Supporting Dental Treatment Decisions for People Living with Dementia

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Abstract

Background: Making dental treatment decisions can be complex for people living with dementia (PLwD), their carers and dentists. There is limited research exploring how PLwD, their carers or dentists may be supported with dental treatment decision-making.

Aim: The work presented in this thesis aimed to support the collaborative production of an intervention to support PLwD, their carers, and dentists with dental treatment decision-making.

Methods: Four related projects comprise this thesis: Project 1 was a systematic review that explored the effectiveness of existing interventions supporting healthcare decision-making for PLwD. Projects 2 and 3 used qualitative interviews to explore the experiences of dentists, PLwD and carers regarding dental treatment decision-making. Constructivist grounded theory methods, where data were simultaneously generated and analysed, were used to develop an understanding of each group's experiences and how dentists approach treatment decision-making for PLwD. Project 4 used co-production where PLwD, carers, dental team members and other stakeholders worked together to develop a prototype intervention to support PLwD, carers and dentists with dental care decision-making.

Results: No interventions were identified that were effective in supporting PLwD with healthcare decisions, including dental care (Project 1). Despite seeking to provide individualised care, dentists reported specific approaches to decision-making for PLwD which focused heavily on biomedical aspects of care, such as medical risk or benefit (Project 2). PLwD and carers explained they wished to be understood and more involved in dental treatment decision-making (Project 3). A series of workshops and separate interactions with PLwD and a dental team led to the co-production of the Dental Decisions Tool, which may support patient and carer involvement in dental treatment decisions (Project 4).

Summary: Informed by qualitative research, the Dental Decisions Tool was co-produced to gather information on PLwD's preferences and values for care, and to support PLwD, carers and dentists with dental treatment decision-making. Once completed, the Dental Decisions Tool may also support best interest decision-making for people lacking the capacity to consent for dental treatment. Further research is needed to explore the acceptability, suitability, and effectiveness of this tool.

Dedication

This thesis is dedicated to my wife Louise, and our two little G-Rs.

Acknowledgements

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Finally, my greatest support and joy has come from my family, my wife Louise and our two incredible boys. This endeavour would not have been possible without their love, support, and encouragement.

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List of Abbreviations

ACP	Advance Care Plan / Advance Care Planning
ADRT	Advanced Decision to Refuse Treatment
AD	Alzheimer’s Disease
BIDM	Best Interests Decision-Making
CDS	Community Dental Service(s)
CDO	Community Dental Officer
CGT	Constructivist Grounded Theory
DCS	Decisional Conflict Scale
DwLB	Dementia with Lewy Bodies
FTD	Fronto-temporal Dementia
GA	General Anaesthesia
GDC	General Dental Council
GDS	General Dental Services
GDP	General Dental Practitioner / General Dental Practice
GMP or GP	General Medical Practitioner
GT	Grounded Theory
HDS	Hospital Dental Service(s)
HRA	Health Research Authority
IMCA	Independent Mental Capacity Advocate
LBD	Lewy Body Dementia
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act (2005)
MCI	Mild Cognitive Impairment
MMAT	Mixed Methods Appraisal Tool
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
OHIP-14	Oral Health Impact Profile-14
OHR-QoL	Oral-Health-Related Quality of Life
OHVS	Oral Health Values Scale
OPTION	Observing Patient Involvement In Decision Making (Scale)

PDA	Patient Decision Aid
PIS	Participant / Patient Information Sheet
PLwD	People / Person Living with Dementia
PPIE	Patient and Public Involvement and Engagement
QoL	Quality of Life
RCT	Randomised Controlled Trial
SCD	Special Care Dentistry
SDM	Shared Decision Making
SDO	Senior Dental Officer
StR	Specialty Registrar / Trainee
VD	Vascular Dementia
YOD	Young-Onset Dementia

Publications and Presentations

Publications

A summary of the literature review presented in Chapter 2 was published in 2023:

> Geddis-Regan, A., 2023. Dental care for people living with dementia: current challenges and planning for the future. The UK perspective. *Community Dental Health* 40, pp.1-6

The systematic review presented in Chapter 5 was published in 2021. The abstract of this is presented in Appendix B:

> Geddis-Regan, A., Errington, L., Abley, C., Wassall, R., Exley, C. and Thomson, R. (2021). Enhancing shared and surrogate decision making for people living with dementia: A systematic review of the effectiveness of interventions. Health Expectations 24, pp.19-32.

A paper discussing qualitative methodology, arising from the preparation of Chapter 6, was published in 2021:

> Geddis-Regan, A., Exley, C. and Taylor, G. (2022). Navigating the Dual Role of Clinician-Researcher in Qualitative Dental Research. JDR Clinical and Translational Research. 7(2) pp.215-217.

The qualitative research presented in Chapter 8 was published in early 2023:

> Geddis-Regan, A., Wassall, R.R., Abley, C. and Exley, C. (2023). Exploring dental treatment decision-making experiences of people living with dementia and family carers. *Gerodontology* (online ahead of print)

Research Presentations:

The work presented in Chapter 7 was presented at an international conference in 2021. The abstract of this work is shown in Appendix G:

> Geddis-Regan, A., Abley, C., Durham, J., Wassall, R. and Exley, C. (2021). Dentists' accounts of planning care for people living with dementia. IADR/AADR/CADR General Session (Virtual Experience).

The work presented in Chapter 8 was presented at an international conference in 2022. This abstract is presented in Appendix H:

> Geddis-Regan, A., Wassall, R., Abley, C. and Exley, C. (2022). “[The Dentist] just kind of gets on and does it” Exploring the experiences of dental care decision making with or for people living with dementia. International Association of Disability and Oral Health Conference. Paris.

Invited Presentations:

> Treatment Decision Making For Older Adults. (2020). Royal College of Surgeons of Edinburgh: Webinar Series. (Virtual).
>
> Facilitating effective decision making in dental care for people living with dementia. (2020). European College of Gerodontology Conference (Virtual).
>
> Person-Centred Dental Care Decision Making. (2022). British Dental Association Community Dental Services Group - North East Regional Meeting. Newcastle upon Tyne.
>
> Dental Decisions Study: Key findings and implications. (2022). British Society of Gerodontology Winter Meeting. London.

Chapter 1. Introduction and outline of thesis

1.1 Introduction

Whilst many people live independently and have good health in older age, conditions such as dementia, frailty or multimorbidity can develop in isolation or combination as people age (Whitty et al., 2020). Patients with these conditions are more likely to have complex and heavily restored dentitions (Watt et al., 2013) and experience oral diseases (Delwel et al., 2017, Foley et al., 2017). Dentists may find it challenging to plan how to address oral health problems for people living with dementia (PLwD) and related comorbidities (Rozas, Sadowsky and Jeter, 2017). In particular, certain aspects of dental care may be associated with significant medical, psychological, or medico-legal complexities (Faculty of General Dental Practitioners, 2017). However, failing to provide appropriate dental care can result in the proliferation of dental diseases and orofacial pain, which can be detrimental to quality of life (van de Rijt et al., 2019a). Dementia may affect the extent to which people living with dementia (PLwD) can contribute to decisions about their own care (Bhatt et al., 2020) and ethical issues can be faced when others make decisions that impact PLwD (Wright et al., 2019). This thesis explores the perspectives of dentists, PLwD and carers[1] regarding dental treatment decision-making in the context of dementia. The work also considers what existing interventions may support this process, and proposes a new intervention to support dentists, PLwD and carers in this process.

1.2 Thesis structure

This thesis contains 13 chapters, including this introductory chapter. Firstly, I present context for the research and summarise key concepts and literature (Chapters 2 and 3). In Chapter 2, I summarise dementia and its impact on oral health and dental care. I then describe dental services for PLwD and the guidelines that may inform the treatment dentists may provide for PLwD. In Chapter 3, I describe approaches to healthcare decision-making for those with and without the capacity to consent for

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[1] Throughout this thesis, I use the term *carer* to refer to informal, unpaid carers such as family members or close friends. When referring to non-family carers, additional descriptors are used, such as *professional carer.*

their care, before exploring how the quality of decision-making quality may be determined or measured. I describe the justification for the research and the specific aim and of this thesis in Chapter 4 alongside the specific objectives of the four projects it presents:

Project 1: A systematic review to identify interventions that effectively support healthcare decision-making with or for PLwD (Chapter 5)

Project 2: A qualitative study exploring dentists' views on, and approaches to, dental treatment decision-making with or for PLwD (Methods: Chapter 6, Data and Discussion: Chapter 7)

Project 3: A qualitative study with PLwD and carers exploring their experiences and views on dental treatment decision-making (Methods: Chapter 6, Data and Discussion: Chapter 8)

Project 4: Co-production of an intervention to support dental treatment decision-making with or for PLwD (Chapters 9, 10, and 11).

As co-production is a less established approach to research that can take various forms, I provide a reflection on my experience using this approach to develop an intervention in Chapter 12. Finally, I summarise the findings of the four projects in Chapter 13 where I also propose some next steps for research in this area.

Chapter 2. Dementia, oral health, and dental treatment

In this chapter, I summarise dementia and its pathology, prevalence, and progression. I then describe the substantial burden of oral diseases that may affect older people and those living with dementia and summarise the impact of dementia on oral health and oral healthcare for PLwD. I explore how these conditions and orofacial pain may impact PLwD's oral health-related quality of life. By summarising the prevalence and impact of oral diseases and orofacial pain for PLwD, I note the likelihood that PLwD will require dental care for which treatment decisions will be needed. I then summarise services where dental care may be delivered before describing the relevant guidelines or publications that aim to support dental professionals in caring for PLwD.

2.1 Dementia

Dementia is a broad descriptor incorporating a range of different conditions. Each condition features progressive neurodegeneration, beyond that associated with healthy ageing, which adversely impacts activities of daily living (Camicioli, 2014; Weintraub, 2014). The International Classification of Diseases (ICD-10) defines dementia as:

> *"a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement".*
>
> (World Health Organization, 2019a, section. F00)

Whilst there are numerous types of dementia, specific pathologies account for most dementia diagnoses, as summarised in Table 2.1. Whilst the ICD-10 definition alludes to some generic dementia symptoms, specific symptoms appear more commonly in certain subtypes of dementia (Levy and Chelune, 2007; Karantzoulis and Galvin, 2011; Camicioli, 2014). A diagnosis of any dementia made before the age of 65 is referred to as young-onset or early dementia (Rossor et al., 2010).

Dementia Type % of cases	Summary of dementia type
Alzheimer's disease (AD) 53.7% (Lobo et al., 2000)	Generalised neuronal atrophy alongside the accumulation of amyloid-β in plaques and atypical tau protein deposition as neurofibrillary tangles (Karantzoulis and Galvin, 2011). This leads to progressive memory impairment and deterioration of visuospatial function (Camicioli, 2014).
Vascular dementia (VD) 15.8% (Lobo et al., 2000)	Occurring either suddenly following a cerebrovascular event or slowly due to the cumulative effect of multiple episodes of cerebral infarction (Smith, 2017). Compared with AD, symptoms typically include better verbal memory, worse executive functioning and low mood (Levy and Chelune, 2007).
Dementia with Lewy Bodies (DwLB) 9% (Lobo et al., 2000)	This falls under the umbrella term of Lewy Body Dementia alongside Parkinson's disease (Ballard et al., 2013). Lewy bodies are protein deposit that develops in nerve cells in the brain regions involved in thinking, memory, and motor control. Symptoms typically present as parkinsonism (Levy and Chelune, 2007; Karantzoulis and Galvin, 2011). Severe psychiatric symptoms can arise, including depression and hallucinations (Karantzoulis and Galvin, 2011) and neuroleptic sensitivity (Camicioli, 2014).
Frontotemporal dementia (FTD), 2% (Prince et al., 2014)	This encompasses a range of disorders with differing aetiology (Moore et al., 2020), leading to the degeneration of the frontal and temporal cortices (Solomon et al., 2019). Onset can occur at younger ages (Camicioli, 2014; Moore et al., 2020) and diagnosis is particularly complex (Karantzoulis and Galvin, 2011; McKeith et al., 2005). This condition features personality changes, language impairment, progressive aphasia and loss of meaning of objects (Camicioli, 2014; Levy and Chelune, 2007).
Mixed Dementia 20-40% (Zekry et al., 2002)	Variable symptoms of dementia commonly arise from a combination of neuropathologies such as those detailed above. Mixed dementia is not always identified, nor does it always inform the diagnosis made (Schneider et al., 2007)

Table 2.1: A description of the most common types of dementia

2.2 Prevalence of dementia

Though dementia is not a component of normal ageing, the risk of dementia increases with increasing age (Alzheimer’s Research UK, 2022). The proportion of the population aged 65 or above is growing substantially. In 2016 there were 11.8 million UK residents aged 65 or above, however, this figure is expected to rise 26% by 2041, equating to 20.4 million people (Office for National Statistics 2018). The number of people aged 85 or above is increasing at the fastest rate, with a projected 113.9% increase from 1.3 million to 2.8 million by 2036 (Age UK, 2017).

Prevalence describes the number of individuals in a specific population with a disease or a condition at a specific time (Elmore et al. 2019). The estimated prevalence of dementia in the UK in those aged over 65 is currently 7.1% (Prince et al., 2014). This prevalence, however, is expected to double by 2040 as the general population increases in age (Baker, Jarrett and Powell, 2019). Considering the number of people affected in the UK, estimates suggest 944,000 people in the UK currently live with dementia (Alzheimer's Research UK, 2022). Wittenberg et al., (2019) suggest this will increase by 80% by 2040, equating to almost 1.7 million people. The number of people living with severe dementia is expected to rise the most significantly and over a million people are expected to be living with severe dementia by 2040 (Wittenberg et al., 2019). Those with the greatest need will become those greatest in number. Over time, a significant volume of resources and finance will be necessary to enable health and social care teams, including dental teams, to support the care of PLwD (Nichols et al. 2022).

2.3 Stages and prognosis of dementia

All dementias feature progressive neurodegeneration leading to a greater number of symptoms or more severe symptoms alongside a higher degree of dependence. The rate of cognitive decline can vary between individuals and diagnoses (Smits et al., 2015). Medication may slow the rate of progression of certain dementias, but there is no cure. Treatment of dementia, therefore, focuses on maintaining function and quality of life (Verma, 2014, p.605). Numerous scales exist for staging dementia which vary in their granularity and complexity (Reisberg et al., 2010). The World Health Organization (2019b) and the Alzheimer's Society (2020) describe a simpler and more commonly used post-diagnostic categorisation. This classification is shown in Table 2.2.

Stage of dementia % of cases *	Description of Stage
Mild (or early) 55.4%	Early symptoms include forgetfulness and disorientation. People can often live independently but may need certain adaptations to support this. It is anticipated people retain decisional capacity.[2]
Moderate (or middle stage) 32.1%	Symptoms increase and a greater impact on people's daily lives. Communication can become more impaired, and behaviours may change. Dependence on others increases significantly for many aspects of daily living and personal care. Decisional capacity may be lacking where decision-making is complex.
Advanced (or late-stage) 12.5%	There is almost total dependence and a substantial reduction in a person's activities, including loss of walking ability. The person may be unable to communicate, verbally or non-verbally and swallowing may also be impaired, leading to inadequate nutrition and hydration. Decisional capacity would generally be lacking.

Table 2.2: A summary of the stages of dementia. (Data from Prince et al., 2014).

2.4 Oral health in older age

To appreciate how increasing age or dementia may impact oral health, it is important to consider what constitutes oral health. Specific definitions of oral health have associated the absence of dental diseases with a state of oral health. To account for the far-reaching implications of poor oral health, including psycho-social considerations, Glick et al. (2016, p.322) developed the below definition:

> *"Oral health is multifaceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow, and convey a range of emotions through facial expressions with confidence and without pain, discomfort, and disease of the craniofacial complex".*

This definition focuses on factors beyond disease alone by considering functional and psychosocial factors, yet it still suggests that a person cannot achieve a status of oral health without all dental diseases being eliminated. In contrast, Dolan (1993, p. 37) proposed that oral health can be:

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[2] Throughout this thesis, I use the term *decisional capacity* as a more straightforward term to refer to a person's ability or lack of ability to consent to specific treatment(s), based on an assessment in line with the Mental Capacity Act, (2005). I explain the processes related to such an assessment in Chapter 3.

> *"a comfortable and functional dentition which allows individuals to continue in their desired social role".*

This definition focuses entirely on a person's comfort and function. However, a comfortable and functional dentition could potentially still occur for some people, even when asymptomatic dental diseases are present. Patients may live well with chronic conditions or asymptomatic disease and not consider themselves to have poor oral health (Locker and Allen, 2007), particularly as they age (Gibson et al., 2019).

Historically, as people aged, they lost their teeth and relied on prosthetic replacements. An edentulous state was commonplace and seen as the ‘norm’; Steele et al. (2012) described a drastic decrease in the prevalence of edentulousness, falling from 28% in 1978 to 6% in 2009. Thus, patients who are living longer are keeping their teeth for longer. Teeth that survive longer may be retained due to increasingly complex restorative dental treatments, such as those shown in Figure 2.1. Teeth are at risk of caries, periodontal disease or toothwear[3] for an extended period, and the potential for these teeth to cause pain or functional problems extends into later life (Watt et al., 2013).

Various age-related and age-associated changes can impact a person’s oral hygiene and increase the risk of developing dental diseases, specifically dental caries and periodontal disease. Physiological changes such as xerostomia can increase the risk of dental caries, whilst reduced oral clearance may accelerate the risk of plaque accumulation (Gil-Montoya et al., 2016). With time, older people – with or without dementia - may become increasingly reliant on the support of others with oral hygiene measures alongside other aspects of their personal care (Marchini et al., 2019). Several challenges can arise when older people require support with personal care, specifically when living in care homes and with frailty (Grönbeck Lindén et al., 2017). This can lead to higher levels of plaque in the oral cavity, as shown in Figure 2.1. Aw, Silva and Palmer (2007) summarise immunosenescence, the changes in the immune system associated with age. Holm-Pedersen et al (1975) first highlighted how older people may have an exaggerated response to dental plaque. Since then, Ebersole et al., (2016), expanded upon the mechanisms behind such changes, summarizing how quantitative and qualitative immune-system defects can impact the body’s response to plaque, leading to an exaggerated host

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[3] Loss of tooth tissue due to mechanical or chemical processes aside from dental caries.

inflammatory response and a greater suppressibility to periodontal disease and gingival inflammation in later age. As plaque accumulation and the response to plaque can be greater in older people, the risk of dental diseases developing is substantial and may arise concurrently with age-related morbidities and cognitive impairment (Marchini et al., 2019).

Figure 2.1: A mouth in 'crisis'

Note partial dentition, with suboptimal oral hygiene, retained roots adjacent to the upper front two teeth, a complex fixed dental prosthesis (lower anterior bridge), and edentulous spaces, which compromise function.

2.5 Oral diseases and orofacial pain in dementia

In dementia, challenges with oral hygiene may be more significant as memory loss may precede forgetfulness concerning self-delivered oral care (Brennan and Strauss, 2014). Furthermore, motor function may be impaired so that even if a person remembers to clean their teeth, they may do so less effectively (Gil-Montoya et al., 2017; Grönbeck Lindén et al., 2017). These factors can arise independently or in combination and can contribute to the risk of dental diseases and the deterioration of oral and dental tissues, complicating dental treatment requirements (Ettinger, 2015). In addition, dental attendance can decline in later age and following a dementia diagnosis (Lee, Wu and Plassman, 2015; Fereshtehnejad *et al.*, 2018; Jockusch, Hopfenmüller and Nitschke, 2021). The potential for preventative dental support or the early detection of dental diseases may, therefore, be lost.

Specifically, PLwD may refuse oral hygiene support, and both professional and non-professional caregivers may have limited motivation and knowledge to persist in delivering this (Hoben et al., 2017; Göstemeyer, Baker and Schwendicke, 2019; Weening-Verbree et al., 2021; Gomez-Rossi et al., 2022). Specific guidelines have been produced to support oral health care in care home settings in which a high proportion of residents are PLwD (National Institute for Health and Care Excellence, 2017) yet the reported standards of oral hygiene provided in care homes remain poor (Care Quality Commission, 2019). The reasons behind the poor standard of oral hygiene in care homes or for people with advanced dementia are beyond the scope of this discussion, yet it is clear that suboptimal oral hygiene can mean oral diseases are more prevalent in dependent adults, as I summarise in the remainder of this section.

Multiple studies have examined oral health in PLwD, generally by comparing oral health between PLwD and those without dementia. There are two systematic reviews in this area (Delwel et al., 2017; Foley et al., 2017). Delwel et al. (2017) stated that the heterogenous nature of included studies prevented a meta-analysis from being completed yet Foley et al., (2017) did complete a meta-analysis. The key findings of the two studies are summarised below.

Delwel et al. (2017) found that PLwD typically have poor oral health and oral diseases are highly prevalent in this group. The only reported major differences between PLwD and those without dementia were the mean number of teeth with coronal caries[4] (0.1-2.9 vs 0.0-1.0 $p<0.05$), the number of teeth affected by root surface caries[5] (0.6-4.9 vs 0.3-1.7 $p<0.05$) and the number of retained tooth roots[6] (0.2-10 vs, 0.0-1.2 $p<0.05$). In addition, this review identified that the prevalence of orofacial pain in dementia ranged from 7.4 - 21.7%. The study concluded there is no difference in pain prevalence between PLwD and control groups though it is unclear how this conclusion was drawn. The later review (Foley et al., 2017) focuses on oral health in general without

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[4] Caries (decay) affecting the ‘crown’ or top part of the tooth.

[5] Caries (decay) on the sides of the teeth, typically arising due to dryness of the mouth.

[6] Pieces of tooth tissue, which may be carious, that remain when the top of a tooth has broken away due to decay or fracture. These generally have no functional value. Retained roots can be large or small, placed superficially or buried within soft or hard tissue. They may or may not cause pain or infection.

specifically focusing on pain. Foley et al. (2017) present similar findings to Delwel et al. (2017), stating that PLwD have more carious teeth (standardized mean difference 0.29, p=0.028).

Unlike Delwel et al. (2017), Foley et al. (2017) did not separate retained roots from carious teeth and combined the data regarding retained roots with data regarding carious teeth. A retained root may or may not be carious or functional, and there is a variation between studies regarding how data have been grouped and discussed. The separate key conclusion that differs between the two studies regards the number of teeth PLwD retain. Though Delwel et al. (2017) state that PLwD and those without dementia have a similar number of teeth, Foley et al. (2017) found from their meta-analysis that this was not the case and that PLwD have a mean of 1.52 fewer teeth (p=0.003) than those without dementia.

Delwel et al. (2018a) also published a separate narrative review article focusing on the status of oral soft tissues. The narrative discussion in this review describes similar findings to those presented by Foley et al. (2017), stating that PLwD have high levels of dental plaque and soft tissue disease, specifically gingival bleeding. From the narrative summary Delwel et al. (2018a) present, it is unclear whether these conditions were more prevalent in PLwD than in people without dementia. Despite how different types of dementia may affect people in different ways, this review suggested that the type of dementia is not a key determinant of oral health status. It suggested, instead, that poor oral health is reported in all sub-types of dementia. As may be expected, they also noted that more severe cognitive decline is associated with a more significant burden of oral diseases.

In a separate study, Delwel et al. (2018b) specifically studied the prevalence of orofacial pain and its potential causes for PLwD recruited from memory clinics. Orofacial pain was present in 25.7% (n= 46) of those able to self-report (n=179) though the prevalence of oral disease with the potential to cause pain was far higher, affecting 50.3% (n=175) of total participants (n=348). Another study focused on 101 hospital inpatients diagnosed with dementia: van de Rijt et al. (2018) found a similar prevalence of orofacial pain during function (21.9%, n=21) and a lower prevalence of orofacial pain at rest (11.9%, n=12). In addition, this study found that orofacial pain during rest and during function was more prevalent for those unable to self-report pain (due to advanced dementia) than for patients who could express pain verbally (p=0.034 and p=0.001, respectively). A similar finding was noted when care home residents were considered (van de Rijt, et al., 2019b). Here, the prevalence of orofacial pain in dementia was reportedly far higher than in earlier studies: 37.8% (n=37) of PLwD able to self-report said they experienced orofacial pain whilst a separate assessment tool for non-verbal individuals identified that 48.8% (n=41) of PLwD experienced orofacial pain.

These studies described have demonstrated a substantial burden of oral diseases and orofacial pain in the older population and PLwD. Whilst PLwD may have slightly fewer teeth than those without dementia, they are more likely to live with coronal and root caries and retained roots, all of which could lead to pain or infection. These studies suggest that this disease burden shifts to affect those unable to self-report pain and who may also struggle to tolerate dental treatment. The impact of these conditions is explored below.

2.6 The impact of poor oral health

Various studies have explored how PLwD feel about their oral health Kc et al. (2021) summarise studies that have examined PLwD's perspectives on oral health and dental care. Most studies that explore the impact of oral diseases have used quantitative methods to explore how oral diseases impact the quality of life. Specifically, the oral health-related quality of life is commonly studied (OHR-QoL), generally through using the Oral Health Impact Profile-14 tool[7] (OHIP-14) (Slade, 1997). The concept of OHR-QoL arose from attempts to consider the psychosocial implications of oral diseases and to lessen the focus on biological processes (Locker and Allen, 2007). In addition, assessing OHR-QoL aims to overcome how the mouth has typically been isolated from both the person's body and the person themselves (Locker 1997, p.14). Various studies, which I summarise below, explore the impact of oral diseases on OHR-QoL for older people. Studies generally do not focus solely on those with dementia or other cognitive impairments, yet these studies still provide insight into how dental diseases may affect many PLwD.

A systematic review in this area was presented by van de Rijt et al. (2019a), who explored oral health factors associated with OHR-QoL in older people. In this review, older people were defined as those aged 65 or above, regardless of residential setting and the presence of cognitive impairment. This

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[7] The Oral Health Impact Profile-14 is a 14-item questionnaire, proposed by Slade (1997) that measures how people feel about the impact of various oral conditions on their general well-being. It has been widely used in research on OHR-QoL.

review of 53 studies described a lack of consensus on whether dental caries or periodontal disease is associated with a reduced OHR-QoL. It did, however, find that those experiencing orofacial pain had a worse OHR-QoL. This suggests that asymptomatic dental caries or periodontal disease may not adversely impact a person's psychosocial well-being, but a detrimental impact on OHR-QoL is experienced when symptoms arise. When considering oral function, this review reports that having a greater number of natural teeth and more occluding pairs of teeth were positively associated with OHR-QoL, whilst poor chewing function was associated with reduced OHR-QoL. Notably, however, the review concludes that older people may benefit more from well-functioning dentures than natural dentitions due to the reduced potential for pain in edentate patients. It is worth noting that such a conclusion is somewhat flawed as studies compared experienced denture-wearers with fully or partially dentate patients and those facing a new status of edentulousness in older age may well not adapt or cope with denture-wearing.

A limitation of the review from Van de Rijt et al. (2019a) is that the entire population of older adults is grouped together despite having a wide variety of physical and cognitive health statuses. Whilst four of the studies in this review included PLwD as participants, Van de Riet et al. (2019a) do not discuss the findings of these studies to consider how oral diseases may impact OHR-QoL for PLwD specifically. Cognitive impairment is likely to impact a person's attitudes, preferences, priorities and oral function separately from ageing alone (Kc et al., 2021; Scambler et al., 2021). Another consideration is how dementia does not exclusively affect older people, so studies of older people alone may not provide insight into the impact of poor oral health in younger people with dementia.

Specific studies have focused on the direct relationship between dementia and OHR-QoL. Zuluaga et al. (2012) carried out a cross-sectional analysis to identify how cognitive impairment was associated with OHR-QoL for people in residential care settings. This study found that mild cognitive impairment (MCI) was significantly associated with better OHR-QoL than that experienced by those without cognitive impairment ($p<0.05$), but no such association was identified for those described as having ‘moderate cognitive impairment’ equating to mild dementia. In contrast to this study, Lee et al. (2013) explored a similar association for community-dwelling individuals. They found that compared to controls, self-perceived OHR-QoL worsens in people with MCI ($P<0.05$) and further worsens in mild dementia ($p<0.01$). Zenthöfer et al. (2014) and Klotz et al. (2017) also used cross-sectional approaches to explore associations between dementia and OHR-QoL, yet both studies failed to identify any difference in OHR-QoL between PLwD and those without cognitive impairment.

It should be noted that none of the studies discussed specifically explored OHR-QoL for people with moderate or advanced dementia. Only one study that explored OHR-QoL for people with dementia included those with advanced dementia: Van de Rijt et al. (2021) explored oral function, nutritional status and quality of life for those in residential care settings and did include those lacking capacity to consent for research involvement. The study found that oral function and nutritional status were worse in those with dementia than in those without dementia. However, when considering quality of life, the authors did not use the OHIP-14 measure to assess OHR-QoL for those with advanced dementia as it is unsuitable for those who cannot self-report. Therefore, despite their inclusion in a study, the extent or way OHR-QoL may be impacted for people with advanced dementia remains unknown.

2.7 Dental care provision for people living with dementia

Previous sections of this chapter have highlighted the high prevalence of oral diseases and orofacial pain affecting PLwD. Considering these prevalent conditions and their impact, many PLwD might require some form of dental treatment. This may be provided in numerous settings. Many PLwD can access dental care in general dental practice (GDP) either funded through the NHS or privately. General practice settings are suitable for many PLwD, yet when dementia symptoms increase in number or severity, it may be more appropriate for care to be provided in alternative settings or services. The same dementia symptoms that can affect the delivery of oral hygiene in dementia, detailed in Section 2.5, can also affect dental treatment delivery. Specific issues can arise with patient communication (Chalmers, 2000; Aaltonen et al., 2021), and tolerance of treatment, which can impact communication with dental teams and the safety or feasibility of delivering certain treatments (Jablonski, Therrien and Kolanowski, 2011; Kerr et al., 2020).

Factors such as limited patient cooperation, unstable comorbidities, complex ethical matters, or treatment requirements that are beyond a dentist's skillset may lead dentists to refer certain patients to specialist services, such as Community Dental Services (CDS) or Hospital Dental Services (HDS). Where the necessary procedures can be accepted and tolerated by PLwD but are technically demanding, specialists in restorative dentistry, prosthodontics or oral surgery may be well-placed to provide certain aspects of dental care. Alternatively, where issues such as treatment tolerance, severe anxiety, or specific medical risks arise, Special Care Dentistry (SCD) teams – in CDS or HDS - are well placed to support dental assessment and appropriate holistic treatment. The ideal pathways for NHS Special Care Dentistry, and who should provide this for different patient groups, are summarised in commissioning standards (NHS England, 2015). These standards are, however, aspirational, limited to England, and do not align with patients' reported experiences in accessing dental care (Curtis et al., 2021; Scambler et al., 2021).

Unlike other dental specialities, SCD services can provide most aspects of comprehensive dental care, in addition, SCD services can access specific approaches to support dental care delivery in primary care dental clinics (such as hoists or wheelchair recliners) and others in hospital environments (such as general anaesthetic services). The use of techniques such as intravenous sedation or general anaesthesia to facilitate comprehensive dental care for PLwD is generally limited to SCD teams. The use of sedation in primary care would be contraindicated for many PLwD due to increasing age and comorbidities (Intercollegiate Advisory Committee for Sedation in Dentistry, 2015). Where indicated, general anaesthesia can only legally be facilitated in hospital environments (Department of Health, 2000). This approach, however, can be associated with significant morbidity in PLwD (Mrkobrada et al., 2019) hence its use needs cautious justification and the treatment delivered by this approach may need to be modified (Geddis-Regan et al., 2022).

In addition to pharmacological approaches to support care delivery, CDS teams or GDPs may be commissioned to offer certain aspects of dental care on a domiciliary basis in patients' homes or care homes. Domiciliary care is appropriate to support those who struggle to leave their residence, yet residential settings are not appropriate for delivering a full range of dental treatments (Lewis and Mann, 2022). This approach to care, however, is inconsistently commissioned (Geddis-Regan and O'Connor, 2018) and many barriers may prevent PLwD from accessing this form of specialist care (Göstemeyer, Baker and Schwendicke, 2019; Kc et al., 2021; Legge, Latour and Nasser, 2021). Consequently, patients may not receive dental treatment either by specialist services or on a domiciliary basis, even if this would be the best way to deliver aspects of their dental care.

2.8 Relevant guidelines

Several guidelines are available that may support dental teams. These have broadly been produced with the specific aim of supporting dental teams in caring for PLwD.[8] However, there is a more broadly applicable NICE guideline (National Institute for Health and Care Excellence, 2018a) that applies to dentists as well as other healthcare teams. I summarise each guideline below. I first present the NICE guideline before summarising the specific dental guidelines in chronological order. After describing these guidelines, I summarise the limited primary literature specifically exploring dental treatment decision-making in Section 2.9. The key recommendations made in each guideline are summarised in Table 2.3.

Dementia: assessment, management and support for people living with dementia and their carers (National Institute for Health and Care Excellence, 2018a)

This guideline does not detail specific dental treatments, but it does offer best practice advice on person-centred care before presenting principles of person-centred care that underpin good practice in all settings (page 10). Furthermore, this guideline states that people living with dementia should be involved in decisions about their care, and such a recommendation is not limited to those with earlier dementia alone.

This publication also encourages advance care planning (ACP) through a range of mechanisms. Specifically, the guideline proposes that early consideration is given to appointing a Lasting Power of Attorney (LPA), making an advance decision to refuse treatment (ADRT), or considering a statement detailing their wishes for their future care.[9] It also suggests that relevant information is given to PLwD and their family members or carers so that these individuals can support PLwD to consider their current and longer-term preferences.

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[8] The dental guidelines discussed all describe preventative oral care alongside patient assessment and treatment. In some cases, preventative care is detailed as a specific treatment, yet additional guidelines, such as 'Oral Health In Care Homes' (National Institute for Health and Care Excellence, 2017) place a greater emphasis on how to prevent oral diseases. As preventative care should occur regardless of what treatment decisions are made, the discussion herein focuses solely on the guidance or other publications related specifically to treatment planning or decision-making.

[9] Chapter 3 summarises these mechanisms and legal status and implications of each of these approaches.

Guidelines for the Development of Local Standards of Oral Health Care for People with Dementia (Fiske et al., 2006)

This document aims to assist those developing local standards for providing oral healthcare for people with dementia instead of being a general guideline applicable to every setting. It specifies that it particularly supports the care of those who may be unable to either express their needs, provide their own oral hygiene, or make an informed choice and consent to a course of action. This suggests the document aims to guide the care of those with more advanced dementia as opposed to those who may have been more recently diagnosed.

This document covers a range of domains in its recommendations, including oral health assessment, oral health care planning, dental treatment, and delivery of dental care. Recommendations are made in each domain yet there is substantial overlap, such as between the oral health assessment section and the text on oral health care planning. This document breaks down its recommendations for PLwD based on them having mild, moderate, and advanced dementia (see Table 2.3). The recommendations propose that treatment in the early stages of dementia should account for an anticipated decline in cooperation and self-care. It also states that treatment should be *“high quality and low maintenance”* (Fiske et al., 2006, p.17) to avoid future higher-risk decisions or complex treatment requirements.

The use of general anaesthetic or sedation is briefly mentioned for those in the moderate stage of dementia before suggesting treatment, then focuses on *“prevention, maintaining oral comfort and emergency treatment”* for those with advanced disease (Fiske et al., 2006, p.17). A list of potential symptoms that might suggest a PLwD is experiencing pain is provided, and the presence of symptoms is described as a key driver of active treatment. When considering various factors that impact decision-making, the document states that: *"The benefit of treatment has to be weighed up and at least balanced with the difficulties in providing it, in terms of cooperation, consent, restraint"* (Fiske et al., 2006, p.17). The text does not suggest that a patient’s perspectives on any of these factors - or treatment in general - should be considered in decision-making.

Dental problems and their management in patients with dementia (British Dental Association, 2013)

This document describes itself as an evidence summary as opposed to a guideline. The authors present a comprehensive search of the literature up to August 2012, based on the question: *'What dental problems are seen in patients with dementia and how can they be managed?'* (British Dental Association, 2013, p.3). In response to this question, the review states that no studies were found detailing how to manage dental issues for PLwD. Consequently, the advice presented is from expert opinion and a small number of articles identified in the authors' search. The document's authors acknowledge that its recommendations are based on a low level of evidence.

The document presents a simple list of recommendations for how dental treatment should be approached, based on the guidance from Fiske et al. (2006), as detailed in Table 2.3. The authors emphasise the clinician as a decision-maker, yet they do encourage a basic level of patient or carer involvement in decision-making, stating: *"Dental treatment for a patient with dementia is based on the dentist's clinical judgment together with the input of the patient (if possible) and their family or carers"* (p.6). This statement is a key component of this document, and the need for dentists to involve PLwD and those supporting them with decision-making is under-emphasised in other guidance documents.

Dementia Friendly Dentistry (NHS England 2016)

This document has many similarities with the identically-named publication from the Faculty of General Dental Practitioners (2017) discussed below. The NHS England (2016) toolkit, however, is more concise. It aims to *"improve the general experience of attending the dental practice for those living with dementia and their carers"* (NHS England, 2016, p. 10). The toolkit gives a detailed explanation of dementia and its impacts, as well as practical guidance to support the prevention of dental diseases and enhance communication with PLwD. The publication is aimed at general dentists, but specialist services are mentioned to clarify which factors determine when patients should be seen in specific settings or services. A strength of the publication is the use of case examples describing care for those needing extensive or minimal dental care, and with different dementia symptoms. For each case, the authors summarise how treatment may be approached and the justification for specific treatment approaches in each circumstance.

In addition to the case examples presented, this publication contains a table that summarises dementia symptoms, the impact of these symptoms on dental care, and dental management approaches for each people living with different stages of dementia (NHS England, 2016, pp.50-51). Unlike with the case examples, the recommendations here are generic and place little emphasis on person-centred care. A reference is made to the 'acceptability' of care, (NHS England, 2016, p 51) but the perspective from which acceptability is considered is unclear. Though some dentists may find these recommendations and principles helpful, some of the terms the authors use on page 51, (such as those presented in Table 2.3 above), are vague. *"Realistic and pragmatic"* treatment planning is mentioned (NHS England, 2016, p.51), as is *"palliative care for teeth"* (NHS England, 2016, p.51) yet such terms are not defined or supported with any case examples. In addition, the document refers to *"treatment of symptomatic teeth"* (NHS England, 2016, p.51) without suggesting what treatment this may entail. Furthermore, it explains that *"treatment may not be possible"* (NHS England, 2016, p.51) but does not expand upon what approach to care, if any, might be considered instead. In summary, the document provides useful case examples to highlight principles of practical care delivery, yet the use of such broad and non-defined terminology may mean some dentists find the guidance may not support them in caring for PLwD in some instances.

Dementia-Friendly Dentistry (Faculty of General Dental Practitioners 2017)

This guideline aims to: *"provide the profession and their teams with guidance on how they can help ensure the best contribution to individuals living with dementia"* (Faculty of General Dental Practitioners, 2017, p.7). This guideline is aimed primarily at general dental practitioners and offers less insight into what may or should happen in specialist settings. Recommendations in this document are classified as A (aspirational), B (basic) or C (conditional upon circumstances). The role of a general dentist with whom a patient has an established relationship is detailed both for familiarity and anxiety reduction in a patient and allows a clinician to identify changes in behaviour (Faculty of General Dental Practitioners, 2017, pp.25-26).

	Recommendations for		
Guideline	Mild Dementia	Moderate Dementia	Advanced Dementia
Dementia: assessment, management and support for people living with dementia and their carers (NICE 2018a)	Encourage and enable PLwD to give their own views and opinions about their care. Offer early and ongoing opportunities for PLwD and people involved in their care to discuss: • the benefits of planning ahead • lasting power of attorney • an advance statement about their wishes, preferences, beliefs and values • an advance decision to refuse treatment. •At each care review, offer people the chance to review and change any advance statements and decisions they have made.		•Use an anticipatory healthcare planning process •Involve the person and their family members or carers as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions
Guidelines for the development of local standards of oral health care for people with dementia (Fiske et al., 2006)	•Treatment should be planned to anticipate the person's decline in cooperation and ability for self-care •Key teeth can be identified and restored to function •Restorative treatment should be high quality and low maintenance •Advanced restorative treatment should only be planned when a patient or carer can maintain it	•The focus of oral care changes from restorative and rehabilitative to maintenance and prevention •Sedation or general anaesthesia may be necessary for treatment •The decision will be based on the individual's ability to co-operate, dental treatment needs, general health and social support	•Dental interventions should be as non-invasive as possible •If treatment is beyond the individual's coping capacity, ask 1) Is the treatment necessary? If yes, then 2) How can it best be carried out? •Treatment planning should take account of the treatment modalities used to deliver it •The benefit from treatment should be at least balanced with the difficulties of providing it
Dental problems and their management in patients with dementia (British Dental Association, 2013)	As per Fiske et al. (2006) plus: •Treat sites of infection and possible sources of acute/chronic pain or pathology •Fixed prostheses are preferable to removable	As per Fiske et al. (2006) plus: •Consider short appointments	•Complex or time-consuming treatment should be avoided •Sedation and short appointments •Interventions should be as non-invasive as possible
Dementia Friendly Dentistry (NHS England, 2016)	•Assess the risk of dental disease •Management as per dental risk •Robust and appropriate treatment planning •Consideration of shortened dental arch	•Clinicians should re-assess risk and management should be based on dental risk •Consider acceptable conservative treatments •Support carers with oral hygiene	As per moderate dementia plus: •Palliative care for teeth •Treatment of symptomatic teeth •Treatment planning should be realistic and pragmatic, but treatment may not be possible
Dementia-Friendly Dentistry (Faculty of General Dental Practitioners, 2017)	•Most types of dental care are possible •Dentists should keep in mind that the person with dementia will eventually be unable to look after their own teeth •Care planning should be based on a risk assessment •Consideration should be given to long-term outcomes	•The focus on treatment is likely to be on prevention •If capacity issues are present, we must choose the least restrictive option	•Treatment at this stage focuses on the prevention of dental disease, maintaining oral comfort and provision of emergency treatment •Dental interventions should be as non-invasive as possible

Table 2.3: A summary of guidelines’ key recommendations on care planning or decision-making

Many of the recommendations made about providing active dental treatment align with those made by Fiske et al. (2006). At the early stage of dementia, it is suggested that dentists recognise how dementia may impact future dental care (p.29) and that a proactive approach to care may be appropriate. The document suggests that referral to specialist services may become more appropriate as the complexity or risk of treatment planning or delivery increases (Faculty of General Dental Practitioners, 2017, p.28). It is not expected that a general dental practitioner can or should manage every patient with dementia that may attend their surgery.

The document does refer to decision-making with PLwD, suggesting a dementia diagnosis should lead to a timely dental appointment so that a person can take *"an active role in decision making"* (p.49). This recommendation is sensible, yet it implies that an active decision-making role may not be possible in later dementia. Section 3.7.4 of the publication (Faculty of General Dental Practitioners, 2017, p.51-54) discusses mental capacity and its assessment, as well as what factors a dentist may consider if making decisions for a person with more advanced dementia assessed to lack decisional capacity. Though the information presented is largely taken verbatim from the Mental Capacity Act (MCA) (2005), it presents this in the context of both dental care and dementia. Referring to this information may support a dentist to consider each PLwD as an individual and consider a range of relevant factors related to the delivery of dental care. The document does not mention the potential value of considering the current wishes of a person with or without decisional capacity.

Guideline summary

Various guidance documents have been published regarding care for PLwD. The presence of numerous guidance documents suggests that caring for PLwD, specifically with more advanced dementia, is an ongoing challenge for healthcare teams generally, and for dental teams. The dental guideline documents are mainly based on expert opinion, and there is little primary research underpinning the recommendations they made. The publications vary in their structure and format, but they contain numerous similarities, as shown in Table 2.3. The differences in these documents relate mostly to their structure, and the legislative and policy bases underpinning certain recommendations they make.

Dental guidance documents allude to aspects of decision-making to various extents, primarily focusing on the clinician as a decision-maker. In contrast, NICE (2018a) emphasise person-centred care and patient involvement in decision-making, with the support of those involved in their care. Only two dental guidelines specifically mention patient involvement in decision-making (British Dental Association, 2013; Faculty of General Dental Practitioners, 2017) with only the most recent guideline detailing what might factors be considered for a person lacking decisional capacity (Faculty of General Dental Practitioners, 2017, p.51-54). The guidance documents, however, offer little practical support for *how* dentists may facilitate decision-making. In particular, the guidance documents do little to inform what specific factors dentists, PLwD or carers should consider and discuss during these processes. The NICE guideline (2018a) presents a clearer view of *how* peoples' wishes and preferences should be gathered and considered and the mechanisms available to support them in expressing their longer-term views.

When considering how dental treatment decision-making might be approached, dental guidelines should be considered alongside guidelines from NICE (2018a, 2018b, 2021) and legislation. Firstly, the professional standards for dental teams (General Dental Council, 2013) and NICE guidance propose that clinicians should proactively involve patients in decisions about their care (through shared decision-making[10]) (National Institute for Health and Care Excellence, 2018a, 2021). In addition, legislation and NICE guidelines detail how best interests decisions[9] should be approached by clinicians in England and Wales (Mental Capacity Act, 2005; National Institute for Health and Care Excellence, 2018b). Whilst *Dementia-Friendly Dentistry* (Faculty of General Dental Practitioners, 2017) summarises the MCA, there is no single source that practically guides dentists on treatment decision-making with PLwD retaining decisional capacity, supporting those with impaired decisional capacity or determining how to approach care for those lacking decisional capacity.

2.9 Dental care decision-making in dementia

Dentists' experiences of undertaking or supporting decision-making with PLwD – including their experiences of adhering to legislation and abiding by relevant professional and national standards - have not been studied comprehensively. The aforementioned guidelines do not cite any work in this

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[10] These concepts are explored in Chapter 3.

area. The only primary research in this area has been presented in two related qualitative studies conducted in Sweden, where dentists were interviewed about their experiences with treatment decision-making for PLwD (Nordenram, Norberg and Bischofberger, 1994; Nordenram and Norberg, 1998).

The first of these studies (Nordenram, Norberg and Bischofberger, 1994) was a pilot study consisting of four interviews with dentists. The later study (Nordenram and Norberg, 1998) builds upon these findings with a larger sample of 21 dentists (though this included the data generated from the earlier study). These dentists were asked to recall situations where they faced difficulties deciding upon appropriate care for PLwD at an advanced stage. The authors categorised how dentists approached the problem of uncertainty; dentists either saw this as 'my (the dentist’s) problem', 'their (the patient's) problem' or 'our (shared) problem'. The 'my (the dentist’s) problem', has parallels with paternalism, whilst 'our (shared) problem' parallels shared decision-making as summarised by Charles, Gafni and Wheelan (1997, 1999). Regardless of the approach taken by dentists in these studies, they reported conflicting ethical principles (such as autonomy and non-maleficence) which underpinned a sense of ethical tension and ongoing uncertainty (Nordenram, Norberg and Bischofberger, 1994; Nordenram and Norberg, 1998). Nordenram and Norberg, (1998) summarise that dentists' dilemmas could be seen as internal or external. Internal dilemmas related to dentists’ own opinions about appropriate treatment or a lack of treatment. External tensions related to those arising from outward discussions with 'co-actors' such as family members or others advocating for PLwD lacking decisional capacity.

The aforementioned studies (Nordenram, Norberg and Bischofberger, 1994; Nordenram and Norberg, 1998) present research conducted over twenty years ago in a healthcare system that differs from that in the UK. Whilst they offer some insight into the challenges dentists might encounter when caring for PLwD, this insight is limited in its applicability to UK practice. There is, therefore, no research applicable to dental-treatment decision-making in the UK and dentists have little practical guidance in such processes.

2.10 Conclusion

Dementia has a range of impacts on PLwD, and the progression of dental diseases and orofacial pain may be one such impact. PLwD may have significant dental treatment requirements, hence many treatment decisions may need to be made by PLwD, dentists, carers, or combinations of these individuals. The nature of dental care provision for this group, specifically regarding how treatment decision-making is approached, is based on limited primary research. The guidelines available for dental teams offer varied but limited support on how to approach decision-making with or for PLwD as they focus heavily on what treatment the dental team may consider. NICE (2018a) encourage person-centred care, consideration of future preferences, and patient involvement in care decisions. In the next chapter, I will describe these approaches to care, summarise how healthcare decision-and making might be approached by clinicians. I then explore the role of shared decision-making and present the legal routes by which care decisions should be approached for people lacking decisional capacity.

Chapter 3. Healthcare decision-making

In this chapter, I summarise how healthcare decisions might be made, and who may make them. I first detail a broad spectrum of decision-making approaches that may be encountered, facilitated, or delivered for adults - including people living with earlier dementia - who retain decisional capacity. I summarise the importance of patient autonomy, the need for patients to be supported by clinicians, and the ethical and policy bases for shared decision-making. I then explore the legislative and ethical aspects of decision-making for people with cognitive impairments, how decisional capacity is assessed in England and Wales, and how treatment decisions should be approached guided by legislation. Finally, I explore the indices that have been used to measure aspects of decision-making and the perspectives on 'good' decisions.

3.1 Overview of healthcare decision-making

Decision-making for elective healthcare typically occurs when a patient interacts with a healthcare professional. The nature of a consultation, and therefore any decision-making within it, is susceptible to a wide range of influences, only some of which can be modified by those involved (Bekker et al., 1999; Mead and Bower, 2000). Consequently, healthcare decision-making is fraught with complexities (Kushniruk, 2001; Devettere, 2010).

To address the complexities that may be encountered, Elwyn, Edwards and Kinnersley (1999) suggest that a consultation can be divided into two halves. In the first half a patient's presenting complaint is explored before a clinical examination and relevant tests. In the second half, a plan of action is decided by either or both parties. This second half of a consultation is may be 'neglected' by clinicians and there is a risk that insufficient consideration and attention is given to the individual for whom care is being planned (Elwyn, Edwards and Kinnersley, 1999). During the decision-making process that may occur after history-taking and examination processes, there is a spectrum of how involved patients can be in decisions about their care, as shown in Table 3.1. I discuss paternalism, Informed Choice and Shared Decision Making (SDM) in turn below.

