentist characteristics are a barrier to care-seeking, whereas positive dentist characteristics are a facilitator to continued care-seeking but only when other barriers don't exist. Positive characteristics will not necessarily outweigh negative dental experiences when they happen. Dentist characteristics may be more important as a child than later in life when they are able to reflect on negative experiences.	"P002:it acts as a barriermaybe if you had a dentist that you didn't get on well with then you might [be] slightly less likely to go, however if your dentist was nice then you would stillneed reasons to go. You'd still have to value your oral hygiene, want to go for that check-up, however, it would be made easier if you had a nice dentist" "P001: I think positive characteristics are great, butsometimes the negatives really outweigh good ones she was obviously a nice person but that one negative thing just put me off as a kid"
	As young adults are paying for their experience of dental treatment there is a fine line between their identity as a patient or a customer which may influence how they perceive the dentist when they start paying for treatment.	"P004:because you're paying fordental carewith your GP it doesn't matter so muchwhereas you're paying your dentist P006: If you've had that negative experience and you've got to pay it puts you off wanting to pay"
Lack of Knowledge/ Misunderstanding	Important to have knowledge both of dental care (e.g., when to go, what happens at a check-up, why it's important to go) but also the dental system and how to navigate it (e.g., cost of care, how to find or change dentists).  Skills are also important to consider alongside knowledge, e.g., skills associated with finding a dentist, organising time to attend, managing finances to pay.	"P007: a lot of people think that any sort of dental care is unaffordablebecause of that presumption that don't bother to actually find out how much it is" "P009: I would say a lack of judgement with knowing when to go to the dentistI'm only 16 so I'm used to going with my mam I wouldn't really know how to go by myself I don't know what I'm doing. I do have a lack of knowledge on how to do it by myselfhow I'd book" "P001: it's quite a big part on whether you go or notI'm about to transition and I've got to do it myself I'm worried about how am I going to book appointments, how to keep doing all this stuff. Paying."

Dental Anxiety	Anxiety is wider than just dental anxiety, it also encompasses fear of bad news (e.g. tooth need extracting), paying for care and accessing and navigating a complex dental system.  Dental anxiety is a barrier but can be overcome when other barriers are addressed (e.g., with knowledge, awareness of importance of oral health, with parental support).	"P007: The issue of making an appointment [we're] anxious to even do that" "P005: When I came to unimy parents [said] you need to stay at your home dentist you won't be able to get another NHS dentist, I don't know how true that is that's a fear for a lot of people I think P004: or [if] you're going to like or trust them P006: that would be a fear for me"  "P005: if people had good knowledge and understanding and put oral health really high and weren't concerned about making the appointment and everything else then dental anxiety would be lower. But if they didn't dental anxiety can be a real thing in stopping people making appointments"	
Dental Charges	Affordability of dental care will be a barrier that fluctuates over the life course depending on other competing demands and priorities.  Importance of link to lack of knowledge as dental charges are also a perceived barrier.	"P003:I do have to pay when I first got my mortgage and I was still sorting out all my finances I was probably a little bit more put off to go because it is one of those sections of care that's not on the NHS and obviously you have to pay I was just thinkingonce I get everything sorted you've got everything to think about, like bills and mortgage and council tax and everything just kind of racks up [dental care is] a sort of afterthoughtnow that I'm settled, it's not too bad because I can handle it"  "P006:when I was younger and you go back [to the dentist] and you get charged the first time, you're like why am I being charged? You don't realise that you have to pay after a certain timethat definitely puts you offespecially if you need big treatment it's quite expensive  D002: there's also a perceived fear of the costspeople assume it's going to be very	
	The perceived value of a check-up.	expensivethe NHS banding system is fairbut not everyone understands [it]"  "P009: people don't really want to pay to go to the dentist to be told nothing's wrong, like just a check-up people won't really want to be paying that just to be told everything's fine"	
Appointment Making	Need to teach knowledge, practicalities & skills needed to make an appointment.	"P008: For me and my brothers having to figure out exactly what type of appointment I need and prioritise like when to have the appointment and stuff like that where to goorganise my lifeit's all just a bit overwhelming and it's something you don't really get told P007:the barrier there with appointment making is the phone calls. And that is not true for everyone but there's a lot of young people that are hesitant to pick up the phone and I wonder if that's just because it's something that we don't really do that much anymore. Everything is text message and WhatsApp, that sort of thing"	
	A barrier beyond adolescence.	"D002:there are still a lot of patients of mine in their 20s and 30s that their parents still make their appointments"	

	Requirement for parental support can go beyond transition from school.	"P002: I come home from holiday at university and it will be my mum which organises my dentist appointment"
Transition from School	Change in environment can lead to behaviour change related to a number of barriers.	"P008: finding the time to organise myself and knowing where to go which dentist and stuff, definitely coincided with moving to university, because when I moved out I had no idea what I was doing with dentistry and the only time I even properly thought about it was when my parents were like have you been to the dentist and I was like no"
	Oral health as a priority will fluctuate over the life course.	"P002: [oral health] probably maintains its importance throughout [life], but in terms of the relative importance in comparison to other things that are going on in your life Suddenly there's lots of other things going on around, I know that from my experience at university. You've suddenly got a lot more balls to juggle and so it falls away in terms of relative importance, but if you were to look at it in isolation you probably wouldn't say that it's got any less valuable to you. It's just more things to consider"
Importance of Oral Health	Too young to get dental diseases.	"P004: young people sometimes think that because of their age they're immune to all these dental problems [it's] more commonly for older people to have more problems with their teeth. I think that might hold some young people back D002: when I was a dental student I don't think I went to the dentist until I was qualified you do think you'reinfallibleYou're unlikely to be ill, your teeth will be fine, so you just don't worry"
	Oral health compared to whole body health.	"P005:oral health can't go that wrong, people are very scared of other things like cancer and other diseases but people don't have the same fearwith oral healthpeople know that you can have very painful toothache but I don't think people are as nervous or as scared of things going wrong"

### Intervention Ideas

Design Idea	Example Quotations	
Promotional	"P002:if you had posters up saying did you know that one in four people, one in four dental cavities, progress on into duh duh	
campaign or	duh duh, have you had your dental check-up? People might go ohIs that something which I need to do, I need to look	
centralised	intoLike I guess a campaign in the same way you'd have your five a day campaign or yourall that kind of stuff"	
letters/leaflets.	"P003: maybe having a sort of letter sent as a reminder And I suppose it's a kind of thinking on the same wavelength as	
	say like a smear test, obviously women have to have it around about the age of 25. But we get sent letters to give the reminders	
	and it is a very daunting experience, but it's like a thing that you should really go do yeah, I think an individual written letter	
	as a reminder would probably be a good idea"	

Integration of teaching on dental care and associated barriers into school curriculum. "D001: I used to do a little chat to younger school... I think first school, about basically oral hygiene, and I don't see why there couldn't be something targeted so children who are in Sixth Form often get problems with their wisdom teeth so it might be nice for them to know, for example, as part of a chat. So in the school assembly you might get into trouble with your teeth and this is what you would experience. We might take and x-ray and what that involves, what that might feel like. Anything to allay the anxiety before the student or the pupil is actually in the chair."

"P009: I was going to say that in school we had ... personal development and lessons around those sort of things, and they're all to do with drugs or sex and stuff like that, but none of them covered dental hygiene or anything, and I feel like that's somewhere that they probably should be mentioning it, because I think that's where you'd expect to learn about these things when you're in school. And so it's just not on anyone's mind because even if people take the mickey out of those lessons in school at least it's still in your mind and I think maybe that's a good place."

## Meeting dentists outside of the dental practice.

"P001:...if it's an actual dentist [delivering the intervention] you get to know them and ... because you're talking to a dentist and probably people won't realise that they're the least scary people, they're just normal humans doing their job and they're trying to actually help you. ... I think for me personally as well... it would be nice to have a 30 minute talk going over things. See that would help with anxiety. That would give you the information, like how to book an appointment or there's all this, all the key information. But I think meeting an actual dentist before you're having to go by yourself would be great for anxiety because I think that would solve a lot of problems."

"D002: that whole thing of dentist characteristics as well and getting patients, people to meet their dentist, having dentists going to schools and colleges will be a way of doing that too, because then they get to see ah, they're actually just human beings. Or we are actually just human beings and just like every other professional out there... Local dentists would be helpful because then those that have capacity to take on new patients as well so it's not just...it's something that there can be continuity as well so they know they can make appointments and things."

## Use of positive patient stories from dental care.

"P009: ... if you show people that [bad teeth] then they kind of just like some people won't want to look at that and they'll just totally go off it and stuff like that, but I feel like if it's positive and encouraging people to go rather than showing bad experiences and bad photos and stuff like that I feel like that would be better than doing that.