MODEL STAGES	PATERNALISM	SHARED DECISION MAKING	INFORMED CHOICE
Information Exchange			
Flow	One way (largely)	Back and forth	One way (largely)
Direction	Clinician → patient	Clinician ⟷ Patient	Clinician → patient
Type	Medical	Medical and Personal	Primarily Medical
Amount	Minimum legally required	All relevant for decision making	All relevant for decision making
Deliberation	Clinician alone or with other clinicians	Clinician and patient	Patient
Deciding on treatment to implement	Clinician	Clinician and patient	Patient

Table 3.1: Models of decision-making (Modified from Charles, Gafni and Wheelan, 1999)

3.2 Paternalism

Paternalism is based on the notion that a clinician has expertise and authority (Charles, Gafni and Whelan, 1997, 1999; Coulter, 1999). In this model, patients passively receive care (Charles, Gafni and Wheelan, 1997) or are obligated to comply with any recommendations or prescribed therapy (Warren, 2006, p. 1). Paternalistic decisions are made for a person who has not been actively involved in decision-making (Beauchamp and Childress, 2013, p. 215) and a clinician would use their expert knowledge to determine what treatment was appropriate, regardless of the individual’s preferences (Parsons, 1951, p.435). In this situation, there is little scope for a discussion or deliberation on any available treatments (Charles, Gafni and Whelan, 1999), and patients' lived experiences and preferences are typically ignored. Paternalism disregards how some patients may have more knowledge of a condition than the healthcare professional they consult (Nettleton, 1995 p.131).

Paternalistic practice has little regard for patients' autonomy (Stiggelbout, Pieterse and De Haes, 2015) and hence has become unacceptable in modern-day healthcare (Charles, Gafni and Whelan, 1999; Pomey, Denis and Dumez, 2019). This change has coincided with changes to health services, largely resulting from the proliferation of chronic diseases and the frequency with which these are discussed in consultations (Woolf et al., 2005; Warren, 2006, pp. 2–4). With chronic conditions, *"the patient's life experience with the disease becomes a rich source of knowledge, essential for decision-making"* (Pomey, Clavel and Denis, 2019, p. 3). This experience is crucial to inform the care a patient receives, yet with paternalism, it has the potential to be discounted or inadequately considered (Marteau, Dormandy and Michie, 2001).

3.3 Informed choice

Autonomy, the right to self-rule or self-governance, (Beauchamp and Childress, 2013, p. 101) has been described as a *"core pillar of liberal society"* (Kong, 2017 p.1). It is often placed on a pedestal above other ethical principles (Zwitter, 2019). Autonomy considers a person's ability to choose what happens to them, a concept starkly absent in Paternalism. Over time, patients have become more proactive in considering what they wish to gain from health services (Warren, 2006 p.2). Due to this, publications and policy documents have increasingly focused on the importance of patient choice (Robertson and Thorlby, 2008; King’s Fund Institute, 2010; Department of Health, 2012a). Specifically, NHS policy documents have described the concept of *'no decision about me without me'* (Department of Health, 2010, 2012b), preceding the declaration that patient choice is a 'right' for NHS patients (Department of Health, 2015, p. 6).

Providing information is a core responsibility of a healthcare professional and an essential component of the consent process (Kapp, 2007; Cocanour, 2017). In the Informed Choice model, information is passed unidirectionally from clinicians to patients, enabling patients to make decisions independently (Charles, Gafni and Whelan, 1999; Elwyn, Edwards and Kinnersley, 1999). In this model of decision-making, clinicians should provide enough relevant clinical information to allow patients to make independent decisions about their care (Marteau, Dormandy and Michie, 2001). One domain of the information clinicians should provide to patients is information related to risk: this includes risk associated with an intervention, as well as with alternative treatments or a decision not to intervene (Elwyn, Edwards and Kinnersley, 1999; Godolphin, 2003).

Sharing information can promote autonomy by enabling patients to make decisions independently (Charles, Gafni and Whelan, 1997). However, promoting Informed Choice may be seen as a way of transferring responsibility for decision-making away from a clinician and towards the patient, as a component of defensive practice (Elwyn, Edwards and Kinnersley, 1999). The responsibility placed on clinicians to share information, and the right information for each patient, has increased following a landmark court ruling in 2015. In the case of Montgomery vs Lanarkshire Health Board (2015), the court detailed that clinicians are duty-bound to ensure that a patient is aware of *material risks*. In determining materiality, the court stated:

> *“The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient’s position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.”*
>
> Montgomery vs Lanarkshire Health Board (2015).

This ruling highlights how the information provided by clinicians to patients should be based on a considered and active exploration of what might matter to a particular patient. In Informed Choice, a unidirectional transfer of information from a clinician, without any attempt to appreciate the individual’s views on treatment options, may mean that clinicians cannot identify what is ‘material’ to a particular patient. In addition, though patients are experts in their circumstances, many would typically not be able to fully appreciate the clinical aspects or implications of certain decisions (Hargraves et al., 2016). In essence, neither party can fully support the other by making decisions or providing information in isolation. Shared decision-making (SDM) as discussed below, aims to optimise autonomy whilst ensuring patients are comprehensively supported to make decisions collaboratively with healthcare professionals.

3.4 Shared decision-making

Due to a revised focus on autonomy and the aim of improving health services (Stiggelbout, Pieterse and De Haes, 2015), many authors published ideas and concepts for a consulting style that lay between the extremes of Paternalism and Informed Choice (Charles, Gafni and Whelan, 1997; 1999; Coulter, 1999; Elwyn, Edwards and Kinnersley, 1999). Whilst various approaches have been presented, Shared Decision Making (SDM) is the most widely advocated approach to healthcare decision-making. A vast range of definitions of SDM can be found (Berger et al., 2021). A simple definition is that SDM is:

> *"a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care."*
>
> (National Institute for Health and Care Excellence, 2021).

Whilst such a definition highlights the collaboration between patients and clinicians, it does little to explain how the clinician and patient may work together in decision-making. A more comprehensive definition provides more insight into the roles of those involved:

> *"[Shared Decision Making] will usually consist of discussions between professional and patient that bring the knowledge, concerns and perspectives of each to the process of seeking agreement on a source of treatment [and where a] physician or other health professional invites the patient to participate in a dialogue…to help the patient understand the medical situation and available courses of action."*
>
> (President's Commission for the Study of Ethical Problems
> in Medicine and Biomedical and Behavioral Research, 1982)

As the volume of literature on SDM has expanded there has been a continual inconsistency in the components thought to comprise it (Makoul and Clayman, 2006; Bomhof-Roordink et al., 2019; Berger et al., 2021). Despite such variation, the principles detailed by Charles, Gafni and Whelan, (1997, 1999) remain relatively consistent in various definitions. These principles are summarised in Figure 3.1:

1. At a minimum, both the physician and patient are involved in the treatment decision-making process.
2. Both the physician and patient share information with each other.
3. Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences.
4. A treatment decision is made, and both the physician and patient agree on the treatment to implement.

Charles, Gafni and Whelan, (1997), rephrased by Charles, Gafni and Whelan (1999).

Figure 3.1: Core principles of shared decision making

In SDM, patients and clinicians should actively share information with one another, about personal preferences and clinical care respectively. The fact that both parties share information acknowledges the value of their different perspectives: *"clinicians are the experts in the evidence and patients are* *the experts in what matters most to them"* (Spatz, Krumholz and Moulton, 2017, p. 1309). The clinician's expertise should be informed by evidence. However, in many scenarios, there may be limited or no evidence to support any particular decision or course of action (Whitney, 2003; Kaplan and Frosch, 2005; Schwartz and Bergus, 2010, p. 55; Elwyn et al., 2022). In addition, where evidence is available, it may suggest a course of action that a patient feels is inappropriate (McCormack and Elwyn, 2018). This challenge underpins the need for patients to provide information about their preferences to clinicians to support them in determining what options for care may be suitable or appropriate to present to a patient.

In SDM, a healthcare professional should present a range of feasible treatment options available to a patient. This, however, should not simply be a 'menu' from which a patient can choose but a set of realistic proposals considered following a person-centred consultation where a person’s preferences and circumstances are explored. Clinicians can then discuss options for care with patients, considering each approach’s potential outcomes, benefits, and risks (Charles, Gafni and Whelan, 1997, 1999; Kunneman and Montori, 2017). Discussing the potential advantages or problems with each approach with a patient allows a clinician to explore the patient's perceptions of the available treatment approaches. Such discussions enable the patient to consider their preferences and the clinician to appreciate what option a patient prefers and why (Llewellyn-Thomas and Crump, 2013). In this scenario, autonomy is promoted as the patient retains the ability to decide, with support, from the options presented to them (Elwyn et al., 2012).

3.5 Mental capacity and capacity assessment

The models of Informed Choice and SDM assume patients have sufficient cognitive abilities to consider their choices and make informed decisions, either alone or collaboratively. For some patients, this is simply not possible (Elwyn et al., 2022). However, mental capacity is not an all-or-nothing construct; a person with a cognitive impairment may be able to make certain decisions and may only lack capacity when the complexity of a decision increases (Wade, 2019; Wade and Kitzinger, 2019). Alternatively, when capacity fluctuates, a person may be able to make decisions at certain times but not at others. Lahey and Elwyn (2020) discuss a sliding scale of SDM for people with reduced capacity to demonstrate how increasing support with decision-making is needed as cognitive impairment progresses. However, it is necessary to define a cut-off point where decisional capacity is lacking and when another individual becomes responsible for decision-making (Devettere, 2010, p. 73). Legislation details how decisional capacity is assessed and when this cut-off point arises. Applicable legislation varies both internationally and between the devolved nations of the UK.[11] The Mental Capacity Act (MCA) (2005) applies to those aged 16 and over in England and Wales. This is the primary legislation discussed in relation to the research presented in this thesis.

The MCA came into force in 2007 as a statutory framework to support decision-making with or for people with cognitive impairments (Department for Constitutional Affairs, 2007). An MCA Code of Practice has been produced to guide those working with people whose capacity could be questioned and who may be directly affected by the implementation of the MCA (Department for Constitutional Affairs, 2007). The MCA outlines the rights of a person, referred to as 'P', with respect to decisions made which affect them by another person, referred to as 'D'. The MCA is founded on five statutory principles:

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made…for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

(Mental Capacity Act 2005: Section 1)

Each of these principles guides how decision-making should be approached. Point 1 specifically informs the need to assess capacity, which, in turn, determines who is responsible for decision-

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[11] The Adults with Incapacity (Scotland) Act, 2000 and the Mental Capacity Act (Northern Ireland), 2016 support decision-making in Scotland and Northern Ireland, respectively. Whilst some key differences exist between these pieces of legislation and the MCA, the similarities in relation to autonomy and best interests are significant. Due to these similarities, I do not present a debate or discussion of the practical or procedural differences between legislation in this thesis.

making. The MCA details a two-stage process to assess capacity. Firstly, the assumption is that P will have capacity and, in order to refute this, P must have an *"impairment of, or a disturbance in the functioning of, the mind or brain"* (MCA, 2005: section 2(1)) that impacts decision-making. When this is said to apply, the second stage of a capacity assessment must be undertaken as to determine whether P can consent to their own treatment or whether a decision is made on their behalf. In this assessment, P is said to lack capacity to consent to treatment if they are unable to undertake any one or more of the below processes:

> (a) understand the information relevant to the decision.
> (b) retain that information.
> (c) use or weigh that information as part of the process of making the decision.
> (d) communicate his decision (whether by talking, using sign language or any other means).
>
> (Mental Capacity Act 2005: Section 3(1))

As detailed in the fourth statutory principle of the MCA (2005 ,section 1(4)), decision-making for P, when assessed to lack capacity, is based on what is felt to be in their best interest (Best Interests Decision-Making - BIDM). Regardless of who makes a decision, Section 4(6) of the MCA details that the following factors should be considered:

> a) the wishes and feelings of P, including any written statements from when P had capacity.
> b) P's beliefs and values that would affect the decision if they had capacity.
> c) any other factors that P may consider to be relevant.

Many of these factors may be identified through a process of Advance Care Planning (ACP). NHS England (2022 p.6) defines ACP as:

> *"a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversation about these."*

ACP can empower people with cognitive impairment, particularly neurodegenerative conditions, to express their views and preferences (NHS England, 2022). Though ACPs are not legally binding, the views expressed within them can support BIDM that aligns with a person's considered preference. The MCA (2005, section 41(1)) does, however, allow people with mental capacity to produce written statements to refuse certain treatments or care in the form of Advanced Decisions to Refuse Treatment (ADRT). An ADRT would apply if the person were unable to express a preference, either temporarily (such as when anaesthetised) or permanently (such as with advanced dementia). Though people can refuse treatment, they cannot make a written statement that demands a particular treatment is provided (Department for Constitutional Affairs, 2007, p. 161).

In BIDM, it is expected that somebody close to the patient would be consulted to gain information about P, and their person's values and preferences (Section 4(7)). Alternatively, anyone P named as somebody to be consulted or anybody with a legal status such as the donee of a Lasting Power of Attorney[12] for health and welfare (LPA) or Court Appointed Deputyship should be consulted about P's care. Where an unbefriended individual is assessed to lack capacity, an IMCA (Independent Mental Capacity Advocate) must be consulted so P's wishes and feelings can be established independently from professionals (Department for Constitutional Affairs, 2007, pp. 178–201). It is a common misconception that somebody can consent for a person simply because they are a relative or 'next of kin' (Johnston, 2016, p. 56). Though the 'next of kin' may be well placed to advise on P's wishes and feelings and to help establish what may be in their best interests, they are not automatically able to consent on P's behalf.

3.6 Perspectives on best interests

Though the term *best interests* is used in the MCA, different ethical perspectives on decision-making can be found in relevant ethical and clinical literature. Substituted Judgement is one alternative to the *best interests* principle (Devettere, 2010, p. 101; Beauchamp and Childress, 2013, p. 227). In Substituted Judgement, a decision is made for a person that is felt to be the decision the person would make if they were able to do so (Broström, Johansson and Nielsen, 2007). Substituted Judgement may appear to be the approach that respects a person's autonomy, as the same decision

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[12] There are two types of LPA: Health and Welfare, and Property and Financial Affairs. Throughout this thesis, any reference to LPA relates only to Health and Welfare.

the person would have chosen is the one that is made, regardless of whether the PLwD makes this decision or not (Beauchamp and Childress, 2013, p. 226). Despite this apparent benefit, the inherent problems with this approach have been presented (Kuczewski, 1999; Broström, Johansson and Nielsen, 2007; Devettere, 2010, p. 118; Phillips and Wendler, 2015; Wade and Kitzinger, 2019). The first challenge here is that nobody may know what a person would have decided themselves. Secondly, the impact of cognitive impairment on a person's wishes and preferences is disregarded in this decision-making model (Phillips and Wendler, 2015; Wade and Kitzinger, 2019).

Noting the potential problems with Substituted Judgement, the legislative explanatory notes supplied alongside the MCA (legislation.gov.uk, 2005) explicitly state that *"Best interests is not a test of substitute judgement"*. It is, therefore, important to consider what best interests actually is. It is poignant that the MCA does not define best interests, and that the MCA Code of Practice specifically states that a definition is not provided (Department for Constitutional Affairs, 2007, p. 68). This suggests the exclusion of a definition is intentional. As the MCA applies to a vast range of decisions and individuals, it would potentially be impossible to be explicit about what best interests may entail. However, a degree of subjectivity remains in its interpretation, and this subjectivity has led to numerous court cases.

Case law arising from such cases most colourfully highlights the factors that a decision-maker should consider when determining what may be in someone's best interests:

> *"in considering the best interests…decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider the outcome of the treatment is or would be likely to be; they must try and put themselves in the place of individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."*
>
> Aintree University Hospitals NHS Foundation Trust v James. (2013)

The above statement emphasises the importance of holistically appropriately establishing P's views and attitudes and the value of consulting those close to P with an awareness of how care may impact them. When decisions are complex or likely to significantly impact P, or when there are conflicting opinions on interventions, formal best interests meetings can be held to establish the suitability options and determine P's best interests (Royal College of Physicians and British Medical Association, n.d.). Formal meetings may not be possible for emergency care despite the application of the MCA in these scenarios (National Institute for Health and Care Excellence, 2018b). Within these meetings, all relevant individuals can support decision-making using their various areas of knowledge about P (West and Glover, 2014; Wade and Kitzinger, 2019; Royal College of Physicians and British Medical Association, no date) A consensus of opinion is not compulsory. However, these meetings should aim to allow any disagreements to be negotiated, with the additional support of an IMCA if required. The outcome is determined by whoever is responsible for delivering an action or deciding against a specific intervention.

3.7 Decision-making in dementia

Dementia affects a range of cognitive functions such as memory, comprehension, judgement, and general thinking so can complicate decision-making through numerous mechanisms (Wright, 2019). In addition, a PLwD may experience dysphasia or aphasia, limiting the extent to which they can verbally express any preferences and wishes they can understand and consider. PLwD may or may not be able to make decisions about their care at different points in time and for decisions of differing complexity (Wright, 2019). This can mean they exist at the 'margins of autonomy' (Peterson, Karlawish and Largent, 2021) until dementia progresses to a point where capacity is lacking for most decisions.

Dementia differs from other cognitive impairments, such as severe learning disabilities, because PLwD generally make autonomous decisions throughout their lives. The values and preferences that inform these decisions are often known by those close to PLwD and these can be considered when a best interests decision is needed. These past preferences and values are part of being a person or part of personhood. However, there is debate about the nature of the self in dementia. An argument has been proposed that as neurodegeneration progresses, the changes in memory and personality can be sufficient to allow the identification of two separate people, the pre-and post-dementia individual (Hughes, Louw and Sabat, 2006, p. 58). In this paradigm, the previous person ceases to exist, the 'self' has gone, and a new person arises (O'Connor and Purves, 2009, p.58). If this were the case, a person's past preferences or values could be disregarded. On this basis, and aligned with the opinion presented from Aintree University Hospitals NHS Foundation Trust v James (2013), a sole focus on biomedical processes has fallen out of favour.

Based on social constructivist principles, a contrasting perspective is that the self remains and develops further over time instead of being lost altogether (Parfit, 1984; Berghmans, 1997). A leading driver of the focus on personhood and the 'self' was Tom Kitwood. He has provided extensive commentaries on personhood, defined as *"a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being"* (Kitwood, 1997, p. 8). In Kitwood's dialectical approach to dementia, the self is not lost, but evolves throughout the progression of dementia based on the continual interplay between neuropathology, physical health, social and psychological factors, biography and personality (Kitwood, 1993). For each person, therefore, how they individually live with and experience dementia must be considered when decisions are being made regarding their care. Their past values and preferences must be considered, as should the potential for these values and preferences to evolve as dementia progresses.

When PLwD retain some capacity to make decisions, but have significant dementia symptoms, supported decision-making can be used. In this process, somebody such as a family member, carer, or advocate actively supports a person in the decision-making process and helps them to make autonomous decisions (Jaworska and Chiong, 2021; Peterson, Karlawish and Largent, 2021). As mentioned in Section 3.5, Lahey and Elwyn (2020) propose a sliding scale of shared-decision making in which the support a person with cognitive impairment requires increases as their illness progresses. In this situation, a person can be supported to engage in a process akin to SDM (Jaworska and Chiong, 2021). Supported decision-making contrasts substitute or surrogate decision-making, where someone else makes a decision on behalf of another individual. Whilst BIDM may eventually be required, often by the person supporting a person, supported decision-making acts as a bridge between autonomous and substitute decision-making (Gooding, 2013, p. 423). This reflects a core principle of the MCA and the requirement to make all attempts to allow a person to make an autonomous decision (Mental Capacity Act 2005, Section 1(2)).

The appropriateness of a SDM process when determining someone's best interests is less clearly defined in the literature: generally SDM is inappropriate for someone lacking decisional capacity as the decision is not *shared* with that person (Elwyn et al., 2022). In instances where surrogate or substitute decision-making is legally appropriate – such as with a person holding a LPA) – the principles underpinning SDM (see Figure 3.1) as applied to the substitute decision-maker, may still be valuable. Some studies, mostly undertaken outside of the UK, have measured SDM with those making decisions for PLwD,[13] suggesting SDM can occur with someone other than the patient making the decision. In England and Wales, however, the processes detailed by the MCA state that family members do not automatically take a substitute decision-making role. They instead take more of an advisory role (MCA 2005 section 4(7)), supporting a clinician in identifying what may be in a person's best interests. SDM, therefore, is not a suitable model for BIDM either in general (Elwyn et al., 2022) or under the MCA. Decision making, with SDM or other models, can be studied and quantified. Below, I discuss what may constitute a 'good' decision and how decision-making may be measured.

3.8 'Good' decisions

The literature exploring the measurement or evaluation of decision-making generally separates decisions into the two components described by O'Connor et al. (1998): decision process and decision quality.

Decision process

Logically, a good decision should arise from a good decision-making process. Generally, a good decision process is one akin to SDM (Sepucha, Fowler and Mulley, 2004) in which options are presented, and a person's values and preferences are considered, particularly concerning how this relates to known health outcomes or risks (Sepucha, Fowler and Mulley, 2004; Llewellyn-Thomas and Crump, 2013). A good decision process should increase a person's knowledge of the options for their care and the merits or challenges related to these (Hamilton et al., 2017). In addition, a good decision process should allow a person's values to be clarified and understood by both parties (Fagerlin et al., 2013) to inform decision-making. Decisional conflict arises when there is uncertainty about the available options (O'Connor,

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[13] Studies measuring decision-making with family members acting as decision-makers are identified and explored in Chapter 5.

1995; Légaré et al., 2012). Logically, a good decision-making process should reduce decisional conflict.

Decision quality

Decision quality (also referred to as decision outcome) is *"the extent to which patients are informed and receive treatments that reflect their goals and treatment preferences"* (Sepucha et al., 2013, p. 2). Though decision process is important, a high-quality decision could still arise from a suboptimal decisional process. Measures of decision quality include value concordance, patient satisfaction and decision regret. Value concordance is the extent to which a decision reflects what is personally important to a patient (Llewellyn-Thomas and Crump, 2013). Satisfaction is a commonly used measure yet is often affected by patient expectations more than factors a clinician can modify (Cleary, 1998). Decision regret refers to a situation where somebody may wish they had made a different decision to the one they actually made (Joseph-Williams, Edwards and Elwyn, 2011) with high levels of decision regret suggesting a poor-quality decision occurred, potentially due to a problematic decision process.

In addition to the decision quality or outcome, decisions lead to specific health outcomes. A good decision can lead to a bad health outcome and vice versa (Ratliff et al., 1999). When studying decisions, it is essential to separate health outcomes from the measurement of the decision process or quality to prevent a bad health outcome from inappropriately suggesting a decision process was inappropriate or vice-versa (Elwyn and Miron-Shatz, 2009; Schwartz and Bergus, 2010, p. 4).

3.9 Measures of decision-making

As the need for SDM is increasingly recognised, it becomes necessary to demonstrate the extent to which it happens (Elwyn, Edwards and Thompson, 2016, p. 168). Similarly, if interventions to improve SDM or BIDM are proposed, there must be a suitable way to assess their impact (Hamilton et al., 2017). Key domains, such as satisfaction, value concordance and decisional conflict are detailed above, yet a vast range of specific tools exist to measure aspects of decision-making (Shared Decision Making Programme, 2012; Hamilton et al., 2017). Common tools used to assess elements of decision-making are summarised in Table 3.2:

Measure	Summary
CollaboRATE (Elwyn et al., 2013)	A 'fast and frugal' measure of how informed patients feel, and how involved they are in steps of decision-making
COMRADE (Edwards et al., 2003)	A 20-item patient-completed outcome measure to determine a patient's experience of risk communication and a patient's confidence in a decision
Decisional Conflict Scale (O'Connor, 1995)	A 16-item patient-reported 5-point scale measuring decision uncertainty, and factors contributing to this
Decision Regret Scale (Brehaut et al., 2003)	A 5-item patient-reported 5-point scale to measure decision-regret
Dyadic Option (Melbourne et al., 2010)	A 12-item, 4- point scale used by both patients and physicians independently to assess multiple aspects of SDM
OPTION Scale (Elwyn et al., 2005)	A 12-item 5-point scale where an observer assesses the extent of SDM in observed or recorded consultations.
Satisfaction with Decision Scale (Holmes-Rovner et al., 1996)	A 6-item, patient-completed 5-point scale to assess aspects of satisfaction with decisions about care
SDM Questionnaire (Kriston et al., 2010)	A 9-item patient-reported 6-point scale mapped to aspects of SDM
SURE Scale (Légaré et al., 2010)	A patient-reported 4-item yes/no scale to determine decisional conflict

Table 3.2: Commonly used scales to measure aspects of decision-making

3.10 Conclusion

Various factors may impact decision-making, such as the nature of the decision being made, the extent of evidence to support a course of action, the preferences of the person to whom the care relates and the approach taken by the clinician supporting or undertaking the process. The need to consider the individual making a decision, or for whom a decision is being made, is emphasised in models of SDM and relevant legislation and guidance. Whether or not a person has decisional capacity, clinicians should consider a broad range of factors – specifically patients' values and preferences - to inform and guide decisions made with them or on their behalf. Identifying, considering, and discussing these factors should, where possible, lead to decisions to deliver care aligned with a person's values and preferences. Considering the challenges explored in Chapter 2, it becomes clear that doing so may not always be possible in dental settings. In the next chapter, I summarise use the information presented so far to justify the research proposed and present its aim and objectives.

Chapter 4. Aims, objectives and programme of work

4.1 Justification for the study

In Chapter 2, I explored the high prevalence of oral diseases and orofacial pain in older people including PLwD, as well as the impact of such conditions on daily living. I presented an overview of clinical guidelines and how these typically guide dentists on how to approach care. I also noted the lack of primary research on dental care decision-making for PLwD. In Chapter 3, I detailed the principles underpinning SDM and how this approach to decision-making allows people retaining decisional capacity to be supported by clinicians when making autonomous decisions. I also explored how legislation informs BIDM for those lacking decisional capacity and how patients' preferences should be considered in this process.

Looking back on Chapters 2 and 3, a key issue is that guideline documents offer little practical support for dentists on *how* to approach SDM or BIDM with or for PLwD. Arguably this is not their primary intention, yet it is possible that dentists are using the guidance in different ways. Potentially, they could be using it to determine what treatment options to present to patients or carers to guide collaborative decision-making aligned with effective SDM or BIDM. Alternatively, strict adherence to the recommendations may result in paternalistic decision-making, regardless of a patient's decisional capacity. Dentists' views or approaches to dental treatment decision-making have not been studied in recent decades. Furthermore, no literature specifically explores how PLwD have experienced or feel about decisions made for dental care. The views of carers supporting PLwD with dental treatment have also not been explored. Any approach to support the decision-making process in this complex scenario should be informed by an understanding of current processes and practices. Based on these facts, the aim and objectives of the research presented in this thesis are presented below.

4.2 Aim

To collaboratively produce an intervention to support people living with dementia, their carers, and dentists with dental treatment decision-making.

4.3 Objectives

A series of objectives were set to achieve this aim:

1. To systematically explore the effectiveness of any existing interventions that aim to support decision-making with or for PLwD facing healthcare decisions and whether these may support dental care in the dental context (Project 1)

2. To explore the approaches that dentists report using and their experiences in treatment decision-making with or for PLwD (Project 2)

3. To explore the experiences and perspectives of PLwD and their family carers regarding dental treatment decision-making for PLwD (Project 3)

4. To collaboratively develop a prototype intervention to support dental treatment decision-making with or for PLwD (Project 4)

5. To reflect on the challenges and processes involved in co-producing a new intervention to support decision-making in the context of dental care for PLwD

Chapter 5. Project 1: A systematic review of the effectiveness of existing interventions

The systematic review presented herein was published in late 2020 (Geddis-Regan et al., 2021). This work was published as a standalone review. In the context of this Thesis, however, the purpose of the review was to explore whether existing interventions could inform the co-production process presented in Project 4.

5.1 Introduction

Whilst the literature on dental treatment decision-making for PLwD is sparse, there is a vast amount of literature exploring decision-making in the context of dementia (Bhatt et al., 2020). The wider aim of this thesis is to demonstrate the co-production of an intervention to support decision-making for PLwD in the dental context. To address this aim, it was necessary to identify and learn from existing research regarding related interventions. Components of these interventions may be transferable to dental care settings or may support idea generation and discussion in the planned co-production process (Project 4). Therefore, it was necessary to systematically identify and understand what existing interventions were effective.

5.2 Objective and review question

As described in Chapter 4, the objective of this review was to systematically search existing literature to identify any existing interventions that are effective in supporting decision-making with or for PLwD. In addition, the review sought to explore whether any existing interventions may function to support decision-making in the dental context. A Patient and Public Involvement and Engagement (PPIE) process prompted the review to focus on *"what actually works in the real world"* instead of interventions that have been produced but are not effective.

The following research question was used:

What interventions are effective in improving shared decision-making or surrogate[14] *decision-making in relation to the health care of PLwD?*

5.3 Methods

5.3.1 Design

Several factors were considered when designing the review. Firstly, I anticipated that many studies of effectiveness would be quantitative, but that qualitative studies may also be found. I decided these should be included due to their potential value in providing insight into individuals' views regarding the effectiveness of interventions. In addition, I noted that many interventions aiming to support decision-making in the general population, such as Patient Decisions Aids (PDAs), may be effective for PLwD earlier dementia. Having considered the potential role of such interventions alongside the potential complexities of decision-making in dementia, (as detailed in Chapter 3), I felt it was necessary to focus on interventions specifically supporting PLwD or those involved in decisions about their care. This meant interventions not specific to dementia would not be sought even if they may support some PLwD. I felt this was a necessary approach to support the review's objective and its role within the wider program of work. In addition, scoping searches identified that limiting the search to dementia returned a realistic number of results to screen. Finally, the scoping process found studies that evaluated the effectiveness of interventions using hypothetical scenarios or simulated patients. I felt it was necessary to include only those interventions tested in real-world settings as the effectiveness demonstrated in simulations may not translate to effectiveness in live clinical settings.

The protocol for the review was prospectively published on PROSPERO (reference: CRD42019154707): https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=154707.

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[14] This term was used in the searches to account for any potential individual, such as a family member, or clinician, who makes decisions for PLwD lacking decisional capacity. This term is not widely used in the UK, yet its use in the review question supported the identification of literature in a range of settings, jurisdictions and contexts that may provide insight to achieve the study's objective and to support Project 4.

5.3.2 Inclusion and exclusion criteria

Inclusion criteria:

1) Studies that assess the effectiveness of interventions aiming to support decision-making with or for PLwD
2) Studies that examine healthcare decisions
3) Studies of interventions used in actual practice

Exclusion criteria:

1) Studies of interventions that had not been evaluated for effectiveness
2) Studies not specifically related to decision-making in dementia
3) Studies related to non-healthcare decisions
4) Studies exploring decisions related to cardio-pulmonary resuscitation (CPR) alone
5) Studies focussing on clinicians as sole decision-makers where these clinicians do not consider PLwD's values or preferences or discuss options for care
6) Existing systematic reviews
7) Studies in languages other than English

5.3.3 Search strategy

A PICO (Participants, Interventions, Comparators, Outcomes) approach was used to develop a search strategy, as shown in Table 5.1.

Participants	People living with dementia, their caregivers or family members, or clinicians supporting decision-making with or for PLwD.
Intervention	Any intervention designed to improve decision making with PLwD or decisions made for PLwD.
Comparator	Quantitative studies: comparisons with usual care without interventions in place or comparisons before and after an intervention is introduced. Qualitative studies: no control or comparator required.
Outcomes	Any outcome relevant to studies meeting the inclusion criteria, whether quantitative (such as OPTION scale, decision satisfaction, decisional conflict) or qualitative descriptions of perceived effectiveness.

Table 5.1: The PICO approach used to develop the search strategy.

A search strategy was devised with the support of a subject-specific librarian, Linda Errington (LE). The strategy used in Medline via OVID is shown in Figure 5.1. In addition, LE supported me to revise the search terms or modifiers for each of the following databases: Embase (via OVID), PsycINFO (via OVID), CINAHL via EBSCO, SCOPUS, Web of Science, and the Cochrane Library. Grey literature was searched via OpenGrey using keywords. I also used keywords to manually search key journals (Health Expectations, Medical Decision Making, Patient Education and Counseling). The reference lists of included studies were screened, as were the reviews included in existing systematic reviews that were identified in the search. I initially ran the searches on 16 December 2019, then again on 10 July 2020 when preparing to submit the review for publication. No new studies were found at this time. I again re-ran the searches run on 7 November 2022 when refining this thesis chapter: no further additional studies meeting the inclusion criteria were identified during this final search.

Search Strategy used in Medline via OVID:

1. Exp Dementia/
2. Dement*.mp
3. Alzheimer*.mp
4. Lewy bod*.mp
5. Exp Neurocognitive disorders/
6. 1 or 2 or 3 or 4 or 5
7. Decision Making/
8. Decision*.mp
9. Informed consent/
10. 7 or 8 or 9
11. 6 and 10
12. Limit 11 to (English language and humans)

Figure 5.1: Search Strategy used in Medline via OVID

5.3.4 Study screening

The outputs of each search were added to Rayyan (Rayyan Systems Inc, 2020) where duplicate results were removed. First, I screened study titles to exclude studies clearly not meeting the inclusion criteria. Where I had any uncertainty at each stage of screening, studies progressed to the next screening stage. Both LE and I screened the abstracts of the remaining studies against the inclusion and exclusion criteria. Initially, we both reviewed 100 abstracts then met to confirm our interpretation of the inclusion and exclusion criteria and reflect on and resolve any differences in interpretation. A third reviewer, Richard Thomson (RT), supported decisions where there was any remaining uncertainty about study inclusion. I reviewed full texts myself but discussed any uncertainty on inclusion with RT. The PRISMA flow diagram of study screening and selection is shown in Figure 5.2. I exported key data from included studies onto a customised spreadsheet; this supported the production of the summary of included studies (Appendix A) as well as supporting aspects of quality assessment and an understanding of the key findings of each study.

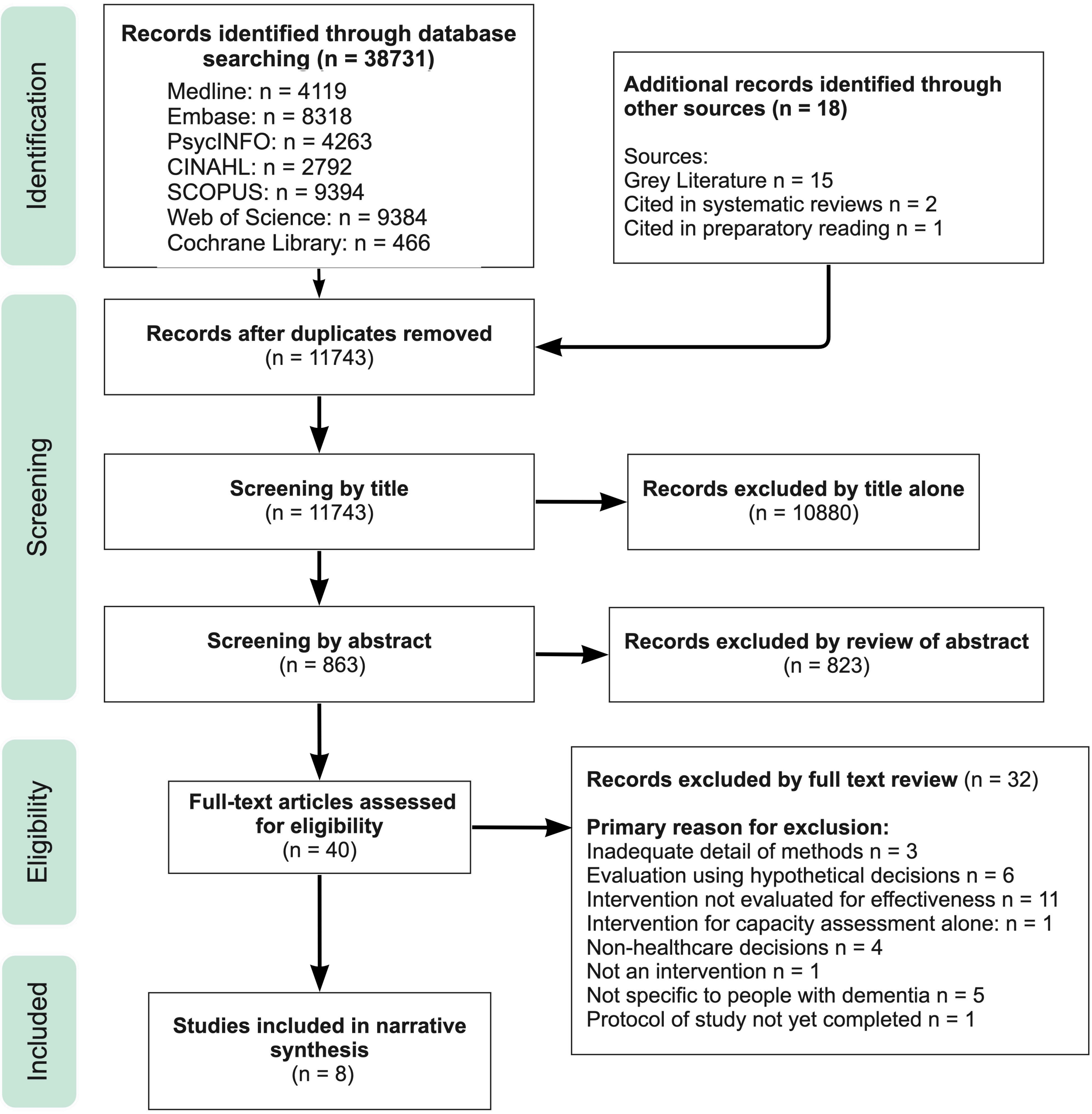

Figure 5.2: PRISMA flow diagram

5.3.5 Quality assessment

I used the McGill Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) to determine the quality of included studies. I chose this tool as I had anticipated the search would identify various types of studies, and this tool would allow each study to undergo a suitable process of quality assessment. Studies were not excluded based on limitations with their quality, yet the MMAT identified methodological weaknesses to support the discussion presented and consider the usefulness of the findings of included studies in informing future work.

5.3.6 Narrative synthesis

A meta-analysis was not possible due to the heterogeneity of studies. A narrative summary of studies is presented using a thematic summary approach (Thomas and Harden, 2008), in which studies are categorised by their common features. This approach allowed similar studies to be presented and discussed to provide a logical flow and structure to the results and interpretation of these (Snilstveit, Oliver and Vojtkova, 2012).

5.4 Results

5.4.1 Overview

Many studies were identified that explored interventions focused on decision-making for PLwD, yet these were largely descriptive studies which did not aim to study effectiveness. There were no studies – either excluded or included – that related to dental care decision-making for PLwD. Eight studies met the inclusion criteria. Of these studies, two related to decisions made by caregivers about artificial feeding via feeding tubes for people living with advanced dementia (Hanson et al., 2011; Snyder et al., 2013). The remaining six studies assessed interventions related to planning future care or specifically Advance Care Planning.[15] (Ampe et al., 2017; Hanson et al., 2017, 2019; Brazil et al., 2018; Goossens et al., 2019; Whitlatch et al., 2019). These are summarised in Appendix A. It was an unexpected finding of the review to have studies that fit within one of two clear categories. This

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[15] Some of the interventions examined in these studies refer to themselves as ACP interventions even though they may not strictly align with the definition presented in Section 3.5. To reflect the terminology used by study authors as well as the broad principles of future care planning that underpin such interventions, I refer to them broadly as ACP interventions in this Chapter and the associated publication.

allowed the two types of studies to be discussed and explored separately due to their different focuses and the properties of the interventions they evaluated. The two categories of studies are detailed below.

5.4.2 Interventions for enteral feeding decisions

Two studies (Hanson et al., 2011; Snyder et al., 2013) explored how PDAs impacted decisions made by family members about using enteral feeding for people with advanced dementia. The studies are presented by related research teams and appear to be part of the same larger body of work. Snyder et al. (2013) published a before-and-after study that informs the second study, a larger randomised trial (Hanson et al., 2011). Curiously, the randomised trial was published two years before the preceding before-and-after study, yet both studies provide insight into the effectiveness of the PDA presented.

Snyder et al. (2013) described using qualitative and quantitative methods to study their intervention. They describe using semi-structured interviews with family carers of PLwD in residential care settings to understand the perceived advantages and disadvantages of enteral feeding. The description of the qualitative methods used in this study is minimal and the results of the qualitative component of the study are not comprehensively presented. In particular, the qualitative aspect of the paper offers no insights into perceptions of the intervention's effectiveness. Quantitative methods were also used to assess carers' knowledge, the expectation of benefit of feeding tubes, and decisional conflict. Hanson et al. (2011) undertook an entirely quantitative study in which people living with dementia were randomised so that their carers supported a decision about a feeding tube, either with or without the PDA. The same quantitative outcome measures of the decision process were used in this study and by Snyder et al. (2013). As shown in Table 5.2, both studies found that the PDA led to statistically significant changes in each of the domains assessed, suggesting it is effective in improving aspects of decision-making processes.

Study / Outcome	Knowledge ^		Expectation of Benefit $^{\#}$		Decisional conflict $^{\$}$	
	Before	After	Before	After	Before	After
Hanson et al. (2011)		Intervention: 16.8 Control: 15.1*		Intervention: 2.3 Control: 2.6*		Intervention: 1.65 Control: 1.97*
Snyder et al. (2013)	15.5	16.8**	2.73	2.32**	2.24	1.91**

Table 5.2: Results of studies evaluating PDAs to support enteral feeding decisions

^Using a specified knowledge scale (scored 0-19). $^{\#}$Using Expectation of Benefit Scale (scored 1-4). $^{\$}$Using Decisional Conflict Scale. *p <0.01, **P<0.001.

Reviewed against the MMAT, the randomised trial of the PDA (Hanson et al., 2011) has the potential for bias as the method of randomisation was not clearly presented, and the outcome data were incomplete. Furthermore, whilst a cluster randomisation approach was justified, the assessors were not blinded, suggesting more bias could have arisen. It is unclear why this blinding was not introduced. In contrast, the before-and-after study (Snyder et al., 2013) presented clear and complete outcome data. However, the explanation of the methods used in this work's qualitative and quantitative aspects was brief and unclear. Though they demonstrate the PDA to be effective in supporting the specific decision made by carers, the results of these studies should be interpreted with awareness of the limitations in methodology and reporting.

5.4.3 Interventions for advance care planning

Of the six studies of ACP interventions, the only non-randomised study (Ampe et al., 2017) is a preliminary study informing one of the randomised studies included (Goossens et al., 2019). The four remaining studies were also randomised trials (Hanson et al., 2017, 2019; Brazil et al., 2018; Whitlatch et al., 2019). These studies typically consider outcomes from the perspectives of caregivers alone (Brazil et al., 2018; Hanson et al., 2019), or PLwD and caregivers in combination (Ampe et al., 2017; Hanson et al., 2017, Goossens et al., 2019; Whitlatch et al., 2019).

Various decision-related outcome measures were used within the studies of ACP interventions. These included family members' decisional conflict (Brazil et al., 2018), levels of SDM (Ampe et al., 2017; Goossens et al., 2019), family's reported concordance with clinicians on the primary goals of care (Hanson et al., 2017; 2019) and the level of agreement regarding care plans (Whitlatch et al., 2019).

Though there are common elements of the ACP interventions, the variation in outcome measures reflects the differences between approaches and the design of studies that evaluate them.

Ampe et al. (2017) present the *WeDECide* intervention that aims to train healthcare providers to use SDM with care home residents and their families when discussing a resident's future care. Twenty-one audio recordings of consultations between care staff, residents and family members were used to assess if the intervention improved SDM. Of the recordings assessed, 11 were from the intervention group and ten from the control group. The OPTION scale was used to assess the level of SDM in the recorded consultations. Whilst this study reported an improvement in the uptake of ACP policy in the settings involved, it found no improvement in the OPTION scores from consultations before and after the intervention was introduced (OPTION score 41.32 vs 38.82 p=0.973). The intervention, therefore, appears to be ineffective in improving SDM.

The *WeDECide* intervention presented by Ampe et al. (2017) was iteratively refined and renamed *WeDECide Optimized*. Goossens et al., (2019) studied this new intervention using cluster randomisation of care homes to receive the intervention or a control. 316 audio recordings of discussions between care staff, residents, and family members were obtained. This included 170, 85 and 61 recordings from the pre-intervention stage and from 3- and 6-month follow-up periods, respectively. These were assessed for both intervention and control groups and comparisons were made at each time point for each group. In contrast to the study from Ampe et al. (2017), this randomised trial showed that the level of SDM increased in the intervention group (OPTION-12 Score 24.98 vs 53.49, p<0.001) and that this persisted six months after the intervention was introduced (OPTION-12 Score 21.27 vs 56.00, p<0.001). This suggests the *WeDECide Optimized* intervention is effective as it leads to an improved SDM process. However, with such a process, PLwD may have been fully involved in the SDM process, or they may be entirely removed from a decision discussed with their family member. As a single assessment was used for the combined discussion with PLwD and their family members, the extent to which SDM improves with either the PLwD or a family member alone cannot be comprehensively understood.

Brazil et al. (2018) studied an intervention where an ACP educator met with families of PLwD and worked with them to provide education about ACP and to discuss and document their preferences for the future care of their relative. The primary outcome measure was the extent of family members' decisional conflict when preparing ACP. Compared to those receiving usual care, the level of decisional conflict was reduced in the intervention group (Decisional Conflict Scale reduction of 10.5, p<0.001). This suggests that the support of an ACP educator can be effective at improving the decision-making process for relatives making decisions about ACP for PLwD. It should be remembered that in England and Wales, family members do not automatically have the authority to make specific decisions for their relatives. When family members do take on this role, Brazil et al.'s (2018) findings suggest that the intervention they describe can effectively improve the process of decision-making with PLwD's family members.

Hanson et al. (2017) presented the *Goals of Care* intervention. This consists of a video decision aid provided three months before formal meetings between care staff and relatives of PLwD to establish care goals for a PLwD. This study explored the effectiveness of the intervention by examining the quality of communication between family and nursing home staff, the concordance between family and physicians on goals of care and the extent to which treatment was felt to be consistent with the PLwD's preferences. Compared to the control, the study found a modest but significant improvement in communication with care teams at a three-month follow-up (quality of communication score: 6.0 vs 5.6 p=0.05) but not at the nine-month follow-up. In the intervention group, an increase in the extent to which family and physicians agreed on goals of care only became apparent at the nine-month assessment or when the PLwD died (88.4% agreement in the intervention group, 71.2% agreement in control group, p=0.001). These findings show that the intervention effectively enhances medium-term communication and longer-term goal concordance between physicians and family members. However, the improvement in communication, though a positive outcome, does not necessarily translate to improvement in SDM. This suggests it is ineffective in short-term decision-making from the carer's perspective. No outcome measures here considered PLwD or their role in decision-making. The study considered whether decisions were felt to align with PLwD's preferences. However, PLwD were not asked to express preferences. Regardless of this key limitation, the intervention did not lead to an improvement in the extent that decisions were felt to align with their preferences.

Hanson et al. (2019) evaluated a dementia-specific intervention that triggered palliative care discussions with family members when PLwD were admitted to hospital. Decision-making was only considered in the secondary outcomes of this study. Within these decision-related outcomes, the intervention group showed an increase in the frequency of discussions of PLwD's prognosis (90% vs 3%, p<0.001) and discussions about goals of care (90% vs 25%, p<0.001). The measures focus on aspects of the decision-making process, yet the study did not assess the level of SDM or any aspects of decision quality. The study concluded that the intervention improved decision-making for PLwD who need palliative care. However, this could be debated: a detectable increase in discussions about goals of care cannot be extrapolated to mean that better quality or value-concordant decisions were made. Furthermore, as with the study presented by Hanson et al. (2017), goals or preferences are only considered from the perspective of caregivers, and the intervention does not impact decision-making outcomes from the perspective of PLwD.

Finally, Whitlatch et al. (2019) assessed the effectiveness of the *SHARE* program (Support, Health, Activities, Resources, and Education). This intervention aimed to support PLwD-carer dyads to address the dyad's shared concerns about future care. This approach aims to capture the voice of the PLwD at the earlier stages of dementia to simplify future care decisions. This was the only study that used measures focusing on PLwD as individuals. Satisfaction was one measurement employed, yet this related to satisfaction with the intervention, not satisfaction with decision-making. When compared to a control group (who were not part of the *SHARE* program but received a one-off consultation with a dementia professional), PLwD expressed an increase in satisfaction, which was only related to the *SHARE* counsellor. Carers were more satisfied with four of five measured aspects of the intervention. The *SHARE* programme did not increase the level of agreement between PLwD and their carers. Although more intervention group participants produced ACPs, the limited outcome measures that specifically relate to decision-making mean this intervention cannot be said to be effective in supporting decision-making processes or decision quality during the construction of an ACP.

In addition to the limitations of each study that have been discussed, the MMAT supported the assessment of specific aspects of each study's methods. In the non-randomised study, Ampe et al. (2017) used a suitable measurement tool (OPTION scale) but in an inappropriate way, thus limiting its suitability to determine the effectiveness of the intervention for PLwD. The MMAT also asks if an intervention was administered as intended: the description presented by Ampe et al. (2017) suggests the use and uptake of the 'WeDECide' intervention were inconsistent within the study, especially as it relied on recordings being taken and provided to the study team. These methodological concerns may have underpinned why effectiveness was not demonstrated. The use of an RCT with more rigorous methods may explain why the related 'WeDECide optimized' intervention was shown to be effective (Goossens et al., 2019). With this study, however, the problem of assessing recordings of complex consultations involving PLwD and family members remained. Furthermore, there were questions about the adherence to the intervention and an unclear randomisation process. PLwD may have, in theory, been entirely excluded from discussions in both studies, but there is only limited information given regarding the nature of the interactions studied.

Table 5.3 shows the assessment of the five randomised trials against the MMAT. Whilst the process of randomisation was generally clear and comparable groups were used within each of the studies, blinding was variable and complete outcome data was often lacking. In addition, assessors in the work presented by Hanson et al. (2019) and Whitlatch et al. (2019) were not blinded. It is unclear why assessors could not have been blinded in these studies, and bias could have been introduced due to this aspect of the study designs. The limitations in outcome measures used across the studies have been discussed, as has their limited ability to identify the effectiveness of the interventions presented. The significance of the methodological issues identified through the MMAT is unclear, particularly as there were few positive findings in the studies presented.

Study MMAT Question	Brazil et al. (2018)	Goossens et al. (2019)	Hanson et al. (2017)	Hanson et al. (2019)	Whitlatch et al. (2019)
Is randomisation appropriately performed?	Y	U	Y	Y	Y
Are the groups comparable at baseline?	Y	Y	Y	Y	Y
Are there complete outcome data?	N	N	Y	N	N
Are outcome assessors blinded to the intervention provided?	Y	Y	Y	N	N
Did the participants adhere to the assigned intervention?	Y	N	Y	Y	Y

Table 5.3: Assessment of randomised studies against MMAT criteria

Criteria taken from Mixed Methods Appraisal Tool (Hong et al., 2018). Y=Yes, N=No, U=Unclear.

5.5 Discussion

The perspectives of PLwD were often a secondary or absent focus in the included studies. This may be appropriate for the studies for enteral feeding, as enteral feeding is not likely to be a consideration for PLwD who retain decisional capacity. However, the broad exclusion of measures of PLwD's views and experiences from the assessment of ACP interventions is regrettable, especially as PLwD can actively contribute to decisions about their future care (Wright, 2019). As mental capacity is decision-specific (Department for Constitutional Affairs, 2007, p.15), and people should be encouraged and supported to make their own decisions (Mental Capacity Act 2005, Section 1(2)), it is disappointing that no studies were identified detailing interventions promoting autonomy and supporting PLwD to making decisions about their own care.

When considering PDAs related to enteral feeding, the strong evidence base for such PDAs should be revisited. A Cochrane review (Stacey et al., 2017) demonstrated how PDAs can both enhance the knowledge of those using them and support patients to understand their values for care. The Cochrane review did not explicitly focus on decisions made with or for PLwD. However, it suggests PDAs may work for those without a significant cognitive impairment and hence may be suitable for those living with earlier dementia. A separate systematic review (Davies et al., 2019) described a range of PDAs related to health and social care decisions for PLwD. Whilst this review did not examine effectiveness explicitly, it suggests that well-designed PDAs may be suitable to support specific decisions with or for PLwD.

ACP interventions were varied and primarily focused on decisions made by caregivers for PLwD with later-stage dementia. Clearly, it is methodologically challenging to study decision-related outcomes directly from the perspective of people with advanced dementia due to the impact of progressive neurodegeneration. This issue is likely why many studies have not considered the views of PLwD when decisions are made for them. One could argue that the perspective of PLwD is not possible to ascertain in advanced dementia and severe cognitive impairment, yet the concept of personhood stresses that the person remains and, therefore, their preferences should be strongly considered (O'Connor and Purves, 2009, p. 59). Ideally, future studies for interventions to support decision-making for PLwD would strive to include PLwD and gather relevant outcomes from their perspective, even as cognitive impairment progresses.

In ACP processes, PLwD should be supported to consider and record their preferences to support future care decisions (NHS Improving Quality, 2014). The MCA (2005, section 4(6)) details how known or documented preferences or wishes should be considered during BIDM for people lacking decisional capacity. This consideration, however, is only one aspect of BIDM. Any documented or known preferences can inform care, but these do not automatically determine what care is delivered (O'Connor and Purves, 2009, pp. 98–99). As dementia progresses, a person's views and preferences can change (Wright, 2019). Due to this, an ACP intervention could support BIDM. Such an approach, however, should not dictate the care delivered due to the potential for a person's views to have changed since they were documented. Not all patients wish to undertake ACP (Samsi and Manthorpe, 2010), and people have a range of decision styles, with many wishing to delegate decisions to family members, particularly in later dementia (Bhatt et al., 2020). Such an approach is the exact rationale for arranging a Lasting Power of Attorney (LPA) as an LPA allows specified individuals to make certain decisions for PLwD. No research has explored the nature and effectiveness of ACPs in informing best interests decisions made by healthcare professionals in situations where no LPA has been authorised.

No ACP interventions were identified for dental care planning or decision-making. However, an ACP-style process could potentially be used for people living with earlier dementia to consider their future dental care preferences. Doing so could ensure that care concordant with a PLwD's preferences and values could be considered when PLwD lack decisional capacity in the future. Due to the potentially varied nature and complexity of dental care decisions that may be needed in advanced dementia, an ACP could not feasibly propose a plan for every circumstance. An approach that seeks to understand the generic views and preferences of PLwD for dental care could support necessary decisions in the future and inform SDM or BIDM related to PLwD.

5.6 Strengths and limitations

The use of a broad search that would have identified any interventions impacting dental care is a strength of this review. This broad approach allowed me to understand interventions in other contexts and how effective or ineffective they are in supporting decision-making either with a PLwD or on their behalf. The support of an expert librarian in designing the search strategy and adapting it for specific databases is another strength of this review. This expert knowledge made it likely all relevant studies were identified.

Three key limitations could be considered. Firstly, the focus on effectiveness alone meant that certain studies were excluded even though these may have offered insight to support the design of an intervention related to dental treatment decision-making. That said, including interventions that have not been demonstrated to be effective could have meant that ineffective approaches or components were incorporated into a new intervention that may, therefore, also be ineffective. Secondly, the search strategy was specific to dementia, so interventions that may support PLwD at earlier stages of dementia who retain decisional capacity were not identified in the search. However, such a search would have led to an unmanageable number of search results to screen. It was arguably unnecessary to search for interventions not specific to dementia as a Cochrane review has explored broader approaches to increase the use of SDM that may apply to people with fewer dementia symptoms (Légaré et al., 2018). Finally, while LE supported screening study abstracts, I searched study titles independently before this. On this basis, my own biases, misinterpretations, or human error may have led to the exclusion of relevant studies at this stage. When there was doubt about inclusion, studies progressed to the next screening stage, so the risk of excluding relevant studies is low.

5.7 Conclusion

Two studies (Hanson et al., 2011; Snyder et al., 2013) detailed that a specific PDA could improve various aspects of carer's decisions regarding enteral feeding for PLwD. Two ACP interventions were shown to improve decision-making processes, with one reducing decisional conflict for carers (Brazil et al., 2018) and one improving the extent to which SDM was used in discussions between care teams, PLwD and family members (Goossens et al., 2019). Only Whitlatch et al. (2019) studied the perspective of PLwD in their outcome measures, but this related to their experiences of the intervention, not decisions associated with it. Aspects of decision quality were rarely measured, and none of the included studies demonstrated any interventions that improved decision quality. No interventions clearly demonstrated effectiveness in supporting PLwD themselves to make decisions about their care. In addition, there were no studies of interventions supporting clinicians undertaking BIDM. The interventions identified offer little knowledge or insight that could support the production of a new intervention in a separate context, such as the context of dental care provision.

Based on the findings of this review, primary research will be completely necessary to guide the design of an intervention specific to dental care decision-making for PLwD. In the next chapter, I discuss the theoretical stance, methodology and method I used to undertake this primary research.

Chapter 6. Projects 2 and 3: Methodology and methods

Here I describe the philosophical and theoretical stances I adopted when undertaking qualitative research. I detail how these stances informed the use of qualitative methods and present the specific methods used to identify participants and generate data from interactions with dentists, people living with dementia, and caregivers. I then describe the use of Constructivist Grounded Theory methods and how I used these to generate and iteratively analyse data.

6.1 Introduction, ontology, and epistemology

Methodology considers a system of methods that inform how a research question might be addressed (Berryman, 2019). A range of methods can be used for both qualitative and quantitative research. With each approach, a researcher's philosophical stance can inform how they perceive knowledge (Ormston et al., 2014, p. 5). It is, therefore, sensible to consider how knowledge is viewed or perceived before considering how new knowledge might be acquired to address a research question (Hay, 2002, pp. 61–65).

Ontology is the area of philosophy concerning the study of being and the nature of existence (Crotty, 2003, p. 3). There are two primary contrasting ontological perspectives: realism and idealism (Ormston et al., 2014, pp. 4–5). Realism states that there is a single external reality that is separate from the mind and peoples'' conceptualisations (Mays and Pope, 2000; Berryman, 2019). In this paradigm, reality can be objectively studied and understood. Idealism, in contrast, states that no external reality exists and that perception of reality is constructed through mental processes (Filmer et al., 2004). Within this perspective, reality only exists as much as people believe it does, making it inherently subjective.

There is a spectrum of perspectives between realism and idealism in which various standpoints consider how a potential reality and cognitive processes may interact (Angen, 2000; Ormston et al., 2014, p. 5). One such approach is subtle realism. Subtle realism stipulates that an actual reality exists but that this reality is only known through our beliefs and understandings of it (Hammersley, 1992;

Ormston et al., 2014, p. 5). This applies to the area of research in question: though a reality may be present, different individuals involved in decision-making will subjectively report their experiences– their reality - through their unique cognitive processes and perceptions. On this basis, I took an ontological stance of subtle realism during the work presented in this thesis.

Epistemology has been described as *"a way of understanding and explaining how we know what we know"* (Crotty, 2003, p. 3). Knowledge can either be discovered (positivism), or it can be interpreted subjectively (interpretivism). Positivism is typically associated with quantitative research, whereby specific methods, often based around numbers, find a 'correct' or quantified answer to a research question (Bowling, 2014, p. 139). Interpretivism is more aligned with qualitative methods where there may be no singular 'right' answer (Ormston et al., 2014, p. 13) Interpretivism is closely related to constructivism. When presenting constructivism, Charmaz (2006, p. 127) states that 'we interpret [research] participants' meanings and actions and they interpret ours'. A constructivist epistemological perspective proposes that our subjective interpretation of experiences is informed by our worldview and our conscious construction of it (Ormston et al., 2014, p. 13). Social constructivism builds on this concept but proposes that our worldview is constructed based on the scenarios in our personal and professional worlds and our interactions with others in these settings (Creswell and Poth, 2018, p. 24).

The social interaction that enables patients, carers or clinicians to share their experiences leads researchers to construct meaning from what a research participant shares (Creswell and Poth, 2018, p. 24). Therefore, I felt that social constructivism was the most appropriate epistemological stance to take when exploring the nature of decision-making in dental settings. In summary, my ontological perspective is subtle realism, and my epistemological approach is social constructivism. These stances align with grounded theory methods, specifically constructivist grounded theory (CGT), as described below.

6.2 Grounded Theory and Constructivist Grounded Theory

Different versions of Grounded Theory (GT) have been presented, varying in their ontological and epistemological positions. 'Classical' Grounded theory methods were first presented by Glaser and Strauss (1967) on the premise that any theoretical understanding of a topic should inductively arise from qualitative data. Glaser and Straus challenged the positivist epistemology dominating published research at the time (Charmaz, 2006, p. 7) and demonstrated how qualitative data could legitimately support scientific enquiry.

The defining aspects of classical grounded theory include the generation of analytic codes inductively from data and the use of a constant comparative method in which data collection and analysis occur simultaneously (Glaser and Strauss, 1967, pp. 101–114). Reflecting a variation in philosophical stances, substantial theoretical and methodological debate arose between the original proponents of GT as it became increasingly used. This led to contrasting and diverging views on how to undertake GT from Glaser (1978, 1992) and Strauss and Corbin (1990; 1998).

Acknowledging the variety of existing approaches, Charmaz (2006) presented a constructivist approach to grounded theory aligned with interpretivism. This approach, Constructivist Grounded Theory (CGT), is described as *"a set of principles and practices, not as prescriptions or packages"* (Charmaz, 2006, p. 9). It retains aspects of Glaser and Straus's original method (Glaser and Strauss, 1967) and Strauss and Corbin's coding processes (Strauss and Corbin, 1998) yet emphasises the need to take a reflexive stance to consider how and why participants construct the meanings of social processes they describe.

CGT uses specific methodological approaches alongside those used in classical GT. Specifically, when using CGT, researchers ask contemplative questions of data and use memo-writing to inductively support their analysis. Asking questions and memo writing supports the construction of meaning from a combination of participants' comments and reflexive practice (Charmaz, 2017). In addition to constant comparisons of new and existing data, the researcher moves backwards and forwards through different stages of data collection and analysis to support an inductive construction of the meaning behind the data generated (Charmaz, 2017).

Though theory can be generated using these methods, and classically this was its intention, Hallberg (2006, p. 146) details that grounded theory *"is more seldom presented as a theory than as a story or a narrative, including categories, told by the researcher with a focus on understanding of social* *processes.*" Consequently, CGT methods can be used - without theory development - to describe social processes. This was how I intended to use CGT through the methods detailed below.

6.3 Methodology

6.3.1 Chosen method of data generation

Various quantities of qualitative data can be generated through different approaches. There are three main approaches by which new qualitative data are commonly generated to gain detailed insight into under-research areas: observations, interviews and focus groups (Creswell, 1994, pp. 150–1). Whilst the extent of interaction with participants can vary during observation (Nicholls, Mills and Kotecha, 2014, p. 244; Creswell and Poth, 2018, p. 90), interviews and focus groups inherently involve significant interaction between research participants and researchers to gain insight into their views and experiences. Interviews generally use a one-to-one discussion to gain in-depth insight into a person's specific experiences and viewpoints. Due to the value of this deeper insight, interviews are the most commonly used approach in primary qualitative research (Taylor, 2005, p. 39). Interviews resemble regular conversations, yet the interviewer and interviewee use much more energy and active thought in this process than in everyday conversation (Yeo et al., 2014, p. 178). This reflects the active construction of meaning that occurs by both parties during the process.

There is variation in how structured an interview might be. One extreme is a fully structured approach that uses a set list of sequential questions. This approach can be somewhat rigid as using only set questions prevents a researcher from prompting participants to elaborate on their responses. This runs the risk of collecting data more closely aligned with that arising from quantitative approaches (Taylor, 2005, p. 39). Furthermore, any questions specified before an interview may be informed by a researcher's biases. The other extreme is an unstructured approach where an interviewer asks ad-hoc questions and a participant talks freely. Flexibility allows a researcher to adapt to the data being generated and seek further insight from participants, helping to overcome any potential biases or limitations induced by pre-set questions. Unstructured interviews may deviate from the topic of interest. A mid-point on the spectrum of interviewing is a semi-structured approach. With this approach, a topic guide can be used to ensure the interview stays on track and covers appropriate topic areas. This interview approach, however, also allows a researcher to exercise flexibility and ask further questions related to participants' specific statements to support their construction of meaning (Hinton and Ryan, 2020, p. 44).

Various methods of qualitative data generation could have been used to gain insight into the roles of dentists, PLwD and carers in dental treatment decision-making for PLwD. I used a process of Patient and Public Involvement and Engagement (PPIE) to inform the design of this primary research. Here, I gathered feedback on the available approaches that could be used from several PLwD and carers directly, the 'Voice' group of public contributors, the North East Dementia Alliance, and the Alzheimer's Society research network. This process highlighted that patients, carers and members of the public would be accepting of a researcher being present in a clinical environment, but also that interviews were felt to be an appropriate and acceptable way of exploring peoples' experiences. I had originally planned to use ethnography in addition to interviews by undertaking observations of dental consultations in various dental services. The COVID-19 pandemic meant that ethnographic methods were not feasible during the time allocated to the research in 2020-2021. Considering the PPIE process and research objectives, I felt that using semi-structured interviews with PLwD, carers and dentists was aligned with my social constructivist epistemological stance and would allow me to gain in-depth insight into participants' unique views and experiences. When using interviews, I had to consider specific methodological and ethical aspects of research processes. These are explored below.

6.3.2 Remote interviewing

Qualitative interviews have conventionally occurred face-to-face. These have required travel and appropriate meeting spaces, yet they risk being prone to interruptions or distractions. A strength of the face-to-face approach is that an interviewer can detect non-verbal cues that accompany responses to questioning. Remote approaches such as telephone or video interviews are lower-cost and potentially more convenient for researchers and research participants (Gray et al., 2020). Unlike telephone interviews, video software can allow some non-verbal aspects of communication to be retained (Archibald et al., 2019; Lobe, Morgan and Hoffman, 2020). Video software packages can also record interviews. Capturing video data in addition to audio recordings requires specific justification as it limits anonymisation if data were inappropriately accessed and may add little to the analysis process (Lobe, Morgan and Hoffman, 2020).

As well as the technological failure that can interrupt or prevent an interview from being completed (Oliffe et al., 2021), certain participants may be inadvertently excluded from qualitative research if they are unable to access or unfamiliar with the use of specific technologies (Kennedy, Holcombe-James and Mannell, 2021). In this research, I had to use interviews remote interviews due to the COVID-19 pandemic. This meant the limitations of this approach had to be accepted. However, video interviews provided an opportunity to engage with a more diverse and geographically varied sample and supported optimal communication despite COVID-related restrictions.

6.3.3 Ethical considerations

Specific considerations are required for interviews with professionals and patients, particularly those with cognitive impairments. I had to consider each participant's capacity to consent to research, confidentiality, and the potential for the topic of interest to be perceived as sensitive. These factors varied for dentists and PLwD. Though more ethical challenges can arise interviewing PLwD than professionals, it is crucial to include those with lived experience and not exclude people purely because of specific diagnoses (Shepherd, 2016).

When considering capacity to consent, I assumed that those practising as dentists could consent to participation based on their professional status. The same assumption could not be made for PLwD. When recruiting PLwD to research, participants may experience difficulties understanding the nature of the study, retaining this information, and using it to make and communicate an informed choice about whether they wish to participate. A person with a cognitive impairment must be able to undertake each of these to be determined to have sufficient capacity to consent to take part in the research. There is a legislative requirement to assume a person can provide consent unless proven otherwise and to strive to support people to provide consent (Mental Capacity Act, 2005 section 1.2). A researcher must gain consent before exploring a person's experiences through research, so a capacity assessment for each PLwD was required for any research involving people with cognitive impairment.

The limitations of a remote platform, discussed above, may also impact capacity assessment that may be necessary before an interview. Technological failure or limited audio-visual data capture and transmission, alongside the loss of non-verbal aspects of communication may make the capacity assessment process more challenging. Furthermore, there is a risk that such an approach concludes a person lacks capacity to consent to take part in a study, which may differ from the results of an assessment undertaken face-to-face. Finally, if a person was assessed to lack capacity to consent to take part in a study on a remote platform, the cessation of a video interaction on this basis may be seen as abrupt or distressing, even if it were appropriate not to interview somebody. A further challenge, applicable to remote and face-to-face interviews is that even if a PLwD can consent to research participation, the varying impact of dementia symptoms means a researcher cannot assume PLwD can easily articulate their views on a phenomenon of interest (Taylor, 2005, p. 49): here, interview data may be of limited value but this may not be known until an interview commences.

The topic in question may be perceived as sensitive to PLwD, carers and dentists. PLwD, and potentially professionals, may find it distressing or upsetting to recall specific events. For PLwD, concerns about sensitive discussions were somewhat mitigated by piloting topic guides and involving patients or their representatives in research design (Samsi and Manthorpe, 2020). To support PLwD, I planned to facilitate simple adjustments such as a slow pace of speech, repeating questions if needed and altering the interview schedule (Beuscher and Grando, 2009). I also planned to support PLwD by allowing family members to be present to offer support. For both groups, clear information about their ability to withdraw from an interview was important and can as detailed in the literature they received regarding their participation.

In addition to legislation requirements surrounding data protection, it is essential to maintain confidentiality and anonymity in research (Allen, 2017). There are two relevant exceptions when confidentiality may need to be broken. If I had identified concerns about dentists' practice, I would have been obligated to raise concerns appropriately as detailed by standards provided to dental professionals (General Dental Council, 2013). A plan was made to disclose information with consent wherever possible and to only breach confidentiality, with advice from the supervisory team, if I suspected patients were at risk of significant or imminent harm. It may also have been necessary to breach confidentiality if a concern had been identified about the well-being of PLwD or carers. Interviewees may disclose that they are at risk of harm, or I could have become concerned by what is observed or heard during an interview. To address such concerns, I would have had to seek the participant's consent to share these concerns with relevant groups (such as local safeguarding teams or the police if I had more urgent concerns). Had this consent been declined, I would have sought advice from the supervisory team and the local NHS safeguarding leads about whether breaching consent was justifiable to protect participants' well-being and manage any imminent harm.

6.3.4 Sampling and sample sizes

A homogenous sample can provide narrow insight into a highly specific area, whilst a more diverse sample can lead to a broader understanding of issues or experiences that offer more insight into under-researched areas (Ritchie et al., 2014, p. 114). Regardless of the sampling approach they use, researchers have to decide whether to seek a homo- or heterogeneous sample (Creswell and Poth, 2018, p. 158). Purposive sampling involves choosing participants based on their specific characteristics (Ritchie et al., 2014, p. 113). The main characteristic or characteristics that are purposively considered, such as age, work setting, or specific experiences, should be identified when research is designed (Palinkas et al., 2013). A purposive but heterogeneous sample can ensure a wide range of views are sought and that diverse views inform any understanding of a phenomenon.

When using CGT, purposive sampling can be used in the first instance. Over time, the sampling approach moves from purposive to theoretical (Charmaz, 2006, p. 100). In theoretical sampling, participants are selected due to a perception that they may confirm, refute or provide greater insight into specific elements of an emerging theoretical understanding (Charmaz, 2006, pp. 96–103). As dental care decision-making in dementia has not been extensively researched, I felt that maximum variation purposive sampling, followed by theoretical sampling, would best support the attainment of the study's objectives.

Sample sizes in qualitative research are highly variable (Saunders et al., 2018; Low, 2019). Authors use multiple approaches to determine sample size before or during a study (Sim et al., 2018). Specifying a sample size before data collection is typically incompatible with an interpretivist epistemological stance. However, the practicalities of study design and ethical approval often mean an estimated sample size must be presented before qualitative research begins, causing tensions between the inductive and exploratory nature of GT or CGT methods and the regulatory systems in which these approaches are used.

Qualitative data collection is often discontinued when 'saturation' is felt to be achieved. Different qualitative methodologies can employ different types of saturation, including data saturation, theoretical saturation, or thematic saturation (O'Reilly and Parker, 2013; Sim et al., 2018; Low, 2019). Many studies treat data saturation as a point where no new information or insights are gained from data (Low, 2019; Braun and Clarke, 2021). However, this concept is problematic as it could be argued that data may never become truly saturated as there could always be a greater degree of insight to be gained from further data generation (Wray, Markovic and Manderson, 2007; Low, 2019). Practically, Charmaz (2006, p. 189) details theoretical saturation as a point when 'gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights'. In CGT, a researcher constructs codes and categories inductively, so the researcher must also determine the point at which they feel their theory is suitably developed and presented and unlikely to be modified by further data generation. Projects 2 and 3 aimed to explore the processes and factors related to dental care decision-making for PLwD. On this basis, I aimed to achieve theoretical saturation to understand each group's experiences.

6.3.5 Managing preconceptions and assumptions

CGT methods accept and account for how a researcher's preconceptions, assumptions, and social roles impact each stage of the research process. When using CGT methods, these factors contribute directly to how a researcher constructs meaning from their interaction with participants (Charmaz, 2008). Reflexive practice was essential throughout the research. In addition to my clinical role as a specialist dentist, this project was funded by an external fellowship award. This award was a result of substantial planning over a prolonged period and extensive engagement with the dental and methodological literature. Considering my existing roles and knowledge, it would have been impossible not to have some conscious and subconscious biases and preconceptions related to the research topic. Using CGT methods allowed me to embrace and accept any preconceptions and exercise reflexivity and reflection to try and appreciate the impact of this prior knowledge on data generation and analysis. Furthermore, prior knowledge can potentially support an inductive analysis process. I aimed to see my existing knowledge as an opportunity to be sensitised to the subtle features within the data and to help me ask probing questions as it was generated (Strauss and Corbin, 1998, pp. 47–49).

Considering how CGT is based on social constructivism, I had to consider how my professional role and knowledge may impact my interaction with participants in Projects 2 and 3. I undertook this research whilst maintaining my clinical practice in a Community Dental Service and a Dental Hospital. Although I was not responsible for the dental care of any of those recruited, being both a clinician and a researcher did lead to specific challenges. These are summarised in a reflective publication arising from this work (Geddis-Regan, Exley and Taylor, 2021). The primary challenge was deciding whether to reveal my professional role as a dentist to those being interviewed. The dental professionals interviewed in Project 2 were aware of my role, but this was not stated clearly to PLwD or carers in Project 3. During Project 3 I was mindful that PLwD or carers may have assumptions about a dentist and that these may affect how and if they shared their experiences. Whilst I withheld my professional status, I did reveal this if asked. This may have alarmed participants, but I hoped the rapport established prior to this disclosure would mitigate the impact my professional status may have had on the interaction.

6.4 Methods

6.4.1 Gaining access and approvals

Newcastle University acted as the Sponsor for Projects 2-4. Ethical and Health Research Authority approval was granted following review by the Yorkshire and Humber - Bradford Leeds Research Ethics Committee in March 2020 (Reference: 20/YH/0048) (Appendix C). A non-substantial amendment was approved in May 2020 allowing methods to be adjusted to account for the impact of the COVID-19 pandemic (Appendix D). The information presented herein reflects the amended approved study. Three NHS Trusts[16] were involved as potential sites to identify participants. I approached the Clinical Directors for each dental service to determine their willingness to support the study. Once this was confirmed, each NHS Trust's research and development team provided their authorisation to facilitate recruitment from their sites.

6.4.2 Interviews with dental practitioners

As summarised in Figure 6.1, I used three routes to identify dentists to invite to take part in the study:

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[16] I do not name the services supporting this project as doing so may allow those familiar with Special Care Dentistry services in the region to identify specific participants of Project 2 based on their characteristics.

1. Dentists who referred patients to specialist services (identified by administrative staff, with a list being sent to me by secure e-mail).
2. Practitioners working in participating dental services (approached purposively).
3. Dentists who registered their interest in taking part through a form on the study website.

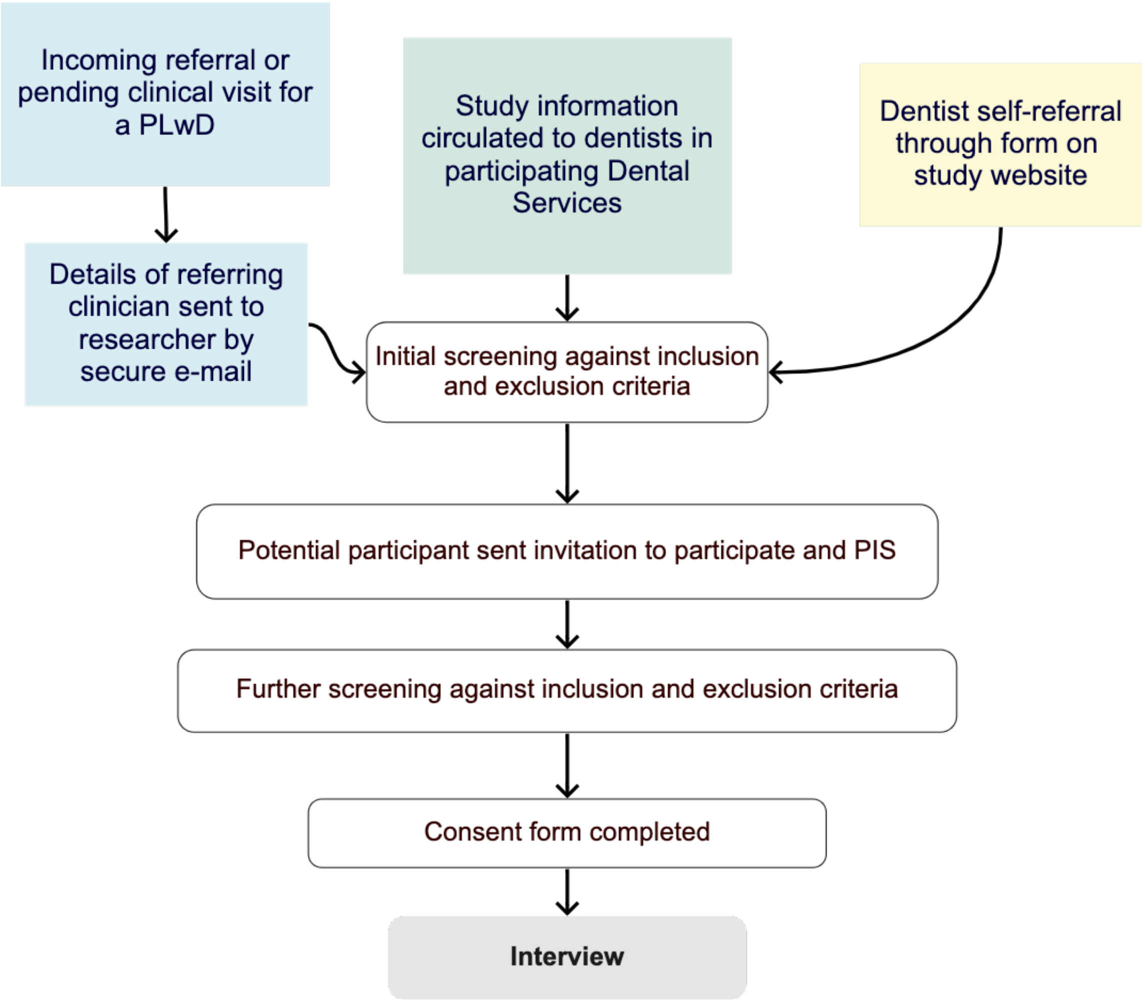


Figure 6.1: The process of recruiting dentists

When considering which dentists to invite to participate in the study, I used purposive sampling, aiming for maximum variation. I sought to identify dentists of different ages and genders, with different professional backgrounds, different types, locations, and durations of practice, and varied experiences providing dental care for PLwD. After the initial 12 interviews, I began to use theoretical sampling to allow me to expand upon specific areas of my initial understanding. Before inviting a participant to take part, I considered the below criteria:

Inclusion Criteria:

- Inclusion on the GDC register, as a dentist, without conditions on this registration
- Able and willing to provide informed consent to participation
- Experience in assessing, treating, referring, or managing a PLwD in a dental context

Exclusion Criteria:

- Those with conditions on their GDC registration or a lapsed registration
- Clinicians whose practice is limited to dental contexts where PLwD would not receive care (such as paediatric dentistry, or those not in active clinical practice, such as professionals working exclusively in Dental Public Health, managerial roles, or commissioning)
- Those without experience in providing dental assessment, treatment, or referral for PLwD

I sent a formal invitation to participate and a study information sheet to dentists who met the inclusion criteria. When I had not received a response after two weeks, I sent a reminder letter. After this point, I sent no further correspondence to these dentists. For those responding to invitations to participate, I confirmed they met the inclusion criteria, then sent them a consent form. Before an interview could be arranged, I had to receive a signed form. Electronic signatures were acceptable as detailed by HRA guidance (Health Research Authority, 2018). Participants could withdraw their consent before or within 24 hours of the interview, as required by the Research Ethics Committee. At the start of any interviews, a basic confirmatory check was made to ensure the participant was eligible to participate, considering the criteria detailed above.

All interviews were conducted using Zoom (Zoom Video Communications, 2021). Interviews were guided by a topic guide (Appendix E). This was informed by the literature presented in Chapters 2 and 3 and my existing knowledge. I had piloted the topic guide informally with one general dentist and one community dentist before it was first used in an interview. I used the topic guide flexibly based on the unfolding conversation in each interview and iteratively annotated and updated this before each subsequent interview.

An a priori sample size needed to be specified purely for the purposes of ethical and regulatory approval. I considered sample sizes of related studies in the fields of dental care and decision-making to make a generous estimate that 25 interviews would be needed with dental professionals. This figure was not a target or absolute requirement. The final sample size was based on attaining a theoretical understanding of the phenomenon of interest, leading to theoretical saturation.

6.4.3 Interviews with people living with dementia and caregivers

I used three approaches to identify potential participants, as shown in Figure 6.2:

1. Consent to Contact forms given to PLwD or carers seen in participating Community Dental Services. These were completed after verbal consent was gained to share information with a researcher. Completed forms were passed to me by dentists via secure email or internal post.
2. The Join Dementia Research platform allowed me to directly invite PLwD who had signed up to this platform and, in doing so, had consented to be contacted about research participation
3. Individuals accessing the study website could fill in an expression of interest form to enable me to contact them.

To achieve a maximum variation purposive sample, I identified PLwD with different stages and types of dementia and carers of PLwD with various stages and types of dementia, in different care settings, with different family relations and with different dental treatment needs. As the interviews progressed, I sought to identify participants whose characteristics differed from those who had already been interviewed. This allowed me to compare and reflect on the data generated through discussions with different individuals. Following this, after 14 interviews, I built on developing concepts by theoretically sampling PLwD and caregivers to identify confirmatory or contrasting viewpoints and to expand on my developing understanding.

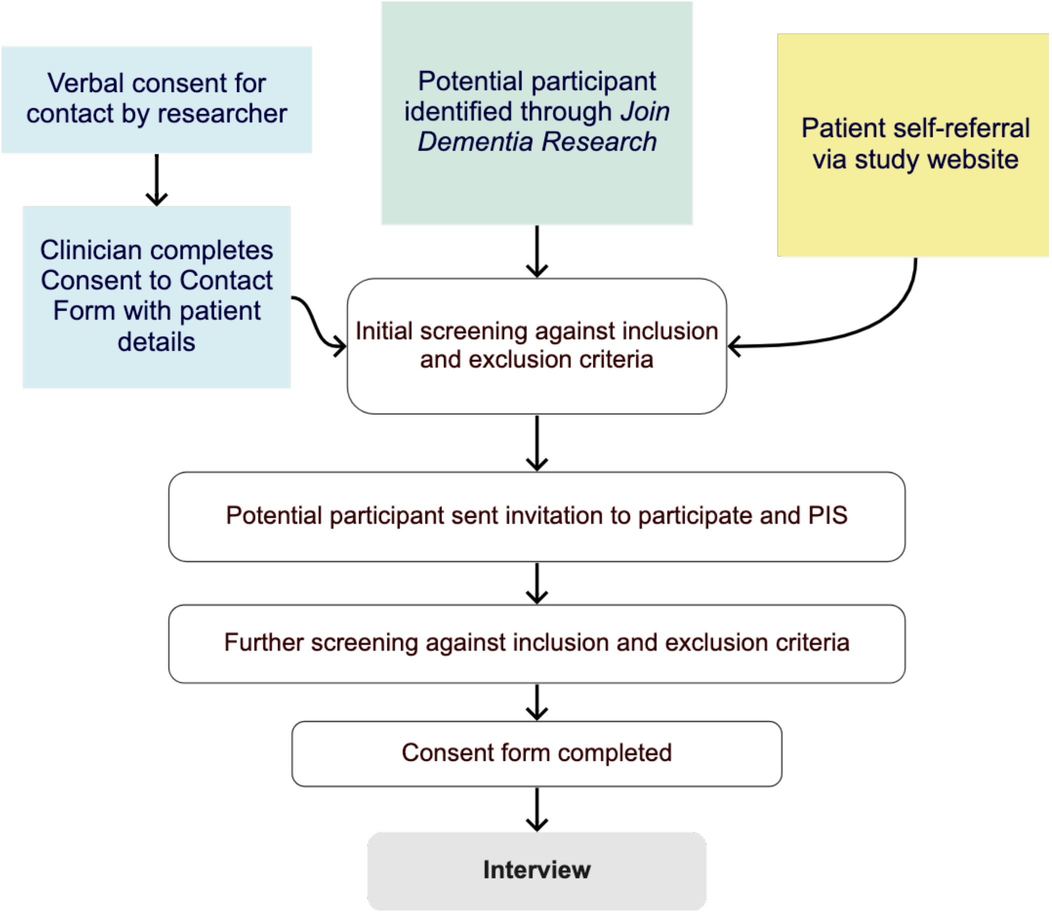


Figure 6.2: The process of recruiting PLwD or carers

I used the below inclusion and exclusion criteria to identify whether potential participants were to take part in the study:

Inclusion Criteria:

- Either received a diagnosis of dementia or be the carer/family member of a PLwD
- Having used dental services (PLwD) or supporting a PLwD to use dental services (carers)
- Aged over 18
- Able and willing to provide informed consent to participation
- Residence in the UK (to allow a suitable mental capacity assessment in line with UK legislation to be undertaken)

Exclusion Criteria:

- PLwD who have not accessed dental care since having symptoms or a diagnosis of dementia.

- Those in receipt of palliative care
- Those with a known history of aggressive or abusive behaviour that could cause harm to an interviewer
- Those patients, carers, or family members who are assessed to lack the capacity to consent to an interview
- People unable to speak English, as resources are not available for interpreters to support interviews in other languages

I completed an initial screen against inclusion and exclusion criteria for participants identified through each route. The Join Dementia Research platform provided additional information about each person, which supported the assessment against these criteria and theoretical sampling. For those identified through other routes, initial correspondence informally identified relevant information to support assessment against the inclusion and exclusion criteria and to support purposive and theoretical sampling. Potential participants were sent a formal invitation to participate and an information sheet by either post or email. I sent reminder letters two weeks later if no reply had been received. If no response was received, this was treated as a declined invitation to participate.

Following a response to a study invitation, a link to an online consent form was sent to participants electronically. This form was a tick-box style form, which was more straightforward to complete than the type of written form provided to dentists. This electronic format was planned to allow a consent form to be easily completed even in the presence of cognitive impairment or limited technological knowledge. Participants' ability to respond to invitations and questions about the study and agree to a date and time for an interview gave early insight into their potential ability to consent to participate in an interview. However, the remote nature of interviewing meant that a completed form alone could not determine a participant's ability to consent to participation.

Interviews with PLwD or carers were undertaken remotely by telephone or Zoom (Zoom Video Communications, 2021) based on the participant's preference. At the commencement of the telephone or Zoom interaction, I used a brief informal introduction to summarise the purpose of the interview and describe what taking part entailed. This process helped build rapport and acted as a further change to screen participants against inclusion and exclusion criteria. These initial discussions were typically adequate to establish whether a person could consent to participation.

Where I had any uncertainty about the mental capacity of a PLwD to consent to participation, a further formal assessment was required as per the MCA (2005, section 3) and the associated code of practice (Department for Constitutional Affairs, 2007). To assess PLwD's capacity to consent to participate, it was necessary to make sure a participant could fully understand this information about the study, retain it, and use it to make a considered informed decision which they could then communicate to me. When it was felt that any of these tasks was not possible or an assessment could not be completed, an interview was not conducted.

Once a consent form was received, I could arrange an interview. As the Research Ethics Committee advised, participants could withdraw their consent before or within 24 hours of the interview. Interviews were conducted and were recorded using a dictaphone or Zoom. A topic guide was used to support and guide the interviews (Appendix F). This topic guide was drafted following similar studies assessing patients' experiences in non-dental settings and was then refined following piloting with three individuals from the PPIE group. I used the topic guide flexibility and exercised more flexibility in the later stages of data generation, particularly with theoretically sampled participants.

As with the dental participants, an estimated sample size had to be specified before the study to facilitate relevant approvals. A maximum sample of 35 PLwD or carers was specified in the study protocol: this was higher than the number of dentists I had considered might need to be recruited due to the absence of any existing insight into PLwD and carers’ experiences. This figure was not a target or benchmark. The final sample size was based on the perception of sufficient theoretical saturation.

6.4.4 Transcription and pseudonymisation

Audio files of interview recordings were transferred to an encrypted folder on a University computer at the first opportunity. Retaining the recordings allowed me to listen back to interviews to support the data analysis process. I self-transcribed the first four interviews from both groups. The value of this self-transcription process is detailed in Section 6.5. It was neither feasible nor necessary for me to self-transcribe every interview. For the remaining interviews, audio recordings were transcribed by a professional transcription service with whom a confidentiality agreement was in place.

Pseudonymisation was undertaken after interview transcripts were completed or received. An electronic list of pseudonyms and participant identifiers was kept separately from consent forms and recruitment information to reduce the risk of participants being identified. The demographic information shown in Chapters 7 and 8 redacts specific information where this might allow the identification of participants with unique characteristics. For example, some regions have only one specialist in Special Care Dentistry, meaning locations and years since qualification had to be redacted, as detailed in Table 7.1. Broad geographical descriptors and age ranges instead of specific figures were used to support pseudonymisation and protect the confidentiality of participants.

6.5 Data Analysis

I analysed the data generated in Projects 2 and 3 separately, using the process described by Charmaz (2006). This analysis process has defined stages (shown in Figure 6.3), between which a researcher moves back and forth when data are simultaneously generated and analysed.

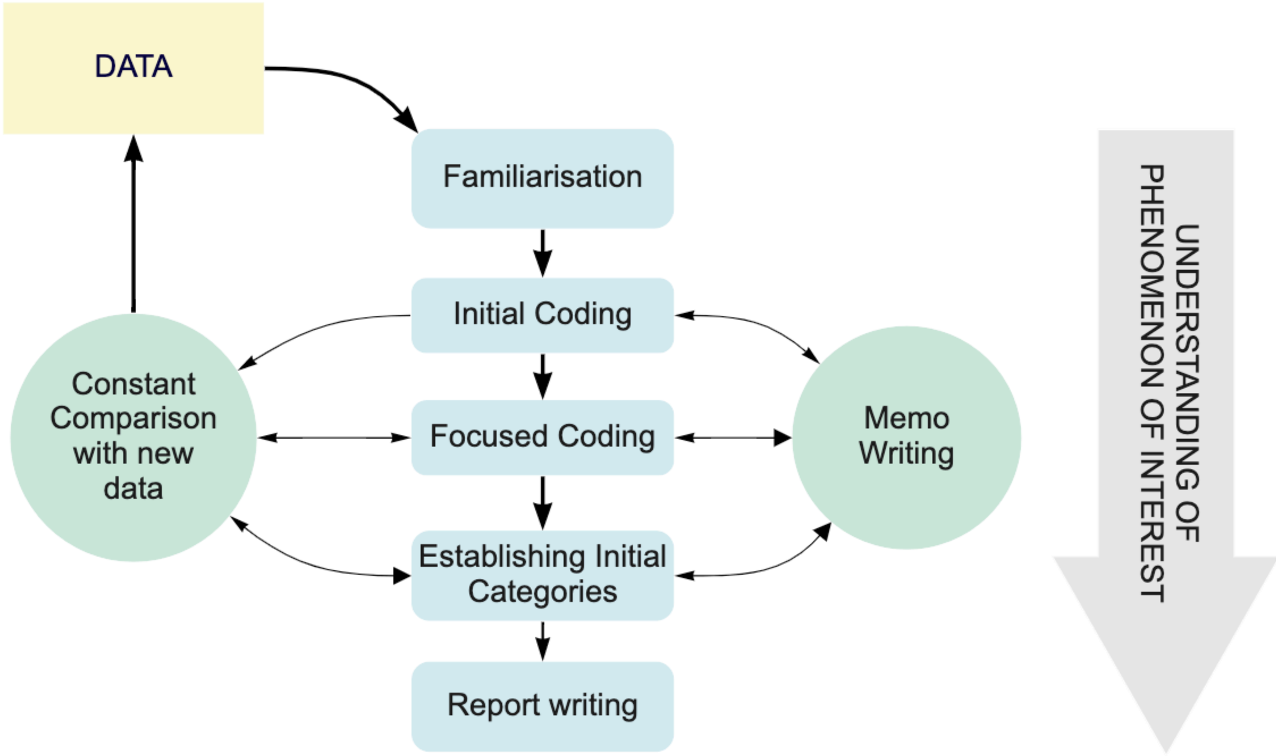


Figure 6.3: The process of iterative data analysis

I imported typed transcripts and scans of hand annotations I had made on printed transcripts into NVivo 12 (QSR International, 2020). I also used this software to support memo writing, apply codes to data, and organise initial codes into broader focused codes. Later, these codes were categorised, as shown in Figure 6.3.

Familiarisation

I self-transcribed the first four transcripts from each of the two projects. In doing so, I gained significant familiarity with the content of the first interviews. For the remaining transcripts, I initially read the transcripts and checked them against the audio recordings to ensure their accuracy. Through this process, I gained greater familiarisation with the data. Reflecting on the maximum variation sample, I sought to familiarise myself with transcripts from participants of different viewpoints and backgrounds, so I revisited transcripts from different groups to familiarise myself with data and the differences between different sources of data (Bazeley, 2007, p. 62).

Initial coding

Once I had reviewed a transcript and was familiar with the entirety of what a participant discussed within it, I began the process of initial coding. When reviewing the transcripts at first, I hand-annotated them. This initial offline approach ensured I focussed on the data instead of the software (Bazeley, 2007, p. 92). I then moved to use NVivo 12 (QSR International, 2020) to organise the coding process.

Codes are ‘essence capturing’ labels applied to segments of data (Saldaña, 2013, p. 3). Codes can then be used to begin to 'separate, sort and synthesise' the data (Charmaz, 2006, p. 3). I aimed to avoid producing purely descriptive codes and to actively produce codes related to processes and actions with a degree of interpretation. To support the exploration of processes, I used gerunds, whereby nouns were converted to associated verbs (Saldaña, 2013, p. 96). Where interview participants made poignant statements, I used in-vivo coding, where portions of quotes were used as the codes themselves (Saldaña, 2013, p. 3). This aimed to preserve participants’ reported experiences and the meaning they attributed to them (Charmaz, 2006, p. 55).

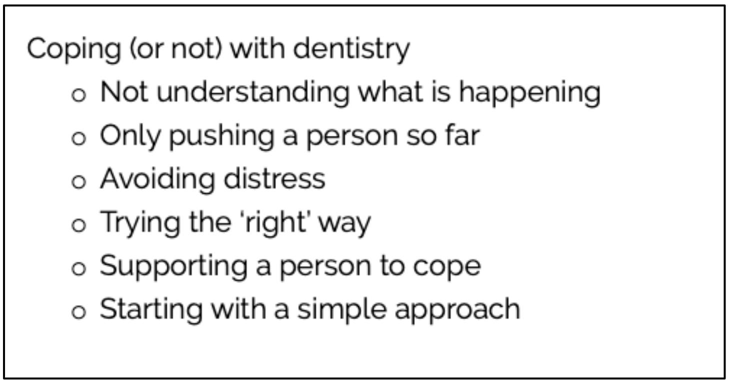
In general, I applied codes as I felt to be appropriate to the data. Initial codes were applied to sentences, fragments of text, or poignant statements. When I started the coding process, however, I used a line-by-line approach. Line-by-line coding involved assigning a code to each line of text, as demonstrated in Figure 6.4. This facilitated a more in-depth coding of an entire transcript and helped me to avoid making assumptions about what the data might be saying (Charmaz, 2008). I used line-by-line coding for the first eight transcripts. This led to a multiplicity of codes being developed that differed between participants. These were constantly compared with codes from other interview transcripts to understand the similarities and differences in data and subsequent codes between participants. Initial codes were discussed with members of the supervisory team separately and in combination. The wider team's varied viewpoints helped me challenge my assumptions before coding further data (Saldaña, 2013, p. 34). I returned to a line-by-line approach when I felt that a closer examination was needed or when I had to explore why I may have jumped to specific conclusions (Charmaz, 2006, pp. 50–51).

"…from the beginning of the treatment where he came in and he had	A journey of treatment
a fairly good understanding and great cooperation, and I felt that we	A good time to deliver treatment
were going to get everything achieved that we set out to, but then in	Goal-orientated treatment
quite a short period of time it was quite obvious that we lost that	Rapid change in the person
ability and there was quite a lot of pressure actually from his son, his	Family pressures
family member that was coming in with him that he wanted the	Support of family
treatment done."	
Except from dentist interview, 'Hannah'	

Figure 6.4: An example of line-by-line initial coding

Focussed coding

Following iterative comparison between new and existing data, I was able to group similar codes together, distilling the initial codes into a smaller number of descriptive but more focused codes (Saldaña, 2013, p. 207). Figure 6.5 shows a focused code applied to data generated from interviews with PLwD and carers. The code 'Coping (or not) with dentistry' was developed from a review and reflection on the initial codes shown below it:



Coping (or not) with dentistry
  - Not understanding what is happening
  - Only pushing a person so far
  - Avoiding distress
  - Trying the 'right' way
  - Supporting a person to cope
  - Starting with a simple approach

Figure 6.5: An example of a focused code and the initial codes from which it was generated

Focused codes were used applied to transcripts generated later in the project, allowing me to 'sift' through data based on a process that arose from the initial analysis process (Charmaz, 2006, p. 209). 'Sifting' did not equate to rushing but provided an efficient way to explore and analyse the content of newer transcripts. Where the data aligned with these codes, I could apply the focussed codes generated to newer transcripts. However, using focused codes when reviewing new data also allowed me to readily detect when data were saying something different to existing data. This supported decisions to revert to initial or specific line-by-line coding to understand new concepts with greater granularity. When I identified new concepts, ideas, or perspectives, I reconsidered and refined focussed codes further.

Memo writing

I used memos to record my thoughts or reflections on the data, initial codes, focused codes, and provisional ideas for categories. An example memo is shown in Figure 6.6. Memos like this were placed directly on transcripts and separately in NVivo using digital 'sticky notes'. As the research process and analysis progressed, memos were highly valuable in supporting the linking of categories and concepts and understanding and reflecting upon the emergent patterns and concepts within the data (Saldaña, 2013, pp. 41–42). Ideas on what I felt the data was saying, or any challenges arising, were noted in early memos. I reflected on these again once the full dataset had undergone either initial or focused coding.

It feels here that the family are keen to advocate for him. They want what's best for him and are proactively supporting him (and each other. However, as much as they want to advocate, they seem to be accepting of what's presented to them. They're pushing on doors, but only to a degree.

I can't quite establish if they're being supportive here or if they're really actually advocating at all…check other transcripts with carers to consider if they're describing pushing the same way, more or less, to see how accepted their views are and how far they describe going to support someone.

Figure 6.6: An example of a memo made regarding an interview with a PLwD

Establishing initial categories

I grouped focused codes where I felt they related to similar aspects of the phenomena of interest (Charmaz, 2006, p. 11). This led to initial data categories. I revisited the memos made throughout the process to help me reflect on why and how I had considered focused codes to be related to one another. The initial categories I proposed were refined as new data was generated and coded using focused codes and initial coding where needed. I made further memos to detail my decisions and thoughts around categorisation.