P007: I probably want to say though that the ads even though positive they shouldn't be cheesy. They should still be quite realistic. So if that does require say, I don't know, following somebody through has got a need, for example, and they're talking about what they had before, I think that's quite crucial. It shouldn't just be a oh if you see the dentist then you're going to have great teeth, x, y, z. It should be this is what it was like before but now I have excellent teeth, x, y, z. Does that make sense?...I think if you only talk about the positives you risk looking like the many, many ads of these brilliant white teeth for this private company, just whitening toothpaste and that sort of thing. And I personally don't think they pay too much attention to those. P008: I feel like if you have, especially with TikToks and stuff, if you have it and it's from a dentist, or someone training to be a dentist, it can come off as very patronising and I don't know about other people but that would just turn me right off it than like if it's from the point of view of a patient because it feels a little bit less patronising, I think that.

P007: Yeah, I think a good personality who would probably be the adverts that we see, but ones like STIs... where it's a doctor talking, instead it was like a patient journey.

P009: Yeah, personally I think it's more relatable because you're not really going to relate to a dentist. But for example if it's a patient then you're going to be like oh OK so it's not just me who doesn't understand how to do something, or it's not just me who

	is struggling to do something. You're kind of seeing someone else who's struggling and what they had to do to get better and get help."
Linking of oral	"P008:if there's a link to oral health they should mention it because one of the problems is that there are so many things
health to whole	that contribute to oral health that you don't realiseyou said if there's anything between HPV and that then you should be
body health to	mentioning it just so it's always in people's minds, like it's not just about brushing your teeth, it's about everything.
increase the	P007: Yeah. I think the link between HPV and cervical cancer and I think Public Health England really caught on to that and did
perceived	like sufficient screening for that, so if there is such a connection between HPV and say oral health I don't understand why that
importance of oral	wasn't also included in the advertisement. It seems to be two distinct separate things when actually if there is a link why isn't it
health.	complete."
Incentivise	"P007: Can we do like you know how Costa Coffee, you get a free coffee after a certain number. Could an initiative, again I don't
adolescents and	see it as being feasible, but if that was say like a government wide thing where if you were to attend three of your routine check-
young adults for	ups without missing one the fourth would have been free. I think that would be an incentive for people to keep up with."
attendance at dental	
check-ups.	
Create a new way of	"D002: like what we were saying earlier, there are some practices that do use apps and some practices use online
making dental	appointments so you can book your own appointments, so it's just making that more widely available and making sure everyone
appointments which	knows about it as wellmaybe devising an alternative method of making appointments to reduce the anxiety of making
would be more	appointments or knowing how to make appointments"
acceptable to	
adolescents and	
young adults.	
Training for dentists	"D002: I know when I was at dental school we did some training but an update of some sort because obviously things change.
to improve patient	And you sort of forget as well so I think that will be quite a good thing having that available."
experiences.	

## Workshop 2

Intervention Recommendation Statements

Intervention	Example Quotations
Recommendation	
Statement	

Promotional Campaign	"P001:when I'm handed the leaflet most times I don't read it and I feel like doing things that way is quite outdated nowadays and it wouldn't speak to younger kids because they don't really pay attention to the leaflets they get through doors, or the letters at school.
	So I think number one isn't for the target audience we're aiming for.  D001: I did think that was a very expensive way to do it and I also agree with [name redacted]'s theory of just leaflets, who really reads them and throws them away. So that would be my feeling as well."
	P007: To tell you the truth I can't remember the last time I looked at a poster and didn't think that it was just wallpaper. I don't think I really read posters."
School Curriculum	"P011: We had a lesson called PSD which was personal social development, so essentially that was, I think, it was twice a week and you learnt about just everything. Like things from in the world to yourself to health to literally it covered all bases. So I could definitely see something like if it was to go on to the school curriculum fallen in to something like PSD in the school I was in anyway. In the way the PSD worked I could definitely see it falling in to that If I'm honest, you learn about, like you say, so much, so I don't see why they maybe couldn't make time for another say full lesson or two about this because you learn so much. Yeah, like you say, there could be a time issue but if there's time to literally go over so many different things why wouldn't there be time for say just two full lessons of this if they had time for a vast array of those things."
Meeting Dentists	"P010: I thought meeting dentists was quite good because I'm petrified of the dentist. I suffer really bad, but I'm frightened to go and see the dentist, and it took me till I was 24 to actually go on my own. So I think me and my dentist, I went through recommendation to my dentist through a family member because of how he was and how we made me feel, and it actually worked. So I think meeting a dentist is really positive thing for people like me who's petrified.  P001: I think seeing someone face to face it's not, it's going to be a little bit more reassuring. It's like oh, they're not this big scary person waiting to stab you in the gums or anything, they're actually just here to help. And match that in the school curriculum and you learn about it from a younger age then it will probably prepare you when you go into adulthood.  D001: I'm not really sure how a young adult would meet a dentist to find out what kind of person they were because you would have then have the dentist going in to school to meet the young adult or in sixth form, so I think that should be, could be incorporated in the school curriculum. So whatever talk was being given could be given by a dentist."
Patient Stories	"P007: I feel that, yeah. I think patient stories, I feel like the preferred media today is video.  D003: the videos, so that might help motivate people to go and it will help with their psychological capabilities knowing that other people have been through that and they've survived, for want of a better word"
Make Every Contact Count	"P005: I kind of think that if like it was in the public consciousness that it was just normal that you do, when you go from school to work or to university or whatever that you just have to continue dental care because it's important and everyone's aware of that then it would justif it was just a normalised thing then everyone would do it, and I feel like that it's about education so if you were just reiterated that you needed to do that and every, like at a lot of contact points over your life then more people would complete them. P011: So that's maybe where it drops back into the school curriculum and where teachers take a responsibility to maybe remind pupils or remind students maybe, for example in that PSD lesson that I was talking about. OK you've got two lessons dedicated to it, but why not every once every three months or twice every three month is something just mentioned for five minutes in a class is everyone's sort of check-up type thing."
Reward System	"D001: I think that the reward system is something worth thinking about. And I don't know how that would be funded in NHS dentistry but I think it's good idea it might remove that [barrier] because of course the young adults are paying all of a sudden so it might be,

	I don't know, have two get the third one free might help them because it's a reasonable amount of money if they had one filling. That would be a reasonable outlay for them and it might dissuade them from going. So that's why I think the reward system was an interesting idea.  P003:the reward system, I think that is a good idea. The reason why I was put off that originally is how expensive it would be depending on say if you do it every third time you go to the dentist you get a check-up for free, that could add up, so I think it would totally depend on the reward but I think the reward system is great"  "P011: my first one was reward. I thought that would work bestI just thought it's a motivation for someone to bookmaybe go right OK I'm going to come out here and here, I get a fiver off or I get a tenner off, I don't know, ASOS if they're linked up with ASOS for example, after five trips to the dentist type thing."
Appointment System	"P001: the appointment system sounds quite like favourable to be honest I've got an app to do an appointment, to set up so easy for my GP. And we had that whole dentist as well that would probably ease a lot of people's worries."  "P005: I think the appointment one would be quite important because I think ringing on the phone is something that quite a lot of people don't enjoy doing, especially young people because we don't use the phone so much. Things are more like texting or booking things online. And I think it would make it a lot more accessible to people with phone anxiety to be able to book on an app or something. I don't know if all dentists do but I know that mine doesn't, and I think that might put a lot of people off just making the appointment and they never get to the dentist because there's that first hurdle, whereas if you could just book it online it will be a lot easier."  "P007: I would definitely wave the flag for the appointment system I think it's almost becoming the norm, especially now with
	COVID, for example if you want to go to a restaurant you'll book ahead and if restaurants can do it and that's been adopted quite readily, I think, by young people, and it does definitely take out the stress, I think, from phone calls and that sort of thing. You can just kind of check when it's free. If that suits you, you just go ahead and that's that.  P012: Out of all that I read my favourite ones were the updated ways of making an appointment, like the online thingsWith experience myself that would help me a lot and I had a similar problem with visiting the doctors as well. I found that I only ever booked appointments for myself if I could do it through online."
<b>Dentist Training</b>	All groups rejected.

### Intervention Design

Intervention	Intervention	Example Quotations
	Design	
School Curriculum	Aim	"P001: if it was just a sit down two hours talking about how to book, how to find the dentist and all the information you need to know transferring to 18 I think that would be really effective as sort of teaching the skills that you would need." "P002: I actually had no concept of what the extent to which dental hygiene, or poor dental hygiene, could go. And I remembered that. So, those kinds of things, I think, stories connecting to real whole body experiences are things that students will take away with them."