Report writing

Writing about the data was an extension of the iterative analysis. I began my report-writing by presenting data in each category and drafting discussions about the data. While writing about the data and preparing the discussions, I continued to reflect on my potential biases and preconceptions, including the thoughts I had detailed in existing memos. I continually revisited data to ensure the analysis presented was based on the data that had been generated. The categories of data were further refined from this process to lead to the content presented in Chapters 7 and 8.

Chapter 7. Project 2: Data and discussion. “There are so many factors at play.”

This chapter presents an exploration of how dentists experience and approach dental treatment decision-making for PLwD. Data generated through semi-structured interviews with dentists are presented alongside a discussion which considers literature from within and beyond the dental context. An abstract of this research presented at an international conference is enclosed in Appendix G.

7.1 Introduction

I undertook 22 interviews with dental practitioners between April 2020 and February 2021. As shown in Table 7.1, the sample was diverse in demography and professional background. Dentists who were recruited worked in 18 different counties across England. Dentists’ ages ranged from 24 – 58 years, with participants having qualified 1-36 years previously. All but two of the 22 interviews were conducted on Zoom, with the remaining 2 being telephone interviews. Interview duration ranged from 24 – 78 minutes, with a mean duration of 41 minutes.

Theoretical saturation was becoming evident after 20 interviews. The final two interviews sought to clarify points regarding a developing theoretical understanding, and data collection was stopped after 22 interviews. Data and a related discussion are presented in six categories:

1) Detective work
2) Providing individualised care
3) Anticipating decline
4) Weighing up risks and benefits
5) Leading the decision-making process
6) Confidence and familiarity

Categories 1-5 are presented in an order that broadly reflects the two 'halves' of a consultation described by Elwyn et al. (1999): information gathering and subsequent deliberation. Categories 1-3 relate to where dentists gather information as part of a history-taking process and clinical examination. Category 4 and Category 5 relate to the second half of a consultation, described by Elwyn (1999) as “neglected” due to the historical underemphasis on patient involvement in decision-making. Category 6 describes dentists reported confidence in the processes described in earlier categories. Finally, I summarise issues that underpin each category's findings.

Pseudonym	Gender	Years qualified	Job Role	Practice Setting
Evelyn	F	5 - <10	GDP	NHS GDP
Claire	F	30 - <40	Specialist in SCD	CDS, HDS
Craig	M	5 - <10	GDP and CDO	NHS GDP
Joan	F	5 - <10	Specialist in SCD	CDS
Hannah	F	5 - <10	StR in SCD	CDS, HDS
Hayley	F	5 - <10	GDP	NHS GDP
Suzanne	F	< 5	CDO	CDS
Harry	M	10 - <20	SDO	CDS
George	M	5 - <10	CDO	CDS
Emily	F	10 - <20	SDO	CDS, HDS
Helen	F	< 5	GDP	NHS GDP
Jane	F	< 5	GDP	NHS, Private GDP
Amelia	F	10 - <20	Specialist in SCD	CDS, HDS
Sam	M	10 - <20	GDP	Private GDP
Gavin	M	10 - <20	GDP	Private GDP
Clark	M	20 - <30	Specialist in SCD	CDS
Colin	M	20 - <30	GDP	NHS, Private GDP
Faizad	M	5 - <10	Out-of-hours emergency Dentist	NHS Primary Care
Dheeta	F	10 - <20	Specialist in SCD	CDS
Rachael	F	20 - <30	GDP	Private GDP
Monty	M	10 - <20	GDP	NHS, Private GDP
Afua	F	20 - <30	Specialist in SCD	CDS

Table 7.1: Demographics of the dentists interviewed

CDO: Community Dental Officer, CDS: Community Dental Service. GDP: General Dental Practitioner / General Dental Practice, HDS: Hospital Dental Services, SCD: Special Care Dentistry, SDO: Senior Dental Officer. StR: Specialty Registrar/Trainee. Locations are intentionally not displayed here to support participant anonymity.

7.2 Category 1: Detective work

As with any patient group, dentists require information about PLwD's medical and dental histories as well as an understanding of relevant social factors. When providing care for PLwD, dentists described gathering various forms of information from a range of sources. Where patients were able to engage in conversation, dentists sought to gather this information first-hand:

> *"we'll talk to the patient and discuss things with them as much as possible. In some instances, it's not always that possible to get the information we want from the patient."*
>
> George (CDO)

As George describes, first-hand information gathering is not always possible. One would expect that the ability of a PLwD to provide the necessary information to support their care may decline as symptoms of dementia progress. When this occurs, the responsibility for information provision gradually moves from a PLwD towards somebody supporting their care (Groen-Van de Ven et al., 2016; Bhatt et al., 2020), meaning dentists may need to interact with those beyond the PLwD to gain information to support appropriate care (Lahey and Elwyn, 2020).

Dentists' accounts demonstrated that they did seek to gather information from those involved in the wider care of PLwD, yet they detailed that much of the information they sought was not always forthcoming. This particularly applied to people living in care homes who attended dental clinics with professional caregivers:

> *"what I found particularly frustrating was the carers who would probably be looking after them weren't very well versed in the needs of their patients, so they couldn't really confirm certain parts of the history. For example, in some cases they couldn't confirm parts of their medical history and then that puts you in a difficult position because you've got a patient that's in pain, it's what do you do?"*
>
> Faizad (Out-of-hours emergency dentist)

Dentists reported spending significant amounts of time finding relevant information, with one referring to this process as 'detective work'. When undertaking such 'detective work', dentists described challenges in knowing what information was required to support care delivery and gathering information they identified to be relevant. For example, dentists felt the knowledge of a diagnosis of dementia was essential to support a person's care. Instances were described where dentists had suspected a person had dementia, but it was unclear whether the patient had been formally assessed in this regard by a medical professional:

> *"I don't think everybody that we see has got a formal diagnosis of dementia, but I think in the care home setting they have a little bit of whether it's dementia or not understanding or I don't know what you want to call it, cognitive impairment or something maybe. But definitely something there."*
>
> Suzanne (CDO)

Separate situations were described where patients had received a formal diagnosis of dementia, but this had not been disclosed to dentists by either care staff or the PLwD themselves:

> *"none of us picked up on the fact that she had dementia…. She'd had a formal diagnosis, it turned out. But none of their medical history forms we'd received or the original dental referral or any of the documentation from the care home told us anything about dementia."*
>
> Craig (GDP / CDO)

There are multiple potential reasons why a patient or carer may not disclose a diagnosis of dementia to a dental team. Firstly, research has identified that healthcare teams involved in diagnosing dementia can be reluctant to disclose a diagnosis of dementia to patients or to use terms such as dementia or Alzheimer's (Lecouturier et al., 2008; Yates et al., 2021). A lack of clarity about making a dementia diagnosis and informing patients of this is reported to persist despite evidence that patients wish to know a diagnosis and that this can facilitate appropriate support (van den Dungen et al., 2014; Yates et al., 2021). Clearly, patients cannot inform dental teams of a dementia diagnosis of which they are unaware. In addition, a diagnosis of dementia would typically occur after the onset of symptoms meaning a person may experience anosognosia where the memory of being diagnosed with a condition can be lost (Norberg, 2019, p.205). Furthermore, it may be that a patient assumes that dentists can access information contained in their medical records, leading to the view that it is unnecessary to disclose such a diagnosis. Finally, patients may intentionally decide not to disclose a diagnosis to a dentist, possibly due to the stigma they may feel is associated with the condition (Barry and Yuill, 2016, p. 198) or the possible perception that a diagnosis of dementia is not relevant to dental teams.

Having knowledge of a diagnosis of dementia is important for dental professionals. Without such information, a dentist would not be able to make any necessary adjustments that may support the person's care, such as altering their communication style or facilitating appointments when the patient feels is most suitable for them. When delivering dental care, guidelines available for dentists (summarised in Chapter 2) work on the assumption that dentists can gain information to establish which aspects of guidance apply to a given scenario. If a clinician is unaware a patient has dementia, they would be unaware of the need to consult such guidelines in care planning. Furthermore, not knowing about a diagnosis can impact the assessment of a person's decisional capacity. The first stage test in the MCA (2005, section 2(1)) is to establish if a person has a 'disorder of functioning of the mind or brain'; where no disorder is present, dentists should assume that a person can consent to treatment. Though compliant with legislation, such an assumption may be incorrect if dementia affects somebody's ability to retain information or use this to express an informed preference for their care. Where PLwD retain decisional capacity, they may require support and modified communication to take part in valid discussions which precede informed consent for care. If dentists are unaware a person has dementia, they may not know that they need to make any form of adjustment to their communication with patients or to the planning of their dental care.

Whilst access to a shared health record may substantially ease the process of information gathering for dental teams, the nature of a person's day-to-day oral or dental symptoms, experiences or problems may be difficult or impossible to ascertain from clinical records alone. To gain insight into patients' symptoms or dental problems, 'detective work' involved collecting information from various sources, including the clinical examination itself. As with other information, a pain history was described as difficult to gather when patients were unable to self-report:

> *"It depends on what you find in clinical findings… sometimes they can be unclear and if the patient can't give a clear history of the pain and the carers don't know a clear history or family members don't know a clear history that's when it can be quite difficult."*
>
> Suzanne (CDO)

Dentists described how incomplete examinations were a further barrier to pain identification and care planning for PLwD:

> *"Sometimes I don't know what's going on inside the patient's mouth because I've not managed a look or a very cursory glance, so we're very much dealing with the unknown."*
>
> Dheeta (Specialist in SCD)

Dentists explained how they used radiographic imaging as a tool to support a clinical examination or assessment of a PLwD. However, as with clinical examination, this was often not felt to be possible for those with more advanced dementia. The ability to make a formal diagnosis of the cause of pain was subsequently impaired:

> *"It can be a process of elimination. You know whether you put a dressing in or you sort of take a guesstimate and extract a tooth that's grossly carious that you think might give them trouble. Quite often because you're doing this without x-rays it can be challenging. But you know, there isn't often a right answer. Like I say, process of elimination."*
>
> Clark (Specialist in SCD)

The lack of information from clinical examinations and diagnostic testing meant that dentists had to try and complete a diagnostic puzzle using information through a more comprehensive history-taking process with patients or professional caregivers:

> *"a lot of times I had to take the account from the care staff. So, what they would do is they would say, 'Oh, so and so is not eating or so and so is acting differently' so, obviously they knew the nature of the patient and the behaviour of the patient much better than I did."*
>
> Monty (GDP)

Tools have been produced that use such indicators to support pain identification for PLwD. NICE (2018a) recommend the use of such tools, alongside patient self-reports of pain. Schofield (2018) provided a summary of pain identification tools scales and their suitability. Examples include Abbey Pain Scale, or the Pain in Advanced Dementia (PAINAD). There are also tools specifically applicable to orofacial pain identification, such as the Orofacial Pain Scale for Non-Verbal Individuals (OPS-NVI) (de Vries et al., 2016). Despite their availability and their inclusion in NICE guidance, no dentists described using such tools or recommending that care settings used them to establish whether PLwD were experiencing orofacial pain. Instead, certain dentists in specialist services reported having to request that professional carers lookout for such indicators and return to the clinic once such information has been gathered:

> *"I'm saying I don't know and sending [care home staff] away to get more kind of history. You know, a diary of when agitation or distress might happen. Whether that's refusing food, or you know, taking food but then refusing…these kinds of things to get a sort of a pattern. But I mean it's still then often a guesstimate from that and sometimes if they're living in a nursing home it's getting everyone on board to be writing that down."*
>
> Clark (Specialist in SCD)

Professional caregivers may identify pain either informally or through the use of specific pain identification tools, there is also the potential for specific tools to be used by family caregivers (Van Ho et al., 2021). The role of professional carers in this context and their ability or willingness to identify orofacial pain has not specifically been researched. Such individuals may be well placed to identify and formally record behaviours or other indicators of pain (Geddis-Regan, Stewart and Wassall, 2018). If the presence or absence of indicators of pain was recorded, this could reduce the extent of detective work dentists had to undertake and support more timely pain management. However, the feasibility of professional caregivers identifying and recording this information could be questioned, especially considering evidence that some caregivers may not be providing adequate oral hygiene to care home residents (Care Quality Commission, 2019).

The barriers to undertaking oral hygiene delivery may also apply to the process of pain identification. Even if indicators of pain were documented, professional carers might have limited potential to provide dentists with insight into how individual patients experience or express pain. Dentists felt that family members, however, held greater insight into how patients may express pain. They, therefore, sought to contact them or encourage them to attend a dental visit:

> *"A lot of families live at different ends of the country and so, quite frequently, I have conversations on the phone. Sometimes, they do come to clinic, and we would always invite them to clinic. I have known siblings and children to drive across the country to come to appointments with their family...I think it's quite a positive experience."*
>
> Emily (SDO)

Pain is a multidimensional experience, and its assessment is subjective (Haggman-Henrikson et al., 2018). General and orofacial pain are under-reported in dementia (Cohen-Mansfield and Lipson, 2002; Hadjistavropoulos et al., 2014), and recording pain as simply present or absent might be inadequate to inform complex care decisions (Lobbezoo, Weijenberg and Scherder, 2011). Family members may hold insight into how the absence or presence of pain may be expressed or experienced by a PLwD. The role of family members in supporting dental care and pain identification has been researched: Newton et al. (2018) detailed that such individuals are generally willing to support dental teams in care provision. One family member in Newton et al.'s (2018, p. 4) research stated: *"Because you're living with each other day by day, you notice little changes"*. This details why family members might be well placed to guide dental teams in establishing the presence and nature of pain for a PLwD.

Family members may also provide insight into factors beyond pain, such as a person's ability to eat or how important an aesthetic dentition was to them. Despite this possible insight and having to combine information from separate sources, dentists did not report routinely seeking this type of information from family carers. The focus on pain as the only 'problem' that could be addressed suggests a misunderstanding of the individual whose care is being planned. An alternative explanation is that this detective work preceded a consideration of the unique individual for whom care was being considered. Consideration of the individual was mentioned by dentists but was distinct from the information-gathering processes described. Dentists' consideration of the individual whose care is in question is detailed below.

7.3 Category 2: Providing individualised care

Dentists had to gather and amalgamate information from various sources that comprise 'Detective work'. Bodegård (2022) details that gathering information unique to individual patients and appreciating their specific preferences can support effective person-centred decision-making. Dentists indeed reported striving to gather such insight about PLwD:

> *"With dementia, it's not going to be a blanket term of how we treat and manage these patients. Everybody is different in terms of the effect that [dementia] will have on them and how they respond in the dental setting and early treatment…I do think each case is different and poses some challenges. You need to look at everyone as an individual."*
>
> Hannah (StR in SCD)

Oral health values are defined by Edwards, Randall and McNeil, (2021, p. 2) *as "the extent to which one views dental status as important, or one's prioritisation of or dedication to improving or maintaining one's teeth, gingiva, and aspects of orofacial functioning"*. This concept has only recently begun to be researched, with a scale to measure such values (The Oral Health Values Scale- OHVS) being proposed (Edwards, Randall and McNeil, 2021). Gathering and understanding patients' expectations of and preferences for their care is crucial to support appropriate decision-making (SDM) (Elwyn et al., 2012). Dentists are responsible for gathering this information, yet patients have their own responsibilities, particularly to provide information to clinicians about their views and values (Elwyn, Edwards and Kinnersley, 1999). Instead of explicitly exploring patients' current preferences or views, dentists in general and specialist settings described gathering information about how individual patients historically approached and accepted dental care:

> *"I think you have to bear in mind…how they were in the past…if they took meticulous care over their teeth in the past, you'd like to try and echo that...so you may try and save the tooth rather than extract it, if that's feasible."*
>
> Claire (Specialist in SCD)

Only two dentists described leading conversations about the current preferences and goals of PLwD. Their shared approach is summarised by Hayley, who explained:

> *"Dementia makes it harder because patients might not be able to communicate that you to effectively, but I ask the patient what their ideal outcomes of treatment would be, how they're getting on in life…what their issues are and what they would like to gain from treatment."*

Hayley (GDP)

The fact that all but two dentists did not describe seeking patients' current views and preferences contradicts their expressed desire to provide individualised care. It is possible that dentists placed less emphasis on PLwD's current values on the assumption that they may not be capable of articulating these. Though no dentists said they made such assumptions, there was an explanation that symptoms of dementia may affect the ability to elicit such views to inform care that reflects a person's current wishes:

> *"If their communication is inconsistent or simply gone it's just so much harder to figure out what's they might have wanted doing about something like a fractured tooth, or loose dentures".*
>
> Helen (GDP)

The potential difficulty in gathering patients' current views may underpin why their historical views were sought to inform care planning. There is some merit in considering a person's previous preferences, values, or attitudes: specifically, the factors or experiences that informed or influenced a person's prior views may also inform how they feel about care they require later in time and as dementia progresses. Therefore, their past views may well be relevant to inform what care may be appropriate in the present moment. Considering tooth loss specifically, Rousseau et al. (2013) reported how people's views of losing a tooth or teeth vary considerably: for some, the loss of a tooth is of little significance, whilst for others, it can be a devastating event. Gibson et al. (2019, p. 15) detail how such views may evolve over the life course, and how for some motivated, *"the loss of a single tooth could be felt as an existential failure".* More recently published studies provide further insight into such contrasting views and the way people manage tooth loss. Warren et al., (2020) detail how people cope or adapt – to varying degrees – with fewer teeth, with some seeing this as a part of natural ageing and some wishing to maintain their dentition as part of their identity. Similarly, Johnson, Morgan and Jones (2022) explored how some patients wish to maintain teeth in order to maintain their identity and dignity, especially following a transition to live in a care home. Where the loss of all teeth is necessary, the above findings are likely to apply to some patients, yet it is noteworthy that some patients may accept the loss of all of their teeth and rehabilitation with complete denture as a status passage (Gibson et al., 2017) or a way to restore self-worth (Nordenram et al., 2013).

Tooth loss is just one possible outcome of treatment, yet peoples' views on other aspects of dental care may vary considerably, both historically and over time. Focussing on historical values or attitudes may give dentists some insight into the person for whom care is being considered. However, focusing purely on historical factors might reduce the potential for PLwD's more recent priorities – that may have evolved over time whilst living with dementia - to inform their care. In addition, a person's ability to adapt to a changing mouth can also deteriorate over time (MacEntee, Hole and Stolar, 1997; Gibson et al., 2019; Warren et al., 2020). In addition, if a scenario presents that a person has not encountered previously, then their historical views alone cannot support clinicians in planning dental care. Finally, a person's general views and preferences may change over their life course due to dementia itself (Dresser, 1995; Wright, 2019). This further highlights the importance of considering a person's current views in addition to their historical attitudes towards dental care.

Building on Kitwood's social constructivist view of dementia (Kitwood, 1997), the Nuffield Council on Bioethics (2009, p. xviii) states that a person remains the same valued person throughout the progression of dementia regardless of how their functioning may change. Not actively seeking information on PLwD's current ideals creates a risk that the dental team may diminish their autonomy or personhood and ignore their lived experience of dementia. This might lead to a treatment outcome that is incompatible with what a person believes to be acceptable or beneficial to them. Dentists should, therefore, strive to gather relevant information about a person's current preferences and current lived experiences, alongside their historical views, when it is possible to do so. When current views cannot be gathered, either due to a lack of insight from carers or an inability to express these, historical views may be a secondary form of insight to guide individualised care (Wright, 2019). Though a patient's changing views do not appear to be routinely gathered by all dentists, the changing health status does appear to be something they acknowledge. The impact of this anticipated change is presented and explored below.

7.4 Category 3: Anticipating decline

For people with early or moderate dementia, dentists described modifying the treatment they plan due to an anticipated of a decline in cognitive status. Specifically, dentists described how they sought to avoid complex restorative procedures based on how they viewed the future for PLwD:

> *"[I'm] not providing really complex crown bridgework, implants at that point for a patient that you know is going to deteriorate."*
>
> Joan (Specialist in SCD)

Some dentists, however, described going a step further than providing more simple treatment alone. The approach multiple dentists described was to manage a dentition proactively and comprehensively, regardless of a person's dental or oral symptoms. This was described as used to avoid dental pain and complex treatment requirements as dementia progressed:

> *"If they've had maybe advanced restorative work that's very greatly at risk as they deteriorate you need to look at that and treatment planning and be probably more aggressive than you would be in an ordinary situation."*
>
> Clark (Specialist in SCD)

The combination of more straightforward and 'aggressive' treatment, referred to by dentists as 'future-proofing', has not been explored in primary research. Although the term 'future-proofing' is not used in relevant guidelines, a proactive approach to future care is recommended by Fiske et al. (2006, p. 17). Multiple studies have demonstrated that PLwD experience poor levels of oral hygiene (Foley et al., 2017; Delwel et al., 2018a) however, dentists assumed that the consequences of such poor oral hygiene would necessitate dental intervention and preclude restorative dental care. Describing one patient she had assessed, Hannah described:

> *"my concern is that as his disease continues to progress that the hygiene level is going to be something that's going to be massively affected and could ultimately end up presenting with quite a high treatment need."*
>
> Hannah (Specialty Trainee – SCD)

Current literature, summarised in Chapter 2, presents information on oral health statuses for PLwD at a population level. Whether a person has cognitive impairment or not, there is variation in how motivated each person may be to maintain a high level of oral care, either independently or with support. Dementia poses further complexities due to the potential for forgetfulness or 'care resistant behaviour' (Jablonski, Therrien and Kolanowski, 2011). That said, the assumption that oral hygiene will be poor does not account for the variation in the ability or motivation for self- or care-provided oral care and the variable trajectories of dementia. From an individual perspective, Gibson et al. (2019) suggest that some people may view poor oral hygiene as a marker of 'unsuccessful ageing'. These PLwD may, therefore, strive to achieve good oral hygiene - either alone or with support - despite progressing symptoms of dementia. When hygiene can be maintained, one guideline does suggest more complex care may have its place, (Fiske et al., 2006, p. 17) yet dentists did not describe considering more complex restorative dentistry even when preventative oral care was optimised.

In addition to the varying motivation PLwD may have to maintain oral health, it should be noted that there are various definitions of treatment 'failure' and definitions are typically formed from clinicians' perspectives (Wong et al., 2021). Regardless of the definition used, there is no evidence to support the assumption that poor hygiene causes dental restorations to fail in a manner that leads to dental attendance or warrants intervention for PLwD. Although both poor oral hygiene and orofacial pain are common in PLwD, a causal link between the two has not been directly established. Poor oral hygiene alone may not mean that treatment always becomes necessary in the way that Hannah's quote (above) describes.

The justification dentists provided for avoiding more complex care was based purely on biomedical risk. Even if treatment were to fail, or if a new disease developed, dentists did describe having considered the way patients might benefit from restorative treatments during the duration of their success. Regardless of the level of oral hygiene, there is specific evidence that functional rehabilitation can provide psychosocial and functional benefits for PLwD (Nordenram, Rönnberg and Winblad, 1994; Jones, Brown and Volicer, 2000; Nordenram *et al.*, 2013). Optimal function contributes to improving nutrition (van de Rijt et al., 2021) and to improved OHR-QoL (Klotz et al., 2017; Zenthöfer et al., 2020). Considering these benefits, as well as the possible impacts of tooth loss and reduced oral function (detailed in Category 2), it could be assumed that some patients may benefit substantially from attaining a functional, aesthetically acceptable dentition. Patients may desire routine or complex treatment to achieve this status, even if remediation work may become necessary at a later stage. Despite the potential benefits, dentists describe avoiding oral rehabilitation on the assumption that managing the sequelae of initial treatment may not be feasible as dementia progresses:

> *"the things I'm considering, you know can I access the tooth? Will I be able to access this tooth in two years or three years, when this patient is less able to open their mouth or accept treatment?"*
>
> Dheeta (Specialist in SCD)

In addition to concerns about the ability to maintain restorative care, dentists expressed concern that patients would have a decreasing ability over time to tolerate any treatment with local anaesthetic alone:

> *"If someone has dementia and they've gone into decline and you're going to assume that they're not going to be able to have treatment without a general anaesthetic in the future, [planning more comprehensive care] is a very big decision to make but it could be the right call."*
>
> Jane (GDP)

Symptoms of dementia such as disorientation, aphasia, or altered pain experiences can affect how some patients can tolerate care provision and the use of pharmacologic adjuncts such as sedation or general anaesthesia may be needed (Faculty of General Dental Practitioners, 2017, p. 28). Whilst dentists broadly sought to deliver individualised care (detailed in Category 2), this did not extend to considering an individual's unique dental experiences, such as whether they were highly dental anxious. Instead, when treatment with pharmacological adjuncts was planned for people with more significant symptoms of dementia. Dentists further justified future-proofing based on the risk they felt accompanied such approaches:

> *EMILY: "if you then need any kind of sedation or general anaesthetic in order to manage the compliance, it's then that the further risks come with that as well...."*

> *AGR: "What risks are you referring to?"*
> *EMILY: "General health risks really. Obviously, the risk of death would be the first and foremost one. Obviously, I appreciate that that is incredibly unlikely and rare, but with more comorbidities and increasing age of patients, that is a factor we do have to consider."*
>
> Emily (SDO)

Pharmacological approaches to support dental care delivery for PLwD have not been widely studied and the limited research examining these approaches focuses primarily on medical and surgical outcomes. For example, a single study showed that using intranasal sedation in care homes was safe to facilitate dental care for a small sample of people with advanced dementia who were felt to be experiencing orofacial pain (Barends, Absalom and Visser, 2021). No studies specifically explore the use of general anaesthesia for PLwD needing dental care, but there is evidence detailing the medical risks of general anaesthesia for older people undergoing other surgeries. Specifically, general anaesthesia in older people carries a significant risk of subclinical stroke, which can precede a faster progression of dementia symptoms (Mrkobrada et al., 2019) as well as postoperative delirium (Aranake-Chrisinger and Avidan, 2017; Sprung et al., 2017). Though these studies offer some insight into the medical risks of pharmacological behavioural support, they provide little insight into the medical risk related to each individual PLwD. As with dental treatment tolerance, each person's health status and the biomedical risk of such approaches may differ. For example, the pathophysiology causing vascular dementia may also complicate anaesthetic care such as thromboembolism. In contrast, somebody with Alzheimer's disease may have no related comorbidities and be at lower risk from pharmacological aids to care delivery. Such variation, and the need for individualised medical risk assessments, was not described by dentists working in services with access to general anaesthesia. The psychosocial risk that may arise from these approaches was also not described by dentists or in any relevant literature, reflecting the absence of evidence on treatment outcomes for PLwD receiving dental care in this manner.

Though there is merit in striving to avoid future problems, it is not possible to manage somebody's mouth in a manner that definitively eliminates all future problems. As an extreme example, even if a dentist removed all a person's teeth (known as a dental clearance), the price paid would be postoperative morbidity and loss of function, aesthetics and possibly dignity. Dentists did not routinely take their future-proofing approach to this extreme:

> *"I'm not someone for diving in and just you know, doing a dental clearance on the risk of somebody may develop issues in the future…it's more complex than that, a clearance is a last resort but sometimes it's what we have to do, not just to avoid future problems but because we have no alternative."*
>
> Clark (Specialist in SCD)

Harry described a situation where a dental clearance may be necessary, suggesting this was based on managing active disease more than on preventing future problems:

> *"If you have a situation where all the teeth present are either grossly diseased or they are grossly mobile and symptomatic, then at that point, that is a reasonable reason to do a clearance."*
>
> Harry (SDO)

The caution used with this most radical of approaches seems pragmatic when the literature on an edentulous state is considered. Though research has suggested this edentulous state can positively affect OHR-QoL (Lee et al., 2012; Souza, Costa Oliveira and Martins, 2017), something as extreme as removing all teeth may not render a person free of dental pain. Other conditions affecting the orofacial region, such as a temporomandibular disorder, could not be definitively eliminated and may even be brought on by such a drastic alteration to the mouth. The studies described in Category 2 regarding views on tooth loss (Nordenram *et al.*, 2013; Rousseau *et al.*, 2013; Gibson *et al.*, 2017, 2019; Warren *et al.*, 2020; Johnson, Morgan and Jones, 2022) further support how the resolution of biomedical problems (by ridding the mouth of diseased teeth) could induce a new range of psychosocial challenges to which a patient may have to adapt or solve, as detailed by MacEntree, Hole and Stolar (1997) and Warren et al., (2020).

Proactive intervention cannot eliminate the full range of adverse biological, psychological, and social outcomes that may result from earlier delivery and the implications of such treatment. In the absence of specific evidence of how 'effective' future-proofing may be, the concept of proactive dental treatment in earlier dementia should be discussed with patients in depth. It would be logical to consider proactive dental treatment alongside standard preventative dental care (such as fluoride varnishes, and oral hygiene advice) as one way to reduce the risk of dental diseases and their sequelae impacting PLwD in later dementia.

Dentists fell into two broad camps in how patients were involved in care planning based on these assumptions when discussing the future with patients. Aligning with a paternalistic approach, some dentists determined that future-proofing was appropriate and provided treatment based on this approach. Such plans were presented, and patients were encouraged to agree to such an approach.

> *"we've had success stories where, especially earlier on in the disease we've been able to engage the patient, get them on board with the plan. It might be quite drastic, the plan, but everybody can see the reason for it."*
>
> George (CDO)

Other dentists actively sought patients' views on a more proactive approach to dental care planning. Sam articulated his approach by showing how he would talk to a hypothetical PLwD:

> *"I'd say like 'Mr Smith, you have this dental problem and health problem, the health problem's going to get worse probably before the dental problem is, but we'd like to fix the dental problem earlier on so it's easier for us to fix and easier for you to be able to manage it over a period of time'. Something like that, then I'd ask what he thought and if he wanted to crack on and make some progress now or leave things which might be a bother later."*
>
> Sam (GDP)

When consulting patients about their longer-term oral health, future-proofing approaches may well involve 'trade-offs' whereby competing adverse and desired outcomes have to be considered and a priority established to guide further action (Charmaz, 1991, pp. 143, 147–149; Case et al., 2015). A trade-off may occur in the dental context, where the current dental function is traded for a longer-term reduced risk of oral infection or orofacial pain. For example, a patient may choose to have a tooth with an asymptomatic low-grade infection extracted to eliminate the risk of a symptomatic infection or pain in the future. The tooth in question, however, might support masticatory function and contribute to a person's smile. It is these factors that may be 'traded off' against one another. Other patients might accept their current dental status in the short term even if they knew about the risks of acute pain or infection. Discussions involving trade-offs are likely to be highly preference-sensitive, so they are highly compatible with SDM when patients can engage in such discussions (King and Moulton, 2006).

Though SDM is advocated in national guidance (National Institute for Health and Care Excellence, 2021), such an approach is only optimised when data regarding risks and outcomes of options are available (Whitney, McGuire and McCullough, 2004; Elwyn et al., 2012; Elwyn, Cochran and Pignone, 2017). The lack of direct evidence about dental treatment outcomes for PLwD - such as outcomes of being rendered edentulous or insight into how the trajectory of dementia may impact care provision - may hamper dentists' efforts to facilitate SDM. Consequently, a greater degree of uncertainty may have to be accepted by both patients and clinicians. Although such uncertainty can complicate SDM, and values can still be used to inform care, the process is far less straightforward for all involved (Elwyn et al., 2022). This uncertainty and the associated lack of evidence on outcomes may explain the variations in dentists' approaches and their reliance on assumptions.

7.5 Category 4: Weighing-up risks and benefits

As well as considering patients’ future care needs, dentists described how they consider and discuss the present-day management of PLwD who experience symptomatic and asymptomatic dental conditions. Aligning with the ethical principles of beneficence and non-maleficence, dentists describe approaching care through a desire to benefit patients whilst avoiding or minimising harm. The volume or nature of dental diseases, or treatment that may be required to address them or their sequelae, affected how readily dentists felt they could adhere to these principles:

> *“If someone just has full upper and lower dentures, they're relatively easy to manage. The decision making is a bit simpler. But where you're having to consider compliance for restorative treatment or extractions and the risks of stuff like medication related osteonecrosis, that makes it a little bit trickier.”*
>
> Craig (GDP / CDO)

Regardless of treatment volume or complexity, the dentists described the difficulties they faced when the numerous potential benefits or harms of treatment in each situation were unknown:

> *"I think it's often challenging because there are so many factors at play. Every patient is different and so there's not really a rulebook you can follow. I think it's just about trying to navigate through and weigh up all those different benefits and harms, or doing things and not doing things, depending on what the situation is."*
>
> Emily (SDO)

The challenge described by Emily reflects tensions between different ethical principles that can arise when considering dental treatment for PLwD, particularly the tension between beneficence and non-maleficence. For example, a benefit may arise from smoothing off the sharp edge of a tooth causing trauma to a patient's tongue (beneficence), yet the patient may find such an approach distressing (conflicting with non-maleficence). Alternatively, a dentist could remove a tooth causing pain (beneficence), but its removal may precede an acute infection and alter a person's appearance (again conflicting with non-maleficence). Considering the adverse outcomes that may arise, dentists described situations where risk-benefit analyses supported their decisions not to provide dental treatment at all:

> *"If teeth are not obviously symptomatic and the person is showing no functional deficit then I'd be more inclined to leave that alone. Also, if a person has quite significant numbers of comorbidities and is difficult to remove from a care setting…taking them from the nursing home to a dental clinic to do treatment is in enough itself a very difficult and dangerous … it makes me more inclined to think that unless we're going to do treatment to remove a source of pain, and frank pain at that, then I'm not going to do that."*
>
> Harry (SDO)

Considering how difficulties with clinical or radiographic assessment may compromise the formation of diagnoses, it is possible that dentists may not be able to identify dental conditions that could be causing pain (Cohen-Mansfield and Lipson, 2002). Pain identification, therefore, may not be successfully undertaken by dentists, mirroring the challenges in pain identification by family members or professional carers. Therefore, dentists who use the perceived absence of pain to justify non-invasive care provision may – despite their best efforts – inadvertently leave their patients in a situation where pain is both present and detrimental to quality of life (van de Rijt et al., 2019a). On this basis, there is an argument that simple interventions to reduce the risk of pain development may be appropriate for some individuals, even those living with advanced dementia.

A lack of pain or infection that could be treated was associated with a lack of perceived treatment benefit. This meant the balance of risk and benefit tipped towards risk when dentists considered actively treating asymptomatic PLwD. Considering pain or infection in isolation neglects the potential wider benefits of treatment for PLwD as detailed in Category 3. Dentists placed little emphasis on broader aspects of patients' well-being beyond dental status or symptoms. One dentist went so far as to imply patients should not be concerned about such factors:

> *"When someone is ill, they don't need to worry about their teeth looking pretty but they absolutely do need to worry about not having infection."*
>
> Evelyn (GDP)

This is a substantial and arguably inappropriate assumption as each person may have their preferences and many PLwD will be concerned about their appearance, despite having a diagnosis of dementia. Whilst other dentists did not make such sweeping assumptions, the absence of known pain did prompt dentists to be less invasive with the care they provided. The presence of known significant pain or infection was described to tip the risk-benefit balance towards benefit, meaning dentists had to provide some form of treatment:

> *"If they were in pain with it or there's an infection, then you're kind of forced to act…not doing something is not really an option."*
>
> Jane (GDP)

The prioritisation of pain management aligns with patient and caregiver preferences identified in existing research (Nordenram, Rönnberg and Winblad, 1994; Jones, Brown and Volicer, 2000) and the recommendations of clinical guidelines (Fiske et al., 2006; Faculty of General Dental Practitioners, 2017). The Delphi process undertaken by Jones, Brown and Volicer (2000) identified that retention of function was a secondary but still high priority alongside pain resolution. If dentists consider approaches to pain management that allow tooth retention (such as root canal treatment), social and masticatory function may be maintained, which may have positive implications for PLwD's quality of life. Reflecting this, dentists described trying to reduce risk by addressing any presenting concerns using the least restrictive or invasive approach possible, where the impact on function may be less:

> *"The sort of conservative approach towards it would be wanting to intervene as minimally as we can. Obviously in some situations you have to intervene. I would really want to keep my treatment options as sort of basic and simple as possible really."*
>
> Colin (GDP)

More straightforward restorative dental treatment was not always suitable or feasible and dentists – both in specialist and general dental settings - detailed instances where teeth could not be restored, meaning tooth removal was potentially necessary. Regardless of the type of care delivered, dentists explained situations where PLwD had struggled to cope with treatment such as dental extractions:

> *"he came with his wife and one of his daughters and like…oh my goodness, he had so much pain from these teeth, constant, constant, constant, constant. He only had four teeth remaining. I tried to extract under local [anaesthetic] and he was yeah, pretty violent. So, this was not going to happen".*
>
> Amelia (Specialist in SCD)

Even after dentists determined that procedural dental care was a suitable approach, treatment was not facilitated by any means necessary. For dentists in specialist settings with access to anaesthetic facilities, a more significant symptom history was described as necessary to justify the greater degree of risk that dentists felt was associated with the use of general anaesthesia or sedation. Referring to a patient who may require general anaesthesia, Afua elaborated on these considerations stating:

> *"It would have to be quite a drastic case where say it's all retained roots with recurrent abscesses, erm, and basically the benefits of actually having a clearance outweigh the risks and all the other possible consequences."*
>
> Afua (Specialist in SCD)

Practitioners also revisited the risk-benefit balance in instances where an attempt to provide treatment had failed or where a change in approach was required due to a patient's changing health status:

> *"We started that procedure and first two visits we managed successfully to do some extractions… following that, he came back for a third visit and it was probably about two months between second and third visit. On that arrival of that I could tell actually he had deteriorated quite significantly. He was more frail, it was a struggle to transfer him from his wheelchair into a dental chair. He seemed a lot more confused. He wasn't able to tolerate local anaesthetic and we actually ended up having to abandon treatment."*
>
> Hannah (Specialty Trainee – SCD)

As discussed, many treatment decisions made with or for PLwD are based on a degree of uncertainty about the outcomes that may arise. MacEntee and Mathu-Muju (2014) summarise how uncertainty imbues all healthcare, including dental care for older people. When this uncertainty is acknowledged, it is implausible to expect all dental care to be definitive and to result in an outcome guaranteed to be satisfactory for all parties. Having to abandon planned treatment due to a patient's intolerance of treatment is clearly problematic; the reports of such experiences highlight the unpredictability that may arise in caring for PLwD and how the planned treatment may not always be possible to deliver in the time and manner originally planned. However, an attempt to provide treatment, such as that reported by Hannah is clearly an unfortunate outcome of dental treatment delivery. Such an outcome, however, provides clear, new information – based on observation, not assumptions – to support a revised risk assessment based on how well a person can tolerate treatment. Specifically, treatment outcomes – positive or negative – provide insight into the person receiving care as an individual from psycho-social perspectives that may be inadequately considered by some dentists when initial treatment decisions are made. That said, certainty in dental treatment delivery for PLwD is likely unattainable. Regardless of what information is sought and considered prior to treatment, it cannot be assumed that treatment outcomes in all scenarios will be predictable. Dentists may need to embrace - or at least tolerate - uncertainty as an inescapable characteristic of healthcare (Simpkin and Schwartzstein, 2016).

7.6 Category 5: Leading the decision-making process

The outcome of a risk-benefit analysis, based on assumptions or the outcomes of treatment delivery, informed what treatment dentists subsequently proposed. Specifically, this informed either decisions not to proceed with active dental treatment, decisions to provide specific treatments (using pharmacological aids if required) or, for GDPs, decisions to refer patients to specialist teams. Where such decisions were made, in either primary or secondary care, clinicians described how they viewed their role in decision-making:

> *"I believe the decision-maker should be me if somebody doesn't have capacity. If the patient has capacity, it's their decision, end of. You know, we can guide them, give them all the options. If the patient has capacity, it's their decision. If not it's the person treating."*
>
> Amelia (Specialist in SCD)

When considering a person's capacity to consent to treatment, dentists described leading the process of capacity assessment, as well as the overall process of decision-making. The assessment of capacity determined the nature of decision-making that they would need to lead – either a decision made with the patient or a BIDM process:

> *"Yeah, so we'd have to do a formal assessment of capacity too so the patient would have to have a reason why they can't function properly. And then they would not be able to understand or communicate the pros and cons of the treatment that's being suggested for them. And then yes, you'd have to decide there actually definitely is a reason to have treatment done."*
>
> Claire (Specialist in SCD)

When decisional capacity was present, dentists reported leading the process and detailed the need to gain consent for treatment, yet only some dentists described how they presented a range of treatment options to patients. When options were presented, some dentists did describe supporting patients to choose from these available options:

> *"what I normally do to patients is I present them with several options, all of which are feasible options or options that are feasible for my competence as a dentist. I will ultimately expect and want the patient to make their own decision and a lot of the times they've said 'can you*

> *tell me what to do' and I've said 'no, I can't, you have to. These are the options that are available to you from me, you need to decide what you want to do…you choose what you want.'"*
>
> George (CDO)

> *"I tend to chat through a lot of options anyway with patients and go into quite a lot of detail [yeah] and I've only ever had positive feedback to say thanks for taking the time just to sit and talk me through it."*
>
> Rachael (GDP)

The variation in whether dentists presented a range of treatment options to patients mirrors the variation in whether dentists discuss a future-proofing approach to care with their patients (as discussed in Category 3, 'Anticipating decline'). Elwyn et al. (2017) describe a 'three-talk' model of SDM in which presenting options ('option talk') is just one aspect of an effective SDM process. 'Option talk' should occur as well as 'team talk' where values are gathered and 'decision talk' which includes collaborative deliberation. Simply presenting options, therefore, aligns with an informed choice model of care and does not equate to effective SDM (Sepucha et al., 2013). Where dentists did not describe presenting various treatment options to patients, this may be because the options are limited to a single specific approach or to not receiving this. Where such 'option talk' was not reported, dentists did describe interactions that aligned with 'option talk' and elements of 'team talk', such as understanding patients' historic preferences for care and, in some instances, facilitating deliberation.

When they presented options for care to patients, dentists did not report either dictating care for PLwD with decisional capacity, nor did they describe ignoring their views entirely. There was also no description of incorporating patients' values into care in a manner that aligns with the definitions and models of SDM. Of course, the approach dentists take may be no different for PLwD with decisional capacity than for any other group. It is possible that either SDM or both extremes of patient involvement (paternalism or informed choice) are occurring in dental settings for PLwD as for other patients. For dentists who did not report presenting options to patients when these are available, the care they deliver may be paternalistic, whether intentionally, or inadvertently. Others, such as George, might be offering patients a choice but may not be supporting them in choosing form options, reflecting the Informed Choice model of care (Charles, Gafni and Whelan, 1997). The use of either approach may explain why dentists did not describe encountering disagreements or conflicting viewpoints with patients. The lack of disagreement may reflect how decisions are made entirely by one party - clinicians or patients - instead of jointly deliberating and sharing the decision-making process. The reality of what happens in clinical settings and whether 'ideal' SDM is occurring could not be easily understood without using positivist numerical assessments, such as validated observation scales as detailed in Chapter 3 (Melbourne et al., 2011; Stubenrouch et al., 2016). However, the apparent exclusion of PLwD's current views, identified in Category 2 (Providing individualised care), would suggest that effective SDM is not commonplace in planning dental treatment for PLwD.

There is a contradiction in how dentists wish to support individualised yet did not report consistently discussing treatment options with patients. There could be many reasons for this apparent lack of comprehensive patient involvement. A range of barriers and facilitators to SDM have been identified through multiple reviews as summarised in an umbrella review (Alsulamy et al., 2020). This review noted that professional factors were just one issue impacting the use of SDM in practice. Hence, even when clinicians are motivated to provide SDM, this process also needs to be supported and embraced at organisational and policy levels. Information provision was felt to be a key facilitator of effective SDM, yet Category 1 (Detective work) has summarised the challenges dentists experienced when seeking relevant information regarding dental treatment for PLwD. Where information is not readily available, time has to be spent seeking this and Alsulamy et al. (2020) specifically noted that lack of time to discuss options was repeatedly identified as a barrier to effective SDM. Rachael’s description of having time to discuss options reflects the nature of her private practice setting, whilst George’s description of presenting choices may be feasible because of working in salaried service. Those in some NHS services, specifically in general practice, may not have time for optimal SDM or to seek information to support SDM, each of which may limit the extent SDM is enacted in practice.

When conversations about options or where deliberation between patients and dentists was not possible, dentists explained how they formally assess a person's capacity to inform the next decision-making steps. This process was detailed as being straightforward for people with either early or advanced dementia. The difficulties reported in capacity assessment mostly related to situations where decisional capacity was less obviously present or absent for people with middle-stage dementia:

> *"I've had one patient, a gentleman, who was living in a residential home. He attended through the emergency service. Capacity was fluctuating. He came across as if he did have capacity initially. But then as the appointment went on you could see that actually maybe his capacity wasn't as strong as what we thought it was."*
>
> Suzanne (CDO)

Where there was uncertainty about capacity or how to proceed in each situation, dentists consulted PLwD's family members. This process, however, was not without its own challenges and discussions with carers were reported to be complex, especially when the dentist had to navigate different views of each party's role in the process:

> *"There are… family members who've got power of attorney who are quite objective with it. I'd say they do try and remove themselves from it and I think that's quite good. There are others, I think, who see it as in like it's entirely their responsibility to manage the patient and everything for them, and make decisions, and that's not the case either."*
>
> George (CDO)

How dentists consulted family members showed their alignment with the legal requirement to consult someone 'close' to a patient to identify what may be in a person's best interests (Department for Constitutional Affairs, 2007, p. 66). It is often assumed that a person 'close' to a patient would be a family member, yet not all PLwD have family, and individuals other than family members can support clinicians in gaining insight into what care may be appropriate for each person. Independent Mental Capacity Advocates (IMCAs) can also support this advocacy process as they can challenge healthcare professionals on their approach to care and any assumptions they may have made about a person (O'Connor and Purves, 2009, p. 101). The role of IMCAs or interaction with IMCAs was not described by any of the dentists interviewed so the way dentists may interact with them or act on their recommendations remains an area for further study.

Whilst the dentists interviewed did not describe disagreements between PLwD themselves and dentists, disagreements with family members were reported to occur often when PLwD were assessed to lack decisional capacity. In these situations, carers may hold viewpoints that differ from those of the dental team. There were descriptions that the views of carers were felt to be unrealistic:

> *"I think for perhaps for, let's say the children of an elderly patient, those children might only be used to the dentistry where all problems are fixed, and they are left with a perfectly restored dentition. So the idea of perhaps not restoring everything or perhaps using glass ionomer a bit more than we would in other patients...they might be alien concepts to those children and they might just might not be on the children's radar at all."*
>
> Craig (GDP / CDO)

There are many reasons why the opinions of dentists and family members might differ, reaching beyond their differing roles in relation to a person lacking decisional capacity. The nationwide improvement in oral health may mean that patients' family members have had little or no need for active dental treatment. If this were the case, their knowledge of dental treatment processes might be insufficient for them to fully appreciate the potential challenges that may arise when delivering certain dental treatments for PLwD. Therefore, family members may expect active treatment to be delivered, especially if it might resolve pain or support functions such as speaking, eating, or smiling. In addition, family members may consider their own personal interactions with PLwD following treatment and be mindful of changes to how the person may look, speak, or smile after treatment. With such factors in mind, the interaction between family members and dentists may become particularly complex, especially when family members erroneously feel that they have specific legal decision-making authority.

When varying viewpoints are identified, a dentist must consider these as part of BIDM. When doing so, dentists described having presented their planned approach to family members alongside the justification behind it:

> *"I think if you have a frank conversation with family members about their loved one and say look, we can do x, y, z but it's probably not going to benefit them. So, say for example with patients who come in with loved ones who say take all the teeth out and put dentures in, I*

> *think having the conversation with the family member about how that might actually be of detriment to the patient, can be useful and most people are quite receptive to that and don't argue too much about those sorts of things."*
>
> Hayley (GDP)

Dentists described how conversations with patients or their family members about what may be most feasible or suitable for PLwD led to agreement about whether or what treatment may be provided. Dentists' accounts specifically suggest that they either educate or persuade family members before reaching an agreement on the approach to care. If dentists are either educating or persuading family members to agree to their proposal, this would logically explain why there were no reports of family members' viewpoints changing treatment decisions regarding PLwD. There could be multiple reasons why the views of family members were not described to affect the decisions made by dentists about care provision. It could be that family members' views are entirely inappropriate and not feasible, so are of no use in guiding decision-making. A further consideration is family members felt disempowered and unable to challenge dentists' views. Finally, as the dentist is generally the legal decision-maker in scenarios where family members do not hold an LPA, dentists may be considering family members' views but intentionally disregarding them due to a perception that they are not relevant or applicable to BIDM.

Intentionally excluding family members' from decision-making may also arise because the opinions family members propose are felt to be incompatible with what a PLwD themselves would wish for. This issue was specifically described by GDPs who had cared for patients over longer-time periods and who were aware of patients' longer-term attitudes to dental care. The discrepancy between patient's preferences and what family members feel are a person's preferences has been explored in the literature from outside the dental context (Shalowitz, Garrett-Mayer and Wendler, 2006; Spalding, 2021). Furthermore, family members may suggest care that aligns with their own wishes instead of what is best for a PLwD (Marks and Arkes, 2008; Reamy et al., 2013). Consequently, when a variety of opinions arise, the views of the family must be considered with an awareness of these limitations. Furthermore, whilst agreement on best interests should be sought, it may be accepted that those without specific legal authority cannot override a dentist's decision, resulting in the dentist's own idea of appropriate care being delivered.

As family engagement was not reported to change the management that was ultimately facilitated in any of the interviews undertaken, it could be argued that consulting family members was simply a formality for dentists. It seems unrealistic that family members' insight was irrelevant, discounted, misinformed or inappropriate in decisions regarding every PLwD lacking decisional capacity. Though such views may not direct a final treatment decision, they should be embraced and comprehensively considered for their relevance. The lack of reports of such deliberation suggests that dentists' decision-making reverts to a paternalistic approach when a PLwD is assessed to lack decisional capacity. If this is the case, decision-making for dental care may be based on consideration of only some of the relevant factors. If this occurs, there is a risk that treatment decisions may erroneously ignore what might genuinely be in a person's best interests.

7.7 Category 6: Confidence and familiarity

Dentists from all settings reported that there were sometimes significant difficulties in planning care for PLwD:

> *"The hard ones were those that were erm not of sound mind really, they were always the most difficult ones…I always felt a bit uncomfortable with that because I always thought about if somebody ever made a complaint?"*
>
> Monty (GDP)

The nature of their dental career history and practice setting meant that dentists had widely varying experiences in assessing or treating PLwD at different stages. For example, GDPs may see patients who go on to develop dementia and care for them after diagnosis and as their condition progresses. However, those in specialist settings may only encounter those with more advanced dementia that has a greater impact on dental care. Those with less exposure to more complex patients described feeling less able to identify or enact appropriate management of dental problems for this patient group:

> *"I've got some experience of assessing capacity from working my previous jobs. I feel able enough to do that. I wouldn't want to make massive decisions, obviously, like life-changing decisions."*

Hayley (GDP)

Dentists who have less exposure to PLwD describe having less of an opportunity to gain familiarity or confidence through gaining relevant experience. In contrast, those familiar with caring for PLwD described how their confidence and comfort in this area had grown as their experience accumulated:

> *"I think it's something that you learn through experience and vicariously through colleagues…You meet various other members of your team that may be specialists and non-specialists that have a lot of experience and I think I've learned a lot through other people's experiences."*
>
> Joan (Specialist in SCD)

Despite their differing experiences, dentists in all settings detailed their professional responsibility to know where one's professional skill set reached its limitations:

> *"If I feel I can do it, I will try it. If I'm not happy with it then I will say, 'we've tried our best, but it would be better if we referred you on where it could be done with a better outcome.' So, I don't have any issues with referring because you've got to be aware of your own skillset, if you can't do something there's going to be someone who has better tools, better equipment who can do it better, and therefore the best interests of the patient."*
>
> Gavin (GDP)

Dentists also referred patients for other reasons, namely the practicalities of surgery access or the lack of access to appropriate hospital facilities. Sam suggested how patients should be able to access care where both physical access and other appropriate modifications can be made to support holistic care:

> *"You can't just have a few bits of the jigsaw; you've got to have the whole package and if you don't have the whole package then there's no point even starting to deliver care."*
>
> Sam (GDP)

In addition to how a lack of experience or access to facilities impacted on dentists' ability to provide appropriate care, dentists described being uncomfortable making decisions not to provide active care. This arose even when such decisions were based on a consideration of both risk and benefit (as detailed in Category 4):

> *"[Leaving things untreated] doesn't sit very comfortably, but I think you just have to consider the patient as having a deteriorating condition and that sometimes you don't have to treat everything that isn't right."*
>
> Claire (Specialist in SCD)

Despite having made such decisions based on information from multiple sources, one dentist went so far as to report that such a decision was incompatible with the expected standards of care:

> *"You feel uncomfortable providing no care… It feels really uncomfortable when you know that the right answer, the gold standard and right answer is something else."*
>
> Evelyn (GDP)

It appears that dentists, especially in general practice settings, saw 'ideal' or 'expected' care from a biomedical perspective where disease is proactively managed with procedural interventions. In contrast, the 'right' approach from a patient's perspective may well be to avoid such intervention. The discomfort explained by dentists may be related to tensions aligned with those described by Nordenram and Norberg (1998) who described the tensions faced when trying to achieve benefit and avoid harm. The dentists interviewed herein implied that decisions to accept asymptomatic oral diseases were a source of potential harm. It is possible that a conventional biomedical stance focuses more on the harm of disease than the potential harm of treating them: this means dentists might need to consider or reframe what they view as 'ideal'. Taking a person-centred approach, dentists should consistently consider the care best suited to a person's best interests when all biological, psychological, and social factors are considered. The fact that tensions were reported over twenty years ago and were still detailed by the dentist interviewed suggests the dental profession has to make further progress in delivering holistic person-centred care for all patient groups. The views of many dentists are rooted in the perceived need to undertake procedural interventions, as demonstrated by dentists' concerns about non-interventive care:

> *"I suppose the worry is that the patient is then seen by another dentist, and you're then accused of neglect, if say you left a retained root, for example. Someone else might have a different opinion."*
>
> Craig (GDP / CDO)

One may anticipate that dentists would be confident in their decision-making having considered the risks and benefit of care options based on the information they had gathered. A risk-informed and non-invasive approach contrasts the proactive and procedural future-proofing treatments described in Category 3 ('Anticipating decline'). Invasive approaches may be more comfortable for dentists to deliver as they reflect the historic surgical roles of dental professionals and the perceived expectations of the dental profession. In addition, whilst uncertainty about appropriate action may arise, delivering some form of treatment may help mitigate this uncertainty by either allowing a suitable outcome of care or by reiterating what care may not be feasible. A decision not to provide care, however, may align with the concern of 'neglect' mentioned by Craig. Furthermore, a higher level of uncertainty must be accepted when a decision is made not to provide care; this may only be comfortably accepted by clinicians with additional experience in care for complex groups. If dentists were to plan care using a person-centred approach that considers factors beyond dental diseases or pain in isolation by considering psycho-social factors, then less invasive dental approaches for PLwD at later stages may be more commonplace and become increasingly perceived as ethical and appropriate.

7.8 Summary discussion

This primary research has explored dentists' experiences and approaches regarding dental treatment decision-making for PLwD. The findings offer new insight into what factors dentists said they take into account as well as what concerns and tensions they face when trying to deliver appropriate care. Six categories of data describe aspects of how dentists approach and plan care for PLwD. However, across these categories, there are two common overarching observations. Firstly, dentists focus heavily on biomedical factors and less on psychosocial factors, or the individual's unique experience of either dementia, oral diseases, orofacial pain, or dental treatment. Secondly, the role of a person's autonomy is under-emphasised, suggesting that a person may have little ability to determine what happens to them, even if the dentist had considered a more holistic range of factors relevant to their care. These over-arching factors will be discussed in turn.

Many of the challenges that dentists recounted related to more complex scenarios where dental care was complex or where symptoms of dementia significantly impacted dental care provision. The more challenging scenarios described were typically related to care provision where there is substantial dental treatment need coinciding with high-risk treatment delivery or where treatment may be poorly tolerated and possibly detrimental to oral function. Complexity also clearly increases in situations where patients lack decisional capacity and cannot express their informed own preferences for their care. When describing their experiences in such scenarios, the data generated across multiple categories of data, particularly Categories 3, 4 and 5, shows dentists describe a focus on biomedical factors in decision-making.

Many dentists may be seeking to achieve a status aligned with the definitions presented in Section 2.4, particularly with reference to the absence of oral diseases. Situations in which they feel they cannot achieve this state so underpin many of the tensions they described and the situations in which they describe having less confidence. The definition presented by Glick et al. (2016) suggests that oral health consists of both the absence of disease and the persistence of social and masticatory function. Dentists described many situations where achieving such outcomes in tandem was impossible. The prioritisation of pain resolution, without considering relevant psychosocial factors that may inform how this pain is managed, reflects how widely the dental profession embraces a biomedical approach to oral health. However, the alternative definition of oral health presented by Dolan (1993, p. 37) focuses on a *"comfortable and functional dentition"* that supports the maintenance of social roles: this may be possible, feasible, and appropriate to achieve despite the presence of asymptomatic dental diseases. This definition reflects a broader consideration of treatment outcomes and suggests oral health can be attained so long as a person is comfortable and functioning. Striving to meet this definition of oral health, therefore, allows for some diseases to remain untreated when they are not adversely affecting a patient. If this definition were considered, dentists might achieve the oral health status they strive to attain by embracing relevant psychosocial factors that contribute to patients' overall health and well-being.

A model for healthcare that views health from a biological, psychological and social perspective was first presented by Engel over four decades ago (Engel, 1977). Such work has led to the appreciation of a person's values and preceded the widespread support for SDM. Despite how much time has passed, papers detailing the approach used for the wider population of dental patients (Apelian, Vergnes and Bedos, 2020; Bedos, Apelian and Vergnes, 2020) and the ageing population (McGrath et al., 2022) suggest dentists continue to focus almost solely on biomedical factors. Taking such a biomedical focus under-emphasises autonomy and psychosocial factors contributing to well-being. The desire described by dentists to deliver individualised care suggests some progress towards more person-centred care has been made. Other data discussed herein suggest that dentists still have significant progress to make in transitioning from paternalistic, biomedical care provision to fully person-centred care, as described by Scambler et al. (2015).

The data discussed in '*Anticipating decline*' and '*Weighing up risks and benefits*' have described how dentists strive to achieve the short- and long-term benefits whilst minimising risk (aligning with the ethical principles of beneficence and non-maleficence). In this weighing-up process, the principle of autonomy is a peripheral consideration at best. Promoting autonomy promotes person-centred care and empowers people to take ownership of decisions about their care. The under-emphasis on autonomy and the heavy focus on risk-benefit balances means PLwD's previous years of autonomous living are ignored (Kapp, 2010).

The process of engaging with PLwD to contribute to care decisions was only described briefly by two dentists, suggesting that seeking patients' views on proposed options is not the norm. Despite the importance of autonomy, Alzheimer's Europe (2021, p. 12) argue that decision-makers should balance autonomy with other ethical principles (such as beneficence and non-maleficence) due to the unique nature of every situation that may be encountered. The data generated show how dentists find weighing risk and benefit to be complex; considering autonomy alongside beneficence and non-maleficence would clearly add another layer of complexity to an already challenging process. In some instances, it may be appropriate that the outcome of BIDM is unchanged when autonomy is considered. This does not negate the need to consider what factors would guide an autonomous person's decision-making. Appreciating risk and benefit from a patient's perspective may even resolve tensions that arise when considering and weighing up additional factors. If dentists were to consider the psychological and social implications of treatment options on individual patients, an intervention decision might become more straightforward or justifiable. Doing so could support a person-centred decision whilst also mitigating the risk of professional criticism about which dentists expressed concern.

In summary, dentists are considering the mouth alongside a person's overall physical health yet are still not embracing the overall person who owns and uses the mouth. In addition, dentists do not actively support a person to have ownership or input into their own care. Embracing the person as a whole, including their physical health and psychological and social needs is an essential area where progress is warranted to facilitating truly person-centred care for dental patients, including PLwD.

7.9 Strengths and limitations

Dentists in the UK work in various settings and services, each of which is structured, financed or commissioned differently, and prone to various influences, limitations and regulations. Specifically, private and NHS care differ substantially, as can the care delivered within or outside of hospital settings. On this basis, a strength of the study is its diverse sample resulting from the maximum variation approach I used. This diversity aimed to capture the difference in individuals' experiences and understand the systems in which dentists work. However, there were no dentists recruited outside of England or Wales. The work, therefore, provides insight into how the MCA is used to guide decision-making but offers no understanding of how dentists in Scotland or Northern Ireland approach decision-making for PLwD in the context of their clinical settings and applicable legislation. In addition, only one dentist cared for PLwD in an out-of-hours emergency role. This setting is unique as it does not allow longer-term dental care to be facilitated. Furthermore, no Consultants in Special Care Dentistry were recruited. There are few consultants in this specialty, even in larger cities. The role of a Consultant in Special Care Dentistry can vary, yet they typically have leadership and management responsibilities in addition to their clinical role. Due to their position, Consultants may have different approaches to care delivery and decision-making or different perspectives on how decisions should be approached and made. Specialists are included, whose role is often very close to that of Consultants, but it would have been ideal to recruit dentists from every staffing group. This group should be included in future research in this area.

Another possible limitation of the study is that dentists who were not recruited may have a very different approach to care than those willing to participate in a research project. This is an issue common in qualitative studies, but recruitment bias could have affected the study's findings. There may well be dentists who are disinterested or unmotivated to care for PLwD and who could be reluctant to participate in a research interview. Whether there are dentists with such views, or how these views might impact care delivery, remains unknown. Ethnographic methods could be used to gain further insight into how dentists approach treatment decision-making for PLwD. However, those unwilling to participate in an interview may also be unwilling to have someone observe their practice.

Whilst I aimed to recruit a diverse and varied sample, it was not possible to fully determine the extent of dentists' experience in caring for PLwD before the interview. Some dentists had far more experience in this regard than others, as aimed for by the purposive sampling approach, yet such purposive sampling was based on vague information about the true extent of each professional's experiences. The semi-structured interview approach allowed me to re-phrase questions to support my understanding of how dentists' experiences affected their approach to decision-making. None of the dentists described experiences working with Independent Mental Capacity Advocates (IMCAs) when undertaking best interests decisions for PLwD lacking decisional capacity: this may be because most PLwD have family members who can support decision-making. The way IMCAs contribute to decision-making and how dentists interact with them and use their reports to guide care has not been explored in this work. In addition, it was not feasible to sample people based on whether they had used an IMCA to determine what care is appropriate for PLwD. That said, theoretical saturation was felt to be achieved, so further interviews with those more familiar with IMCAs may not have changed the understanding generated.

7.10 Conclusion

Dentists reported facing multiple related difficulties in planning and delivering dental care for PLwD. The challenges related to the stage and symptoms of dementia and the complexity and volume of dental care PLwD required. Dentists stated that they sought to provide individualised care yet their descriptions of their experiences suggest they focus heavily on medical and surgical factors and specific assumptions. The data generated suggest dentists under-emphasise the importance of the unique individual for whom care is being considered. Potentially, the under-emphasis on the individual and the reliance on assumptions may mean that care is delivered that is misaligned with PLwD's preferences or wishes, or the views of those supporting them. To account for the potential use of generic assumption-based approaches to care and ensure person-centred care is maintained throughout dementia, dentists could place greater emphasis on the social and psychosocial aspects of treatment or non-treatment. In addition, dentists should be supported to actively involve individuals – with or without decisional capacity - in treatment decisions to the greatest extent possible. If dentists are supported to consider this broader range of factors, they may be more able to support, consider and deliver person-centred care for PLwD regardless of their capacity to decide upon and consent to dental treatment.

Chapter 8. Project 3: Data and discussion. "The dentist always has that little edge over you."

In this chapter, I explore the perspectives and experiences of people living with dementia (PLwD) and their family caregivers regarding dental treatment and dental treatment decision-making. The data generated from interviews with PLwD and carers are presented and discussed in relation to relevant literature within and beyond the dental setting. An abstract of this research presented at an international conference is enclosed in Appendix H.

8.1 Introduction

I completed 25 interviews between April 2020 and March 2021. Of the 25 people interviewed, eight were with people living with dementia (PLwD), and 17 were family members of PLwD who were involved in their care. As shown in Table 8.1, various PLwD and carers were recruited with the aim of generating data based on various experiences, roles, and perspectives. Except for one Northern Irish participant, all participants were from England. The COVID-19 pandemic meant that care home residents could not be readily recruited for face-to-face interviews, therefore, no care home residents were recruited. Participants were from 15 different counties of the UK, with nine from the North-East region. I reflect on the limitations of this sample in Section 8.8. I conducted interviews either by telephone (n=4) or Zoom (n=21). Interview duration ranged from 21 – 59 minutes, with a mean duration of 39 minutes.

I felt that theoretical saturation was becoming evident after 19 interviews. The final six interviews were used to explore specific aspects of the phenomenon of interest identified during earlier interviews. The iterative data analysis process led to a theoretical understanding of the experiences of PLwD and carers based on five categories of data:

1. Dental care as an afterthought and low priority
2. Finding and accessing suitable care
3. Wanting (the PLwD) to be understood
4. Wishing to be involved in care planning

5. Expectations and outcomes of dental care

Here I present the data from each category alongside a discussion about this data informed by existing literature.

Pseudonym*	Role*	Gender*	Age *	Type of dementia #	Dental Treatment Need # $
Jonathan	PLwD	M	50 - <60	Mild YOD – AD	Minimal
Harold	PLwD	M	60 - <70	Mixed: VD and AD	Moderate
Christine	PLwD	F	60 - <70	Mild AD	Extensive
Lynne	Family: daughter	F	50 - <60	Moderate AD	Moderate
Dorothy	PLwD	F	60 - <70	Mild AD	Moderate
Charlie	PLwD	M	60 - <70	Mild AD	Minimal
Liz	Family: daughter	F	40 - <50	Advanced AD	Moderate
Gary	Family: brother	M	70 - <80	Moderate AD	Extensive
Laura	Family: daughter	F	50 - <60	Advanced AD	Moderate
Greta	Family: daughter	F	70 - <80	Advanced AD	Minimal
Gerald	PLwD	M	70 - <80	Mild VD	Minimal
Judith	Family: daughter of two PLwD	F	50 - <60	Advanced VD (mother) Advanced FTD (father)	Moderate (mother) Minimal (father)
Kimberley	Family: sister	F	50 - <60	Moderate DwLB	Moderate
Cassandra	Family: daughter	F	40 - <50	Advanced VD	Extensive
Poonam	Family: daughter	F	50 - <60	Advanced FTD	Extensive
Pauline	PLwD	F	60 - <70	Moderate AD	Moderate
Margaret	Family: wife	F	60 - <70	Mild AD	Moderate
Jean	Family: daughter	F	50 - <60	Advanced AD	Moderate
Janet	Family: wife	F	60 - <70	Moderate FTD	Moderate
Sarah	Family: daughter	F	40 - <50	Advanced VD	Minimal
Jack	PLwD	M	60 - <70	Moderate AD	Moderate
June	Family: wife	F	60 - <70	Moderate AD	Moderate
Barbara	Family: daughter	F	50 - <60	Advanced DwLB	Minimal
Lindsey	Family: daughter	F	60 - <60	Advanced AD	Minimal
Simon	Family: son	M	40 - <50	Advanced AD	Moderate

Table 8.1: Demographics of the PLwD and caregivers interviewed

*Of interviewee. # For PLwD, or PLwD being discussed. $ Estimated based on the experience described by interviewee AD: Alzheimer's disease. FTD: Frontotemporal dementia. DwLB with Lewy bodies: Dementia. VD: Vascular Dementia. YOD: Young-Onset Dementia. An age range, instead of specific ages, is given to support the anonymity of participants.

8.2 Category 1: Dental care as an afterthought and low priority

PLwD and carers explained that they did not regularly seek dental care even when they were aware of dental problems affecting them or the PLwD they cared for. Despite not actively seeking care, each of the PLwD and family carers interviewed explained that they believed oral health to be an important aspect of well-being:

> *"your mouth is so fundamental to everything isn't it, it is speech, it is food intake, it's such a basic part of your being."*
>
> Pauline (PLwD–AD)

Some participants described being aware of how oral health was related to general health:

> *"I thought dental health is really important for someone's overall health. My mum also has a history of cardiac problems, and I knew that there can be a link between dental health and heart health. This was something that I was keen to be on top of."*
>
> Lindsey (daughter of PLwD–AD)

Based on this perceived importance, each family carer of PLwD at an advanced stage sought to provide oral care for the PLwD despite the challenges they encountered:

> *"I used to put the toothbrush in front of her, put the toothpaste on and at one stage she could pick it up and she would really clean her teeth but near the end she would think it was a brush and she'd try and brush her hair. She'd get really confused."*
>
> Jean (daughter of PLwD–AD)

Routine dental attendance is encouraged for all patient groups, specifically to facilitate preventative care (National Institute for Health and Care Excellence, 2004). Many PLwD, however, described taking a problem-orientated pattern of dental attendance:

> *"[Dental care] is really something I haven't touched on at all…because you only go when you've got a problem."*
>
> Christine (PLwD–AD)

Jack gave a specific example of dental problems that led him to seek dental care:

> *"I had a fall…and after that I had a whole week and a half without front teeth, which wasn't good…I didn't like that, I didn't like that at all, but I got my teeth sorted just about."*
>
> Jack (PLwD–AD)

Multiple studies have explored the perceived importance of oral health for older people (Borreani et al., 2010; Warren et al., 2020) and PLwD specifically (Nordenram, Rönnberg and Winblad, 1994; Nordenram et al., 2013; Curtis et al., 2021). These studies have identified how people place value on oral health throughout later life and whilst experiencing cognitive impairment. Oral diseases are largely preventable through home-based preventative care and professional interventions (Department of Health, 2017). Key studies, however, have identified that a problem-orientated approach to dental attendance is commonplace for older people (Borreani et al., 2008; Niesten, van Mourik and van der Sanden, 2013) and PLwD in particular (Curtis et al., 2021).

A problem-orientated approach to dental care suggests that dental care may be a low priority for many PLwD. Legge, Latour and Nasser (2021) indicate that the older population believes pain is the primary indicator of dental disease. Through a pathway analysis process, Torppa-Saarinen et al., (2019) summarised how those reporting high OHR-QoL, such as those without pain or functional deficit, accessed dental care less frequently. PLwD without pain may therefore think that dental care is unnecessary, even if they experience low-level functional problems or cosmetic concerns that do not affect their perceived OHR-QoL.

Mirroring the approach taken PLwD, many carers also sought dental care for PLwD only when significant symptoms or problems were identified for those they cared for. Such issues brought dental care into the spotlight:

> *"It was the loss of teeth. I think she lost a couple which fell out or she pulled them out on the front side and then there was the total deterioration of the gums. She'd never really had difficulty, but she was in a lot of pain and that's when we knew there had to be something done."*
>
> Gary (brother of PLwD–AD)

Some family members felt that they had unique insight into whether their relative was experiencing pain:

> *“I always know if he’s got any kind of pain because he gets very restless…I don’t think that the dentist would necessarily pick up on that.”*
>
> Margaret (Wife of PLwD–AD)

In some instances, this suspicion of pain prompted family members to arrange dental attendance for a PLwD:

> *“I said to [the care home] ‘My mum’s in pain, she keeps pointing at her mouth and saying pain in Bengali’. So, I knew that she was in pain and I was thinking ‘what do I do?’”*
>
> Poonam (daughter of PLwD–FTD)

The data generated describe how, consistent with existing studies, pain is a key driver of dental attendance for PLwD. Dental attendance for PLwD living in the community and care homes has consistently been found to considerably decline following a diagnosis of dementia (Lee, Wu and Plassman, 2015; Fereshtehnejad et al., 2018; Jockusch, Hopfenmüller and Nitschke, 2021; Lexomboon et al., 2021). There may be little motivation to overcome barriers to receiving dental care, such as lack of perceived need, fear, anxiety and concerns about the cost of care (Göstemeyer, Baker and Schwendicke, 2019; Latour and Nasser, 2021). The practical, logistical, and cognitive effort to overcome these barriers may be more significant than any asymptomatic dental issues. Such barriers may explain the lack of urgency in dental attendance explained by those interviewed:

> *"he would always go every six months and really it was only when he started to have his strokes, he was only sixty, mind, when he had his first stroke so then getting to a dentist was always that bit harder because of his mobility issues so, he didn't go."*
>
> Sarah (daughter of PLwD-VD)

Considering the impact of a dementia diagnosis and the symptoms of dementia on peoples' day-to-day living (Robinson et al., 2011; Yates et al., 2021), it is understandable that asymptomatic dental conditions are not the primary concern of PLwD. Charmaz (1991, p. 136) describes how *"Chronically ill people often devote their efforts to the most intrusive ailment."* For many PLwD, the impact of memory loss, confusion, or other impaired executive functions is likely to be more intrusive to daily function than asymptomatic dental conditions. However, when previously asymptomatic conditions become symptomatic, there is likely a more significant intrusion into everyday living. This intrusion appears to lead to action that attempts to resolve the intrusive symptoms. Therefore, this may explain why PLwD and carers described a symptomatic or problem-orientated approach to dental care attendance.

Paralleling the competing priorities that a PLwD may have to balance, carers who had become responsible for dental care and oral hygiene for PLwD describe balancing competing priorities in care provision and their own lives:

> *"Caring for someone with frontotemporal dementia, it's really hard on a daily basis. My mum used to physically attack me, beat me up, she just wanted to go out all the time. So, sort of her dental needs in my life was at the low end of priorities, I was just trying to survive day to day."*
>
> Judith (daughter of mother-VD and father-FTD)

Some family members described how PLwD had moved to a residential setting due to the number of complex and competing health needs and the need for more substantial support with daily living. Oral healthcare is just one area where a PLwD may need formal support. However, the reports of family members suggest that oral hygiene was often neglected or discontinued in care homes, particularly when PLwD resisted this care. Family members explained how they felt professional caregivers disregarded oral hygiene measures due to PLwD's prevailing health and care requirements:

> *"managing his incontinence was top of the list and ensuring that he was having a wipe down was, but then his teeth were lower down in the list, and I think that even though I tried to raise questions about it I don't think that [the care home staff] really knew what to do. So, I think*

> *that's kind of why it became a bit of a dead end."*
>
> Liz (daughter of PLwD–AD)

As with PLwD living in the community, care home staff appeared reluctant to arrange regular dental attendance:

> *"The hairdresser visits, the chiropodist visits, you have to register with the GP because most people in care homes have got conditions and they need prescriptions and things like that. But I'm not sure it's very high on the agenda to think actually 'let's try and register this person with the dentist and let's get some dental treatment for them'…it's just not going to be on anyone's radar."*
>
> Cassandra (Daughter of PLwD–VD)

Reflecting a damning report of UK care homes and their approach to oral health (Care Quality Commission, 2019), the carers interviewed suggested that care homes appeared reluctant to arrange formal dental care even when significant dental problems were identified or suspected. This contradicts national guidance applicable to these settings which encourages routine dental attendance for care home residents (National Institute for Health and Care Excellence, 2016). The low priority placed on dental intervention by care home staff meant that multiple family carers had to arrange dental care themselves following the identification of significant dental problems:

> *"I was told in no uncertain terms, 'No, we don't have anything to do with [dental care].' I said, 'Is there a reason for that?' They just said, 'We don't have time for staff to actually take a resident to the dentist.' That was it…I thought, if the dental check-ups are still going to happen every three months, that's going to be down to me to do."*
>
> Barbara (daughter of PLwD–DwLB)

The low prioritisation of oral care that was described by those interviewed may explain, in part, the poor oral hygiene noted in studies exploring oral health of PLwD (Foley et al., 2017; Delwel et al., 2018a). These diseases that can result from a lack of preventative oral care may substantially complicate dental care decision-making. By PLwD only seeking care when symptoms arise, dentists lose the potential to discuss preventative oral healthcare. These lost opportunities mean dental diseases may affect more teeth, possibly to a greater extent. Managing these conditions in later dementia may also be more complex than if patients had sought care earlier, or the management required may be more impactful to oral function, specifically if any teeth must be extracted. A lack of preventative care may explain why a lack of routine dental attendance has been associated with a higher risk of tooth loss (Åstrøm et al., 2014, 2018) and a reduction in oral health-related quality of life (OHR-QoL) (Åstrøm et al., 2018; Torppa-Saarinen et al., 2019). Delaying attendance, therefore, may mean PLwD are likely to have more significant dental issues and fewer teeth. These outcomes present additional short and long-term complexities for patients and care teams, which could be avoided if care were sought proactively (Torppa-Saarinen et al., 2019).

In addition to the progress of dental diseases, the number and severity of dementia symptoms also progresses over time. Seeking dental care at a later point in time may mean that symptoms of dementia have a more significant impact on dental treatment delivery. As dementia progresses, treatment approaches may need to be modified to those which a PLwD can tolerate. This may mean complex restorative care that supports tooth retention is not feasible without pharmacological support such as sedation. Tooth loss may be more likely in this situation, even if a tooth could theoretically have been retained in other circumstances. The progression of dementia may also mean a PLwD may lack decisional capacity when more complex treatment is being considered. Consequently, dentists may be less able to facilitate SDM or make best interests decisions that facilitate value-concordant care.

It appears paradoxical that oral health was described as necessary, yet PLwD or family carers did not seek proactive dental care. Various mechanisms could mean that such a delay is detrimental to oral health and potentially impacts the extent to which a PLwD may be involved in decision-making. Considering these issues, there is a strong argument for encouraging early post-diagnostic dental attendance for PLwD emphasising the value of routine, proactive and preventative care to reduce the burden of oral diseases as dementia progresses.

8.3 Category 2: Accessing suitable care

PLwD and carers explained facing several challenges in finding appropriate dental care. Some PLwD who did not have an existing dentist found it challenging to find a new service in which to receive dental care:

> *"I started (to) look for an NHS dentist because by now I wasn't working, and nobody was taking NHS patients. So, because of my leg being broken, I couldn't get up...well I just didn't want the journey up to [location]. So, I haven't actually seen a dentist for my teeth since 2013."*
>
> Dorothy (PLwD–AD)

Carers seeking dental care for their relatives also faced difficulties as well as delays in receiving dental care:

> *"we'd been battling to get [dad] an NHS dentist, and we eventually managed to…mum and I were the ones that took him to the appointments…but we did eventually manage to get NHS dentistry and it was a huge, long wait for it."*
>
> Cassandra (daughter of PLwD–VD)

Those interviewed primarily discussed NHS dental care and private care was discussed only briefly. The cost of dental care was not described as a major problem by those interviewed. This may be due to the nature of the sample recruited which broadly contained those able to access and use technology. Having the financial ability to own and use the technology needed for Zoom interviews may mean the sample was limited to those with sufficient financial resources not to be concerned about the cost of dental care. Another explanation for a lack of concern about costs of care may be that those from disadvantaged socio-economic groups are exempt from the cost of NHS dental treatments hence did not face any financial consequences of requiring dental care.

A review of numerous studies, conducted mostly outside of the UK, however, noted that the issue of insufficient *"economic capital"* has been described as a significant challenge encountered by PLwD (Scambler et al., 2021, p. 11). The cost of care has also been described as a barrier that can prevent PLwD from receiving dental treatment (Göstemeyer, Baker and Schwendicke, 2019; Legge, Latour and Nasser, 2021). Instead of describing cost, however, those interviewed described that simply accessing any form of dental care was a significant challenge. This may reflect the inherent challenges of a publicly-funded healthcare system in which access challenges, rather than cost issues, may have arisen as a consequence of a limited volume of resources. Barriers to accessing dental care can arise at any point, from attempting to contact a service to physically entering a building for care provision;

difficulties in each of these processes can increase with increasing age, frailty or ill health (Borreani et al., 2008). Symptoms of dementia may make these processes even more challenging, and PLwD may need additional support to overcome them to access dental care (Göstemeyer, Baker and Schwendicke, 2019; 2021; Latour and Nasser, 2021).

When considering care delivery for those with more significant dental issues and dementia symptoms, it may be more appropriate for a dentist with additional experience or qualifications to plan and deliver the dental care required. Specialist services (CDS or HDS) should be available and accessible (NHS England, 2015). However, a review of multiple studies undertaken by Kc et al., (2021) suggested access to such services was highly variable and was system-dependent. Either a lack of availability, a lack of awareness or inadequate care pathways meant that many of those interviewed sought dental care in a GDP setting instead of a specialist service. Jean described that she felt her mothers' dementia symptoms meant that care in a GDP setting, was inappropriate:

> *"One of the main difficulties was sitting in the waiting room, that was really, really difficult with someone with dementia because you know she'd be swearing or she'd be trying to slap people on the head or she'd just try and run out the door and the other thing was getting the dentist to look in her mouth, she would just try and bite them [right] which was very, very hard."*
>
> Jean (daughter of PLwD–AD)

When more specialist care was required for PLwD at moderate or advanced stages, family members described not knowing how to access relevant services. Some PLwD received care in a specialist setting, yet descriptions of the route by which this was achieved suggest care pathways are convoluted or unknown to relevant professionals:

> *"I had several failed referrals…I would ask the dentist to put pressure and ask for a referral to a special dental service. And the dentist would then be told that they would say no from the get-go, 'oh we'll try but normally they don't see cases like this'. And I just said, 'well where do people go?' and I went literally round and round in circles and even the [Hospital Name] where my mum was seen, they didn't know and couldn't advise. And these are the most specialist*

> *people right, dealing with dementia. They didn't know where to go…nobody actually knew…honestly, I'd say it took about a year to get referred [to a specialist service]."*
>
> Simon (son of PLwD–AD)

The situation detailed by Simon details that various dentists and members of the wider health and social care team might have inadequate knowledge of when or how to refer PLwD with complex care requirements Those interviewed by Scambler et al. (2021, p. 8) detailed that the process of seeking appropriate care was "*overwhelming*" for PLwD and carers whilst PLwD and caregivers interviewed by Curtis et al. (2020) noted that dental care was excluded from a "*package of social care*". NICE guidance on post-diagnostic support for PLwD and carers (National Institute for Health and Care Excellence, 2018a, section. 1.8) discusses the importance of providing care for long-term conditions affecting PLwD, including pain. This document, however, makes no specific reference to oral or dental conditions and their management. On this basis, members of the wider health and social care team may not consider patients' oral health needs and may be unaware of the local specialised services. Having clear and accessible referral pathways and promoting these to health and social care teams may support PLwD to receive more timely care in appropriate settings.

Instead of accessing specialist care, PLwD and family members describe seeking care from any dental service where they could arrange an appointment. In such services, generally in GDP, PLwD and family members felt dentists were not always trained or capable of providing the care that PLwD required. Therefore, they described experiences of receiving dental care that they felt to be unsuitable. 'Suitable' care, from the views of those interviewed, was not explained in terms of services being general or specialist, or the specific treatment or treatments provided. Instead, those interviewed described suitability by referring to specific features of how a service operated and how clinicians interacted with PLwD and family members:

> *"I've had a lot of people who don't understand [dementia], so they're talking to him but they don't really take in the fact that he's not going to remember anything. So, I have to go with him if they'll let me."*
>
> June (wife of PLwD-AD)

Multiple PLwD also communication they felt was unsuitable:

> *"out of the three dentists I've seen there two have been, natter natter…it just drives me bonkers…I can't cope with it. He speaks very fast and says nothing useful… I process things a bit slower, and I can get lost then in conversation once I lose track of the conversation."*
>
> Harold (PLwD–mixed dementia)

Caregivers also reported a perception that dentists' communication skills were suboptimal. Jean elaborated on the consequences of this problematic communication:

> *"if you don't know how to communicate with [PLwD] obviously, you're not going to. So you're going to exclude them and for a lot of people that might mean they don't have a very good experience. Not necessarily the right decisions going to be made and I think a lot of people are very frightened of communicating with a person with dementia. So I think of all the skills that you could give health professionals, how to communicate is probably the most important one."*
>
> Jean (daughter of PLwD–VD)

It is noteworthy that problematic communication was mainly described by PLwD or carers when discussing care received in general dental practices. Dentists should routinely adapt their communication skills to meet the needs of PLwD (Faculty of General Dental Practitioners, 2017, pp. 19–23; Kerr, Curl and Geddis-Regan, 2020). As well as supporting a person's care overall, optimising communication is fundamental to facilitating an effective decision-making process (Kasper et al., 2012; Elwyn et al., 2014). However, enacting significant adjustments to communication to support people with moderate or advanced dementia may exceed what an NHS dentist is able and commissioned to deliver (NHS England, 2015). Where symptoms of dementia substantially impact communication, it may be more appropriate for PLwD to receive care in specialist settings. Clinicians in these settings would typically have additional communication training and resources to practically support PLwD with communication, decision-making and consent processes.

A further benefit to PLwD undergoing at least an initial dental assessment in specialist settings is the ability for such services to discuss and offer a full range of treatment options and modalities. In contrast, a GDP can only suggest and discuss the options for care available in their setting or the possibility of a referral to a specialist setting. Definitive decision-making, therefore, may be limited to the available approaches in a GDP setting or may be delayed when a referral to specialist care is indicated. Early access to a service where a full range of options and approaches to care could be considered to ensure people are signposted to the dental setting most appropriate for their needs. This would, in theory, minimise challenges with access to services as people should be directed to a service that can facilitate both practical access and meet the specific needs of each PLwD.

8.4 Category 3: Wanting (the person living with dementia) to be understood

Within and beyond the dental content, PLwD described feeling that healthcare professionals did not have adequate insight into dementia:

> *"If [dentists] would only simply understand that [dementia] is a brain disease which starts somewhere, and you are anywhere on that huge, long continuum and everybody is different and progresses at different speeds. And everybody has different symptoms or different combinations at least."*
>
> Harold (PLwD–mixed dementia)

Many PLwD explained how they felt dentists were unaware of the reality of living with dementia. Charlie presented a specific example of how a routine aspect of dental care was traumatic for him since experiencing symptoms of dementia:

> *“You know when dentists do that little wash thing, and the water hits the back of your throat? It feels like it’s waterboarding…it never used to before, I could get my head around it as part of a dental procedure, but you know, when they do that…it feels as if you’re drowning, and even though it’s only a bit, it triggers that drowning feeling.”*
>
> Charlie (PLwD–AD)

Although Charlie recounted this problematic aspect of care, he did not report having explained this experience to his dentist. He also did not describe that the dentist he visited sought to identify his concerns before treatment began. However, dentists clearly cannot pre-empt each potential difficulty PLwD may face in the dental setting. They could, however, ask patients about their experience of living with dementia and if any changes to care delivery might support them to receive dental care. None of those interviewed reported being asked about their preferences regarding how dental care is delivered. This meant that PLwD sometimes had to proactively express these preferences at a less ideal time following the beginning of dental treatment:

> *“He didn’t tell me what he was doing. They seem to just carry on. And he said, ‘oh I’m going to give you an injection now’. I said ‘no, I don’t need it, I don’t want it, I don’t need it’…And I think it’s that I still want to be in control kind of feeling but I don’t know if it’s because of the diagnosis or if it’s just because they give everybody an injection, but [I’d] rather [they] discuss it with me.”*
>
> Christine (PLwD–AD)

Other PLwD may not feel able to express their views as Christine did. Fumagalli et al. (2015, p. 386) describe empowerment as *'the possession of conditions that make patients "willing and able" to play an active role in their care’*. Therefore, to express their individual views and preferences, PLwD must be able to communicate their preferences and be willing to do so. Symptoms of dementia such as dysphasia, dysarthria and disorientation may all affect PLwD's ability to express their preferences for care to a dentist, even if they were willing to do so. Dorothy presented her concerns about this situation arising in her future dental care:

> *"It really worries me that people with dementia like me are not able to communicate the problem, or the person trying to get the message isn't clever enough to work out what the problem is. And then, if they do work it out, will I understand that they're actually trying to help me?"*
>
> Dorothy (PLwD–AD)

Dental fear and anxiety may also impact how empowered a PLwD may feel to express their views in a dental setting. Numerous PLwD provided reports of dental fear, which originated from childhood dental care experiences. They described how these experiences shaped their current attitude towards dentistry:

> *“the dentist would take over the headmaster’s study and then he would walk in through the door and there was a big gas cylinder with the mask hanging there. And you sat in the chair and the nurse would come along and tell you to do things and this terrifying man in a white coat would come to do...something...whatever it might be. Some people could have nightmares about things like that, I was scared, I don’t mind admitting that.”*
>
> Gerald (PLwD–VD)

Göstemeyer, Baker and Schwendicke, (2019) and Legge, Latour and Nasser (2021) summarise how older people accumulate adverse dental experiences over the life course and that the aggregation of these experiences adversely affects perceptions of dental care over time. Neither of these studies explored the specific experiences of PLwD. However, when considering the accumulation of experiences in the context of dementia, Kitwood (1993) described that a person's experience is shaped by interacting factors, such as personality, physical health, neuropathology, psychosocial factors, and biography. This 'biography' of past experiences becomes highly relevant when considering how to support a PLwD (Nuffield Council on Bioethics, 2009, p. 31), especially when dental care is considered part of their physical health that may contribute to psychological factors and social interaction. Facilitating person-centred dental care and recognising personhood means dentists need to understand each of these factors and how they may change over time.

Understanding these interacting factors becomes particularly crucial if a PLwD cannot express their views, preferences, or other factors they feel are relevant to their care. Family members described how PLwD had approached their oral health and how this had impacted their current oral status and attitudes toward dental treatment:

> *"[My dad] didn't have good teeth before he developed dementia anyway. He had a bit of a sweet tooth so he enjoyed things like honey, and he would sometimes have orange juice at bedtime and things like that. So, he was doing some things that weren't great for his dental health even before he developed dementia."*
>
> Cassandra (daughter of PLwD–VD)

Both PLwD and family carers emphasised the importance of understanding these experiences and considering them for each individual. However, many participants described feeling that dentists had not sought to gain this understanding:

> *"[dentists] didn't have the wider picture of who dad had been…they all saw him as somebody who was already bedbound, so I think it's important to get different viewpoints from people who have a different understanding of the individual".*
>
> Liz (daughter of PLwD–AD)

The accounts of PLwD and caregivers suggest that they feel little attention is given to PLwD as unique individuals. Not only did PLwD and carers report that they felt PLwD were misunderstood, but they also felt that there was no attempt even to try to understand their unique needs and preferences. In SDM, understanding such values is paramount to supporting appropriate decision-making (Elwyn et al., 2017). When decisional capacity is lacking, the lack of consideration of these factors diminishes personhood and ignores the individual nature and preferences of each person. Dentists must seek the required information about individuals directly (Nuffield Council on Bioethics, 2009, p. 74) or work with carers to identify what factors PLwD may have considered when approaching decision-making (MCA 2005, section 4(6); Wade and Kitzinger, 2019). Doing so could ensure the person remained central to decisions made with or for them, optimising autonomy and ensuring a person-centred approach is used, even if the PLwD cannot contribute to this.

8.5 Category 4: Wishing to be involved in decision-making

PLwD expressed strong views about how they felt they should be involved in decisions about their dental care. Gerald summarised the various ways he felt a PLwD could respond to the treatment proposed by a dentist:

> *"You can do one of three things. You can say thank you very much, okay I'll go with you. You can ask about other options, or you can say thank you very much, go away and go to another dentist. You have freedom of choice".*
>
> Gerald (PLwD–VD)

Whilst Gerald reported that a patient could ask a dentist about other options, he did not report ever having done so. No further participants described proactively asking dentists about what options were available to them or seeking further opinions, but multiple PLwD described acquiescence when advised on what treatment to receive:

> *"…you go to see the expert, the expert tells you what to think…you say 'right, fine, okay I'll go with you'".*
>
> Jonathan (PLwD–YOD-AD).

Simple acceptance of a dentist's suggestion may be due to PLwD not having prior knowledge of dental care options or possibly due to dentists not actively informing them of any options that might be available. Research in the field of SDM details that patients have a strong desire to be given a range of options for treatment, even if they may not always wish to make a decision independently (Flynn, Smith and Vanness, 2006; Chewning et al., 2012). The fact that most PLwD did not describe asking their dentists about treatment options may reflect a sense of disempowerment. The issue of empowerment is relevant and similarly important in decision-making as during treatment provision. If a person were empowered to explore and discuss the options for their care, then the care provided may be based on an understanding of what support or adaptations a PLwD may need for dental treatment to be tolerable and acceptable to them.

Patients may expect recommendations to be offered, and some models of SDM suggest this is appropriate (Makoul and Clayman, 2006). The General Dental Council even encourage dentists to make recommendations (General Dental Council, 2013, section 3.1.3). Therefore, it may be entirely appropriate for a dentist to suggest which of multiple treatment options they feel is most appropriate in each situation. If a recommendation is not open to discussion, however, a paternalistic approach to care may be occurring. Ploug (2018) details that clinicians may 'nudge' patients towards a specific treatment and that patients may be adversely influenced by the recommendation of a specific treatment approach. Eggeling et al. (2020) studied the impact of recommendations and noted that these significantly influenced patients' attitudes towards treatment. Recommendations could, therefore, be either appropriately based on an SDM process or could reflect a more paternalistic approach to care where knowledge is not adequately shared with a patient. Charlie explained how he felt dentists' knowledge was significant compared to what a patient may know about the options recommended to them:

> *"the expert always has that little edge over you. You can be a clever clogs, you can say what you like but you're never as good as the professional. Because the professional…it's their living, it's their way of life. Whereas you go in you've got a problem once every five years or something."*
>
> Charlie (PLwD–AD)

Charlie's statement could be interpreted in numerous ways, but one could argue his perspective is one of distrust or feeling less capable to express his views in a dental setting. Clinicians could proactively strive to provide appropriate knowledge to patients as part of SDM, yet Joseph-Williams et al. (2014) highlighted that both knowledge and power are needed to optimise patient involvement in decision-making. Consequently, providing knowledge alone to PLwD may not translate to active involvement in decision-making. To fully contribute to decision-making, a person would have to be empowered to do so (Fumagalli et al., 2015). A lack of empowerment may explain why multiple PLwD described being completely absent in a decision-making process:

> *"[The dentist] just makes the decisions on his own and says what he's going to do. And instead of saying these are the options or what would you like me to do or something. He just kind of gets on and does it…I don't like that. He must discuss it with me and talk to me. It's like I'm not a baby…you mustn't tell me what to do."*
>
> Christine (PLwD–AD)

To support patient involvement in decision-making, clinicians need to actively address power differentials as part of patient-centred care delivery (Pauley, 2011; Nimmon and Stenfors-Hayes, 2016). This is particularly important in dementia, where the condition's symptoms can affect the cognitive and practical abilities a patient needs to actively engage in decision-making processes (Hulko and Stern, 2009, p. 70). Qualitative research has found that PLwD seek to *"hold on to their decision making abilities for as long as possible"* (Fetherstonhaugh, Tarzia and Nay, 2013, p. 147). The support of carers could help mitigate disempowerment and support a person to 'hold on' to decision-making despite dementia symptoms (Sinclair et al., 2019). Multiple PLwD expressed how they wish for family members to support them in the dental environment. Charlie detailed the impact this may have on a decision-making process:

> *"if you're with your carer you'd have a three-way discussion like, you know, and explain what are the best options for you, you know. You'd be surprised how many people will then make the decision themselves, like."*
>
> Charlie (PLwD–AD)

Charlie's statement suggests that family member presence can facilitate ongoing autonomy for PLwD. Caregivers similarly felt that their role could support a PLwD to continue to be involved in decision-making:

> *"These days obviously I'd know a great deal more and I would totally advocate that the person was still to be involved. Even if they lacked the capacity and can't actually go on to make the decision themselves, they should be involved."*
>
> Kimberley (sister of PLwD–DwLB)

The extent to which a PLwD can contribute to decision-making is likely to reduce over time (Groen-Van de Ven et al., 2016; Bhatt et al., 2020; Lahey and Elwyn, 2020), meaning there is a risk of PLwD being less involved in decision-making as dementia progresses, even when decisional capacity is retained (Miller, Whitlatch and Lyons, 2016). Family members can support the ongoing involvement, of their relatives in decision-making, but clinicians involved in the process need to be similarly invested in hearing the PLwD's voice. Whilst some PLwD such as Christine (see above) described simply not being involved, Lindsey detailed that her mother was essentially ignored during conversations in a dental clinic:

> *"mum was always talked over, it was always a question of, 'what are we going to do with her teeth now?'. It was never a question of, well 'what would you like to have happen?'. You know, it was never like that. It was like she was there, but also that she wasn't."*
>
> Lindsey (daughter of PLwD–AD)

The suggestion that Lindsey's mother was 'talked over' in healthcare settings suggests that she was not acquiescent in the decision-making process, but that she did communicate and attempt to contribute to it. Such 'talking over' silences the voice of PLwD (Purves and Perry, 2009, pp. 172–173) and undermines their autonomy and value in making decisions about their care. Triadic consultations involving PLwD and carers and clinicians can limit the ongoing involvement of PLwD (Tuijt et al., 2021), Both PLwD and carers require specific support and accommodation in their unique roles in supporting the care of PLwD (Pauley, 2011; Aaltonen et al., 2021; Tuijt et al., 2021). To account for the complex dynamics of a triadic interaction, dentists need to proactively focus on the PLwD and strive to hear their comments before inviting others into a discussion.

Mirroring PLwD's desire to be involved, family members also described a desire to support decision-making and how they wished to be actively involved in this process, especially when decisional capacity was absent. Some family members felt that their role was to specifically act as decision-makers:

> *"I mean I feel that morally and emotionally, in my mum's best interest, it should be me [making decisions] but I don't feel that I've got all the skills and information to make that decision on my own."*
>
> Barbara (daughter of PLwD– DwLB)

Legally, a family member could only act as a decision-maker when holding an LPA for health and welfare, which none of those interviewed described having. Family members described having supported PLwD with a range of health and social care decisions, hence expected to be involved in decisions about dental care. Despite their desire to support the decision-making process, however, family members described feeling passive or absent role within it:

> *"the home was almost made the port of call for the dentist and it was assumed that the nursing home would know what to do by her…the dentist contacted the home and then the home would have contacted us, but we didn't have any direct communication with the dentist."*
>
> Laura (daughter of PLwD–AD)

When family members had actively facilitated dental care for a PLwD, a similar lack of involvement was described:

> *"they haven't involved me in the past…I get frustrated… because [Name of husband] won't answer the questions and people presume he can remember it…so I don't feel involved at all even though I've got to help them figure what's wrong."*
>
> June (wife of PLWD–AD)

June's explanation of her experience suggests that the value of her knowledge of a PLwD was disregarded. A similar lack of involvement in decision-making was reported by Poonam, who explained she was simply informed about what would happen with her mother's care:

> *"they said, 'right we really have to go in and look at what's going on under a general anaesthetic' which scared the living daylights out of me because a lot of people with dementia don't do very well under a [general anaesthetic], and then they said 'be prepared, we might have to remove all of her teeth'."*
>
> Poonam (daughter of PLwD–FTD)

The care decision made for Poonam's mother clearly aligns with a paternalistic decision-making approach, even if the decision made was felt to be in her best interests. The lack of involvement of Poonam in the decision-making process also suggests there was little effort made to seek her view on her mother's care. Paternalistic care is typically seen as inappropriate (Charles, Gafni and Whelan, 1999; Pomey, Denis and Dumez, 2019, pp. 96–98) and the explanation provided here suggests that a comprehensive BIDM process may not have been followed. To support appropriate care, family members may be able to provide appropriate information about PLwD to dental teams. This knowledge can allow PLwD's known views and preferences to be considered during BIDM (National Institute for Health and Care Excellence, 2018b, p. 27). Though dentists may have considered such factors in situations like those detailed by Poonam, it is unclear how relevant information about a PLwD would have been gathered if a family member was not consulted.

Whether or not families were intentionally or inadvertently excluded from decision-making cannot be identified from interviews with caregivers alone. However, it is possible that dentists did attempt to consult family members, but that family members felt the extent or nature of this consultation was insufficient. Exploring the factors that can support SDM, Sepucha et al. (2013) summarise how a good decision-making process includes sufficient involvement of the decision-maker, making sure that they feel informed about options and that their values and preferences are gathered. However, in many instances, families – especially those without LPA – are not decision-makers meaning the extent to which they are consulted may not need to be so comprehensive. This may lead them to feel excluded, even if a dentist has sought to involve them and complied with the legal requirements of the MCA.