	"P010: I think the patient journey I think that would be a useful way to teach people."
Materials needed	"P010: if someone comes in from experience I know that going through a whole tube of oragel doesn't help when you've got wisdom tooth pain. That's me. I'd rather go through a whole tube of oragel, numb my mouth than go anywhere near a dentist before I had to during COVID and had my wisdom teeth out. That type of experience would then go to me to hearing something from that person, like we said, personal experience, would then go to me I don't want to go through that pain. Like that would not scare me but it would make me think more, and I was that type of student, someone wouldn't have paid attention, so then a dentist coming in to be saying this this, because I would have just been like oh yeah, whatever."
	"D001: I think that's a good idea. Maybe more relatable to young adults than listening to me would be, as [name redacted] suggests, somebody saying this is what happened, this is how I fix my problem. Yeah, I think it's a good idea I think that yeah, a recorded, pre-recorded video would be useful as part of that talk."
	"P003: So I would think doing it visually via video, but not as a real life example so you don't freak the students out. So maybe like a cartoon video sort of thing to kind of give them an idea. Because I think a lot of children seem to learn better off visuals rather than just being told about it. And it seems to make them grasp a little bit better and to actually get them to pay more attention usually. Because if you have someone say talking straight for two hours, I think a lot of them are just going to, well, not a lot of them but some of them are at least going to just drawn out and think oh God I'm bored
	now."  "P002: I think if you can have something that's practical, engaging, I know that there are various healthcare initiatives about washing your hands and they'll give you the gel which shines bright under UV and they'll go around the class and they'll put the gel in people's hands and something to wash their hands and then they'll shine the UV light to show people how well they washed their hands and they make it practical and engaging and I don't know whether there would be a way of being able to do that with oral health, whether, you know, for particular interventions. But I think having it in person but instead of just speaking at the students, getting them to get hands on practical is at least something to incorporate within that just to raise their attention levels and then maybe deliver a bit of insights like that information whilst you've got their focus"
Procedure, provider & delivery mode	"P001: for life skills, you do it in early year during Year 10. But throughout Year 11 even in sixth form you have days where you spend the day learning interviews skills for me in sixth form, but in Year 11 there was a day on prison and crime and things like that, so it would probably be on one of those days I think most schools usually do that now where they have a day where they develop skills that aren't a part of like biology, chemistry, they are life skills and I think that's where you would teach how to book an appointment and finding a dentist."
	"D001: I think that some folk do leave [education] at 16 which seems to be forgotten in this whole which bit of the curriculum to put it back into So therefore it's important that it does come in, in that before you leave school 16 stage. But then maybe a reminder again in sixth form and I don't know at what point or in what lesson."  "P001: I don't think it would matter to see the dentist nurse or a dentist because no matter what they're going to know more knowledge than your English teacher or your head of year. So I think as long as they come from the background or the profession I think it's going to be better than having a teacher explain it as they're more likely to be able to answer all the questions that get thrown at them and things like that. I also think I used to pay more attention when someone came

Appointment Making	Aim	in to talk about something than say my English teacher talking about how tax worked. So I think it would more interesting if someone came in and explained than if a teacher, so it doesn't really matter to me if was a dentist or a dentist nurse as long as it's from the profession."  "P007: I think it should do is give a list of dentist in their locality when you put in a post code then once you click on that particular dentist, once you click on whichever dentist you want then it should take up to their appointment book which will show that they have got an appointment at such and such a time it should have a as soon as the appointment has been booked it should have a link to say put it on your iCal, Google calendar, or something of that nature with the reminder for the patient to say right, there's an appointment at such and such a time for."  "P012: I think when you click on a dentist near me and prioritising which one you want to choose, for me it would be through user reviews. So if they had a list of reviews on just public opinion of how they were treated there, or just the general things like that, along with maybe a link to just some sort of, I don't know if each practice has their own website or something, a little bit of information about people there, the pricing things like that, before you go ahead and book the appointment stuff like that. Just a little bit about that care so you choose which one you want to go to."  "P007: A potiont story labout the doors to being
		"P007: A patient story [should be included]. Kind of a from setting the appointment to walking through the doors to being in the chair to what happens afterwards. When do you expect the next appointment to be? And I think cost as well. I know it's difficult to give an exact cost but at least a rough estimation of what you could expect to be paying when you walk though those doors  D003: Can we add other educational videos and material about fluoride, water fluoridation? Toothpaste fluoridation.  Fluoridated toothpaste. About snacks, the NHS has built a new app which is called the food app where you scan the app and then it talks about different sugar contents and different drinks. Can that be added on in the knowledge base with flossing and taking care of the gums, tooth brushing, diet"
	Materials needed	"D003: I think that it makes sense that the website and the app both be very similar."
	Procedure, provider & delivery mode	"P007: Perhaps it's at that point that some sort of printed leaflet could be given to them with like a scan this QR code to download the app kind of thing could it be linked to maybe sexual health that people that age normally receive again maybe via the GP do you know anything that goes out for contraception, something like that.  P012: I suppose it could be given with a promotional like the leaflets and again the QR code and stuff could be handed out alongside contraception that's giving out to young people. But in terms of equality I don't think that would capture everybody. I suppose maybe that's it. None of these will capture everybody so you have to do a combination of a few. P007: [the leaflet] could be on toilet doors of
		P012: Community centres. Community centres where usually like sports halls and things like that, those places might be another place to concentrate."
Reward	Aim	Agreed to accept aim from the intervention recommendation statement.
System	Materials needed	"P004: I just about the link to the app and I was just thinking actually this could link through the app."

Procedure, provider & delivery mode	"P011: if you're looking at people maybe leaving high school or just going into sixth form, anything, I'd always say, anything like a high street brand. Even if it is just a tenner after say five times. These days that tenner could go far say in ASOS, or could you maybe do it say if it's students supermarket, so then actually if you have just moved out from your parents it's a case of it's that tenner a week can actually help you quite a bit I think if you got a brand on board that is where maybe you've got more leeway because then other brands will see what's happening and see what's being done, see the good publicity for them and then it might obviously give other brands ideas if they want to try and get involved." "P011: Maybe during, if we're on about the curriculum, maybe during one of the lessons with the curriculum the app could be introduced and you could maybe target the part of the app that people would be, or the target audience would be interested in, like the reward scheme and things like that. If say 15 minutes of your lesson showing them how to work the app and stuff, but you finish it off with, or and this is the rewards bit on the app. That will probably be when they remember the app. And they might download it because of the rewards. And just to have a look. But then once they've had a look they might end up getting in to depths of it.  P004: They could have like a quiz on it that started you off with your rewards couldn't they?  P011: Yeah. Like you get a certain amount of points for doing a health quiz or something.  P005: I like that because it could convince people, motivate people to download the app and to start using it."  "P007:in order to accumulate your points or whatever you have to leave a review for that particular visit. And that's like the incentive then I suppose."
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## Workshop 3

Intervention Component	Changes Suggested	Example Quotation
School Curriculum	Should include a practical, hands-on component.	"P010 if I had a lesson like that in schoolI'd probably find it quite boring if it was done in the wrong way it needs to be more hands-on even like have plasticine I don't know just to get people engaged otherwise they will just forget it immediately."
	Reduce length to 30-50 minutes and change aim to introduce app/website.	"S001I would be extremely cautious about the amount of time you'd be asking to take away from lessons for [the intervention] especially given what's happened the last couple of years [pandemic]. We are now running after school interventions from Year 10 for the next two years so you'd have to be extremely cautious about asking teachers to surrender lesson time The fewer visits you could do it in probably the better for us. Just as an example The police coming in talk it's one period of a day, we don't see them again for a year, but the impact's there. So as long as it's impactful enough maybe reconsider how many sessions you're actually doing with them."  "Facilitator: But is it really important that the lesson introduces the app? P014: Yeah, I think so. DefinitelyAnd shows the functionality of it as well."