Whilst it is possible that dentists simply did not seek to involve family members, there are further potential explanations for why family members described feeling their involvement was insufficient. One possible explanation for the perceived lack of involvement is that decisions were required in situations where only one treatment option was possible to address a presenting concern. Generally, SDM is sensible where multiple options for care exist and where such options are "preference-sensitive" (Llewellyn-Thomas and Crump, 2013). Situations may have arisen for PLwD where only one approach to care was possible (for example, a simple repair of a broken tooth or removing a symptomatic heavily decayed tooth). In this situation, decision-making is simplified, especially if treatment is indicated to address a specific problem and no alternative approaches are felt to be available. There may be less need for deliberation in such instances, and families may feel as if they have not been adequately involved in decision-making even though they were consulted. A further explanation for a perceived lack of involvement is that family members were in fact consulted but that this occurred only superficially, meaning the extent of involvement was misaligned with their expectations.

An additional explanation for carers feeling excluded may be that they may have contributed to discussions about a PLwD's care but that these contributions did not alter the care provided. A systematic review (Spalding, 2021) highlighted that there could be significant dissonance between the preferences of PLwD and their family members. Furthermore, family members often support decisions that reflect their wishes for the PLwD instead of the PLwD's wishes (Marks and Arkes, 2008), and due to this, family members can under-emphasise PLwD's preferences as dementia progresses (Reamy et al., 2013).

When considering what may be in the best interests of a PLwD lacking decisional capacity, dentists need to consider the discrepancy between the ideas shared by family members and any preferences or wishes a patient might previously have expressed. In addition, dentists must consider a wider range of factors – such as what is feasible to deliver, or a person's systemic health – than caregivers may have thought about. By navigating inconsistencies and considering these broader factors to determine what is in a PLwD's best interests, it may be that dentists' actions lead carers to feel excluded from the process of decision-making.

As PLwD and caregivers both explicitly describe how they wish to be involved in decision-making for dental care, clinicians will need to proactively strive to meet this expectation by facilitating and encouraging genuine in-depth discussions about appropriate care. The data generated herein suggest that PLwD and carers would be receptive to this. If dentists were to facilitate such discussions with PLwD, they could support empowerment, promote autonomy, and provide value-concordant care. Dentists should initiate open discussions with caregivers based on a shared desire to deliver the most appropriate care for each PLwD. Such discussions should be sufficient for family members to feel involved and that their views have supported the delivery of appropriate care. When the views and preferences of PLwD are only partially relevant to best interests processes, the partial relevance of these views should be discussed with family members considering a person's broader interests to collaboratively agree upon the treatment required.

8.6 Category 5: Expectations and outcomes of dental care

In addition to the expectation of being involved in treatment decision-making, PLwD and carers sought dental treatment that led to specific outcomes. PLwD described a desire to avoid adverse outcomes, such as pain and infection, whilst living with dementia:

> *"Infections do seem to make dementia go downhill quicker, particularly bladder infections. I'm guessing dental abscesses would do the same with something to do with the sepsis process. So, if you have got toothache, it's miserable isn't it? I'd much rather got it sorted."*
>
> Lynne (daughter of PLwD–AD)

Multiple PLwD detailed a willingness to undergo extensive treatment to avoid dental pain in the future:

> *"I just do not want to be sitting there with a tooth ache like that, I would do anything to avoid that. Which is going as far as having no teeth, I would be okay with that."*

Dorothy (PLwD–AD)

Caregivers also accepted that an extensive amount of dental care might be necessary for PLwD:

> *"The final outcome should be that [my sister's] health, her gums and the teeth are at a stage that they don't cause her any more problems. If that would mean full extractions then I would even go that far..."*

Gary (brother of PLwD–AD)

Pain management was often the driver for seeking care (as detailed in Category 1), which aligns with how PLwD and carers prioritised this as an immediate aim for treatment. However, as summarised in Category 1, the desire to avoid pain and infection did not mean proactive care was not sought to prevent these outcomes. As detailed in Chapter 7, a qualitative study (Nordenram, Rönnberg and Winblad, 1994) and a Delphi process (Jones, Brown and Volicer, 2000) both explored priorities regarding dental care outcomes for PLwD. Both studies found pain management to be a top priority. Infection was not such a significant concern to those involved in the aforementioned studies. Regrettably, neither study included PLwD, so their applicability may be limited when considering what outcomes may be important to PLwD individually or as a group.

In many situations, various treatments could be provided to address dental pain. Therefore, the type of dental treatment provided should be determined based on an individual's expressed or known preferences and what is feasible considering their dementia symptoms and dental status. In the absence of pain, PLwD specified additional goals of care, particularly regarding the loss of teeth and the need for dentures:

> *"I'm conscious I don't want to lose any more teeth, and that's a big thing…I'm more conscious now and more conscious of it…I think just with the teeth I've realised that they don't grow back. I can't afford to lose any more and I wouldn't like a plate, it would be very uncomfortable. I'm not too bad at the minute but I wouldn't want to get a big plate."*

Jonathan (PLwD–YOD-AD)

Paralleling Jonathan's statement, PLwD at an earlier stage were often wary of tooth loss. This was partly because they equated tooth loss with the need for a denture and felt dentures would be associated with problems:

> *"I can't imagine getting used to dentures or anything now. I don't know what they are these days, but I can't imagine having to get used to something knew."*
>
> Pauline (PLwD–AD)

For those who already wore dentures, there was a reluctance to lose teeth as this could cause further denture-related problems:

> *"I've got…an insert thing. A bridge? Anyway, I've got something which has teeth there and a couple of teeth for chewing back here. Uncomfortable. I don't typically like wearing it."*
>
> Harold (PLwD-mixed dementia)

Though the PLwD interviewed were wary of tooth loss, studies exploring tooth loss have highlighted how the broader population has contrasting views about losing teeth as summarised in Chapter 7 (Category 2, 'Providing individualised care'). Alongside concerns about dentures, the negative perspectives on partial or complete tooth loss described in Chapter 7 could explain why the PLwD interviewed - all of whom were partially dentate - sought to avoid further tooth loss. The legitimacy of this goal could be debated as research has identified how denture-wearing can be positive and can contribute to oral function, positively affecting impacting OHR-QoL (Klotz et al., 2017; Zenthöfer et al., 2020; van de Rijt et al., 2021). Furthermore, wearing dentures may restore a sense of self-worth (Nordenram et al., 2013). These studies highlighting the value of prosthetic rehabilitation did not specifically explore oral health outcomes for PLwD. While PLwD may benefit from wearing dentures, they may also encounter unique challenges. All patients receiving dentures will need to adapt to wearing them yet age, cognitive impairment, or neuromuscular disease can limit a person's ability to adapt to accept dentures. Wearing dentures is, in part, a learned process reliant on neuromuscular control (MacEntee, Hole and Stolar, 1997; Eberhard et al., 2018; Tôrres et al., 2019) hence diseases affecting cognition, motor control, or both can limit how easily a person can tolerate a denture or whether they can adapt to wearing one (MacEntee, Hole and Stolar, 1997). For some, a greater degree of time and perseverance may be required (Eberhard et al., 2018). Whilst tolerance may be an issue, it is essential to consider self-worth and the value of at least attempting to provide such rehabilitation for PLwD, especially when tooth loss cannot be avoided.

In addition to the outcome of dental treatment, PLwD and caregivers wish to avoid distress when treatment is provided. Both groups felt that any dental care had to be delivered in a way that was appropriate for each PLwD and that managed any anxiety or significant dementia symptoms:

> *"I was sitting on the floor holding his hand and he's telling me take the pain away, stop him [Janet], [Janet], he's hurting us, and ah it was horrendous, absolutely horrendous."*
>
> Janet (wife of PLwD–FTD)

Based on a desire to avoid distress, carers felt that even basic treatment in the absence of pain should be avoided for people living with advanced dementia:

> *"my mum wouldn't have coped with [dental treatment], she would have been frightened, she wouldn't have opened her mouth, we wouldn't have got her in the dentist chair, it was just too much stress for her and too much stress for us."*
>
> Jean (daughter of PLwD–AD)

The desire to avoid distress has been identified in studies beyond the dental context (Jennings et al., 2017). Of the two studies exploring patient's priorities and preferences in the dental setting (Nordenram, Rönnberg and Winblad, 1994; Jones, Brown and Volicer, 2000), only the latter study alludes to avoidance of distress by mentioning a *"relaxing oral care environment"* far down a list of priorities (Jones, Brown and Volicer, 2000, p. 332). These studies of dental priorities predate the broad acceptance of the need to maintain personhood throughout the progression of dementia. More recent perspectives emphasise the retention of the self throughout dementia (Kitwood, 1997, pp. 14–16; Hughes, Louw and Sabat, 2006, p. 246; Tsai, 2009, p. 67). From this perspective, distress or agitation may not simply be dementia-related symptoms or behaviours. In fact, the prevailing view is that such distress is a sign of an unmet need of a patient who cannot verbally express this (Hughes, Louw and Sabat, 2006, p. 245; Kontos and Naglie, 2009, pp. 187–188). This distress could be a manifestation of a person's historic dental anxiety or fear, which could be retained or potentially amplified as cognitive impairment progresses. It is also possible that distress is purely a symptom of dementia and that distress arises during dental care for those with no history of dental anxiety but who may not understand what is happing during dental treatment provision.

Specific forms of additional support may be required where treatment is necessary but associated with a risk of distress. The primary approaches sought by PLwD and caregivers were pharmacological aids such as benzodiazepine premedication or procedural sedation. Considering their potential to cope with dental care in the future, PLwD expressed how some sort of pharmacological anxiety management would support them, and they desired such an approach for their future care:

> *"if it was me and my brain was now at that stage, today, I would say, when I get to the stage, sedate me. Cause it would be much less distressing for me, being sedated you do what's needed to be done, than somebody trying to reassure me and I'm not understanding it."*
>
> Dorothy (PLwD–AD)

These approaches require caution and are often inappropriate for those with comorbidities, increasing age, or psychiatric symptoms of dementia (Girdler, Wilson and Hill, 2017, p. 104). Due to the potential for complications where these factors are present, these approaches are typically reserved for use in hospital settings (Intercollegiate Advisory Committee for Sedation in Dentistry, 2015). Even if their use were possible, pharmacological support might increase the medical risk of care delivery. Furthermore, sedation or general anaesthesia is more restrictive to a person's autonomy and freedom. Therefore, unless strictly necessary and deemed in a person's best interests, using these approaches may not adhere to the MCA's requirement to use the least restrictive approach to facilitate care (MCA, 2005 section 1(6)). When treatment is likely to cause distress, or when it is not feasible or safe without using these approaches, their use may be justifiable. As suggested by the broader literature and the content of the interviews conducted in this research, the nature of both treatment and how it is delivered should be determined collaboratively by dentists working with PLwD, and their carers where appropriate. In doing so, decisions should be made to ensure pain is managed, PLwD's other concerns are met, yet where distress is minimised or avoided when it is possible to do so.

When decisions about dental care had been made, including for teeth to be removed, relatives described how PLwD coped in the longer term. Specifically, family members detailed how their relatives coped with wearing dentures. Contrasting the concern expressed by multiple PLwD, some were able to adapt to wearing dentures:

> *"he was alright with his dentures; he had a wonderful appetite and ate very healthily I might add. But once, whether the dentures just got forgot about when he got increasingly poorly and then the last few years of his life he was just on soft food."*
>
> Greta (daughter of PLwD–AD)

Many PLwD, however, were described as experiencing problems wearing dentures and some were reported to be unable to wear dentures at all. Where this had occurred as part of a decision to address pain, however, the ends appeared to justify the means and this outcome was seen as acceptable:

> *"they did indeed remove all of her teeth which did then affect my mum's swallowing, her ability to eat and swallow. But basically, it needed a wee think around the food that's all. And so actually having all of her teeth removed was the best thing. My mum used to do this repetitive thing with her mouth and constantly stick her tongue out and she'd be dribbling and drooling. All of that has subsided, it's actually quite unbelievable."*
>
> Poonam (daughter of PLwD–FTD)

Treatment outcomes from the perspective of PLwD were mainly discussed in terms of ideals or hypothetical future situations. Carers were able to reflect on observed outcomes of dental care for PLwD, such as their experiences of losing teeth. Despite feeling insufficiently involved in dental care decisions, carers typically accepted and understood the outcomes of dental care that PLwD underwent. The concept of decision regret is detailed as 'remorse or distress' over a decision (Brehaut et al., 2003). Though decisional regret has not been measured in dental care for PLwD, Elidor et al. (2020) found that decisional regret was typically low for informal carers involved in a wide range of decisions for family members. The data generated in this research seem to align with this finding. This implies that health outcomes acceptable to PLwD or carers are arising, although any measures of decision processes or outcomes may highlight limitations in how dentists facilitate decision-making with or for PLwD.

The potential that ‘suitable’ decisions are being made without the active involvement of patients or carers does not mean that they should not be proactively and comprehensively involved in decision-making for dental care. Proactively involving patients or carers in decisions by seeking to understand their goals for care can support the management of expectations and the attainment of acceptable outcomes of care. Goal-orientated care has been described for PLwD and carers (Kaldjian et al., 2010; Kelly, Rid and Wendler, 2012; Jennings et al., 2017, 2018; Dutzi et al., 2019) and has parallels with value-concordant care. SDM may include discussing outcomes and what a person hopes to achieve to inform care discussions. Goal setting, however, is distinctly separate from SDM as it focuses on an outcome of a decision or intervention, as opposed to whether it matches a person's known wishes. Goal-orientated care is generally acceptable to carers and can support their involvement in facilitating best interests decisions (Wendrich-van Dael et al., 2020). Goal-setting and the related concept of advanced care planning have not been extensively explored in relation to dental care, yet dentists could proactively support patients to set short- and long-term goals.

If goal setting were to be conducted, two possibilities must be considered. The first is that it may not be possible to adhere to specific goals in the short term or as time progresses. In the short term, if a patient has unrealistic expectations of dental services, their goals may not be possible to achieve. Here, an SDM process could negotiate and explore the available options considering a person's specific preferences. For example, if a patient's goal was to retain their teeth, but they developed a substantial recurrent infection in later dementia that could not be resolved by other means, removal of teeth may then be in their best interests. This approach to care may be best for them even if it contradicts their previously expressed preference. The second consideration is that a person's goals may change over time. This can be due to their changing circumstances and competing priorities (such as other conditions and needs, as explored in Category 1) and is a key aspect of remaining a person (Kitwood, 1993). People's goals or preferences may also change due to advancing dementia (Wright, 2019). Therefore, if goal setting for future care were to be undertaken, the possibility for a person's future goals to evolve from those initially expressed should be accepted and acknowledged as an essential part of this process.

The data generated in this research suggest that appearance is a particular area in which patient or caregiver perspectives may change. Despite the value of appearance in self-worth (Nordenram et al., 2013; Warren et al., 2020), no PLwD expressed substantial concern about their appearance when their future dental care was discussed. Two possible explanations are that those interviewed did not view appearance as a significant issue or that they do not feel that their future dental care would impact their appearance. An alternative explanation is that PLwD accepted that their appearance might be affected over time. Discussing this possibility for himself, Jack reported:

> *"I suppose, well once you get to that stage, you don't care what you look like. I believe I wouldn't care what I looked like, I mean I wouldn't have the capacity to understand that people were judging me on my looks or whatever, so from that perspective, it wouldn't bother me."*
>
> Jack (PLwD–AD)

Such a statement highlights how PLwD may have some insight into their future, including how their dental needs and personal preferences may change. That said, it is arguably impossible for PLwD to be certain about how they would feel at an unspecified future time about where dementia symptoms and their severity have progressed (Wright, 2019). Though PLwD may express a preference and be aware of how their priorities may change, they cannot definitively predict these new priorities, preferences, or goals. If we recognise personhood as dementia progresses, then PLwD may continue to hold the same preferences or may choose to take a different view of their care.

The way the progression of dementia may impact the views of PLwD could potentially be explored as part of planning for future care. Any changes to PLwD's preferences could potentially coincide with a point where a formal lack of capacity is determined for decisions about dental care. Family members who were consulted when their relative lost decisional capacity for dental care described an awareness that a person's past views might be less relevant or applicable to a presenting scenario:

> *"with my mum, I'd be less concerned about her having fewer or no teeth and I don't actually think she'd be aware of that. I think a few years ago, it would have been very different because a few years ago, I'd take her to get her hair done and she'd come out and one of the few things she'd say to me was, 'Oh, does my hair look nice?' I'd say, 'Oh Mum, it looks lovely.' That was*

> *still there but that's not there now. For me, the priority would be that she wouldn't have pain."*
>
> Laura (daughter of PLwD–AD)

Explaining why a similar change in preferences or priorities arose, Gary articulated, concerning his sister, that:

> *"If you asked her what she wanted, she might give an answer, but it might be a different one today and a different one tomorrow…when she was still playing bowls and going out socialising, I think she'd have been more interested in sorting things, but she doesn't seem to care now…she's not bothered, she doesn't know. She's not going out and she's only visited by the family. I would go for her being able to eat and not be in pain before I'd go for cosmetic surgery that would enhance her smile…that just seems fruitless at this stage."*
>
> Gary (brother of PLwD–AD)

People's variable views of oral health (MacEntee, 2006; Borreani et al., 2010) and how these may change over time (MacEntee, 2006; Gibson et al., 2019) can affect how each person may value or view oral health whilst living with dementia. The possibility that these views, preferences and priorities may change in cognitive impairment is why the best interests standard is the cornerstone of legislation in the UK instead of a substituted judgement approach (see Chapter 3 Section 6). The former allows all relevant factors to be considered whilst the latter promotes autonomy, allowing unwise decisions to be enacted, despite the risk of harm. Though dentists should take previously expressed views seriously (Hughes, Louw and Sabat, 2006, p. 64), the best interests standard means it may be necessary to make decisions that contrast a person's past views to protect them from harm such as acute pain or distress.

Manthorpe (2009, p. 97) explores this tension yet suggests the competing aims of promoting autonomy and striving to protect PLwD may converge. If a person's views change over time, they may change to allow the same avoidance of harm that surrogate decision-makers would seek to achieve. In the dental context, the adverse outcomes of concern to PLwD and carers are primarily pain or infection, meaning a decision may be made to discount certain preferences (such as tooth retention) where necessary to protect the person from harm (pain). Known views or those identified from goal setting may not always be able to be implemented, yet there is a greater likelihood of delivering person-centred care if they are known than if they had never been established in the first place.

8.7 Summary discussion

Interviews with PLwD and caregivers identified multiple factors that affected engagement with dental services and individuals' involvement in decision-making for dental treatment. A theoretical understanding spanning five categories has been presented, produced by iteratively generating and analysing data and comparing new and existing data from interviews with PLwD and carers. This study provides a new exploration of the perspectives of PLwD and carers regarding dental treatment decision-making. The need to proactively consider the person for whom care is provided and to engage in a discussion about their preferences was identified in Categories 3-5 yet understanding broader aspects of individuals' circumstances may also explain their reluctance to seek dental care and the challenges they face when seeking to access dental care.

Gathering a comprehensive understanding of a patient and their preferences can support person-centred care, facilitate patient involvement in decision-making, and identify goals of care that can then be discussed. Therefore, dentists should strive to gain insight into the individual they are caring for. Ideally, doing so at an earlier stage in dementia could simplify the process of getting to know and understand patients and involving them in decision-making. It is likely that seeking patients' preferences will need to be an intentional and active process, especially as their ability to express preferences for their care can decline with time. In addition, a perceived imbalance of power (with the clinician seen as having more power) can affect how empowered patients may be to speak up about their preferences for each aspect of their care (Pauley, 2011). Therefore, as well as supporting PLwD with communication, dentists should strive to address any real or perceived power imbalances (Pauley, 2011; Nimmon and Stenfors-Hayes, 2016) in order to foster an environment that fully considers the unique person for whom care is being provided (Apelian, 2017) and empowers PLwD to make autonomous decisions about their care.

Seeking dental care at an earlier point could allow PLwD to be more involved in decision-making and enable their preferences to be gathered and understood as their experience of dementia progresses. The nature of patient involvement may be complicated as dementia progresses, particularly where the views of PLwD change over time. If care is sought when PLwD cannot easily express their preferences, dentists should strive to proactively gather these through alternative communication approaches and engage with those involved in the care of each PLwD. PLwD and carers described the possibility of views and preferences changing over time, yet the nature of evolving views is likely to vary from person to person based on the combination of different factors that shape their dementia experience (Kitwood, 1993). Best interests processes should actively involve caregivers and consider the relevance and applicability of existing knowledge about patients' preferences to achieve outcomes that are most beneficial to their overall well-being.

8.8 Strengths and limitations

This project has multiple strengths but also some limitations. A key strength is that I sought the views of those living with dementia and a varied sample of family carers. The views and experiences of PLwD have not been comprehensively explored, especially not regarding dental care decision-making. The involvement of both PLwD and caregivers group supported a theoretical understanding of their dental care experiences and decision-making.

I sought to recruit a diverse range of both PLwD and carers. However, the summary of participants shown in Table 8.1 reflects that those recruited, specifically the PLwD, were not particularly diverse. Only one was aged over 70, even though the majority of PLwD are older than 70 (Prince et al., 2014; (Alzheimer’s Research UK, 2022). In addition, all the PLwD recruited lived in the community, not in care homes even though nearly 40% of PLwD live in care homes (Prince et al., 2014). In addition, all had access to the technology required to take part in an interview and were able to use this. The sample recruited, therefore, does not reflect the demographics of PLwD across the UK and, potentially, further purposive sampling could have identified a more diverse group of PLWD, even in the presence of COVID-related restrictions which limited access to care home settings for recruitment or face-to-face interviews with PLwD. Potentially, the views presented are those of younger, community-dwelling PLwD with access to technology, so may not reflect the views and experience of many PLwD.

Table 9.1 also shows that I recruited a disproportionate number of people from the North of England, specifically the North East. The higher number of participants from the North East of England arose from the geographical restrictions contained in the *Join Dementia Research* System used to support recruitment. The administrators of this system limited recruitment to an initial 20-mile radius from central Newcastle. These administrators intentionally instil this limitation on most studies for two reasons. Firstly, it prevents large amounts of sensitive identifiable information from being accessible to researchers, reducing the risk of data breaches. In addition, this limitation reflects how studies have historically recruited participants local to a research site. I was unable to convince the administrators of this system to remove this limitation to support more diverse geographical sampling for remote interviews. Instead, they requested that the recruitment radius be increased, if necessary, as the study progressed. The progress of recruitment meant that this was not necessary. I had recruited participants from further afield, such as through the study website, yet the final sample was also somewhat limited in its geographical diversity. For example, I only recruited one participant from outside of England. In addition, no carers under the age of 40 were recruited. This may mean the views of younger people supporting relatives living with dementia are not fully accounted for in the theoretical summary presented. A further demographic issue was that the ethnic and cultural diversity of those recruited was limited. Those from different cultures may hold different views on the roles of their family in decision-making and regarding dental treatment approaches; the research discussed, therefore, may not reflect the views of specific cultural groups.

NHS dental services and funding differs in each of the devolved nations of the UK. Furthermore, mental capacity legislation in Scotland and Northern Ireland differs from that applying to England and Wales. These differences could impact how readily care could be accessed for PLwD and what barriers impact them in accessing or receiving dental care. I felt the data generated provided an in-depth understanding of PLwD and carers' experiences. However, the data and discussion presented may not provide detailed insight into the experiences of PLwD or carers outside of England. Future research could consider the experiences of those in other healthcare services within or beyond the UK and how cultural variations may affect preferences for dental care decision-making.

In addition, I recruited more caregivers than PLwD. I had to rely on my own understanding and appreciation of the data generated to determine when I felt further interviews with PLwD would not yield any greater understanding: this led to the final number of PLwD that were involved, so it is arguably not a limitation per se. However, as detailed above, the diversity of the sample was limited on reflection, so further sampling may have in fact led to a more comprehensive or representative understanding of the experiences of PLwD. Whilst I felt theoretical saturation was achieved, I cannot definitively state that interviewing more PLwD would not have provided new insights into the phenomena of interest. Dental care decision-making becomes increasingly complex as dementia progresses: PLwD with more advanced dementia who have may complex also have dental needs may be less able to participate in research. As the most significant complexities in dental care planning are encountered for those with more advanced dementia, it could be argued that it was appropriate to include more carers than PLwD to address the study's objectives. Carers can provide insight into their views of a PLwD's experience and their own experience supporting a PLwD. Again, I felt theoretical saturation was achieved, yet a larger sample may have provided a greater level of understanding of concepts that I was unaware had not been identified.

As I interviewed carers, there were few instances of discussion about care decisions for PLwD without family beyond those presented by two patients. IMCAs, who support decisions made for unbefriended PLwD, were not included as participants. This was intentional. Firstly, there was no clear route through which to identify IMCAs. In addition, their role is formal and limited to supporting decisions made regarding PLwD lacking decisional capacity. The views of IMCAs could have offered additional insight into the area being studied, yet it was not an objective of the study to explore the views of this group. Finally, as with the data presented in Project 2, there may be an element of recruitment bias as people willing to contribute to research may have specific features that could also impact their dental care experiences as patients or caregivers. Of course, I could only interview those willing to be interviewed, so this limitation had to be accepted. Future research in this area could employ ethnographic methods to study the experiences of a larger or more diverse sample of those who seek dental care. Recruitment bias may have less of an impact on data generation where participants do not have to agree to specific research involvement outside the clinical setting. This may lead to a greater understanding of PLwD's dental care and decision-making experiences.

8.9 Conclusion

The accounts of PLwD and family members detailed how many individuals from both groups faced multiple barriers in accessing dental care, maintaining oral health, and contributing to decisions about care. PLwD and carers described specified hopes and expectations for dental care but they also reported experiencing a passive role in dental care decision-making despite their desire to contribute to this process as patients or as family members. Their desired treatments, or the treatments most appropriate for a PLwD, may not be delivered if they are not shared with dentists or identified by dentists during consultations. PLwD and family members also described how their preferences for treatment modality and anxiety management were not comprehensively discussed with them by dentists. Whether or not PLwD can consent to dental treatment, dental teams should actively seek to empower them and to actively explore what matters to them. When the treatment outcomes or modalities that PLwD or carers seek are not possible to achieve, a more comprehensive process of SDM delivered by dentists may lead to PLwD and carers feeling autonomously and actively involved in decision-making processes.

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Chapter 9. Project 4: Ideation, methodology and methods

Here, I summarise some of the key challenges identified in Chapters 7 and 8. I then broadly consider how new interventions may address some of the challenges reported during Projects 2 and 3. I then summarise co-production methodology and the specific methods I used to plan and deliver the co-production process of Project 4.

9.1 Ideation

Projects 2 and 3 detailed the different experiences and perspectives of dentists, PLwD and carers regarding dental care decision-making. When the findings of the two projects are considered together, it becomes clear that there are some similarities but also some substantial differences in each group's views and the challenges they described having encountered. Any intervention to support dental care decision-making would ideally address all or some of the issues participants described. However, it may be that some of the issues described are non-modifiable and any new intervention has to function in a system where specific changes may not be feasible (Robert and Macdonald, 2017, p. 118).

Below are my initial considerations of how interventions may function to support dental care decision-making with or for PLwD. When considering the initial ideas I present below, it must be kept in mind that these are purely generated from my analysis and interpretations of data and the problems that may be encountered by dentists. My thoughts, therefore, may not be suitable from the perspectives of other stakeholders (Spencer et al., 2014, p. 343). 'Methods' below (Section 9.3) and Chapter 10 detail the value of working with a wider co-production group in which various stakeholders worked together to define specific problems and transform these into a new intervention.

Before considering interventions that may function in a dental clinic, it is worth considering what interventions may impact decision-making before a patient even attended a dental visit. Patients face barriers and challenges that prevent them from attending dental appointments (Chapter 8, Category 2). More accessible dental care in earlier dementia may support PLwD to receive preventative and proactive oral healthcare (Chapter 8, Category 2): PLwD may, therefore, experience less oral disease and fewer symptoms, (Torppa-Saarinen et al., 2019) meaning decision-making processes may be less complex. An intervention could, therefore, potentially support access to dental care for those diagnosed with dementia to capture the opportunity for preventative advice and management of dental problems at an earlier stage. Separately, an intervention could facilitate the provision of relevant information about PLwD to dentists before a patient attends an initial appointment. This could reduce the level of 'detective work' (Chapter 7, Category 1) a dentist may have to do; this may mean decisions can be made based on accurate information without delay due to information-seeking processes.

Many interventions to support decision-making could function within a dental consultation. Dentists appeared to describe a biomedical stance to care provision (Chapter 7, Categories 3 and 4), whilst PLwD or carers explained focussing on psychosocial considerations (Chapter 8, Categories 3 and 5). This difference in the perspectives from which care is viewed is particularly evident when considering the concept of risk and asymptomatic dental disease. PLwD or caregivers often sought care in response to a specific problem that had become impactful and detrimental to daily function (Chapter 8, Categories 1 and 2). This suggests PLwD and their carers accepted the presence of asymptomatic dental diseases when function is not substantially impacted. Dentists, however, described being uncomfortable leaving asymptomatic conditions untreated (Chapter 7, Category 6). When treatment was planned, dentists explained how they focused on weighing up the risk of interventions with the benefits of treatment to ensure there was a net benefit to PLwD. This process was described as particularly difficult when more complex dental problems arose or when care delivery was less straightforward (Chapter 7, Category 4). PLwD or carers described being concerned about the care delivery process and how they often hoped for pharmacological support for anxiety, regardless of the medical risk accompanying this (Chapter 8, Category 5). An intervention to support decision-making could potentially aim to facilitate a re-orientation of the views of PLwD, carers and dentists so that biological, psychological, and social factors are holistically and collectively considered and discussed by both parties.

Building on considerations of psychosocial aspects of care, dentists did describe a desire to provide care aligned with individuals' needs and preferences. However, when striving to provide individualised care, dentists reported placing a greater emphasis on PLwD's historical views than on their current preferences (Chapter 7, Category 2), even though PLwD could readily articulate these views (Chapter 8, Categories 3 and 5). Despite dentists' intentions, PLwD reported feeling misunderstood and less involved in decisions about their care than they think they should be (Chapter 8, Category 4). Proactively gathering patients' current values and preferences could mitigate the dissonance between dentists' approach to individualised care and the reported experiences of PLwD and carers. If dentists discussed and documented these views, they could be better placed to deliver care that aligns with them in a process akin to SDM.

A difference in views between carers and dentists was also evident regarding decision-making and care delivery for PLwD lacking decisional capacity. Dentists reported how they involved family members in care decisions. Still, the analysis of the data generated in Project 2 highlighted that this was generally a formality that did not affect the care delivered (Chapter 7, Category 5). This finding could explain why carers felt less involved than they would like when care was being planned for their relatives (Chapter 8, Category 4). It is interesting that dentists felt they should be decision-makers when PLwD lack capacity,(Chapter 7, Category 5) but also that family carers also felt that they should be the decision-makers (Chapter 8, Category 4). The statements made by dentists and carers suggest that there is a misunderstanding by carers without an applicable LPA regarding their legal standing in decision-making. An intervention to support the active and collaborative involvement of carers in decisions made regarding PLwD and to enhance BIDM processes could be beneficial, and this could detail the roles and responsibilities of each party in decision-making processes as well as supporting collaborative decision-making where the voice of a PLwD and those who know them are more actively considered.

Understanding the challenges encountered by dentists, PLwD and carers – together or in combination – provides a foundation on which interventions to support better decision-making may be built. Project 1 identified no existing interventions to support dental care decision-making for PLwD, suggesting a new intervention specific to dental treatment decision-making was required. To generate an appropriate intervention, I facilitated a co-production process that considered various stakeholders’ views on what specific problems existed and transformed these into ideas for interventions. The specific approach that was used is described below.

9.2 Methodology

Various theory-driven and pragmatic approaches can be used to develop healthcare-related interventions. These approaches can be used to develop interventions that focus on healthcare delivery (O’Cathain et al., 2019) or specific areas such as self-management of chronic illness (Araújo-Soares et al., 2019), clinicians' behaviour (Colquhoun et al., 2017) or public health policy (Wight et al., 2016). The many approaches have broad similarities, and the reported stages of their use have many common elements (O’Cathain et al., 2019). There is no consensus on the 'optimal' method to produce any form of intervention (Robert and Macdonald, 2017, p. 119). However, the variation in methods reflects the extent to which different methodologies employ theory, the specific problem being approached, and the nature and extent to which various individuals or groups support or contribute to the process.

Co-production is a broad and flexible approach to developing interventions which has gained increasing prominence in recent decades (Masterson et al., 2022). As a broad concept, co-production acknowledges that service users – typically patients or carers – and other stakeholders have unique knowledge and perspectives that should be incorporated into production processes (Knowles et al., 2021; Robert et al., 2021). The 'co-' refers to two groups of actors working in tandem: those who typically would produce something (such as researchers) and partners (such as laypeople, patients or caregivers) (Nabatchi, Sancino and Sicilia, 2017). Despite their different origins and meanings, the various ‘co-‘ terms (such as co-design, co-production or co-implementation) are often used interchangeably (Sanders and Stappers, 2008; Robert et al., 2015; Masterson et al., 2022). The emphasis of each term reflects its origins. Co-production is typically traced back to Elinor Ostrom, who recognised the potential value of including service users in improving policing in Chicago (Ostrom and Whitaker, 1973). Ostrom laid a foundation for citizen involvement in service delivery and planning (Realpe and Wallace, 2010; Osborne, Radnor and Strokosch, 2016; Nabatchi, Sancino and Sicilia, 2017). Co-design originated in participatory design in Scandinavia in the 1970s (Spinuzzi, 2005; Sanders and Stappers, 2008).

Under the umbrella term of co-production, terms such as co-design, co-creation and co-evaluation have been used to describe design or production processes that collaboratively involve patients and other stakeholders (Verschuere, Brandsen and Pestoff, 2012). Whether these actors are designing, producing, evaluating, or implementing something could affect what 'co-' words are most applicable or appropriate in a specific scenario. Anything ‘produced’ under the umbrella of co-production may require an element of design and the input of professional designers (Sanders and Stappers, 2008; Rousseau et al., 2019). Therefore, co-design is a narrower concept emphasising a production process's creative and tangible aspects (Sanders and Stappers, 2008; Masterson et al., 2022). I use the term co-production to describe the work presented herein. This is because various things could have been produced which may or may not have needed specific design insight. I was mindful that I collaborated with a team of design researchers (detailed in Section 9.3) and that a design model informed the approach to co-production that was delivered (see Section 9.2.4). Still, the definition of co-design felt too limited in a project that aimed to collaboratively identify what would be produced and, therefore, the extent to which creative practice and design may be necessary. The broader umbrella of co-production reflects the overall process used, including the design work within it.

9.2.1 Ontology and epistemology

Ontology and epistemology are discussed in Chapter 6 in relation to qualitative research. An ontological stance of subtle realism was taken for the qualitative work to account for how different individuals interpret reality through their own experiences. The same stance is relevant for co-production, which functions to develop new knowledge by accepting different interpretations and perspectives of reality by those with different experiences. When considering epistemology, it is essential to accept that a fundamental foundation of co-production is how a group collaboratively creates something through interaction. Reflecting the interaction it uses, co-production is aligned with the epistemological perspective of social constructivism (Spinuzzi, 2005). This stance was taken in Projects 2 and 3 and remains applicable to co-production.

9.2.2 Principle-led co-production

Co-production is not limited to the production or design of services: it can support the production of any tangible or intangible product (Sanders and Stappers, 2008). For example, co-production processes have led to the development of complex interventions (Madden et al., 2020), resources to guide practice (Langley et al., 2022), decision aids (Davies et al., 2021) and service improvement approaches (Wolstenholme, Grindell and Dearden, 2017). Attempts to define co-production have varied significantly, yet the processes commonly used result from an intersection of historical approaches and a set of common principles (Masterson et al., 2022).

A summary of the principles that underpin co-production is presented by INVOLVE (2018) and is shown in Figure 9.1. I sought to adhere to these principles throughout the work presented. Adhering to core principles ensures that whatever is collaboratively produced is more likely to be suitable, effective, and acceptable to all involved in a given context (Turakhia and Combs, 2017; Wolstenholme, Grindell and Dearden, 2017). A range of methods can be used in which these principles can be followed, based on the needs of each project and what it aims to produce.

Sharing of power – the research is jointly owned, and people work together to achieve a joint understanding.

Including all perspectives and skills – make sure the research team includes all those who can make a contribution.

Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance.

Reciprocity – everybody benefits from working together.

Building and maintaining relationships – and emphasis on relationships is key to sharing power. There needs to be mutual understanding and clarity over roles and responsibilities. It is also important to value people and unlock their potential.

Figure 9.1: Key Principles underpinning co-production (Taken from INVOLVE, 2018)

9.2.3 The fuzzy front-end of production

The nature of anything that is co-produced is typically unknown at the start of a project (Sanders and Stappers, 2008). This reflects the shared and collaborative approach to defining a problem and delivering a solution. As detailed above, I had ideas about what may eventually be produced (Section 9.1). However, if the specific nature of an intervention were specified before co-production began, the process may be somewhat redundant. The earlier stages of collaborative processes involve discussions and considerations from multiple perspectives that precede the refinement of a specific output. This process is typically associated with unpredictability and uncertainty (Sanders and Stappers, 2008; Almqvist, 2017). Sanders and Stappers (2008) detail that this front-end of production is ‘fuzzy’ because of its inherent complexity and that this ‘fuzzy’ front-end precedes later stages of development (see Figure 9.2).

The need for a researcher or research team to navigate a ‘fuzzy’ front-end differentiates production from conventional approaches to knowledge generation, which typically reflect a positivist epistemology and linear processes (Robert and Macdonald, 2017, p. 117). In contrast to linear and well-defined processes, the front-end of production reflects, accepts, and embraces a range of viewpoints and subjectivity. Collaborative processes accept that this ‘fuzziness’ is inherent in formulating ideas.

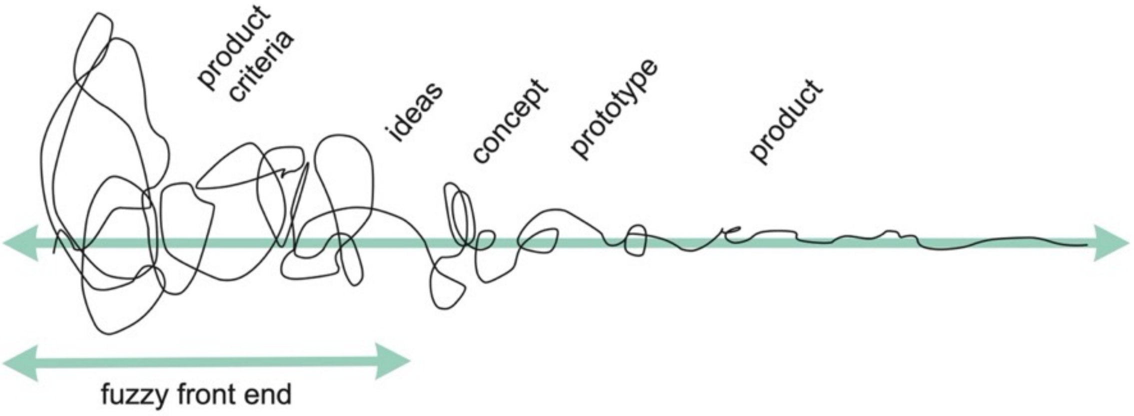

Figure 9.2: Production and the 'fuzzy' front-end (adapted from Sanders and Stappers, 2008)
Note that the ‘front-end’ appears chaotic but precedes a series of less 'fuzzy' stages.

9.2.4 Double Diamond Model of Design

I needed a mechanism to move from this entangled fuzzy front-end toward a more clearly defined output. The literature on co-production offers little practical advice on how co-production may be enacted. For example, two core publications summarise co-production but provide little insight into how it could be delivered (Realpe and Wallace, 2010; INVOLVE, 2018). Design models can support a movement from the 'fuzzy' front end to delivering an output. The Double Diamond Model is one such model, shown in Figure 9.3 (Design Council, 2021). This model, designed to be used by designers and non-designers alike, was produced and published based on a comprehensive qualitative study examining how large organisations approach design (Design Council, 2007). Using such a model can, in theory, reduce the need for subsequent specific iterative design processes (Wilson et al., 2015; Rousseau et al., 2019).

The first diamond within the framework details how 'divergent' thinking is used to explore a concept widely before 'convergent' thinking focuses on a specific idea or ideas. This first diamond reflects the 'fuzzy' front end where exploratory uncertainty abounds before a period of greater focus (Almqvist, 2017). In the second diamond, 'divergent' thinking occurs before the product or process being designed is more narrowly defined through a final 'convergent' process (Design Council, 2021).

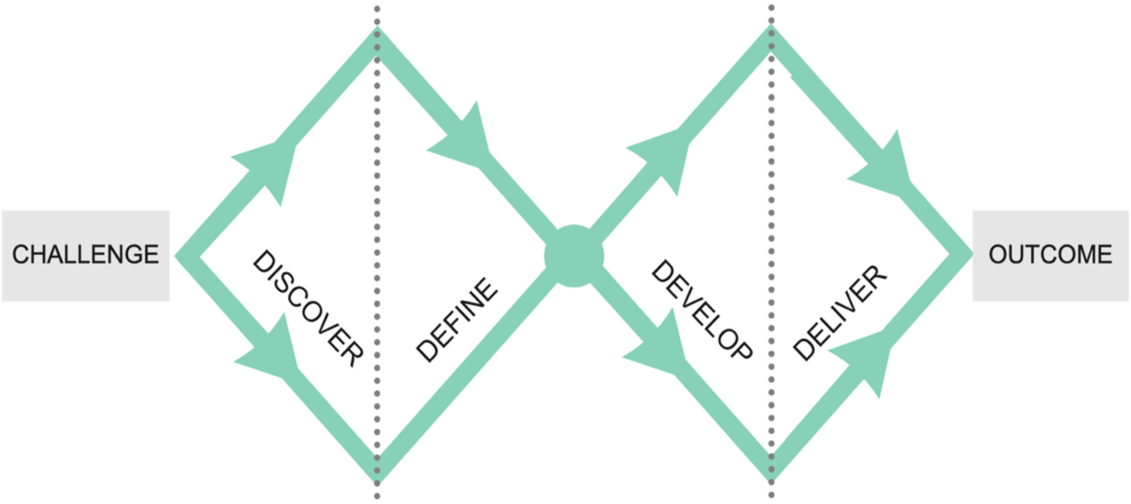

Figure 9.3: The UK Design Council's Double Diamond model of design

The four stages (Discover, Define, Develop, and Deliver) and an explanation of their purpose are presented in Table 9.1. Each step is typically employed in a workshop, but stages can be spread across multiple workshops. If required, the stages in the second diamond (develop and deliver) can be repeated as part of the iterative refinement of a co-produced output. I used the double diamond model to scaffold the collaborative production process described below.

Stage	Purpose of Stage
Discover	Individuals and groups can understand what problem is being addressed. This can involve hearing the group's lived experiences and reviewing other reported experiences, such as those in qualitative research.
Define	The specific problem or problems to be addressed can be defined as a group process. The nature of the group's experience and understanding of the information shared in 'Discover' can mean the problem is defined differently from earlier research objectives.
Develop	Participants are encouraged to propose solutions or ideas to address the defined problem. This stage involves seeking inspiration from other sources and co-designing initial idea(s). The group can focus on which ideas are suitable to develop and which are not.
Deliver	This stage of work involves exploration or initial testing of proposed ideas and iterative progression of these ideas. This stage focuses a focus on achieving suitable output(s).

Table 9.1: The four stages of the double-diamond model. Modified from Design Council (2021)

9.2.5 Ethical considerations of co-production

Reflecting the inconsistency and misuse of terms related to 'co-' methods (Masterson et al., 2022), co-production has been described as 'muddled' (Nabatchi, Sancino and Sicilia, 2017) 'messy' (Thomas-Hughes, 2018) and 'poorly formulated' (Osborne, Radnor and Strokosch, 2016). These descriptions are apt for co-production in research, especially when study design, research governance processes, and project facilitation are considered. As a less established form of research, there is less precedent on expected ethical standards and research processes. The way co-production actively involves patients and stakeholders is a strength of the process, yet it does come with specific challenges, as explored below.

Whilst patient and public involvement and engagement (PPIE) in research design is advantageous and viewed as essential, PPIE differs from patient participation in co-production processes (Williams et al., 2020). In the former, patients or patient representatives provide insight to guide research design and planning. In the latter, similar individuals have a more formal role, akin to a partnership, where there is mutual respect, reciprocity, and sharing of power (as per the principles shown in Figure 9.1). A key challenge is that researchers and clinicians are often perceived to hold a position of power over those subject to clinical care or research processes (Karnieli-Miller, Strier and Pessach, 2009; Hay-Smith et al., 2016; Råheim et al., 2016). When a researcher initiates a project and invites others to support it as co-production partners, there is likely to be a continued expectation that a researcher or research team retains a position of authority. I had to consider how this might be mitigated and sought to facilitate a friendly and less formal environment for discussions in each project stage. Participants were informed of the nature of co-production and their role as partners. Still, my role in delivering the project might have led to an ongoing sense of inequality in the partnerships created. I strived to adhere to the principles detailed in Figure 9.1 to minimise power imbalances and support an equitable and constructive co-production process. A reflection on my attempt to do so is presented in Chapter 12.

When delivering co-production, the partners supporting this process are doing the research with the research team, so they are arguably researchers, not research participants (NIHR Applied Research Collaboration West, 2020, p. 6). On this basis, it could be considered unnecessary to gain their consent for participation. Despite the research being done by a participant with the research team, the nature of involvement, particularly the sharing of lived experiences with a group, is not risk-free (Oliver, Kothari and Mays, 2019). Furthermore, participants needed to maintain confidentiality and build trust with the co-production group members. This trust starts with clearly laying out expectations and the nature of involvement and ensuring a person understands what involvement entails. Although there is a partnership, partners must understand their role in involvement and agree to the requirements of this role. As group members would share their ideas and experiences, I felt it was appropriate to gain their consent to participate in the co-production process.

I also had to consider how national standards state that patients or members of the public supporting research should be reimbursed for their contribution to research processes (National Institute for Health Research, 2021). In co-production, those involved are not research participants, but active participants contributors; payment acknowledges the value of their time and effort and mirrors how researchers are generally paid a salary to undertake research. If equality is sought, paying co-production participants seems fair and necessary. However, financial reimbursement is not without challenges (Surmiak, 2020). Reimbursement could inappropriately incentivise people to take part in co-production (Head, 2009). There is a theoretical risk that people agree to support a project for this reason alone and that they offer little insight to support a project. Furthermore, there may be financial implications for those supporting a study in this way, which may significantly affect those receiving state benefits (National Institute for Health Research, 2021). The consent process with co-production group participants also ensured these issues were discussed transparently. I discussed the issue of remuneration transparently and ensured participants were suitably informed that they could receive financial reimbursement for their role in co-production and the implications of this. This discussion further justified the use of a formal consent process.

The involvement of PLwD is essential to support the design of interventions or services that benefit them (Treadaway, 2020). Many of the challenges of involving PLwD in qualitative research (discussed in Chapter 6) apply when seeking to involve PLwD in co-production. However, the nature of a partnership is a crucial difference between qualitative interviews and co-production. The purpose of co-production and qualitative work differ. The involvement described herein aimed to gather feedback from PLwD to support a developing intervention. This is less time-consuming, less invasive than qualitative interviews, and less cognitively demanding, thus reducing ethical risks (Keogh, Carney and O'Shea, 2021). I sought to achieve an ethical and balanced level of involvement where PLwD could express their views but where burdens of involvement were minimised.

To consent to any degree of involvement in co-production, I had to ensure that PLwD could understand the project and consider their preferences to guide their participation decisions. The determination of consent in co-production mirrors that regarding interview participation (see Chapter 6), and I was prepared to make reasonable adjustments to specific processes or information formats to support PLwD in understanding the nature of involvement (Keogh, Carney and O'Shea, 2021).

Even though considered adjustments may make it easier for PLwD to support co-production, involving PLwD separately from a wider group, as presented herein, blurs the definition of their involvement. Co-production can involve contributors across different times and spaces (Davis et al., 2021; Langley et al., 2021), yet their role as co-production partners could be debated, as the partnership is only with the research team, not with the wider co-production group. Whilst deviating from the principles shown in Figure 9.1, some form of active involvement was undoubtedly preferable to none, and flexible or alternative forms of involvement allowed the voice of PLwD to be heard in the larger project.

9.2.6 Practical considerations of co-production

Co-production typically demands substantial resources (Robert et al., 2015; Oliver, Kothari and Mays, 2019), particularly for facilitating and delivering workshops or other co-production interactions. In-person workshops have been the mainstay of co-production (Davis et al., 2021) yet face-to-face workshops may exclude some individuals, such as those unable to travel or those with specific communication needs (O'Connor et al., 2016). However, if online workshops are planned, other individuals may instead be excluded or face difficulties in participating, such as those unfamiliar with or unable to use the technology required with this format (The Bridging Gaps Group et al., 2021). I had to consider the different approaches to involvement that would support the involvement of different participants and ensure their voices were heard. Davis et al. (2021) summarise how a 'low contact' approach to involvement can be used by disseminating involvement stages in both time and space. Disseminating projects across time and space was one approach that supported PLwD to be involved in co-production despite the complexities of such a process and how dementia may mean conventional involvement approaches are not suitable. The specific methods used in the co-production process are presented below.

9.3 Methods

9.3.1 Planning co-production processes

To gather support in planning and delivering co-production and to support my professional development, I formed a collaboration with a team from the Lab4Living group of design researchers at Sheffield Hallam University: Joe Langley (JL), Rebecca Partridge (RP) and Chris Redford (CR). This expert team supported the design and delivery of the co-production process. The methods used were also guided by a period of PPIE.

The PPIE process involved input from the North East Dementia Alliance, the Alzheimer's Society, and the 'Voice' group of public advisors. This process identified that PLwD wanted to be actively involved in research, including co-production. Still, PLwD felt it inappropriate for them to participate in busy large group workshops. Instead, they felt they could contribute more effectively if their involvement was separated from more complex group workshops. The PPIE process identified the perception that actual dental teams should support the project to ensure anything designed worked in a dental setting. Though dental input was seen as sensible, the PPIE contributors were keen to avoid interacting with multiple dental professionals at any given time. It was impractical, and arguably unnecessary, to involve an entire dental team in the main co-production workshops. If this had been planned, the volume of dental participants might have introduced barriers preventing others from contributing and sharing their experiences and perspectives.

The PPIE process also guided the type of interactions involving PLwD. This process highlighted that PLwD preferred to use one-to-one discussions or written correspondence to provide feedback and share their experiences. PLwD were able to choose to provide either one-to-one feedback through discussion or written feedback. In-person feedback sessions with a dental team were planned as this group had extensive experience facilitating dental care for PLwD, and they met regularly in clinical sessions. Though these groups supported the co-production process, they were not active co-production partners with whom the overall project progress would be determined.

Based on the PPIE process, the co-production process consisted of four mixed-group primary workshops, supported by separate interactions with PLwD and a dental team, as shown in Figure 9.4. The four primary co-production workshops were planned to broadly reflect the four stages of the Double Diamond model. These sessions were the primary space where the intervention was produced collaboratively. Within these workshops, a mixed group shared experiences from a range of personal and professional perspectives and collectively supported and agreed upon the progress of the intervention design. A diverse group with various relevant experiences and perspectives was involved, including patient representatives, dental or other healthcare professionals and academics with relevant expertise on dementia, dental care, or intervention design (see Table 9.3). Separating PLwD and dental team interactions from the main co-production workshops allowed the co-production group to make initial progress that could be shared in these separate interactions. The format of the process also allowed the co-production group to consider and act upon the feedback provided by the PLwD and dental team interactions.

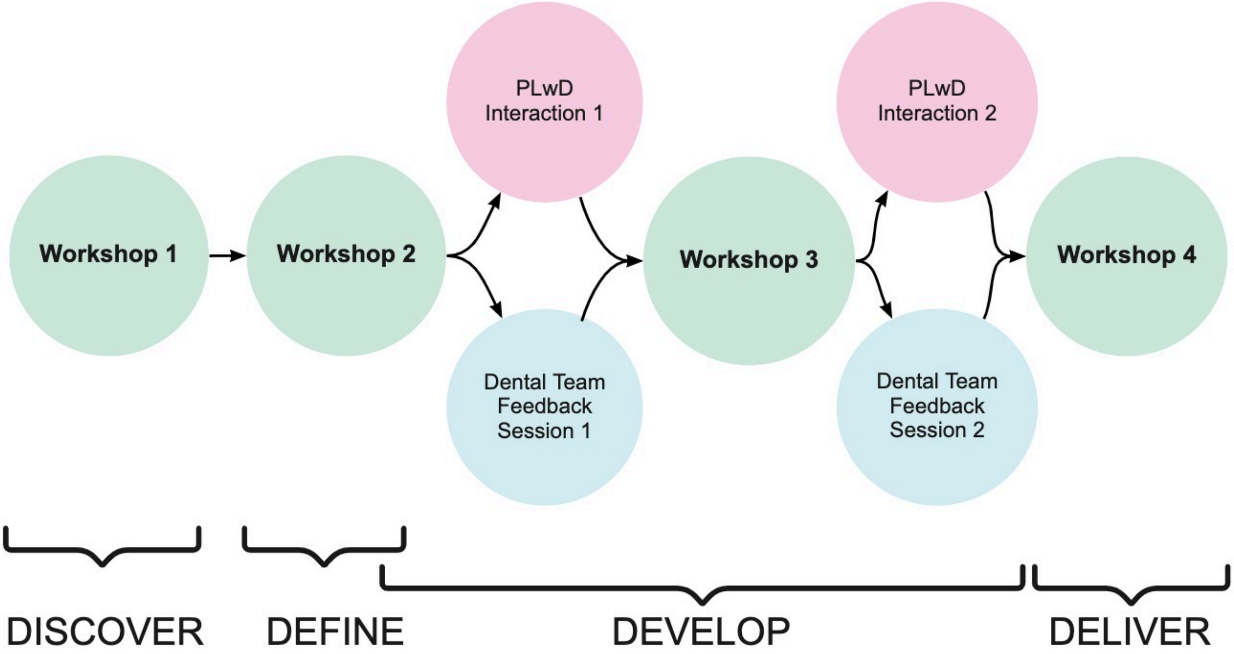

Figure 9.4: A outline of the co-production process

The main co-production meetings, Zoom meetings with PLwD and the dental team workshops were audio-recorded. Recordings were transferred to an encrypted folder on a secure University computer and then transcribed by the same private transcription company that transcribed interviews from Projects 2 and 3. A confidentiality agreement was in place with this company. I kept the audio recordings files accessible to confirm the accuracy of transcripts and allow the full nature of interactions within each session to be understood where required. Revisiting transcripts, or recordings where necessary, allowed me to revisit the discussions within each workshop or interaction and consider each participant's comments when planning subsequent stages of the co-production process. Ethical approval for Project 4 was gained through the same application as for Projects 2 and 3 (Yorkshire and Humber - Bradford Leeds Research Ethics Committee Reference: 20/YH/0048).

9.3.2 Adjuncts to support co-production processes

The Miro digital whiteboard (Miro, 2022) was used to plan and deliver the co-production workshops. We used this platform to share visual content such as summary slides and early ideas. In addition, JL, RP, CR, or I typed participants' thoughts and comments onto this platform with screen-sharing so they could see their contributions in real time. The Miro whiteboard also provided a continuous record of the project and its progression to support reflection on the interactions to guide decision-making and project progress within and outside the interactions described. We also considered a range of further tools that may support co-production partners in interacting with data, concepts and ideas proposed. These included illustrations that present data or key concepts in primarily non-text formats, the use of physical poster boards to allow hand-written annotations, and 'Impact and Effort charts' (Kovach and Ingle, 2020). With the support of the Lab4Living team, I used of specific adjuncts based on the unfolding co-production process I describe in Chapter 10.

9.3.3 Recruitment and Sampling

The recruitment and sampling of the co-production group, PLwD and a dental team are summarised below. Different inclusion and exclusion criteria were produced for each group, as shown in Table 9.2. I sought to identify up to 16 participants from various backgrounds to form the primary co-production group supporting Workshops 1-4. A maximum size of 16 participants per workshop was planned. This figure was chosen to allow a diverse group to be involved and to allow more focused discussions in breakout rooms containing 3-4 people. I used a purposive sampling approach, aiming for maximum variation. Individuals were approached directly based on their relevant professional or personal role. I sought to recruit patient representatives, specifically informal carers, dentists from various settings, and academics whose research related to decision-making, care of PLwD or intervention development. I sent initial invitations to participate by post or e-mail alongside an information sheet describing the nature and purpose of involvement.

	Inclusion Criteria	Exclusion Criteria
Co-Production Group	•Those having an interest in improving decision-making for dental care for PLwD •Those able to provide informed consent for participation in the workshop •Those able and willing to actively participate in the co-production process •Those aged 18 or over	•Those with no interest in improving decision-making for dental care for PLwD •Those without experience as a patient of professional in caring for either dental patients or PLwD •Those unable to commit to attendance at co-production group meetings •Those who are unable to provide informed consent to participate in the interaction
PLwD	•Those having received a diagnosis of any type of dementia •Those able to provide informed consent to participate in an interaction •Those aged over 18	•Those with significant ill-health in receipt of palliative care •Those with known poor or aggressive behaviour in group contexts •Those who are unable to provide informed consent to participate in the interaction •Those unable to speak English
Dental Team	•Dental clinicians included on the GDC register or those employed in a dental service in a non-clinical patient-facing role (e.g., receptionist) •Those with experience of working in a dental service where PLwD undergo assessment, treatment, or referral •Those aged 18 or over	•Those whose role is not patient-facing (e.g., decontamination staff) •Clinical staff with no experience in managing or treating PLwD in the dental setting •Those who wish to self-exclude due to personal/family experience of dementia who may find participation upsetting

Table 9.2: Inclusion and exclusion criteria for each component of the co-production process

Each of the two interaction stages with PLwD used maximum variation purposive sampling to recruit up to 8 participants with different experiences and types of dementia. This was felt to be a sufficient maximum sample size to allow the team to gain appropriate insight from PLwD with different types of dementia, at different stages and with different dental experiences. The number sought was proportionate to the input from clinical and non-clinical dental team members and the non-academic co-production group members. I recruited PLwD through multiple routes. Firstly, those who supported Project 3 and consented to be contacted about future research were invited to participate in Project 4. Further PLwD were recruited from those who had completed an online expression of interest in supporting the study. For the second stage of PLwD interactions, I invited those who supported the first PLwD interactions to support the study through a second episode of involvement. In each instance, a PIS was sent inviting a response for those interested in supporting the study.

The two dental team feedback sessions were held with a Community Dental Service team in the North East of England.[17] This team had supported recruitment in Projects 2 and 3 and were familiar with the project's aims and progress. Also, staff from this dental service provide dental care for PLwD at different stages of dementia and in different settings. A maximum group size of 18 was proposed to reflect the number typically present at staff team meetings and to ensure a range of individuals with clinical and non-clinical roles could support the process through three smaller breakout groups of up to six individuals.

9.3.4 Consent

The co-production group members were given a specific Participant Information Sheet (PIS), and each contributor completed and returned a consent form before participating in a workshop. There were no anticipated concerns about individuals' capacity to consent to and contribute to this co-production process: PLwD were not recruited to support these workshops directly, and other contributors had no known cognitive impairments.

For interactions with PLwD, the initial e-mail correspondence about involvement, reading the PIS, and completing electronic consent forms typically indicated their capacity to consent to support the project. I proceeded on the basis that the MCA (2005, section 1) states it should be legally presumed that someone can consent to specific decisions. Where any concerns about capacity arose, I assessed the participant's ability to consent as per the MCA (2005, section 3). I did not formally assess the capacity of the PLwD who returned written comments as the return of paper-based forms by e-mail or post and completion of the online consent form indicated sufficient capacity to consent for supporting the project in this manner. The PIS mentioned audio-recording of any one-to-one Zoom discussions. The agreement of PLwD to use audio recordings was checked when confirming the consent process for those taking part in verbal discussions.

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[17] As with the qualitative studies (Projects 2 and 3), I do not name the specific service involved to ensure the anonymity of participants who might be identifiable to those aware of service provision in the region.

Dental team members were informed of the nature of the feedback session through a PIS that was e-mailed to all staff in advance of the planned workshop dates. The PIS detailed that the meetings would be audio-recorded but that their confidentiality and anonymity would be maintained. Staff were invited to contact me if they had any queries or questions or wished to opt out. I gained written consent from those willing to support the project, and participants were free to withdraw from participating.

9.3.5 Workshop and interaction formats

Table 9.3 describes the nature and participants involved during each stage of the co-production process. I led each interaction with PLwD, the dental team feedback sessions and the main co-production workshops. Joe Langley (JL), Rebecca Partridge (RP) and Chris Redford (CR) supported the delivery of each workshop and led breakout rooms.

As the project progressed, there were some changes to the group's composition, as demonstrated in Table 9.3. Unplanned events and professional commitments meant some participants withdrew from specific workshops. When participants indicated their inability to attend a workshop, I purposively approached additional relevant participants to compensate for the contributors that had been lost. It was not always possible to recruit individuals with similar roles and experiences. For example, two academics were recruited to support Workshop 3 due to the absence of a carer and a clinical psychologist. New participants were also given a PIS and underwent the same consent process as existing participants. They were also given a written summary of the group's progress to ensure they understood their role within the process and the progress made before their involvement. Introductions were repeated at the start of each workshop to ensure that each group member was familiar with one another.

Stage of co-production Date	Objectives	Participants	Format of interaction
Workshop 1 (Discover) 26/04/2021	To get to know other contributors and to understand and collaboratively explore the problem being addressed	N=16 4 carers, 1 dementia nurse 3 academics, 6 dentists (3 GDP, 2 CDS dentists. 1 policy maker) 1 dental nurse 1 clinical psychologist	Zoom workshop with posted materials beforehand
Workshop 2 (Define and Develop) 10/05/2021	To define the specific problems to address and to generate initial ideas for interventions.	N=16 As for Workshop 1	Zoom workshop with posted materials beforehand
PLwD interaction 1 (Develop) 14/06/2021 – 16/08/2021	To gain feedback on the six core ideas informed by earlier workshops and to gain a sense of prioritisation of these ideas	N=7 [$] 7 PLwD (1 DwLB, 3 AD, 2 VD, 1 FTD)	Zoom one-to-one discussions (n=5) Written forms returned with comments (n=2)
Dental Team Feedback 1 (Develop) 04/08/2021	To gain feedback on the six core ideas informed by earlier workshops and to gain a sense of prioritisation of these early ideas	N=17 [#] 4 dentists (1 restorative dentist, 3 CDS dentists) 2 Dental therapists 8 Dental nurses 3 Administrators	Face-to-face workshop in an open-plan dental clinic
Workshop 3 (Develop) 13/09/2021	To further develop ideas and sense how ideas may function.	N=12 [£] 3 carers, 5 academics[¢] 4 dentists (1 out of hours emergency dentist,[§] 2 CDS dentists, 1 policy maker)	Zoom workshop with posted materials beforehand
PLwD interaction 2 (Develop) 12/11/2021 – 17/12/2021	To gain feedback on the prototype idea and how it may be used	N=6 [$] 6 PLwD (1 DwLB, 4 AD, 1 VD)	Zoom one-to-one discussions (n=4) Written forms returned with comments (n=2)
Dental Team Feedback 2 **(Develop)** 15/12/2021	To gain feedback on the initial prototype idea To identify what mechanisms may be needed for ideas to work in the dental setting	N=16 [#] 4 dentists (4 CDS dentists) 1 Dental therapist 8 Dental nurses 1 Administrator 2 Receptionists	Face-to-face workshop in an open-plan dental clinic
Workshop 4 (Deliver) 17/01/2022	To use the feedback gained from PLwD interaction and dentist workshop to iteratively refine the prototype and consider its usability	N=10 [£] 2 carers, 1 dementia nurse 4 dentists (1 GDP, 1 out-of-hours emergency dentist, 1 policymaker, 1 CDS dentist), 3 academics	Zoom workshop with materials sent by e-mail beforehand

Table 9.3: Dates, objectives, participants, and format of each stage of co-production

[$] Some PLwD supported interactions at both PLwD interaction stages. [#] Most participants supporting the first dental team feedback session also
supported the second session yet the composition did change slightly. [£] Note the change in the composition of the Workshops 1—4 over time. [¢] Two new academics supported the work from this point onwards. [§] This participant was first involved in workshop 3 as another dental participant could not attend the remaining planned sessions.

9.3.6 Data

The data generated from this co-production consisted of:

1) My reflective logs
2) Audio recordings and transcripts of audio recordings of the co-production workshops
3) Audio recordings and transcripts of audio recordings of one-to-one Zoom interactions with PLwD
4) The e-mail correspondence with co-production partners and PLwD
5) Audio recordings and transcripts of audio recordings of the dental team feedback sessions
6) Comments placed on the Miro whiteboard
7) Annotations on paper prototypes, impact and effort charts, and other documentation
8) Developing ideas, concepts, and prototypes

To achieve the objectives detailed in Table 9.3, each stage of the co-production process used different tools and techniques. I did not formally analyse these data. Instead, their purpose was to inform the iterative collaborative intervention development and justify the decisions made as part of this process. In Chapter 10, I describe the iterative and unfolding co-production process where data from each of the above formats is presented and used to guide co-production.

Chapter 10. The Co-production process

This chapter presents a stage-by-stage description of the co-production process that comprised Project 4. I detail the content of each planned co-production workshop, dental team workshop and interaction with PLwD. I also document what happened between the specific co-production stages and the decisions the collaborating team and I had to make to guide the project's progress. Some of these decisions were challenging and uncomfortable to make either independently or with other parties: after describing the initial prototype intervention in Chapter 11, I use Chapter 12 to present a personal reflection on the co-production processes detailed below.

10.1 Workshop 1: Discover

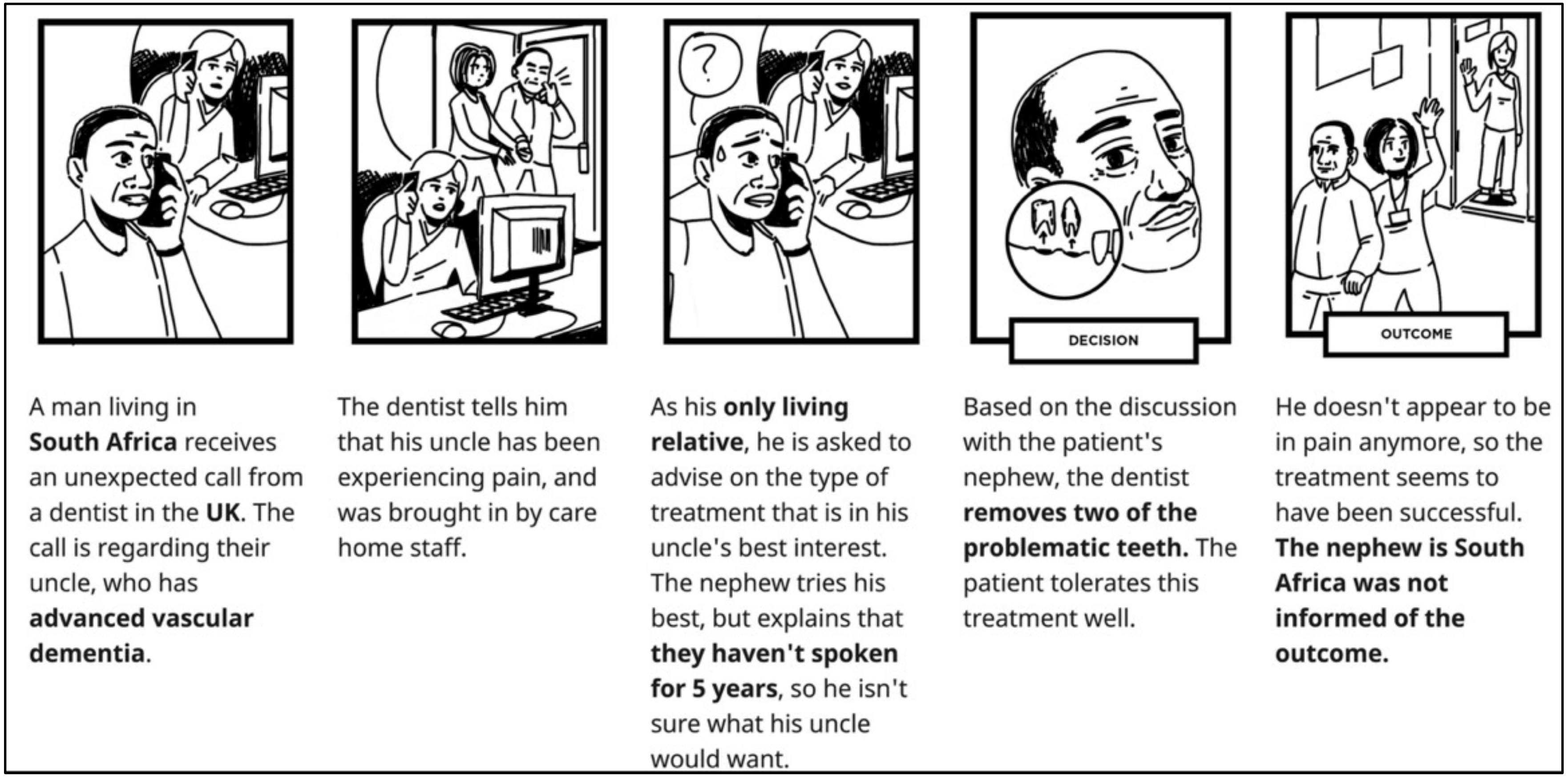
An initial aim of Workshop 1 was for contributors to be introduced to one another and understand each other's roles and experiences. The start of the workshop consisted of group introductions and an ice-breaker activity. The introductions aimed to ensure the co-production group members knew who else was supporting the project and the roles and backgrounds of each person involved. In the ice-breaker activity, participants were asked to pick three image cards from a selection of random cards they had been sent by post before the workshop. Explaining their choices of cards allowed the group members to understand each other better, and to identify common interests which supported cohesive informal interactions between participants. Ground rules for the co-production process were also shared to ensure the group were aware of co-production principles (Figure 9.1), the need to ensure confidentiality and their role as active partners in the project.

The second aim of Workshop 1 was for the group to collectively explore the problems related to dental care decision-making for PLwD. One way the group could understand such challenges is by reviewing qualitative research such as that undertaken in Projects 2 and 3. However, qualitative research may not be generalisable to other contexts or settings (Lewis et al., 2014) and the findings presented in Chapters 7 and 8 may not reflect perspectives from those in other contexts, such as high-end private practice or healthcare systems other than the NHS. Therefore, to optimise the co-production process, the co-production group needed to form their own interpretation and understanding of the problem area being discussed and establish their views on potential solutions

(Design Council, 2021). Sanders and Stappers (2014, p. 6) detail how storyboards can support co-production participants to *'experience, test, transform, develop and complete'* their initial thoughts and ideas. To facilitate these processes, CR produced storyboards of fictitious scenarios (Figures 10.1-10.3). Data from Projects 2 and 3 somewhat informed the scenarios that CR produced, but I strived to ensure the scenarios presented the problem we were working to solve, not my analysis of the data that had been generated. Producing and discussing these storyboards also supported the Lab4Living team's understanding of the problem area the co-production process aimed to address. Before the workshop, the storyboards were shared with participants alongside an introductory booklet (Appendix I), which summarised the project and the nature of involvement in co-production.

The bulk of the workshop was based on exploring and discussing the storyboards CR had produced. Three breakout groups were formed and facilitated by JL, RP and CR to enable this process. Each breakout group contained participants from different backgrounds (dental, academic, PPIE). Groups were allocated one scenario and given a series of quotes from the qualitative research undertaken as part of the wider project. The group was asked to consider these quotes from the perspectives of patients, carers, and clinicians in each scenario. Key issues or concerns were noted on the Miro whiteboards used by each breakout group. Each group facilitator shared a summary of their group's key thoughts and comments on the storyboards with the whole group. Each group highlighted different specific challenges or problems; understanding what other groups identified supported a shared understanding of the broader challenges with dental care decision-making for PLwD.

The end of the workshop asked participants to consider what they felt were the most significant challenges in dental care decision-making for PLwD. In addition, they were asked to consider what support patients, carers and dental teams may need to support optimal decision-making. Towards the end of the workshop, I summarised the findings from Projects 2 and 3. This allowed the group to understand the findings of these projects and to appreciate the views of a larger group of dentists, PLwD and carers. The group could also consider if or how these findings aligned with the knowledge or understanding they had gained during the workshop. This workshop supported a shared understanding amongst the co-production group; not only did the participants understand the challenges in dental care decision-making for PLwD, but I also began to understand the participants' perspectives on these challenges. This shared understanding was a critical foundation to support the work undertaken in subsequent co-production stages.



A man living in **South Africa** receives an unexpected call from a dentist in the **UK**. The call is regarding their uncle, who has **advanced vascular dementia**.

The dentist tells him that his uncle has been experiencing pain, and was brought in by care home staff.

As his **only living relative**, he is asked to advise on the type of treatment that is in his uncle's best interest. The nephew tries his best, but explains that **they haven't spoken for 5 years**, so he isn't sure what his uncle would want.

Based on the discussion with the patient's nephew, the dentist **removes two of the problematic teeth.** The patient tolerates this treatment well.

He doesn't appear to be in pain anymore, so the treatment seems to have been successful. **The nephew is South Africa was not informed of the outcome.**

Figure 10.1: Storyboard 1 - a fictitious scenario to support the ‘discover’ phase

This patient was **only recently diagnosed with dementia.** His partner noticed regular memory lapses and his GP referred him to a memory clinic.

He still insists on going to his dental check ups on his own, **just like he always has.**

The dentist recommends two options to manage some heavily filled teeth:
1) **Replacing some fillings**
2) The more expensive (but more permanent) option of **crowns.**

The dentist thinks **crowns** would be the best option.

The dentist thinks **the work would be beneficial.** Ultimately the patient makes the decision to have no work done.

The patient may develop **pain** over time. There is also the risk that **teeth might break.**

Figure 10.2: Storyboard 2 - a fictitious scenario to support the ‘discover’ phase

An **experienced dentis**t is asked to see a 72 year old lady with **advanced dementia**.

Her daughter tells the dentist that **toothbrushing is increasingly challenging** and that **the teeth look broken and stained**.

The patient **resists the dentist** when he tries to look in her mouth but he think he glimpsed some **damaged teeth**.

The dentist **doesn't want to distress the patient** anymore by recommending surgery but **discusses the options with her daughter**.

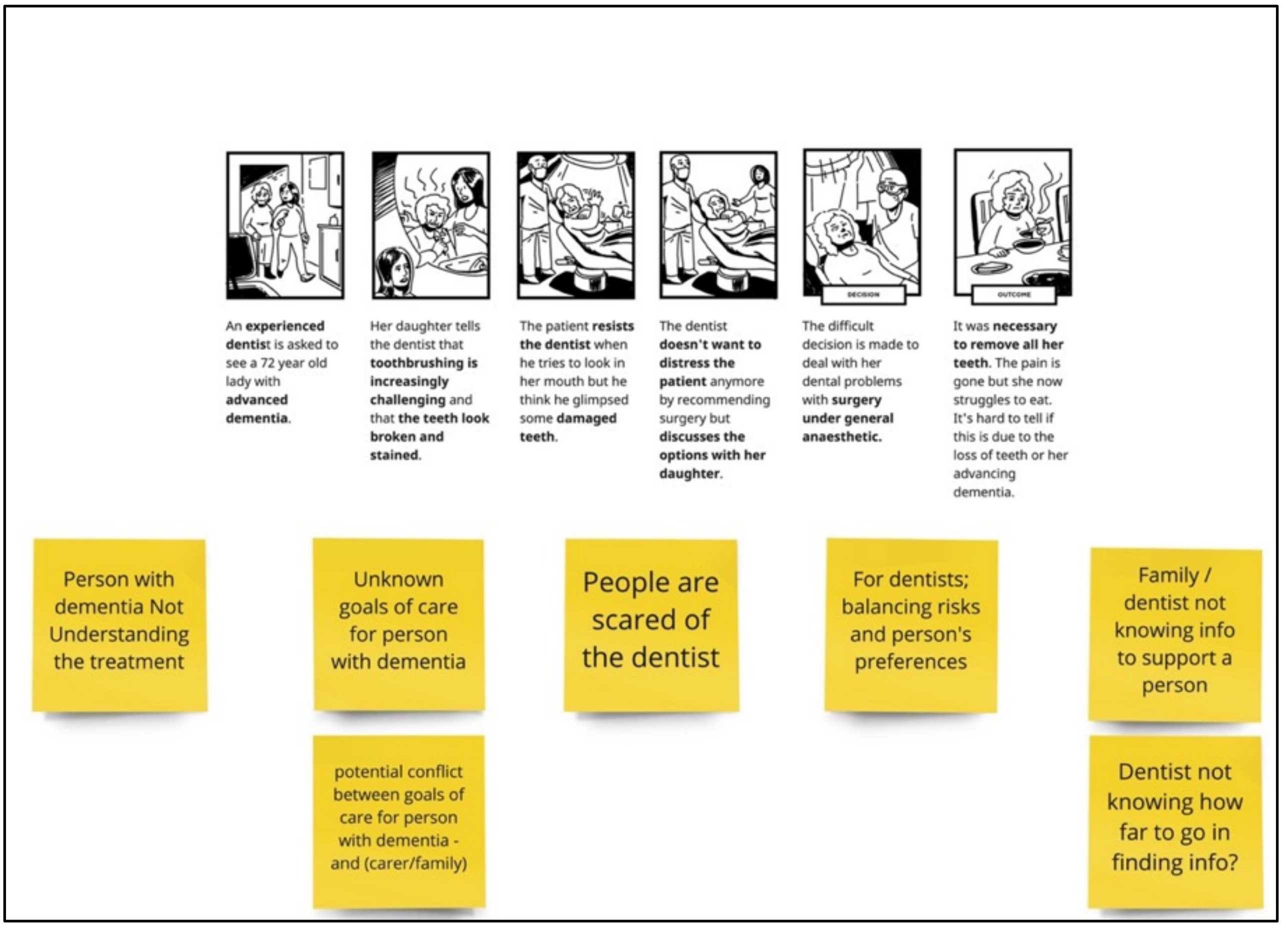
The difficult decision is made to deal with her dental problems with **surgery under general anaesthetic.**

It was **necessary to remove all her teeth**. The pain is gone but she now struggles to eat. It's hard to tell if this is due to the loss of teeth or her advancing dementia.

Figure 10.3: Storyboard 3 - a fictitious scenario to support the ‘discover’ phase

10.2 Workshop 2: Define and Develop

Workshop 2 aimed to define specific problems with more granularity and consider initial ideas for solutions. The same breakout groups used in Workshop 1 were re-formed. Within these smaller groups, the participants revisited the storyboards they had previously discussed, and then collectively explored and defined problems related to their specific scenario. Figure 10.4 shows some of these problem statements presented on the Miro Board related to Storyboard 3. The group then returned to the main Zoom meeting where problem statements related to each idea were presented to the whole group. An open discussion highlighted which problems might apply to more than one scenario.



An **experienced dentist** is asked to see a 72 year old lady with **advanced dementia**.

Her daughter tells the dentist that **toothbrushing is increasingly challenging** and that **the teeth look broken and stained**.

The patient **resists the dentist** when he tries to look in her mouth but he think he glimpsed some **damaged teeth**.

The dentist **doesn't want to distress the patient** anymore by recommending surgery but **discusses the options with her daughter**.

The difficult decision is made to deal with her dental problems with **surgery under general anaesthetic.**

It was **necessary to remove all her teeth**. The pain is gone but she now struggles to eat. It's hard to tell if this is due to the loss of teeth or her advancing dementia.

Person with dementia Not Understanding the treatment

Unknown goals of care for person with dementia

potential conflict between goals of care for person with dementia - and (carer/family)

People are scared of the dentist

For dentists; balancing risks and person's preferences

Family / dentist not knowing info to support a person

Dentist not knowing how far to go in finding info?

Figure 10.4: Example problem statements related to a scenario

In a subsequent exercise, the group was asked to come up with ideas for how these problems might be tackled. The Miro board also recorded these ideas to support the ongoing intervention development process. Some of the ideas proposed are shown in Figure 10.5. A summary of the ideas produced by each small group was shared with the wider group at the close of the workshop.

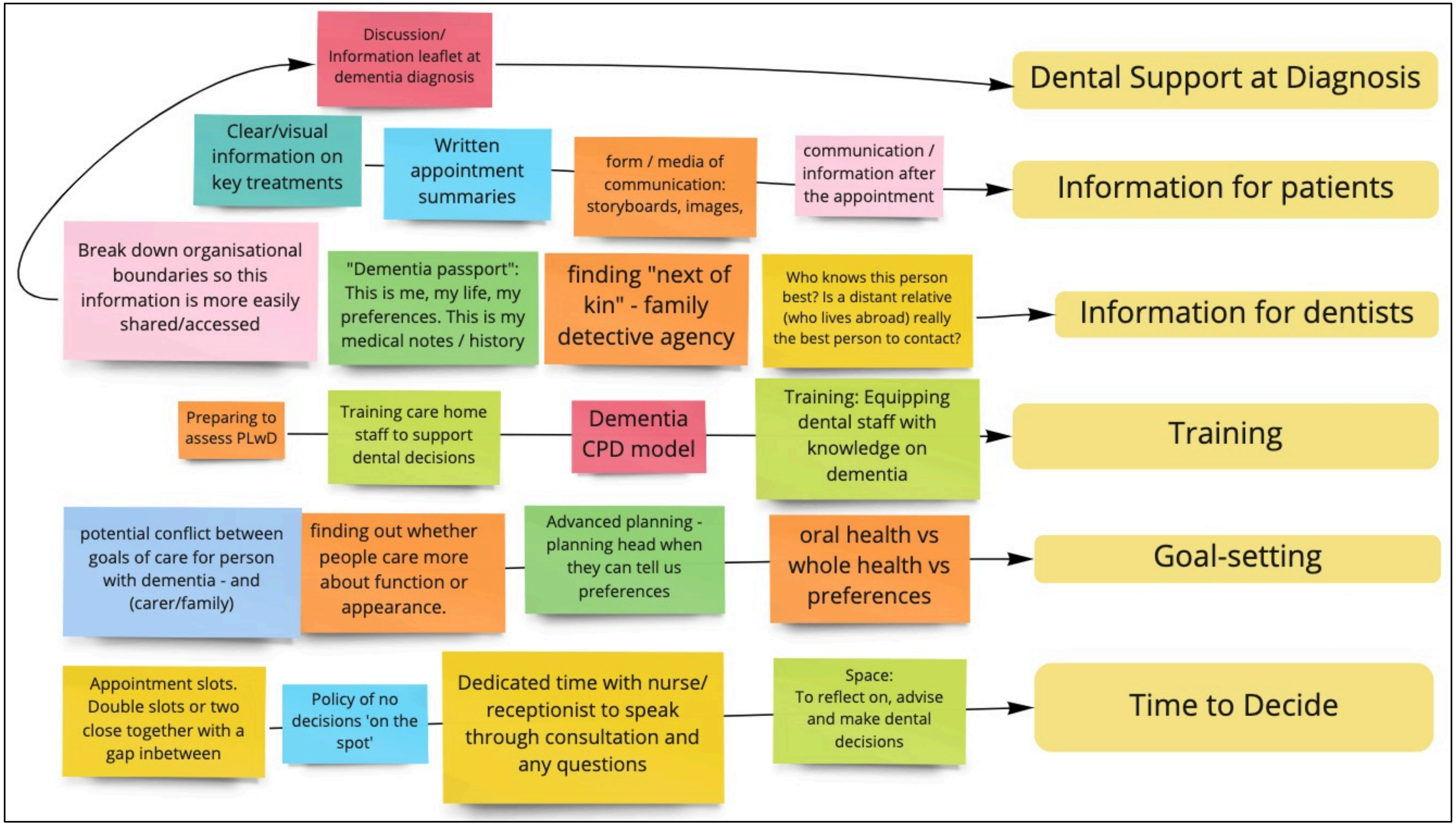


Figure 10.5: Mapping of problem statements and ideas to six key concepts

10.3 Research team activity after Workshop 2

After Workshop 2, I met with JL and RP to discuss how to build on the progress made in Workshops 1 and 2. The ‘Discover’ stage was completed in Workshop 1, and the ‘Define’ stage was completed in Workshop 2. Workshop 2 also included the first foray into the ‘Develop’ stage. After revisiting the ideas proposed in Workshop 2, the Lab4Living team and I grouped these ideas into themes having identified that they related to six key areas. Figure 10.5 shows the ideas presented by co-production group members and how they relate to the six core ideas. Figure 10.6 shows visual summaries of the six broad ideas that CR produced to support their ongoing exploration and development.

10.4 First interactions with PLwD: Develop

Seven PLwD were recruited to provide feedback and comments on the six broad ideas and support the process of developing these ideas further and establishing a sense of priority. Five PLwD shared their thoughts on these ideas during Zoom meetings separate from the main co-production workshops. In the Zoom meetings, I shared the ideas and associated images on screen and asked for each person’s opinions, comments and questions regarding each idea in turn. During these discussions, I made handwritten notes on paper printouts of the ideas. An example of these annotations on one idea concept is shown in Figure 10.7.

Two PLwD supported the project by providing written comments. I sent the graphical summaries of the ideas by email and invited PLwD to consider whether they thought the ideas would or not be helpful and to provide any feedback they thought would be useful. I also asked these individuals to identify which ideas they thought would be most beneficial, or feasible to implement. The lack of live discussion about the options with these PLwD meant I could not ask specific probing questions to explore their perspectives in greater detail. However, the comments of those who did not feel able or willing to discuss the ideas on Zoom were still valuable.

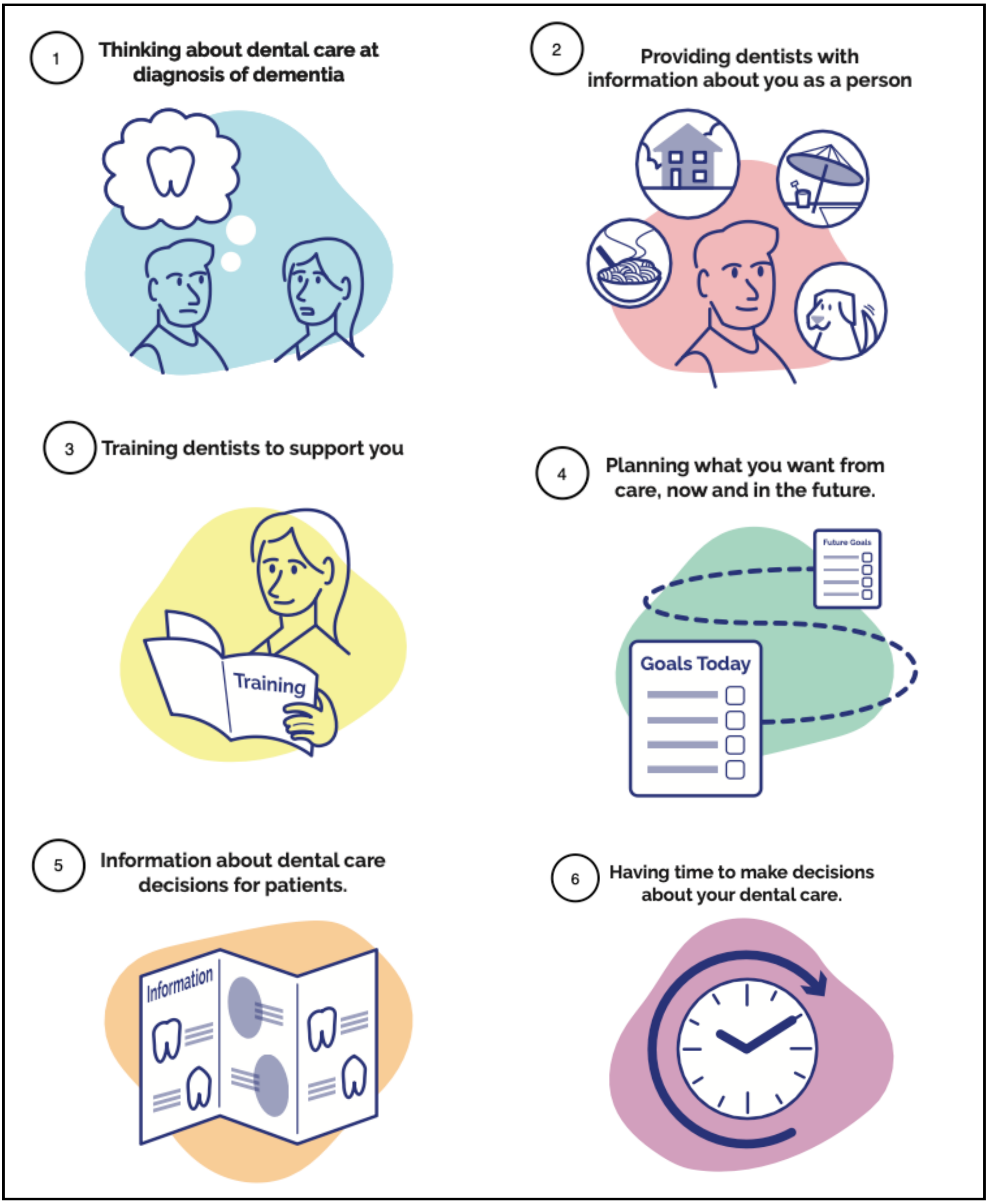
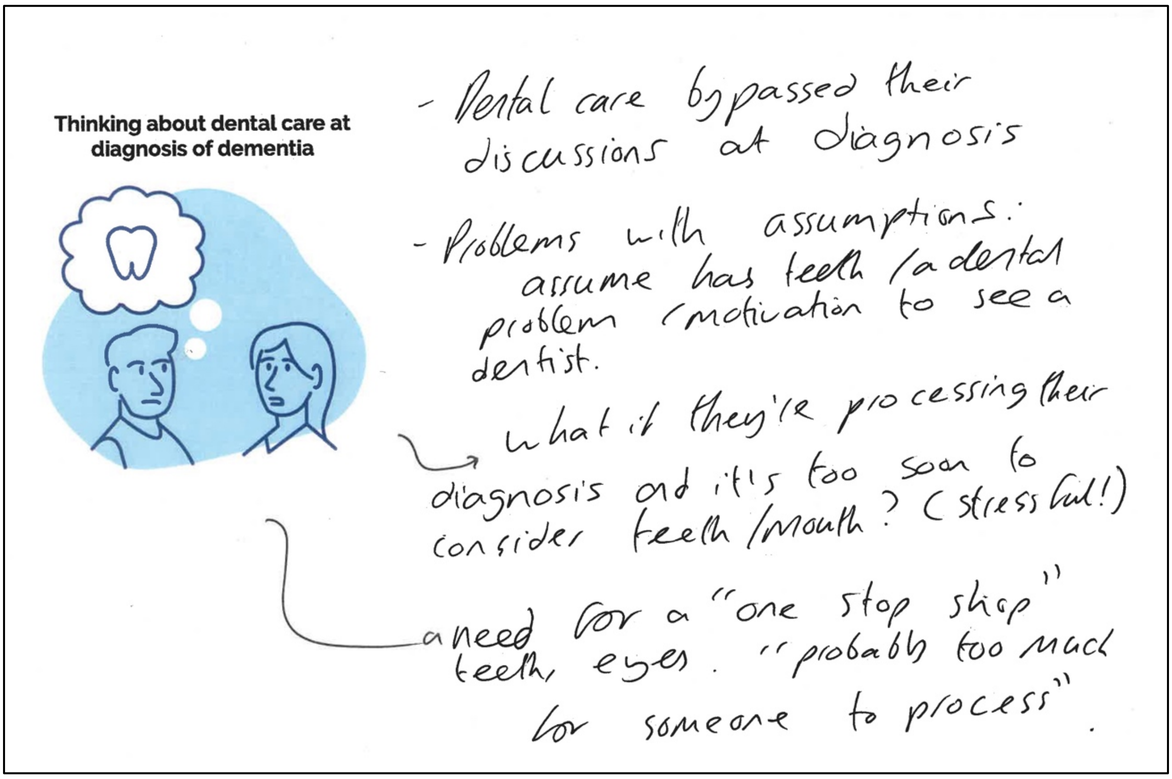


Figure 10.6: The six broad concepts presented as illustrations and text



Thinking about dental care at diagnosis of dementia

- Dental care bypassed their discussions at diagnosis

- Problems with assumptions: assume has teeth / a dental problem / motivation to see a dentist.

what if they're processing their diagnosis and it's too soon to consider teeth / mouth? (stressful!)

a need for a "one stop shop" teeth, eyes. "probably too much for someone to process".

Figure 10.7: An example of annotations made during a discussion with a PLwD

By revisiting my annotations on ideas (such as those shown in Figure 10.7), transcripts of discussions with PLwD and my written reflections, I identified that there were specific ideas to which PLwD responded more positively. Firstly, PLwD described that considering dental care near a diagnosis of dementia (Idea 1) would be sensible:

> *"We all eat [laughter] and we all get pain in our teeth, so I think that would be pretty crucial, I'd guess, to discuss your teeth early on."*

Jimmy (PLwD–AD)

Different PLwD, however, suggested that this should not be an immediate consideration at diagnosis. Instead, they considered that this idea should be discussed after a person has come to terms with their future. Concerns about the feasibility of this idea were also raised based on people's lived experience of healthcare:

> *"The diagnosis can be stressful enough anyway without thinking about future dental care, but it's an important issue for the months afterwards. But who would talk about it because the doctors just want to give you a diagnosis and push you out?"*

Sonny (PLwD–DwLB)

Participants felt that any training package that aimed to dentists with dental treatment decision-making for PLwD (Idea 3) would need to consider a range of issues related to the care of PLwD. Due to their perception of dental care in general, one PLwD stated in their written feedback that:

> *"Training should be mandatory. They should have to do training in helping people with dementia, just like I'm sure there's other things they are obliged to do."*
>
> Chantelle (PLwD–FTD)

When exploring the issue of training in Zoom discussions, multiple PLwD said that dentists also needed training to consider individuals as unique people. Each PLwD felt that Idea 2 (providing dentists with information about you as a person) was worth building on. One participant described a negative view of when a person-centred approach had not been considered, suggesting that PLwD would value such an approach:

> *"It's like most medical people when you see them. They don't actually find out about you as a person. All they're interested in is the disease, and as they see it, they think they can do something about the disease without necessarily knowing us but also they don't realise that the way they treat us, the way they talk to us, the way we will respond to them, especially in the middle to later stages, will depend upon them understanding our life…they have to ask us if they want to figure out what we need."*
>
> Gordon (PLwD–AD)

The discussions about personal preferences naturally led to consideration of how PLwD felt about their long-term care and how they might want their care to be considered in the future. The PLwD involved in one-to-one discussions each felt that considering their longer-term dental care would be beneficial (as per Idea 4). The terms ‘goal setting’ and ‘planning’ were used, and one PLwD reflected on when this had not occurred:

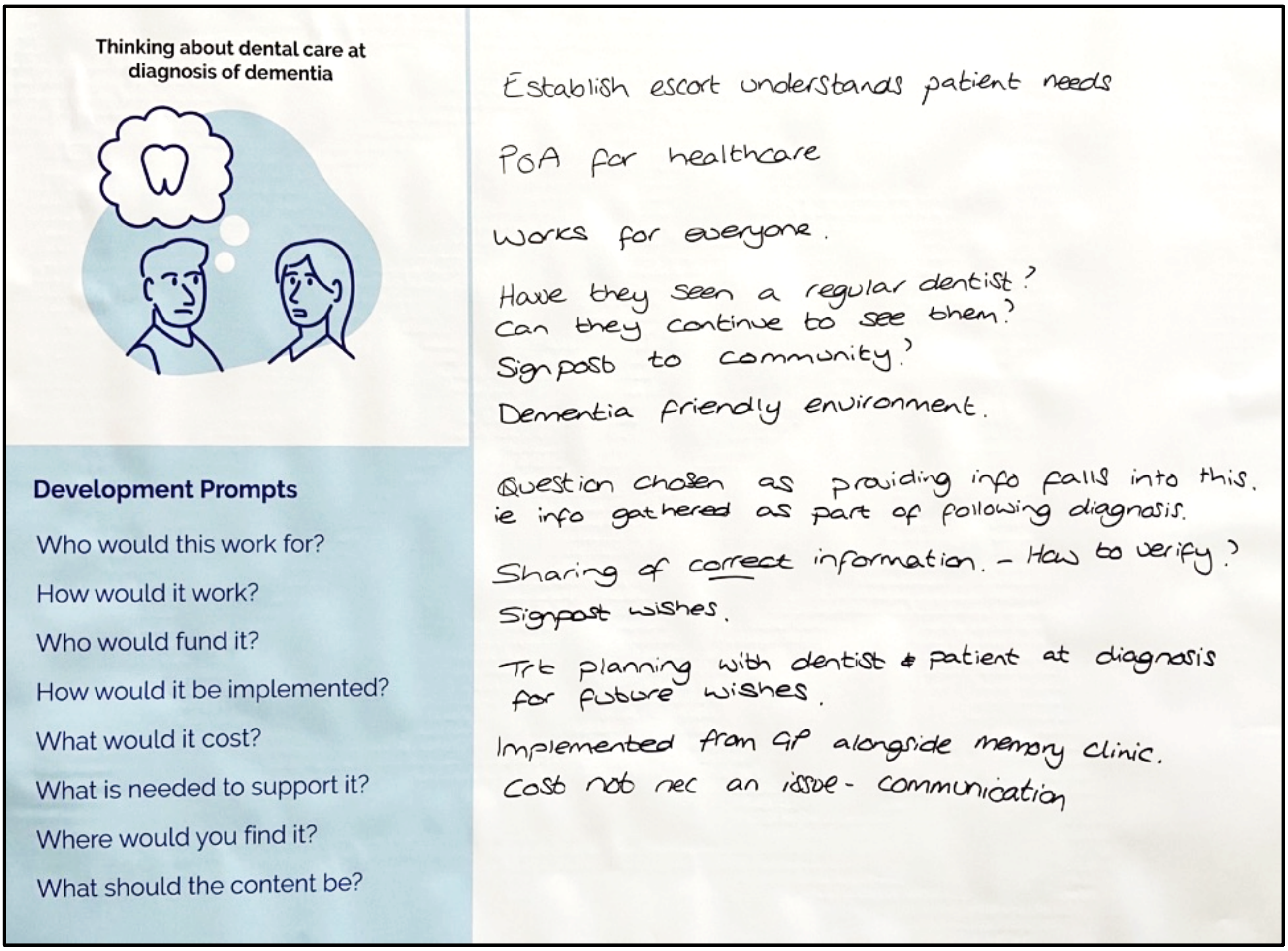
> *"The dentist didn't have the courage to tell me - and he'd been a dentist for years - that this deterioration of my teeth was happening…so there was no option to consider a plan for if it all went wrong in the future."*
>
> Patricia (PLwD–AD)

This person explained that they felt it was important to plan how dental issues that might develop over time might be addressed. One PLwD specifically suggested that specific questions might help to gather the information that could support decision-making in certain situations. Another PLwD detailed how such information potentially unknown long-term outcomes might help to address drastic changes to the mouth that can occur for some PLwD.

Whilst the interviews presented in Project 3 identified that PLwD might be disempowered, PLwD suggested that information about their role and rights in decision-making and extra time to support decisions (Idea 5) would not change how they acted or approached discussions with a dentist. PLwD felt they needed time to make complex decisions (as per Idea 6), but they noted this might need to happen outside of a dental visit as they felt dentists were unlikely to allocate extra time to them in the surgery setting. There was a strong feeling that dentists had a duty to actively facilitate their involvement and needed training or other resources to do so. Anonymised comments and quotes related to each idea were placed on the Miro whiteboard to inform the discussions in Workshop 3.

10.5 First dental team feedback session: Develop

I led the dental team feedback session face-to-face in a dental clinical building. After presenting an introduction to the work, I split the dental team into three groups, two of 6 participants and one of 5 participants. Each group was allocated two of the six ideas and was provided with A2-sized boards containing prompt questions to support the development of the ideas. These boards could be drawn or written upon, so I asked the groups to consider what they thought the idea might look like and detail this on the boards. An example of an annotated board is shown below in Figure 10.8. Each small group fed back their comments on their two ideas to the wider group to ensure the whole dental team could understand each of the ideas.