	Delivery by the dental team, this may require an incentive such as flexible commissioning or the potential to book patients in with the practice.	"P007. It's not been that long ago since I was at school If they're [health lessons] just delivered by our form tutor it was time to chat to your friends we did have some wherewe had visiting parties come in it's always more interactive and you actually engage I just think to make it [work], do activities, bring people in from the outside"  "S001 I had to deliver [a lesson] which was slide shows anddiscussion about mental health. Total car crash. Really boring. [The students] Didn't want to do it. Not interested. Probably because I was delivering it. We had the prison service come in completely different set of people completely engaged and talked about it for a week So, definitely I think bringing people in. Maybe something physical that they can get involved in, like seeing equipment But anything that's paper based they're just not engaged with at all."  "D003. The same dentistmight not be willing to go all the time, but probably if there was a rotation or something like that they might be able to do it. I would think as a practice principal, [we] might be interested in doing this because they can promote their surgery as well to bring more patients into their practice".
	Will require access to computers or tablets in the school.	"S001we will use things like class Chromebooks which they will all have access to, so that would certainly work for probably a lot of schools who might have access to iPads, Chromebooks or an IT suite that might be a safer option, particularly from a safeguarding point of view thinking about mobile phone accessing the internet during lesson time."
Appointment Making	Well supported with minimal changes.	"P007. I think that the app is a fantastic idea and I'm surprised that it doesn't already exist"
System	Access to app/website for those from most deprived areas.	"P006: Obviously there is a massive concern with the people who can't get on the internet to do this website Most young people that we [youth workers] do work with do have phones, but it's the internet access that's probably the only issue that I would have with thatmost of our young people won't have any access because they're from the deprived areas where their mums can't afford it and stuff like that. So that's the onlyit's weird because the mams can't afford internet but they have this phone but they all connect to our Wi-Fi when they come to our youth sessions"  "S001: I think as they [adolescents] gain more freedom they're more likely to be given a smart phone, but it certainly will not necessarily be new or up to date or have data that they can use So although they might have a smart phone it might be an issue of paying for data, paying for access, using a hot spot, that kind of thing. So it might not be a case of that they haven't got the equipment, it's that they just can't physically use it outside of the house, say, or out and about because they haven't got data."
	Logistics of booking an appointment within the app/website, an online form would be acceptable if needed but appointment confirmation from the	"P007 if you need to send off an email to the practice, and [they] respondwith a phone call that defeats the purpose of the app and would be intimidating and delays the whole process I supposethere's two routes either you're presented with the practice's availability you'll select a slot and then you know you've got A good compromise you give your availability by selecting all of the different slots that you could do you have no idea whether or not those are free or not the practice responds by email [saying] you've been booked in on this particular time"

	practice should be via the app/website.	
	Use of dentist reviews supported and might cause positive spill over.	"D001it might invite perhaps a bit of competition between practices to get really good reviews online and be more inviting for young people that's a positive that could come from an app like this"
	Include dental history and treatment plans	"P005: I'm very in favour of the app because it's very easy and very quick access tooI've got like an app for my GP from where I live, and it makes it very simple to book appointments and I can look up my whole medical history, see what I need checking up on and any booster vaccinations I needI think that would probably be quite beneficial if we applied that to dentistry as well."
Reward	Need for brand partners and/or centralised funding.	"D003: That might work, as long as it's some kind of a centralised funding P011: I agree we looked at finding someone like say Sainsbury's or Colgate obviously it's going to make someone want to get more Colgate products if they get say free, I don't know, toothbrush, toothpaste from them, it's a case of people will actually want to go back to them and it just heightens the fact that actually it's positive feedback to Colgate themselves. That's just one example I could maybe think of. But I agree with the centralised funding aspect of it."
	Include other healthy behaviours.	"P011: [other behaviours] actually appeal to someone like me who, if I'm honest, I wouldn't have done it [gone for a walk], and other people sort of my age, maybe if you'd done something like on the app there was a case of you had a daily target of your 10,000 steps. If you do them steps you get so many points." "P005: I feel like activity is probably going to be very crucial and there's plenty of already popular apps that, like there's one call Strava that I use for running and cycling and it tracks the distance and the steps and stuff, and if we could intertwine that with the app maybe"
		"P013: I feel like it would be a good way to motivate more people my age to go to the dentist. Especially after it's like a time in your life where you're going from secondary to college, it's kind of like that moment where you realise you're getting a bit older and you can start taking on a bit more responsibility, and especially with a lot of people my age as well who are struggling with things like mental health, they might need that extra motivation to try and stay in good health and stuff."
	Reward continued and sustained behaviour change.	"P005if someone went for their yearly check-up they'd get a voucher or whatever and if they went for every single yearly check-up there could be some kind of bigger reward, and that would encourage people to keep going throughout the whole time and that builds those habits"
	Age range for reward system should be 16-years-old to mid to late 20's.	"P012: I agree with 16. I think at 16 people begin to get perhaps somewhat financially independent of their parents" "P003: we're obviously 25, 26 I mean I'm coming up to 27 now and I've got my own place and I have to do the medical and dental stuff so I do kind of agree with what [name redacted] was saying it would be more beneficial, especially to students and all being discussing in previous workshops that they kind of said you should register for a dentist but it seems that a lot of students still don't and it maybe just needs a little bit of an extra push to get themselves registered."

Link appointment system and rewards system to ensure other barriers to attending can be	"RT4: So you've made the appointment, how or why do you keep it when you maybe are a bit anxious? So reward then has got to be decent enough to, or the motivation to keep the appointment has got to be strong enough, so I think this is more about linking up the elements of it now as much as just thinking about these things in isolation."
overcome once	
appointment is made.	

# Appendix V. Linking TDF to COM-B to create the COM-B model (Chapter 7)

COM-B Component		Explanation	TDF
Capability	Physical	Physical ability to carry out the required behaviour (e.g., skill, strength, stamina).	Skills
	Psychological	Psychological ability to carry out the required behaviour (e.g., knowledge, comprehension, reasoning).	Knowledge Skills (Cognitive & Interpersonal) Memory, Attention & Decision Processes Behavioural Regulation
Opportunity	Physical	Physical opportunities created by the environment to allow the behaviour (e.g. time, finance, access).	Environmental Context & Resources
	Social	Social opportunities created by interpersonal influences, social cues and cultural norms (e.g., social influences, social norms)	Social Influences
Motivation	Reflective	Reflective processes of plans and evaluations (e.g., self-conscious intentions and beliefs).	Professional/Social Role & Identity Beliefs about Capabilities Optimism Beliefs about Consequences Intentions Goals
	Automatic	Automatic processes involving sub-conscious processes of emotional reactions, desires, impulses, inhibitions, drive states and reflexes (e.g., anxiety).	Reinforcement Emotion

**Table V.1:** A summary of the COM-B model and linked TDF domains (adapted from (Michie, Atkins and West, 2014).

## Appendix W. Intervention Recommendation Statements for Co-Design Workshop 2 (Chapter 7)

1.

#### **TITLE: Promotional campaign**

RECOMMENDATION: The intervention should aim to increase knowledge and skills around attending a dentist.

RATIONALE: A lack of knowledge and skills around attending a dentist plays a role in patients not seeking regular dental care. These include a lack of knowledge on why visiting a dentist regularly is important, what happens at dental appointments (including paperwork that needs completing), the potential cost of dental care, the importance of oral health and a deficiency or lack of confidence in the skills needed to find a dentist or make an appointment. If patients have this knowledge and these skills it will improve their decision-making on whether to make and attend a dental appointment as they become independent from their parents and transition from school, to further education and/or employment. They may also have reduced anxieties surrounding dental care, for example knowing how to book an appointment, what will happen and how much it will cost.

ADDITIONAL DETAIL: This could be achieved using promotional materials such as leaflets or posters displayed in places such as education and healthcare settings, leisure centres, sports grounds, digital or social media campaigns or by individual letters or leaflets posted out to patient groups.

#### APEASE CRITERIA:

Affordability	Potential costs would include design and printing of promotional materials, postage for letters or leaflets, translation costs for non-English speakers. These costs would need to be scaled for delivery to all of the country. There will also be environmental costs associated with mass production of printed materials.
Practicability	Where the promotional materials are placed would need to be considered to ensure maximum exposure, for example education settings, cinemas, leisure centres and healthcare settings such as GP surgeries, A&E departments, pharmacies. These places would need to agree to take part and be happy to display the material. For materials to be posted out a centralised system is likely to be required which contains details on the patient groups targeted and their correct contact details, this will require access to GP records which will require ethical and data protection approvals to access which will be challenging. If this centralised system is chosen for distribution of materials it will most likely need to be NHS endorsed and carried out as a nationwide screening campaign rather than having a period of initial small scale trial.
Effectiveness &	A previous promotional campaign to increase dental
Cost-Effectiveness	attendance was largely ineffective for changing attendance

	behaviour of irregular dental attenders but did raise awareness of the need for a check-up¹. Generally, use of promotional materials on their own can have a low potential for behaviour change, however may be effective when combined with other interventions. This intervention only targets one part of the COM-B model, however depending on the design of the intervention may also reduce anxiety surrounding dental care, and if knowledge and skills can be targeted from a younger age then these may be maintained into adulthood thereby potentially resulting in long term behaviour change.
Acceptability	Promotional materials are likely to be acceptable to the target audience, however adolescents and young people may not choose to read them in detail. It may also be difficult to teach skills, such as appointment booking, using written materials only.
Side-effects/Safety	This intervention would also target non-attenders and therefore have a positive side effect of encouraging them to seek dental care. It is unlikely there would be any negative side-effects, however the potential to increase inequalities needs to be considered (see equity).
Equity	The materials would need to be designed and displayed to be accessible by all otherwise they could increase inequalities, this would need to be considered in their design and placement, ensuring they were available in different languages and designed for people who may be unable to read.

<sup>1</sup>Anderson R, Morgan J. Marketing dentistry: a pilot study in Dudley. Community Dent Health 1992;9 Suppl 1:1-220.

2.

#### **TTILE: School curriculum**

RECOMMENDATION: The intervention should aim to increase knowledge and skills around attending a dentist by being integrated into school curricula.

RATIONALE: This has the same rationale as IRs 1, but involves a different form of intervention delivery. Dental health has very recently been added to primary and secondary school curricula (2020)<sup>2</sup>; however this relates only to knowledge of dental health, the benefits of good oral hygiene, flossing, healthy eating and regular check-ups and does not include specific skills around navigating dental systems, such as how to find a dentist and make an appointment. Additionally, it does not provide knowledge on what happens at dental appointments (including paperwork that needs completing) and the potential cost of dental care.

ADDITIONAL DETAIL: An intervention could involve an extension to the new relationships and sexual and health education curriculum to include the knowledge and specific skills detailed above and could include provision of standardised teaching materials to schools targeted at different ages.

Potential costs would include design and production of teaching materials with user and stakeholder engagement (school teachers, students, headteachers), such as lesson/assembly plans, worksheets, videos, PowerPoint slides.
Specific skills surrounding navigation of dental systems and further knowledge as mentioned above could be formally added to the curricula, this would require approval from the Department for Education, alternatively schools could chose to add additional content locally, however not all schools may prioritise this. Teaching materials would need to be quality assured and schools would need to agree to use the materials. The teaching materials would also need reviewing on an annual basis and updating as required.
Formalising the teaching into the curricula would mean that all those attending school would receive the intervention however the long-term effect is unknown. Other trials are currently ongoing looking at use of classroom-based teaching and text message reminders on toothbrushing and as this could be built on and provide information for cost analysis once completed <sup>3</sup> . This intervention only targets one part of the COM-B model, however depending on the design of the intervention may also reduce anxiety surrounding dental care, if knowledge and skills can be taught at a young age then these may be maintained into adulthood thereby potentially resulting in long term behaviour change.
This may be acceptable to the target audience, however it would also need to be accepted by teachers and schools.
This intervention would also target non-attenders and therefore have a positive side effect of encouraging them to seek dental care. It is unlikely there would be any negative side-effects.
The minority of children who do not attend school or who are home-schooled may not receive the intervention, therefore there is the potential to increase inequalities.

<sup>&</sup>lt;sup>2</sup>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/908013/Relationships\_Education\_Relationships\_and\_Sex\_Education\_RSE\_and\_Health\_Education.pdf

<sup>&</sup>lt;sup>3</sup>Marshman Z, Ainsworth H, Chestnutt IG, Day P, Dey D *et al.*, (2019). Brushing RemInder 4 Good oral HealTh (BRIGHT) trial: does an SMS behaviour change programme with a classroom-based session improve the oral health of young people living in deprived areas? A study protocol of a randomised controlled trial. *Trials*. 20:452.

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#### **TITLE: Meeting dentists**

RECOMMENDATION: The intervention should aim to increase knowledge and skills around attending a dentist and improve dentist-public relationships by dentists visiting schools or public places.

RATIONALE: This has the same rationale as IRs 1 and 2 but in addition, if dentists delivered this teaching outside of the dental surgery this would provide the public with the opportunity to meet dentists in a less emotional setting.

ADDITIONAL DETAIL: Dentists or other members of the dental team could provide teaching of knowledge and skills outside of the dental surgery at events such as school assemblies or career events. They could meet future potential patients and have the opportunity to form a relationship away from the surgery and make a future appointment for the patient to attend.

APEASE CRITERIA:	
Affordability	Loss of earnings for the dentist (or team member) would need to be covered. This could be achieved using a flexible commissioning approach. This could be expensive given the area (e.g. number of schools, individual year groups) each dental practice would need to cover on an annual basis. Additional teaching or promotional materials for the dentists to use would also need designing (with user engagement) and printing.
Practicability	This may be achievable using a flexible commissioning approach, if not policy change in terms of NHS dental contracts may be required to remunerate (pay) dentists for time spent outside of the surgery for this kind of activity. An increase in workforce may also be required to ensure access to dental care can be maintained, particularly in areas where dental access is already challenging such as rural areas. There would need to be significant organisation between dental practices and schools to arrange appropriate times and dates for the dentists to attend. There will be a significant number of schools for the dental team to attend on an annual basis.
Effectiveness & Cost-Effectiveness	A previous study used a "dental update" appointment whereby members of the public could attend a dental practice to look around and informally meet the dentist <sup>1</sup> , which has some similarities to the idea proposed here, however the uptake of this by the public was very low and did not result in behaviour change. There is likely to be a large cost associated with an intervention which could be achieved without reliance on the dental team to deliver it. It does, however, target more than one part of the COM-B model so is more likely to result in behaviour change, and if knowledge and skills can be taught at a young age then these may be maintained into adulthood thereby potentially resulting in long term behaviour change.
Acceptability	This may be acceptable to the target audience, however it may require policy change and would need to be acceptable to dentists and the dental team delivering the intervention as well as local dental commissioners.

Side-effects/Safety	This intervention would also target non-attenders and therefore have a positive side effect of encouraging them to seek dental care. There is the potential to decrease access to dental care if workforce is not maintained when dentists are delivering the intervention.
Equity	It may be possible for dentists to visit non-education settings and hard-to-reach patient groups who are rarely heard therefore decreasing inequalities. It may be difficult to provide this intervention in areas where dental access is limited (e.g. rural areas) and therefore there is the potential to increase inequalities in these areas.

<sup>1</sup>Anderson R, Morgan J. Marketing dentistry: a pilot study in Dudley. Community Dent Health 1992;9 Suppl 1:1-220.

4.

#### **TITLE: Patient stories**

RECOMMENDATION: The intervention should aim to increase knowledge and skills around attending a dentist and decrease anxiety surrounding dental care using videos which share positive patient stories when engaging with dental care services.

RATIONALE: This has the same rationale as IRs 1 & 2 but in addition, if positive patient stories are shared this may help reduce anxiety surrounding the process of making an appointment and seeing a dentist.

ADDITIONAL DETAIL: Videos could be shared on social media which young people are known to engage with, they could also be played in other places such as healthcare and education settings and be incorporated into other educational materials.

#### APEASE CRITERIA:

Affordability	Costs would include design (with user engagement), recording and editing of videos and payment for role players for the patient stories (based on real stories). There would be a cost associated with promotion of the videos on certain social media platforms (e.g. Facebook) though the videos could also be added to relevant NHS platforms, such as NHS 111 and Change4Life.
Practicability	Depending on where the videos are shared approvals may be required. The videos would need reviewing and updating when required which may bear an additional long-term cost.
Effectiveness & Cost-Effectiveness	Effectiveness is unknown but likely to be low cost in comparison to other interventions and could be incorporated into other intervention ideas and shared in multiple locations. If knowledge and skills can be taught at a young age then these may be maintained into adulthood thereby potentially resulting in long term behaviour

	change. It also targets more than one part of the COM-B model so more likely to result in behaviour change.
Acceptability	Likely to be acceptable to the target group. Would need approval from healthcare and education settings to share the videos on some platforms.
Side-effects/Safety	This intervention would also target non-attenders and therefore have a positive side effect of encouraging them to seek dental care.
Equity	The videos could be made accessible by use of subtitles, audio descriptions and translated into different languages. There would be the potential to increase inequalities if they were only shared on social media therefore consideration would need to be made on where to share them for those who do not have access to the internet and/or social media (e.g. GP surgeries, A&E departments).

5.

#### TITLE: Make Every Contact Count

RECOMMENDATION: The intervention should aim to increase the perceived importance of oral health by linking oral health to whole-body health.

RATIONALE: The reported importance of oral health appears to decrease from adolescence into young adulthood, and in addition other life priorities start to take precedent (are seen as more important) over dental attendance. Oral health is often considered as being distinct from whole body health and therefore considered less important. In addition, there are clear links between oral health and whole-body health, such as infection with HPV virus which is known to cause cervical cancers can also cause oral cancers. If perceived importance of oral health can be increased this would play a role in patients deciding to seek regular dental care.

ADDITIONAL DETAIL: This intervention could be based on the current Make Every Contact Count<sup>4</sup> (MECC) behaviour change approach which has been endorsed by organisations such as Public Health England and NHS England. This would involve people who are regularly in contact with adolescents, such as teachers, social care or healthcare professionals (e.g. GPs, pharmacists, health visitors, district nurses) briefly discussing oral health when patients see them, or dentists and other members of the dental team delivering more information when they see patients for check-ups or urgent care. Oral health could also be included in other interventions or current campaigns on aspects of general health which oral health is directly linked to.

#### APEASE CRITERIA:

Affordability	This is likely to be an affordable intervention and may	
	include costs associated with development of materials to	
	aid healthcare professionals with delivery of information,	
	such as leaflets. Depending on who delivers the	
	intervention they may also need training.	

Practicability	If this was based on MECC then this is likely to be a practical approach. Whoever is delivering the intervention would need to be involved in designing the intervention to ensure it is practical for them to deliver in their current role.
Effectiveness & Cost-Effectiveness	MECC is a well-established behaviour change approach and therefore is likely to be effective. The intervention could target more than just oral health so may have multiple health benefits. It could also be combined with other IRs to target more than one part of the COM-B model to increase the likelihood of behaviour change.
Acceptability	Many healthcare professionals and other organisations will be familiar with MECC and may already be delivering interventions in this way, it is therefore likely to be acceptable to those who deliver it, particularly if they are involved in the intervention design. This may also be acceptable to adolescents and the general public although consideration would need to be given to where and how this information is delivered to ensure they do not feel overloaded with information and that the information will be received (e.g. will adolescent read a leaflet?).
Side-effects/Safety	There may be positive side effects if the intervention also targets other areas of health. It is unlikely there will be any negative side effects or safety concerns.
Equity	The location of the delivery would need to be considered to ensure that as many people are reached as possible, and if this is delivered in multiple locations by different people the intervention could accessible by many patient groups and therefore decrease inequalities.

4 https://www.makingeverycontactcount.co.uk

6.

#### **TITLE: Reward system**

RECOMMENDATION: The intervention should aim to increase regular dental attendance by offering a reward for continued attendance for check-ups and also contribute to decrease barriers.

RATIONALE: As adolescents and young adults transition into independence and have to begin to pay for dental treatment they need to make the decision on their own whether to continue to seek regular dental care against other life priorities. If a reward was offered for continuing their regular attendance pattern this may incentivise them to continue to seek care. In addition, dental charges are often a perceived barrier as well as an actual barrier, therefore if the intervention could also include help with navigating the dental system, such as information on cost, how to access care and make an appointment then behaviour change would be more likely to occur and be maintained long term.

ADDITIONAL DETAIL: The intervention would need to be tailored to when dental charges would take effect on an individual basis (i.e. 18-years-old or 19-years-old in full time education). The reward could be similar to a loyalty card whereby after a certain number of consecutive visits they receive a voucher, or discounted dental treatment/free dental check-up. This could also involve incentives for dental teams to encourage adolescents to continue to seek regular dental care when they see them (e.g. registration payments, continued care payments).

#### APEASE CRITERIA:

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Affordability	Affordability would depend on the reward offered and how often it is given. The long term affordability would need to be considered, however given that regular check-ups will help to prevent dental disease and therefore the need for treatment it may be affordable long term.
Practicability	Depending on the type of reward given it would likely require a change in current dental policy and legislation for dental practices to be paid for the reward (e.g. if the reward was a free check-up the practice would need to be reimbursed for this by the NHS). A system would also need to be designed to ensure it is transparent, fair and could not be misused. If the reward was a gift voucher the voucher would need to be selected so that it doesn't appear that the NHS or Department for Health are endorsing a specific brand or company. Awareness of the reward system would need to be considered and may require additional promotion.
Effectiveness &	Incentives can be effective in behaviour change however if
Cost-Effectiveness	the reward scheme was stopped the behaviour change may not be maintained long term. A previous reward campaign was trialled for 15-17 year-olds which included free dental hygiene materials, a discount voucher for a local retailer and entry to a prize lottery when they attended for a dental check-up, however only 8% of the target population attended, and only 2% attended as a result of the reward campaign <sup>5</sup> .
Acceptability	This is likely to be acceptable to the target group, however other stakeholders (e.g. the government) may not find this to be acceptable.
Side-effects/Safety	This intervention may also encourage non-dental attenders to begin to seek care.
Equity	There is unlikely to be any increase in inequalities.
	A, Schou L (1994). A campaign encouraging dental attendance among

<sup>5</sup>Craven RC, Blinkhorn A, Schou L (1994). A campaign encouraging dental attendance among adolescents in Scotland: the barriers to behaviour change. *Community Dental Health*. 11:131-134.

7.

#### **TITLE: Appointment System**

RECOMMENDATION: The intervention should include a new system for making dental appointments which is more accessible to younger people.

RATIONALE: Adolescents and young adults report anxiety surrounding appointment making, specifically in relation to in person or telephone communication, and in relation to the paperwork that needs completing at appointments.

ADDITIONAL DETAIL: A new appointment making system could be designed which allows appointments to be made online or via an app, and that automatically suggests dental practices near the person's postal code who are accepting new patients. This could also incorporate reminders about appointments and information on dentistry, such as cost of treatment, information on the paperwork that will be required at the appointment and what to expect during a check-up.

#### APEASE CRITERIA:

Affordability  Development of an online system or an app will involve design and maintenance costs as well as on going IT support.  Dental practices currently use their own appointment booking systems and are provided by different companies, the new system would therefore need to integrate with all current dental practice systems, or be a stand-alone system which all practices are able to access and use. It would need to be designed to ensure data protection and patient confidentiality is maintained.  Effectiveness &  Cost-Effectiveness  For this intervention to be effective the patient would have to have made the decision to seek dental care and overcome the other barriers associated with care-seeking. The cost of the intervention may therefore not be justified against the potential effectiveness if other barriers aren't addressed. There is evidence, however, that mobile phone-based SMS interventions are effective in behaviour change, although it is a small effect and under-researched for use in dentistry <sup>6,7</sup> .  Acceptability  This would be acceptable to young patients, however, may not be acceptable to those who are not computer literate, or who do not have access to the internet or a smart phone. It may also not be acceptable to dental practices if they need to purchase additional software.  Side-effects/Safety  There may be concerns regarding data protection and patient confidentiality and these would need to be carefully considered in the design.	7 11 27 10 2 01 11 1 21 117 11	
booking systems and are provided by different companies, the new system would therefore need to integrate with all current dental practice systems, or be a stand-alone system which all practices are able to access and use. It would need to be designed to ensure data protection and patient confidentiality is maintained.  Effectiveness & Cost-Effectiveness  For this intervention to be effective the patient would have to have made the decision to seek dental care and overcome the other barriers associated with care-seeking. The cost of the intervention may therefore not be justified against the potential effectiveness if other barriers aren't addressed. There is evidence, however, that mobile phone-based SMS interventions are effective in behaviour change, although it is a small effect and under-researched for use in dentistry.  Acceptability  This would be acceptable to young patients, however, may not be acceptable to those who are not computer literate, or who do not have access to the internet or a smart phone. It may also not be acceptable to dental practices if they need to purchase additional software.  Side-effects/Safety  There may be concerns regarding data protection and patient confidentiality and these would need to be carefully considered in the design.	Affordability	design and maintenance costs as well as on going IT
to have made the decision to seek dental care and overcome the other barriers associated with care-seeking. The cost of the intervention may therefore not be justified against the potential effectiveness if other barriers aren't addressed. There is evidence, however, that mobile phone-based SMS interventions are effective in behaviour change, although it is a small effect and under-researched for use in dentistry <sup>6,7</sup> .  Acceptability  This would be acceptable to young patients, however, may not be acceptable to those who are not computer literate, or who do not have access to the internet or a smart phone. It may also not be acceptable to dental practices if they need to purchase additional software.  Side-effects/Safety  There may be concerns regarding data protection and patient confidentiality and these would need to be carefully considered in the design.	Practicability	booking systems and are provided by different companies, the new system would therefore need to integrate with all current dental practice systems, or be a stand-alone system which all practices are able to access and use. It would need to be designed to ensure data protection and
not be acceptable to those who are not computer literate, or who do not have access to the internet or a smart phone. It may also not be acceptable to dental practices if they need to purchase additional software.  Side-effects/Safety There may be concerns regarding data protection and patient confidentiality and these would need to be carefully considered in the design.		For this intervention to be effective the patient would have to have made the decision to seek dental care and overcome the other barriers associated with care-seeking. The cost of the intervention may therefore not be justified against the potential effectiveness if other barriers aren't addressed. There is evidence, however, that mobile phone-based SMS interventions are effective in behaviour change, although it is a small effect and under-researched for use in dentistry <sup>6,7</sup> .
patient confidentiality and these would need to be carefully considered in the design.	Acceptability	not be acceptable to those who are not computer literate, or who do not have access to the internet or a smart phone. It may also not be acceptable to dental practices if
	Side-effects/Safety	patient confidentiality and these would need to be carefully
Equity  This could increase inequalities in those who do not have access to the internet or a smart phone.	Equity	

<sup>6</sup>Armanasco AA, Millr YD, Fjeldsoe BS, Marshall AL (2017). Preventive health behaviour change text message interventions: a meta-analysis. *Am J Preventive Med.* 52:391-402. <sup>7</sup>Albino J, Tiwari T (2016). Preventing childhood caries: a review of recent behavioural research. *J Dent Res* 95:35-42.

8.

**TITLE: Dentist training** 

RECOMMENDATION: The intervention should include training for dentists on communication and other interpersonal skills.

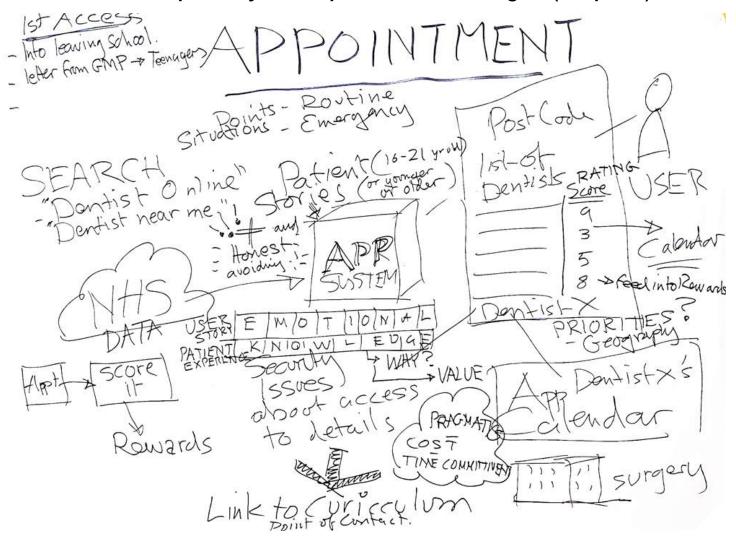
RATIONALE: The professional role of the dentist plays a part in patients deciding whether or not to seek regular dental care. A positive dental experience related specifically to positive characteristics of the dentist encourages regular dental care-seeking. Perceived negative dentist characteristics are associated with future dental attendances being less likely. Specific dentist characteristics reported as being negative include dentists creating feelings of judgement or penalisation, showing a lack of empathy, being cold, disengaged and condescending. In addition, adolescents report feeling left out of conversations between their parents/guardians and the dentist. If the dentist-patient relationship can be improved then patients may be more likely to continue seeking regular care.

ADDITIONAL DETAIL: This may involve training for dentists in the form of postgraduate education or continuing professional development, and/or training of student dentists. This intervention is based on the evidence statement relating to dentist characteristics, and is based on research talking to patients only and did not involve dentists or observation of the dentist-patient interaction, further research would therefore be beneficial to base this intervention on.

#### APEASE CRITERIA:

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Affordability	The cost would include development of teaching plans and		
	materials and is likely to require work with role players.		
Practicability	Communication skills and interpersonal skills are already		
	taught and assessed as part of the undergraduate dental		
	curriculum, however more focussed training could be		
	added for certain patient groups. Dentists already have to		
	attend a set number of courses every year to maintain their		
	registration as a dentist therefore this could be		
	incorporated with this. It would be beneficial to include the		
	training in contract reforms so that dentists could be		
	offered incentives to undertake the training, however this		
	would require a change in policy.		
T# otive a second			
Effectiveness &	This may be effective, and could map to more than one		
Cost-Effectiveness	.		
	the final intervention, however the dentist-patient		
	relationship and specific communication skills required in		
	different patient groups requires further in depth research		
	for this intervention to be based on and to be fully effective.		
Accontability	This is likely to be acceptable for undergraduate dental		
Acceptability			
	students as part of their training. Dentists attending post		
	graduate courses would need to take time off work and		
	sometimes pay for the course and this may not be seen as		
	a course they would prioritise against other training needs.		
Side-effects/Safety			
Equity	This is unlikely to negatively affect inequalities, but is more		
	likely to be of benefit for those accessing dental care and		
	therefore may not be of benefit to non-attenders.		
	therefore may not be of benefit to non attendere.		

Appendix X. An Example of the Pictorial Representations of the Intervention Design Discussions in Workshop Two by the Graphic Facilitator/Designer (Chapter 7)



## Appendix Y. Patient Stories Suggested by Workshop 2 Participants Mapped to BCTs (Chapter 7)

Stories are mapped to BCTs from (Michie et al., 2013).

Patient Story	BCT Category	Actual BCT
Positive treatment experience (treatment	Natural consequences	Information about emotional consequences
relevant to someone of a younger age,	Comparison of behaviour	Demonstration of the behaviour
e.g., extraction of a "wisdom tooth" [3 <sup>rd</sup>		Information about others' approval
molar]).	Associations	Remove aversive stimulus
	Comparison of outcomes	Credible source
The impact of not attending the dentist for	Goals and planning	Problem Solving
check-ups leading to dental pain and the	Shaping knowledge	Instruction on how to perform a behaviour
impact of this on everyday life, through to	Natural consequences	Information about health consequences
the person seeking dental care for the		Salience of consequences
pain and showing that it's not as daunting		Anticipated regret
as it was assumed to be and that barriers		Information about emotional consequences
can be overcome so they wish they'd	Comparison of behaviour	Demonstration of the behaviour
attended earlier for prevention.		Social comparison
		Information about others' approval
	Comparison of outcomes	Credible source
		Pros and cons
		Comparative imagining of future outcomes
	Identity	Framing/reframing
	Covert learning	Vicarious consequences
Stories showing how oral health links to	Natural consequences	Information about health consequences
whole body health, e.g., HPV and oral		Salience of consequences
cancer.		Anticipated regret
	Comparison of outcomes	Comparative imagining of future outcomes
	Covert learning	Vicarious consequences
Patient journey through a dental check-	Shaping knowledge	Instruction on how to perform a behaviour
up, including making an appointment,		Information about antecedents
entering the surgery, completing	Comparison of behaviour	Demonstration of the behaviour
paperwork and having the check-up.		Social comparison

		Information about others' approval
	Associations	Prompts/cues
	Comparison of outcomes	Pros and cons
The long-term impact of avoidance of	Natural consequences	Information about health consequences
dental care resulting in the need for		Salience of consequences
extractions and dentures and the		Anticipated regret
subsequent impact of this in later life.		Information about emotional consequences
	Comparison of behaviour	Social comparison
	·	Information about others' approval
	Associations	Prompts/cues
	Comparison of outcomes	Credible source
		Pros and cons
		Comparative imagining of future outcomes
	Identity	Framing/reframing
		Incompatible beliefs
	Covert learning	Vicarious consequences
Positive story of management of dental	Goals and planning	Problem Solving
anxiety.	Natural consequences	Information about emotional consequences
	Comparison of behaviour	Demonstration of the behaviour
		Social comparison
		Information about others' approval
	Comparison of outcomes	Credible source
	Regulation	Reduce negative emotions

## Appendix Z. Semi-Structured Topic Guide for Workshop 3 (Chapter 7)

#### School curriculum topic guide:

- 1. Brief introductions for participants and research team members
- 2. Reminder of ground rules:
  - No right or wrong answers to the exercises; we just want to find out what you think and what your opinions are.
  - Confidentiality information collected during the study is confidential and access will be restricted to the research team.
  - Please allow all members of the group to speak, if you wish to make a comment based on something someone is saying please raise your hand to make the facilitator aware and avoid speaking over the top or interrupting another participant.
  - Any questions?

Turn on recorder on zoom (and separate back up recorder), inform participants that the session is now being recorded.

- 1. Using the storyboard what are your thoughts and opinions on the intervention?
  - a. Any problems or issues? Do they think it will work?
  - b. Explore from different view points using the characters in the storyboard
  - c. Does anything need changing or adding to overcome any problems or issues identified?
- 2. The scenario is just one example of how the intervention may or may not work for different people and the potential outcomes of it, are there any other groups of people who may use the intervention who need considering? Will it work for them or do we need to make any adjustments?
  - a. Explore different groups of young people who may be relevant
  - b. Explore different potential outcomes of the intervention, are they positive or negative and does anything need changing in the design related to these?
- 3. Thinking about the intervention from the point of view of those delivering it (teachers and the dental team), does anything need changing?
  - a. Is this acceptable to teachers?
  - b. Would FD's/dental students/young dentists be happy to deliver the intervention?
  - c. Would the rest of the dental team be happy to do this if FD's/dental students aren't able to deliver it?
  - d. If the dental team don't deliver the intervention will this impact on the outcome of the intervention?
- 4. Now looking at the intervention details in your reading, if we could only develop three or four patient stories which from the list would you pick and why?
- 5. One option for developing these patient stories is to use interactive videos where participants can make decisions and then see what happens as result, do you think this is a good idea?
  - a. For an example they should have looked at https://www.trylife.tv
- 6. What other learning materials do you think we should design?
- 7. What parts of this should be delivered by the dental team and what could be delivered by school teachers?

- 8. Would it be acceptable to meet the dental team virtually if needed in certain areas?
- 9. Where in the school curriculum should this be delivered? Personal, social and health lessons or elsewhere?

#### App/website/reward system topic guide:

- 1. Brief introductions for participants and research team members
- 2. Reminder of ground rules:
  - No right or wrong answers to the exercises; we just want to find out what you think and what your opinions are.
  - Confidentiality information collected during the study is confidential and access will be restricted to the research team.
  - Please allow all members of the group to speak, if you wish to make a comment based on something someone is saying please raise your hand to make the facilitator aware and avoid speaking over the top or interrupting another participant.
  - o Any questions?

Turn on recorder on zoom (and separate back up recorder), inform participants that the session is now being recorded.

- 1. Using the storyboard what are your thoughts and opinions on the intervention?
  - a. Any problems or issues? Do they think it will work?
  - b. Explore from different view points using the characters in the storyboard
  - c. Does anything need changing or adding to overcome any problems or issues identified?
  - d. Specifically explore what would happen when participants are not eligible for the reward system any longer, would they carry on seeking regular dental care? Does anything in the design need changing related to this? What age range do they think the reward system should be aimed at and why?
- 2. The scenario is just one example of how the intervention may or may not work for different people and the potential outcomes of it, are there any other groups of people who may use the intervention who need considering? Will it work for them or do we need to make any adjustments?
  - a. Explore different groups of young people who may be relevant (no access to internet, smart phone etc)
  - b. Explore different potential outcomes of the intervention, are they positive or negative and does anything need changing in the design related to these?
- 3. Now looking at the intervention details you've been given in your reading if it isn't possible to book an appointment directly on the app/website would it be acceptable to fill in the web based form as described?
- 4. Would you be happy storing personal information on an app/website such as this? (Very briefly cover)
- 5. How could someone collect and record points and exchange for rewards if they didn't use the app/website?
- 6. Should the user be rewarded for going for a dental check-up only or should they be able to earn points for having dental treatment too? Are there any pros or cons to them gaining points for dental treatment?

- 7. How could the user earn points for interacting with the learning materials on the app/website? There could be quizzes incorporated but would everyone find these acceptable? Are there other ways we could do this for those who didn't want to take part in quizzes?
- 8. Would the rewards be appealing? Would the offer of a free dental check-up be an appealing reward?

## Appendix AA. Framework for the Reward System Component of the Intervention (Chapter 7)

Based on the framework developed by Adams et al. (2014).

Domain	Definition	Intervention	Literature & Theoretical Basis
Direction	A positive gain for engaging in a healthy behaviour, or avoidance of a negative loss for not engaging in a healthy behaviour.	A positive reward by receiving points which can be exchanged for vouchers as a result of healthy behaviours (e.g. attending a dental check-up).	Rewarding healthy behaviours, including those which are already healthy prior to intervention, is of upmost importance otherwise the incentive is seen as unfair (Giles <i>et al.</i> , 2015).
Form	The nature of the incentive.	Points will be exchangeable for a range of reward vouchers identified by workshop participants, ideally including: shopping vouchers, activities and days out (cinema tickets, National Trust etc.), transport (e.g., bus and train tickets), food and drink (with some restrictions for products such as alcohol or tobacco), oral hygiene products, mobile phone data, dental check-up. Cash incentives will not be offered.	Cash incentives may be more valued by those with lower disposable incomes but may be inappropriate if they can be used to finance unhealthy behaviours (Adams <i>et al.</i> , 2014). Use of vouchers is therefore seen as more acceptable as they are less likely to be abused (Giles <i>et al.</i> , 2015). Terms and conditions will be included in vouchers to ensure they cannot be exchanged for products such as alcohol and tobacco. Incentives should also be tailored to individual preferences (Giles <i>et al.</i> , 2015) which is considered by use of different rewards the end-user can select from.
Magnitude	The total value of incentive available to participants, expressed as a continuous variable.	This will be variable dependent on the behaviour performed, points accrued and when they are exchanged. Smaller rewards may be equivalent to the cost of a toothbrush, toothpaste, metro ticket, larger rewards may be equivalent to the cost of a day out. This domain will be confirmed in the next stage of development when brand partners have been approached and the rewards available clarified.	Little evidence base exists around magnitude of the incentive (Giles et al., 2014), however there some evidence that increasing magnitude may increase effectiveness (Paul-Ebhohimhen and Avenell, 2008; Giles et al., 2014), however a recent Cochrane review of incentives for smoking cessation found no noticeable difference between behaviour change and magnitude of incentive (Notley et al., 2019). Given this it is probably more beneficial to determine the magnitude of the reward based on cost-effectiveness.
Certainty	How sure the participants can be from the start of the programme that they	This will be a certain incentive, if the participants carry out the behaviour they will receive points they can exchange for rewards. There will be rewards available	To date there are too few studies with low risk of bias to be able to compare different types of certainty in incentive based interventions (Notley <i>et al.</i> , 2019).

	will receive the incentive if they are successful. Possible levels include certain, certain chance incentive and uncertain chance incentive.	for low numbers of points to ensure they can be exchanged early if the participant wishes to.	
Target	The target behaviour outcome is either process (engaging in a process that is likely to help individuals achieve healthy behaviour outcomes by providing behaviour change skills which are not healthy in themselves), intermediate (can be considered healthy in themselves but are intermediary to other outcomes), or outcome (healthy distal behaviours).	The target will be a mix of process (e.g. attend a dental check-up) and intermediate (e.g. improving diet, oral hygiene).	Targeting process behaviours are seen as being preferable over outcome behaviours as end-users should be rewarded for changing behaviour and therefore trying to obtain an outcome even if said outcome is not achieved (Giles <i>et al.</i> , 2015). In oral health this could be justified as there will be underlying inequalities in dental diseases (e.g., exposure to fluoridated water) therefore it would be important to reward process behaviours over outcome. It may also affect end-user motivation if they achieve process behaviours (for example attendance for a check-up) but still develop dental disease, as this could send a mixed message about the importance of seeking regular dental care if they still develop dental disease and therefore aren't rewarded.
Frequency	The proportion of occurrences of the behaviour that are incentivised, categories are either "all" or "some".	Some as not every healthy behaviour will result in a reward, however will contribute to points to exchange. Some healthy behaviours will accrue more points than others and therefore may potentially be exchanged immediately for a reward.	This reward system is based on intermittent reinforcement theory (as part of operant conditioning theory) (Michie <i>et al.</i> , 2014) meaning that the behaviour change is likely to be maintained for longer in comparison to continuous reinforcement (Bitterman, 2006).
Immediacy	How soon after the behaviour occurs the incentive is provided.	This will be variable, different behaviours will earn different numbers of points therefore some behaviours may take longer to accrue points than others. The point system will be designed to ensure that participants can receive a reward early	Too long a delay between behaviour and reward may mean that the two are not linked and the incentive will not become an effective reinforcer (Adams <i>et al.</i> , 2014), this would be in keeping with the workshop participants concerns over ensuring points could be accrued quick enough to be rewarded quickly.

		to motivate them, however the more points they accrue the larger the reward will be.	
Schedule	A dichotomy of incentives that either offer fixed magnitudes of incentives for each instance of the behaviour and those that offer variable incentives in response to prolonged behaviour change.	This will be variable as additional points will be awarded for continued behaviour change. In addition, over time points may be reduced as behaviour is maintained and motivation to carry out the behaviour becomes intrinsic.	Contingency management theory suggests that gradually increasing the value of the incentive as behaviour is maintained leads to sustained behaviour change (Adams <i>et al.</i> , 2014). However, as the end-user's motivation to carry out the behaviour becomes intrinsic (as opposed to extrinsic at the start of the intervention) as a result of other components of the intervention increasing the perceived importance of dental attendance, points can be decreased and behaviour should be maintained (as per self-determination theory; (Michie <i>et al.</i> , 2014).
Recipient	Incentives are either given to individuals, groups of people based on average group performance, clinicians or parents.	Individuals are rewarded for their own behaviours.	N/A.

#### Chapter 9. References

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