Thinking about dental care at diagnosis of dementia

Development Prompts

Who would this work for?

How would it work?

Who would fund it?

How would it be implemented?

What would it cost?

What is needed to support it?

Where would you find it?

What should the content be?

Establish escort understands patient needs

POA for healthcare

Works for everyone.

Have they seen a regular dentist?
Can they continue to see them?
Signpost to community?
Dementia friendly environment.

Question chosen as providing info falls into this.
ie info gathered as part of following diagnosis.

Sharing of correct information. – How to verify?
Signpost wishes.

Trt planning with dentist & patient at diagnosis
for future wishes.

Implemented from GP alongside memory clinic.
Cost not nec an issue - communication

Figure 10.8: Comments on Idea 1 made by a small group of dental team members

Note: ‘POA’ in the image is incorrect terminology that was used to discuss the principles of Lasting Power of Attorney

Comments fed back to the wider group included the view that dentists should naturally ask patients about key information, so Idea 2 may only be valuable if used alongside future planning (as per Idea 4). In addition, the small group discussing Idea 3 (training) felt that training might be beneficial, but ‘other’ dentists and dental teams needed this training the most. One dentist expressed a concern that even an excellent training package would potentially not be used, especially by those with little motivation. There was also a feeling that additional time to make decisions (Idea 6) was of little value or relevance to their setting:

> *“The idea we didn’t spend very much time on was having time to make decisions about your dental care so, like adding a bit of time at the end of appointments, and we said that probably*

> *wouldn’t work because we couldn’t just add a little bit of extra time… it’s not that simple…if they need more time, we give it, but a blanket addition of time isn’t helpful.”*
>
> Savannah (CDO)

The dental team members also felt that providing patients with information to inform them of their ability to take part in decision-making (Idea 5) may not change the complexities they faced and the challenges that they had to navigate. They assumed this would be in the form of a generic information leaflet given to patients. On this basis, they provided the below summary to the wider group:

> *“We don’t think that another leaflet is useful because people don’t want another bit of paper when they’ve come for a dental appointment… Our [suggestion] was quite simple that we’re just going to dump the leaflet.”*
>
> Adele (SDO)

After each group shared their thoughts on their two ideas, they were asked to discuss the remaining ideas briefly. They were prompted to consider how these might work alongside or instead of the ideas they had initially discussed in their small group.

I then asked the group to undertake a prioritisation exercise. The dental team were asked to complete *Impact and Effort* charts by placing cut-outs of the ideas onto a separate board. The participants were also asked to annotate ideas or draw arrows to consider which ideas may fit together. This process supported prioritisation by establishing which ideas were felt most impactful to support dental care decision-making for PLwD. In addition, the participants explored which ideas may be most straightforward to use and accept in routine practice. Each group completed this activity independently then a consensus was agreed upon during a full group discussion. The consensus on prioritisation was placed on a final board, shown in Figure 10.9. Crucially, the group felt that planning care for the future (Idea 4), considering dental care at a diagnosis of dementia (Idea 1) and providing information about the individual (Idea 2) were all impactful. Gathering information about the person was felt to be the most impactful approach for the least effort.

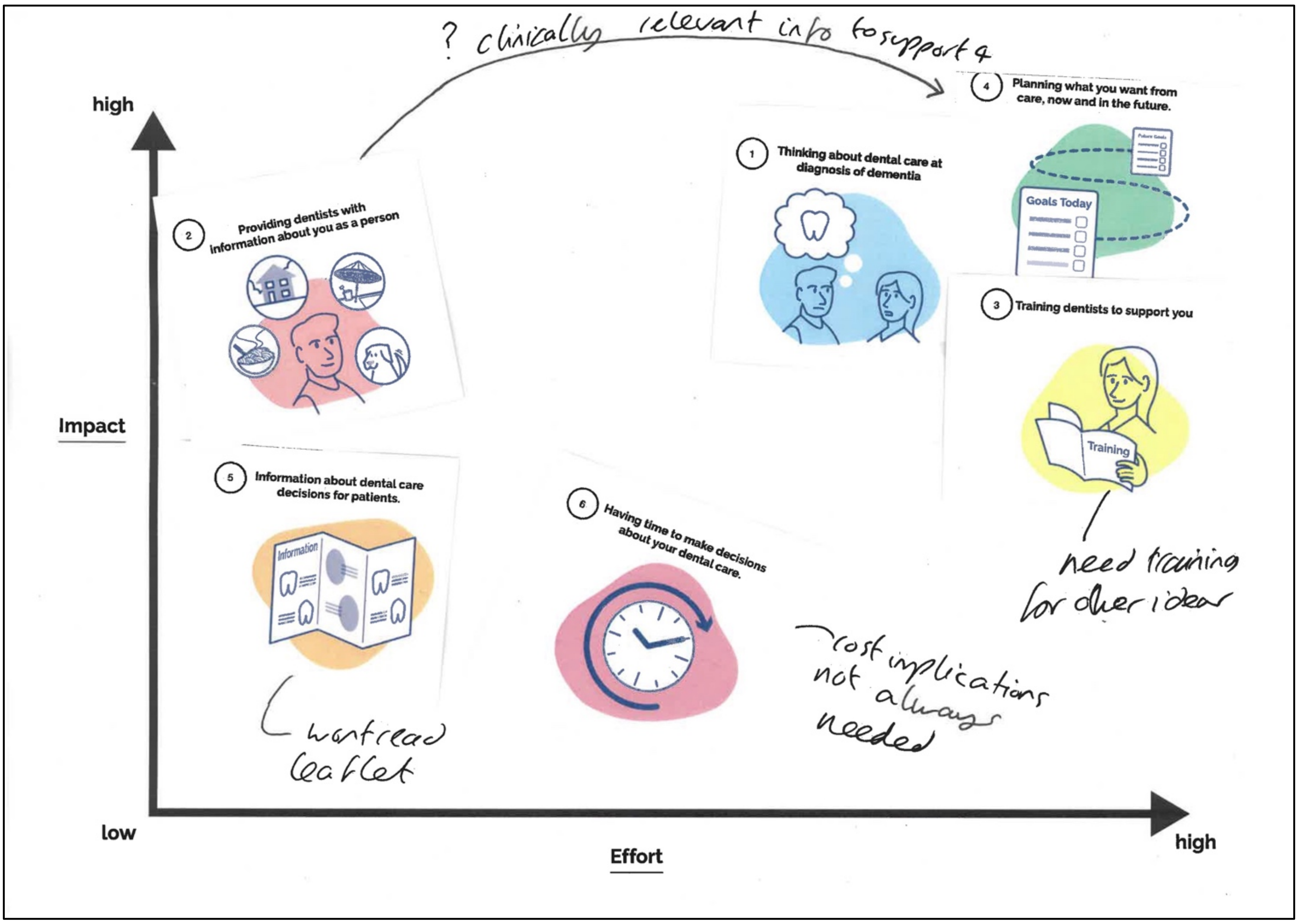


Figure 10.9: Impact-Effort chart to support idea prioritisation

10.6 Workshop 3: Develop

Of the six ideas presented, Ideas 1, 2, 3 and 4 (thinking about dental care at diagnosis of dementia, providing dentists with information about you as a person, training dentists to support you, and planning what you want from care, now and in the future) were felt to be the most appropriate by PLwD and those attending the dental team feedback sessions. The overlap and commonality of Ideas 2 and 4 were repeatedly highlighted. Therefore, as shown in Figure 10.9, the maturation of idea 4 incorporated the idea of knowing relevant personal clinical information (arising from Idea 2). This resulted in three broad ideas, hereon referred to as Ideas A, B and C, respectively:

Idea A: Thinking about dental care at a diagnosis of dementia

Idea B: Planning what you want from care, now and in the future (including information about a person's preferences)

Idea C: Training dentists to support PLwD

These three ideas were the core content of Workshop 3 and were used as a basis for discussions and ongoing intervention development. Before the workshop, I produced a summary sheet that presented each idea alongside key summary statements informed by the PLwD and dental team members, as well as from existing evidence and Projects 2 and 3. This summary is shown in Figure 10.10. This summary document was shared with the group by email before Workshop 3.

Based on a PLwD proposing that set questions be used to gather peoples' preferences and values, I completed a basic literature search to identify existing scales or tools to record these. Edwards, Randall and McNeil (2021) presented an Oral Health Values Scale (OHVS) that captures patients' values for care in specific domains. The values recorded in this scale have substantial commonality with factors that patients need to consider for their current and future care and those that dentists and other advocates may discuss in future BIDM. Understanding the answers to such questions could potentially address some of the specific challenges that dentists described in Project 2 when discussing the provision of individualised care. Because of its potential relevance, I planned to share the OHVS with the attendees of Workshop 3 to gauge the group's views on this and consider the value of a similar scale.

At the start of Workshop 3, I shared a summary of the study's progress and the interactions that had taken place since Workshop 3. I also presented a verbal summary to build and elaborate on the content of Figure 10.10 which participants had seen in advance of the workshop. After I presented this summary, participants were then moved into breakout rooms where each group discussed the development of one idea at a time, supported using prompt questions (examples of which can be seen in Figure 10.11). Each facilitator (JL, RP, CR) led discussions about one idea and moved between breakout rooms so each group could discuss each idea. This approach meant the facilitator allowed the idea to be iteratively developed as each group discussed it. Because of its potential relevance, the OHVS was shared with the groups as they explored and developed Idea B. The groups provided extensive comments on each idea, guided by prompt questions such as those shown in Figure 10.11, which summarises key discussion points made on the Miro whiteboard for Idea B.

Idea A was described as potentially beneficial, but there was little progress in considering how or where dental care might be facilitated post-diagnosis:

> *“We had some ideas around potentially referring everyone as a one-off within the first six months [post-diagnosis] to kind of a specialist dentist who could have the conversations about the future and a provide a proper check…the barriers at the minute seem to be around this idea of time and…it would make sense, but there’s clearly an issue in how it would be done for everyone when services are so inaccessible and under pressure”.*
>
> RP (Group Facilitator)

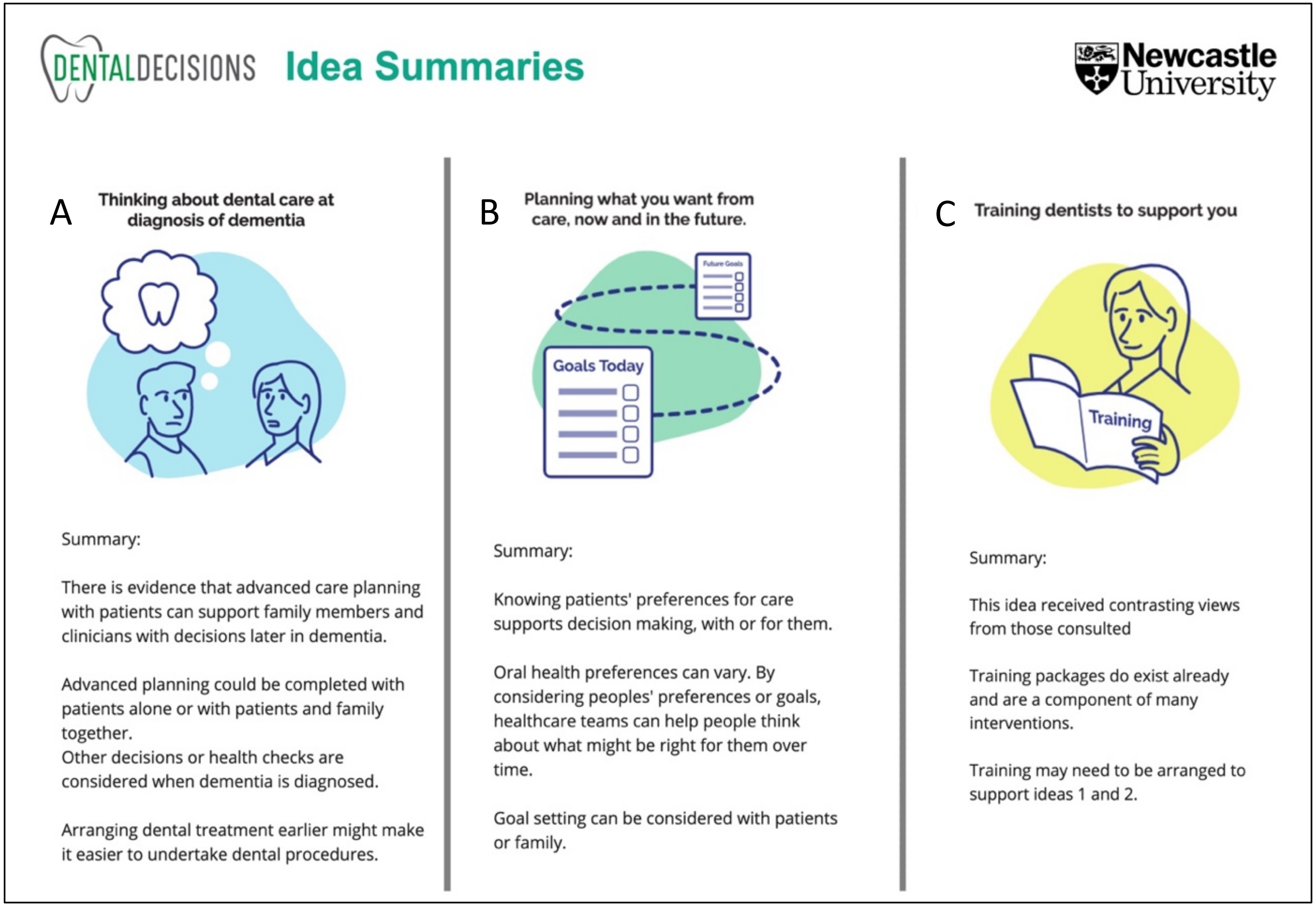
A concept aligned with Idea B was felt to be logical, sensible, and potentially usable in a range of settings or services. The group felt that a dentist could lead and coordinate future planning for people with a known diagnosis of dementia:

> *“We looked at where this planning should take place - should it be at the dental clinic, should it be at home? And the opinion was that it should sort of primary care linked with dentists…you could start off with a one-off appointment with a specialist dentist...who can help you have these discussions, start thinking about your preferences.”*
>
> CR (Group Facilitator)

The OHVS (Edwards, Randall and McNeil, 2021) was presented and discussed when exploring Idea B. Figure 10.12 presents a summary of comments about the scale. In summary, a specific scale was generally felt to be a pragmatic tool, if modified, but only as one way to gather information about peoples’ preferences. Participants noted there was a need to consider *how* such information may be used:

> *“You need to get this information, but you can’t just give them yet another survey without any context, without a plan to use the information.”*
>
> Caitlyn (GDP)

Building on such comments, the group discussed how information gathered in a specific or bespoke scale may be used to support decision-making. Each breakout group supported the concept of a 'baseline' recording of values. The groups were surprisingly engaged with the concept of a simplified scale resembling this to support the identification and documentation of what matters to a person.



DENTALDECISIONS **Idea Summaries**

Newcastle University

A **Thinking about dental care at diagnosis of dementia**

Summary:

There is evidence that advanced care planning with patients can support family members and clinicians with decisions later in dementia.

Advanced planning could be completed with patients alone or with patients and family together.
Other decisions or health checks are considered when dementia is diagnosed.

Arranging dental treatment earlier might make it easier to undertake dental procedures.

B **Planning what you want from care, now and in the future.**

Summary:

Knowing patients' preferences for care supports decision making, with or for them.

Oral health preferences can vary. By considering peoples' preferences or goals, healthcare teams can help people think about what might be right for them over time.

Goal setting can be considered with patients or family.

C **Training dentists to support you**

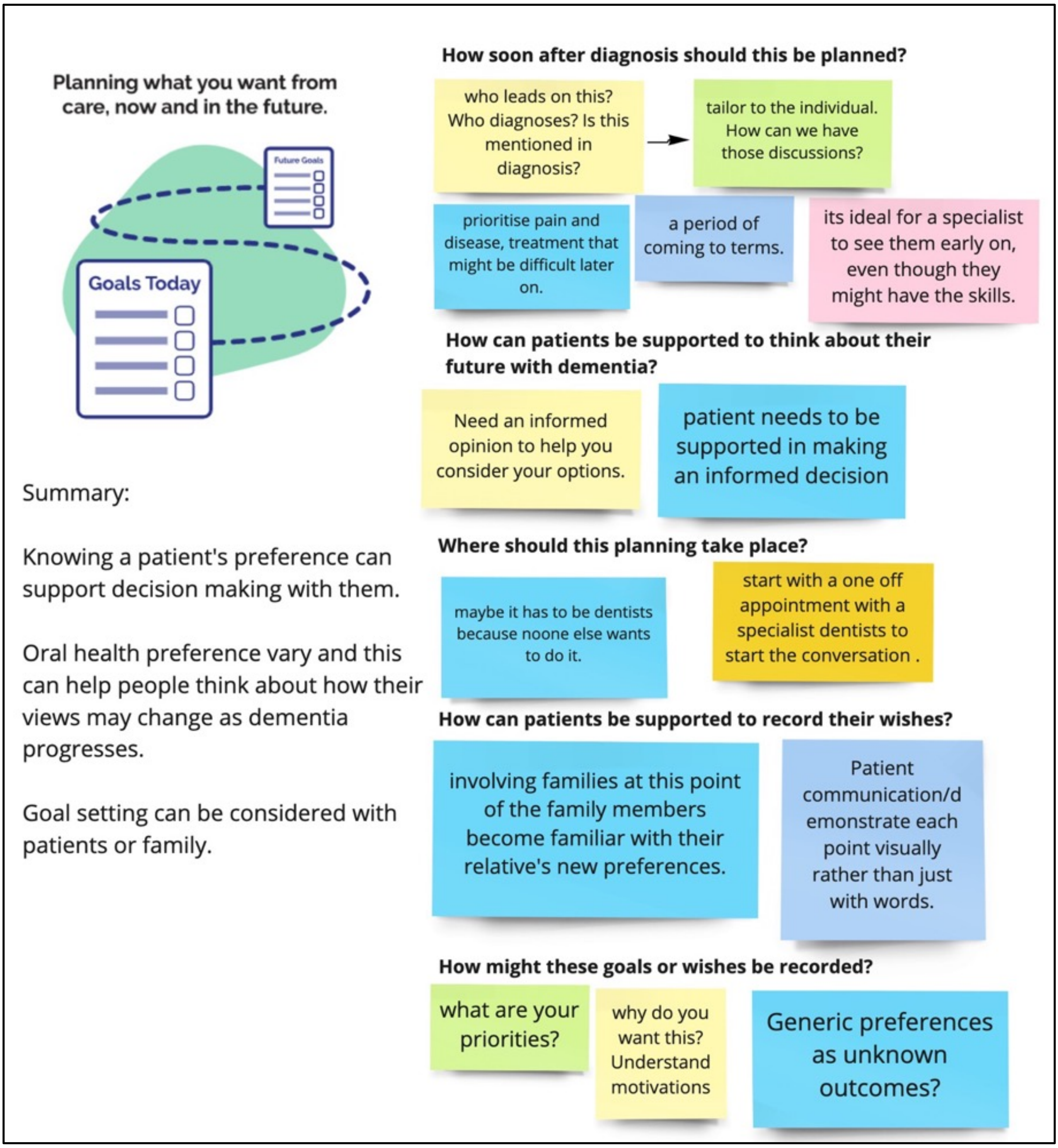
Summary:

This idea received contrasting views from those consulted

Training packages do exist already and are a component of many interventions.

Training may need to be arranged to support ideas 1 and 2.

Figure 10.10: Idea summaries taken to co-production Workshop 3



Planning what you want from care, now and in the future.

Summary:

Knowing a patient's preference can support decision making with them.

Oral health preference vary and this can help people think about how their views may change as dementia progresses.

Goal setting can be considered with patients or family.

How soon after diagnosis should this be planned?

who leads on this? Who diagnoses? Is this mentioned in diagnosis? → tailor to the individual. How can we have those discussions?

prioritise pain and disease, treatment that might be difficult later on.

a period of coming to terms.

its ideal for a specialist to see them early on, even though they might have the skills.

How can patients be supported to think about their future with dementia?

Need an informed opinion to help you consider your options.

patient needs to be supported in making an informed decision

Where should this planning take place?

maybe it has to be dentists because noone else wants to do it.

start with a one off appointment with a specialist dentists to start the conversation .

How can patients be supported to record their wishes?

involving families at this point of the family members become familiar with their relative's new preferences.

Patient communication/demonstrate each point visually rather than just with words.

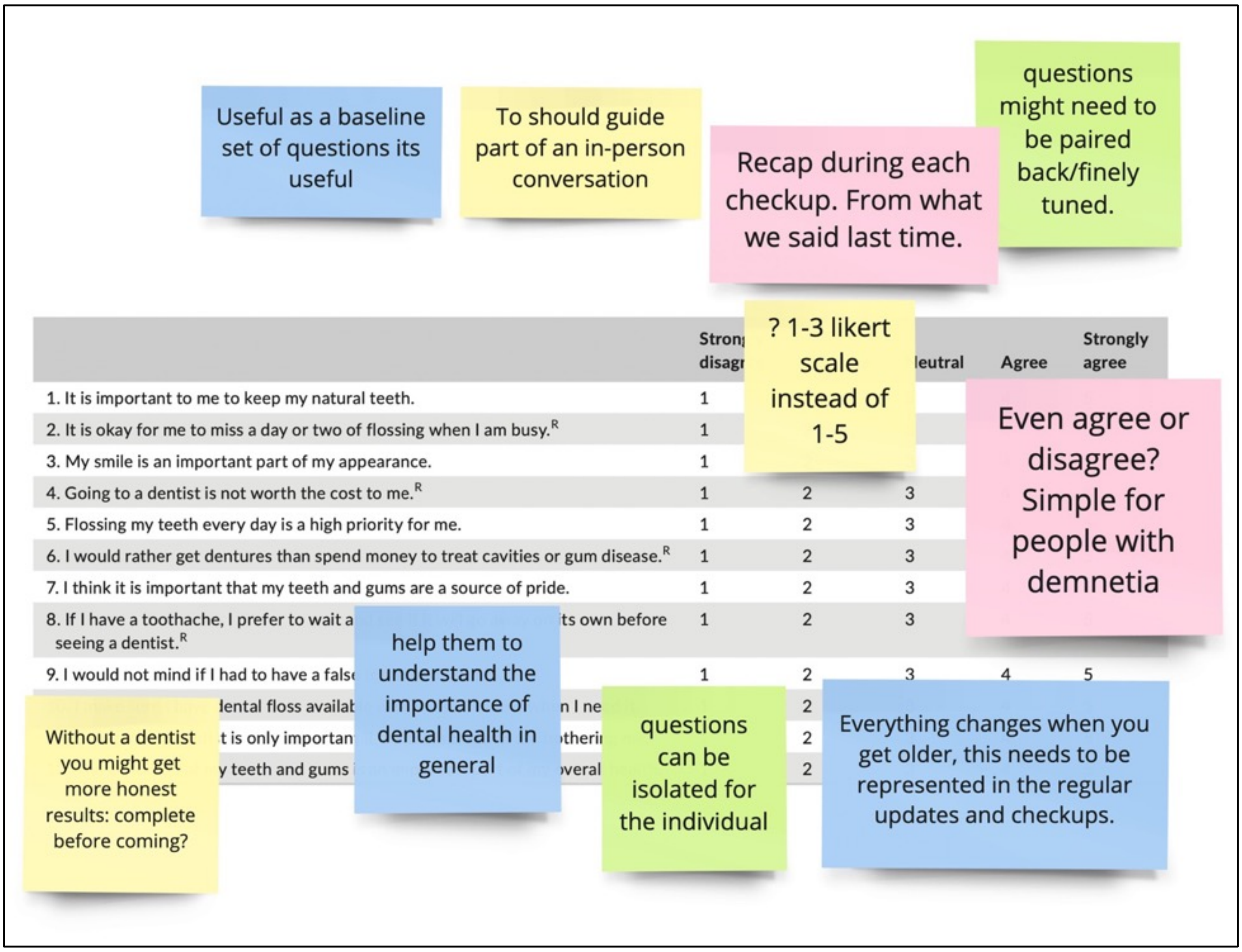
How might these goals or wishes be recorded?

what are your priorities?

why do you want this? Understand motivations

Generic preferences as unknown outcomes?

Figure 10.11: Comments made by the co-production group regarding Idea B



Useful as a baseline set of questions its useful

To should guide part of an in-person conversation

Recap during each checkup. From what we said last time.

questions might need to be paired back/finely tuned.

? 1-3 likert scale instead of 1-5

Even agree or disagree? Simple for people with demnetia

help them to understand the importance of dental health in general

Without a dentist you might get more honest results: complete before coming?

questions can be isolated for the individual

Everything changes when you get older, this needs to be represented in the regular updates and checkups.

	Stron disagr		leutral	Agree	Strongly agree
1. It is important to me to keep my natural teeth.	1				
2. It is okay for me to miss a day or two of flossing when I am busy.R	1				
3. My smile is an important part of my appearance.	1				
4. Going to a dentist is not worth the cost to me.R	1	2	3		
5. Flossing my teeth every day is a high priority for me.	1	2	3		
6. I would rather get dentures than spend money to treat cavities or gum disease.R	1	2	3		
7. I think it is important that my teeth and gums are a source of pride.	1	2	3		
8. If I have a toothache, I prefer to wait a ts own before seeing a dentist.R	1	2	3		
9. I would not mind if I had to have a fals	1	2	3	4	5
lental floss availab n I ne		2			
t is only importan therin		2			
y teeth and gums veral		2			

Figure 10.12: Comments made on Oral Health Values Scale (Edwards, Randall and McNeil 2021)

The summary of Idea C highlighted how training alone would be insufficient to address the problems the group had defined unless there was encouragement or an incentive for dentists to complete it. Even then, the participants expressed a concern that training alone may not lead to a change in practice:

> *"We also had some practical policy ideas around how this can be incentivised…once people graduate with a degree, there's no real incentive to take up specific forms of training again. So, there was quite a lot of agreement that it should be part of undergraduate training in some way, shape or form."*
>
> JL (Group Facilitator)

In the discussion of Idea C, the groups each detailed that any training should involve PLwD in its development and that training should focus on decision-making principles instead of specific rules or requirements. One group also felt that training should explore more complex scenarios to show these principles in use, including situations where it may be most appropriate not to deliver invasive dental care.

Throughout the session, there were intense discussions about each of the ideas. However, besides a brief description of how Idea B may look, there was little progress in developing a tangible product or output related to the other ideas. Workshop 3 ended with the facilitators of the breakout rooms presenting a summary of the key discussion points about each idea and how the discussions informed its development.

10.7 A turning point: research team activity after Workshop 3

Following Workshop 3, I reflected on how the planned interaction with PLwD and the dental team informed the remainder of the ‘Develop’ stage of the double diamond model across the second PLwD interaction, the second dental team workshop and Workshop 4. I noted that three ideas had been proposed but were fairly intangible at this point. A plan had to be prepared for Workshop 4 to facilitate further development and delivery of an appropriate output, but I was unsure how to build upon the ideas presented and explored in Workshop 3. To explore how progress might be achieved, I arranged to meet members of the supervisory team and Lab4Living collaborating team to discuss the next steps in the process and how to further develop the ideas proposed in the single final workshop.

While considering the next steps in the project and waiting for scheduled meetings to discuss the project's progress, one of the workshop participants contacted me to share some information about existing tools and processes that they were aware had been produced to support dental care for PLwD. They had briefly mentioned one of these existing ideas at Workshop 3 during a breakout room discussion, yet they had not actively shared this knowledge in the workshop setting or with me outside of the workshops. Neither approach had been presented in academic or grey literature, so they were not identified in the search undertaken in Project 1, nor were these identified when preparing the literature review in Chapters 2 and 3.

The participant explained that a memory service in the South of England with a team from Health Education England had worked together to develop a resource to direct people to dental services when they receive a diagnosis of dementia. This was done in the form of a double-sided card given to patients. One side contains text that encourages the person to book a dental appointment. Once an appointment is booked, patients are advised to give the card to the dental team as the reverse has information about the person having dementia to support the dental team. This card had been introduced into a memory service, but I was informed that the teams behind this had not considered monitoring the impact or suitability of this card, nor were they aware of any route by which its use, uptake or value could be quantified. I was informed the work was 'on hold' due to the reorganisation of specific services and the COVID-19 pandemic, but that there were discussions about using this card in the future and aspirations to consider how its impact might be evaluated. This idea aligned closely with Idea A as it supported dental care attendance and discussions about dental care when a person is diagnosed with dementia. I felt there was a risk of duplicating something that had been developed by another team and that exploring a related intervention may be an inefficient use of the co-production group's efforts and energy. Therefore, I considered whether it might be appropriate to discount Idea A from this project to allow a greater focus on other ideas during Workshop 4.

This same individual signposted me to a training program supporting dental teams in delivering person-centred dental care for PLwD. I was informed that this training had not been promoted, so it was not being frequently accessed by those at whom it was aimed. The training package strongly parallels Idea C as it aimed to support awareness of SDM and BIDM. As with the card detailed above, it seemed inappropriate for the co-production group to develop something that potentially duplicates an existing resource, especially when alternative potential alternative interventions, such as Idea B, were being explored and were more novel. To see if it would duplicate an existing training package, I examined this training whilst reviewing the comments made about the idea of training for dentists. The training did discuss appropriate aspects of decision-making for PLwD. However, the comments from the dental team feedback sessions did not refer to this package, suggesting dentists were unaware of or accessing it. Furthermore, dental team members in the specialist setting insinuated that they may not use or access training resources and that dentists in general practice would be unlikely to do so. This made me cautious about its suitability. I also doubted whether it would be possible to address the barriers related to existing training or to produce training collaboratively with PLwD within the proposed project timescale, approvals, or resources.

Using information about these existing approaches and from the earlier workshops, I worked with the Lab4Living team to assess Ideas A-C against the APEASE criteria for designing and evaluating interventions (Michie, Atkins and West, 2014, pp. 23–24). These criteria are typically used to evaluate finalised interventions, yet they also enabled us to consider wider aspects of the suitability of ideas that had been generated. This assessment is shown in Table 10.1. Interventions aligned with Ideas A and C already existed and these ideas both posed specific challenges that meant their further development may not be feasible. Idea A would not address the challenges in accessing dental care, and patients who did access dental care would still require support with decision-making, such as through an idea aligned with Idea B. Progressing with a training program (Idea C) in isolation may lead to a duplicate or similar product to one that already exists.

Evaluating these ideas against the APEASE criteria and revisiting the comments on the Miro board made it clear that progressing with the development of Idea B (Planning what you want from care, now and in the future - including information about a person's preferences) was the most suitable next step for the project. I also noted that the co-production partners had each contributed to this idea and its development and were supportive and enthusiastic about this concept. In addition, Idea B was novel, as no existing intervention was identified in Project 1 that considered any aspect of SDM, advance care planning or value elicitation for PLwD needing dental treatment. The specific format of the Idea still required further development. The remaining interactions with PLwD and dental teams and the remaining dental team and co-production workshops were an opportunity to build on Idea B to produce a novel intervention and effectively use the limited resources to produce a tangible prototype output.

Idea Criteria	**Idea A** Thinking about dental care at a diagnosis of dementia	**Idea B** Planning what you want from care now and in the future	**Idea C** Training dentists to support PLwD
Affordability	•Low cost to introduce, but cost may increase if professionals are involved in supporting dental care at diagnosis •Potential high cost to evaluate	•This would be a low-cost intervention to introduce. •Evaluation may have a high cost depending on how it was evaluated and where it was used	•The cost would depend on the nature of the training program and its method of delivery •Higher quality training may be associated with a greater cost
Practicality	•It is possible to implement consideration of dental care into the pathway of dementia diagnosis at multiple points •Other teams have been unable to evaluate this approach	•The practicality of this approach would depend on when and how people consider their current and future care •This could be practical both before and during a dental consultation	•This could be readily delivered to dentists if they were willing to take part in such training •Online training may be more accessible to a dentist
Effectiveness	•It is unknown if earlier consideration of preferences improves later decision-making •This might improve access to dental care but, in isolation, may not impact decision-making	•There is evidence to support consideration of future preferences and ACP •Approaches based on similar principles can support SDM processes for PLwD and other groups	•The number of dentists who may take part in training and the impact of training is unknown •Training could address many barriers to SDM but may not translate into altered clinical practice
Acceptability	•Co-production participants suggest this would be acceptable but not at the immediate dementia diagnosis •This was acceptable to dental teams providing there was capacity and reimbursement for their time	•Stakeholders felt this approach was appropriate, yet some PLwD may not find such an approach acceptable, especially if they have a preference to be passive in decision-making processes •Dentists may accept this if reimbursed for time spent using it	•Dentists are used to taking part in both mandatory and non-mandated professional development activities •Dentists may find lower-cost training more acceptable •Training that is mandated is more likely to be widely accepted
Side-effects and safety	•The point of diagnosis emotional: considering dental care too early on could be seen as inappropriate and an additional stressor	•Patients could be by thinking about how dementia may progress •Providing this information in a suitable format before a dental visit may help to minimise distress	•There are no known safety concerns related to the delivery of training
Equity	•This intervention may offer little to those with more significant symptoms of dementia •This would benefit those who can access private dental care more significantly	•This intervention would benefit PLwD who can access appropriate dental care where there is time to consider current and future preferences •Those accessing private care may find their dentists have more time available to undertake such discussions: this may create more benefit to more affluent individuals	•This approach should not lead to greater disparities in health or patient involvement •If only motivated dentists took part in training, PLwD cared for by those less familiar with the care of PLwD may receive care that is further removed in quality from that provided by motivated clinicians.

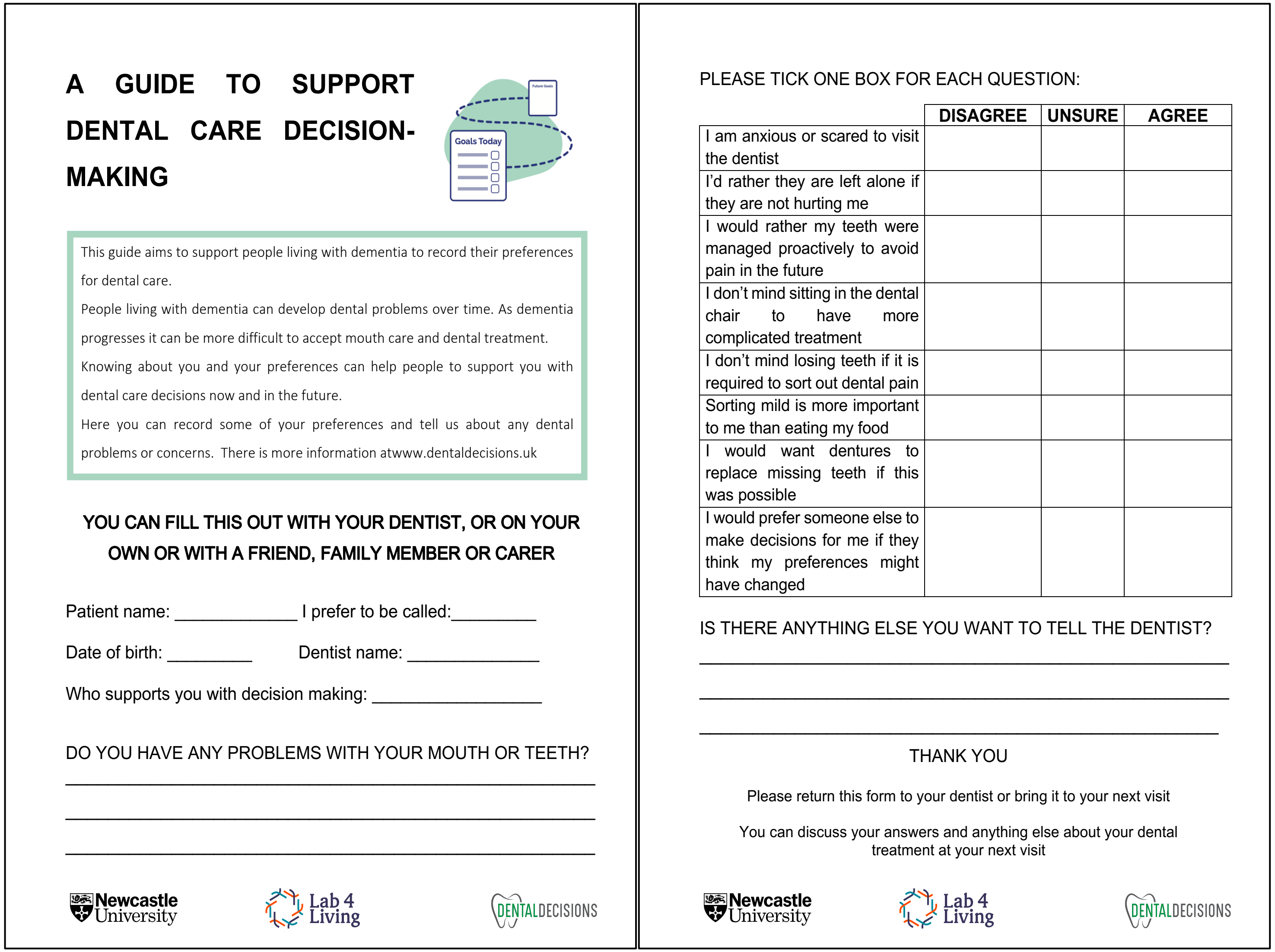
Table 10.1: Considering intervention ideas against the APEASE criteria

10.8 An initial prototype

As discussed above, the leading idea was a way to support PLwD to consider and plan their care and document or identify their preferences. As discussed in Chapter 7, dentists described how they primarily focused on the historical preferences of PLwD more than what may currently matter to them. However, dentists sought to provide individualised care (Chapter 7, Category 2), and patients wished to be understood as individuals (Chapter 8, Category 3). A method of capturing PLwD's current preferences was felt to have the potential to empower patients and enhance decision-making processes with patients retaining decisional capacity. If such preferences were documented, these might support later decisions if they lose decisional capacity. Considering how preferences could be detailed, I reflected on the comments made about the suitability of this OHVS (Edwards, Randall and McNeil, 2021) in supporting PLwD. Using these comments and the comments made that led to Idea B being identified, I began visualising what Idea B may look like and how it might include a modified scale. To facilitate ongoing progress, I felt it was necessary to prepare an initial tangible prototype concept to discuss in future stages of the co-production process. The initial prototype is presented in Figure 10.13.

In essence, this prototype aimed to promote discussions about PLwD's broad preferences for their current and future care and to record these. A series of statements to which PLwD could respond was prepared. This had some commonality with those included in the Oral Health Values Scale (OHVS) (Edwards, Randall and McNeil, 2021) but was not merely a duplication of an existing tool. Both the prototype and the OHVS focus on value establishment, so some similarities were unavoidable. However, I also used the feedback received from the dental team feedback session and discussions with PLwD to revise the questions included in the initial version of the prototype and to guide the remaining content of the prototype presented. The prototype was simply an initial idea of how preferences and values may be captured to support current and future care planning. It was not presented as dogma. Before Workshop 4, I shared my initial prototype with the team from Lab4Living and one of the research supervisors. There was an agreement that it was logical and pragmatic to take this prototype forward to the co-production group, PLwD and dental team members supporting the remaining co-production stages. We accepted that the co-production group might reject the idea, wish for it to be changed substantially or suggest that we revisit existing ideas. The potential for drastic change was not discounted, yet the prototype was presented to prompt ongoing discussions and explore its suitability. To support PLwD and dental team members' feedback, CR supported the creation of a more formal and refined usable prototype (Figure 10.14).

I was mindful that whilst the co-production group had supported the discussions that led to this prototype, they had not produced it directly. Arguably, online workshops with a large group may never have enabled such a tangible output to be produced. To ensure the ongoing involvement of the co-production group, to gather their views and ensure they could support or reject this prototype, I decided to provide an email update to the group members. I invited comments and feedback on the prototype shown in Figure 10.14 to ensure the main co-production group would not progress with the development of an idea with which they disagreed. There was complete acceptance from the co-production group about this approach, and many members of this group offered early comments to allow basic refinements before discussions with PLwD and a dental team began. Though the group had not produced this initial prototype directly, I was satisfied that the comments suggested they accepted and agreed with this draft approach and the plan to actively seek feedback later in the project. There is the potential that members of the group may have felt unable to disagree or reject this prototype. As the co-production partners were aware of the principles of co-production, the group should have been able to express any concerns if these existed. The lack of rejection or negative comments either meant they felt unable to express their true views, or that they were fully accepting of the idea. The acceptance of the prototype was pleasing and I aimed to ensure future stages of the work provided ample opportunity for numerous individuals to express their thoughts on the initial prototype that had been shared with them.



A GUIDE TO SUPPORT DENTAL CARE DECISION-MAKING

This guide aims to support people living with dementia to record their preferences for dental care.

People living with dementia can develop dental problems over time. As dementia progresses it can be more difficult to accept mouth care and dental treatment.

Knowing about you and your preferences can help people to support you with dental care decisions now and in the future.

Here you can record some of your preferences and tell us about any dental problems or concerns. There is more information atwww.dentaldecisions.uk

YOU CAN FILL THIS OUT WITH YOUR DENTIST, OR ON YOUR OWN OR WITH A FRIEND, FAMILY MEMBER OR CARER

Patient name: _____________ I prefer to be called:_________

Date of birth: _________ Dentist name: ______________

Who supports you with decision making: __________________

DO YOU HAVE ANY PROBLEMS WITH YOUR MOUTH OR TEETH?

____

____

____

PLEASE TICK ONE BOX FOR EACH QUESTION:

	DISAGREE	UNSURE	AGREE
I am anxious or scared to visit the dentist			
I'd rather they are left alone if they are not hurting me			
I would rather my teeth were managed proactively to avoid pain in the future			
I don't mind sitting in the dental chair to have more complicated treatment			
I don't mind losing teeth if it is required to sort out dental pain			
Sorting mild is more important to me than eating my food			
I would want dentures to replace missing teeth if this was possible			
I would prefer someone else to make decisions for me if they think my preferences might have changed			

IS THERE ANYTHING ELSE YOU WANT TO TELL THE DENTIST?

____

____

____

THANK YOU

Please return this form to your dentist or bring it to your next visit

You can discuss your answers and anything else about your dental treatment at your next visit

Figure 10.13: Prototype intervention V0

Let your dentist know about your dental care preferences

This form is for people living with dementia to record their preferences for dental care as well as any problems or concerns they might have.

As dementia progresses it can be more difficult to accept mouth care and dental treatment. Knowing more about you and what you want can help people support you with dental care now and in the future.

You can fill this out on your own, with a friend, family member, carer or with your dentist

My name:

I prefer to be called:

Date of birth:

My dentists name:

Who supports me with decision making:

Do you have any problems with your mouth or teeth?

Please tick one box for each statement:

	Disagree	Unsure	Agree
I am anxious or scared to visit the dentist	☐	☐	☐
I want my teeth to be left alone if they are not hurting me	☐	☐	☐
I prefer pro-active dental work that will help prevent future pain	☐	☐	☐
I don't mind sitting in the dentists chair for long treatment	☐	☐	☐
I don't mind losing teeth if it means I have less dental pain	☐	☐	☐
I would want dentures to replace missing teeth if possible	☐	☐	☐
I would tolerate mild pain if it meant I could eat solid food	☐	☐	☐
I would allow someone else to make decisions on my behalf if my preferences change in the future	☐	☐	☐

Is there anything else you want to tell the dentist?

Thank you

Please return this form to your dentist or bring it to your next visit.

You can talk to the dentist about these answers and anything else concerning your treatment during your next visit.

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Figure 10.14: Prototype V1.0 following the input of a professional designer

10.9 Second interactions with PLwD: Develop

A usable prototype (V1.0, shown in Figure 10.14) meant that feedback could be easily gained from PLwD. Six PLwD supported this process. Four took part in one-to-one discussions via Zoom, having been sent a digital copy of the prototype in advance alongside an explanation of its purpose and how it might be used. The remaining two participants preferred not to use Zoom but answered a series of questions about the idea through email correspondence. The one-to-one discussions allowed the prototype to be explored and discussed in more depth. I used open-ended questions to allow the PLwD to detail what they liked and disliked about the prototype and the general idea of using it before or during a dental appointment.

PLwD were broadly supportive of the prototype and understood its purpose:

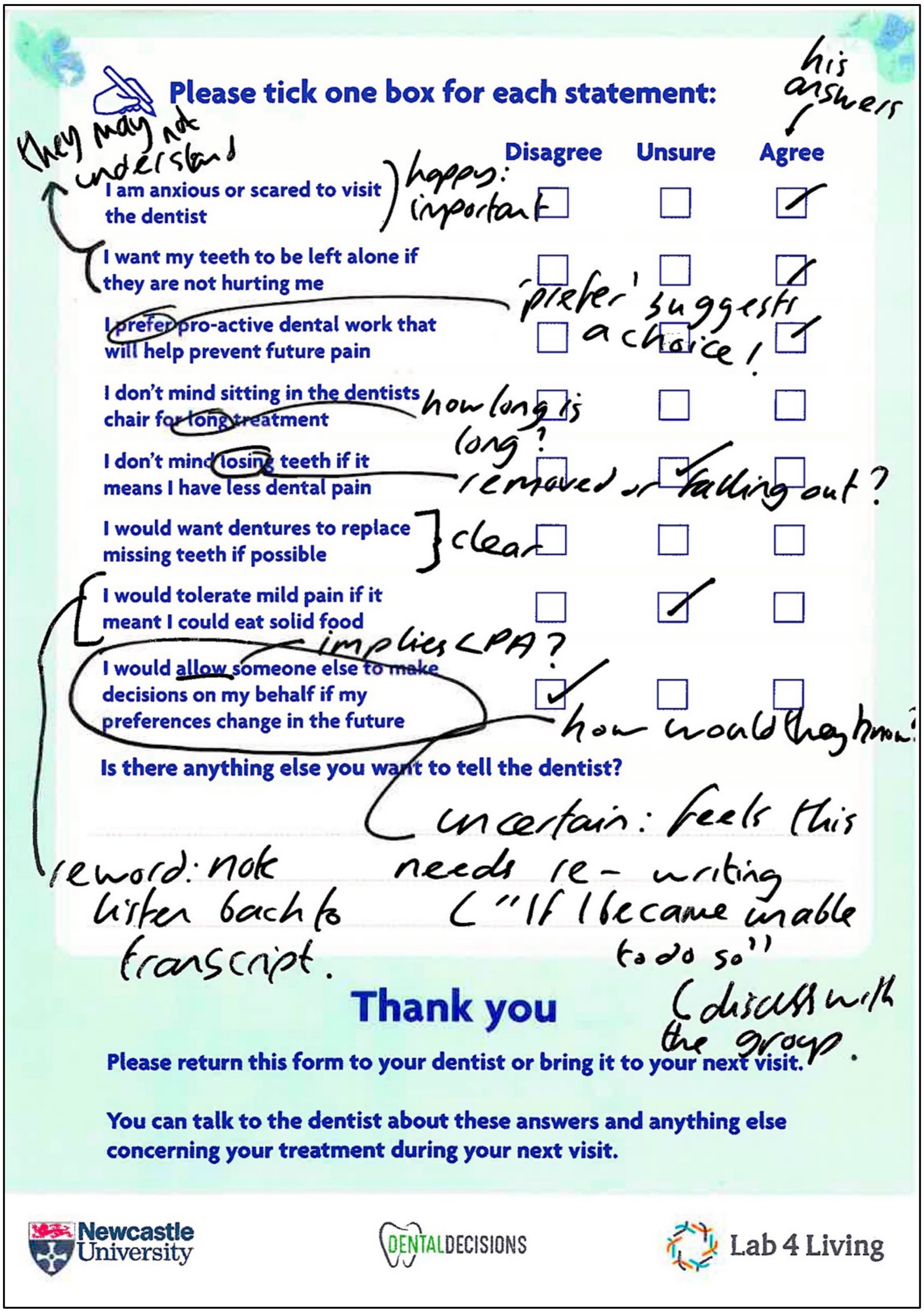
> *"It certainly made me think about what I want…it triggered a lot [of thoughts]. I am a very nervous patient, and this helped me think about what I'd want to do about dental problems."*
>
> Oscar (PLwD – DwLB)

The simplicity of the prototype was praised, but there was a concern expressed by two PLwD about whether it would be properly used:

> *"No, honestly, I think it's really, really good. There's only one, maybe two elements that I just would question…mainly if someone would use it!"*
>
> Owen (PLwD – AD)

This insight highlighted the need to explore the usability of this or any related idea in the subsequent co-production stages. Training specific to the intervention may support its use, yet this would differ from training proposed in Idea C which proposed more generic training to support decision-making with or for PLwD.

During these Zoom calls with PLwD, I annotated paper copies of the prototype to highlight what changes may need to be considered and discussed in Workshop 4. An example of annotations made is shown in Figure 10.15. PLwD detailed what aspects had been confusing or unclear for them. Such insight was valuable in informing the revisions that may be required in subsequent stages of the co-production process.



Please tick one box for each statement:

his answers

	Disagree	Unsure	Agree
I am anxious or scared to visit the dentist	☐	☐	☑
I want my teeth to be left alone if they are not hurting me	☐	☐	☑
I prefer pro-active dental work that will help prevent future pain	☐	☐	☑
I don't mind sitting in the dentists chair for long treatment	☐	☐	☐
I don't mind losing teeth if it means I have less dental pain	☐	☑	☐
I would want dentures to replace missing teeth if possible	☐	☐	☐
I would tolerate mild pain if it meant I could eat solid food	☐	☑	☐
I would allow someone else to make decisions on my behalf if my preferences change in the future	☑	☐	☐

They may not understand

happy: important

'prefer' suggests a choice!

how long is long?

removed or falling out?

clear

implies LPA?

how would they know?

Is there anything else you want to tell the dentist?

uncertain: feels this needs re-writing ("If I became unable to do so") (discuss with the group.

reword: nok listen back to transcript.

Thank you

Please return this form to your dentist or bring it to your next visit.

You can talk to the dentist about these answers and anything else concerning your treatment during your next visit.

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Figure 10.15: Annotations made on the read of prototype 1.0 during a Zoom call with a PLwD

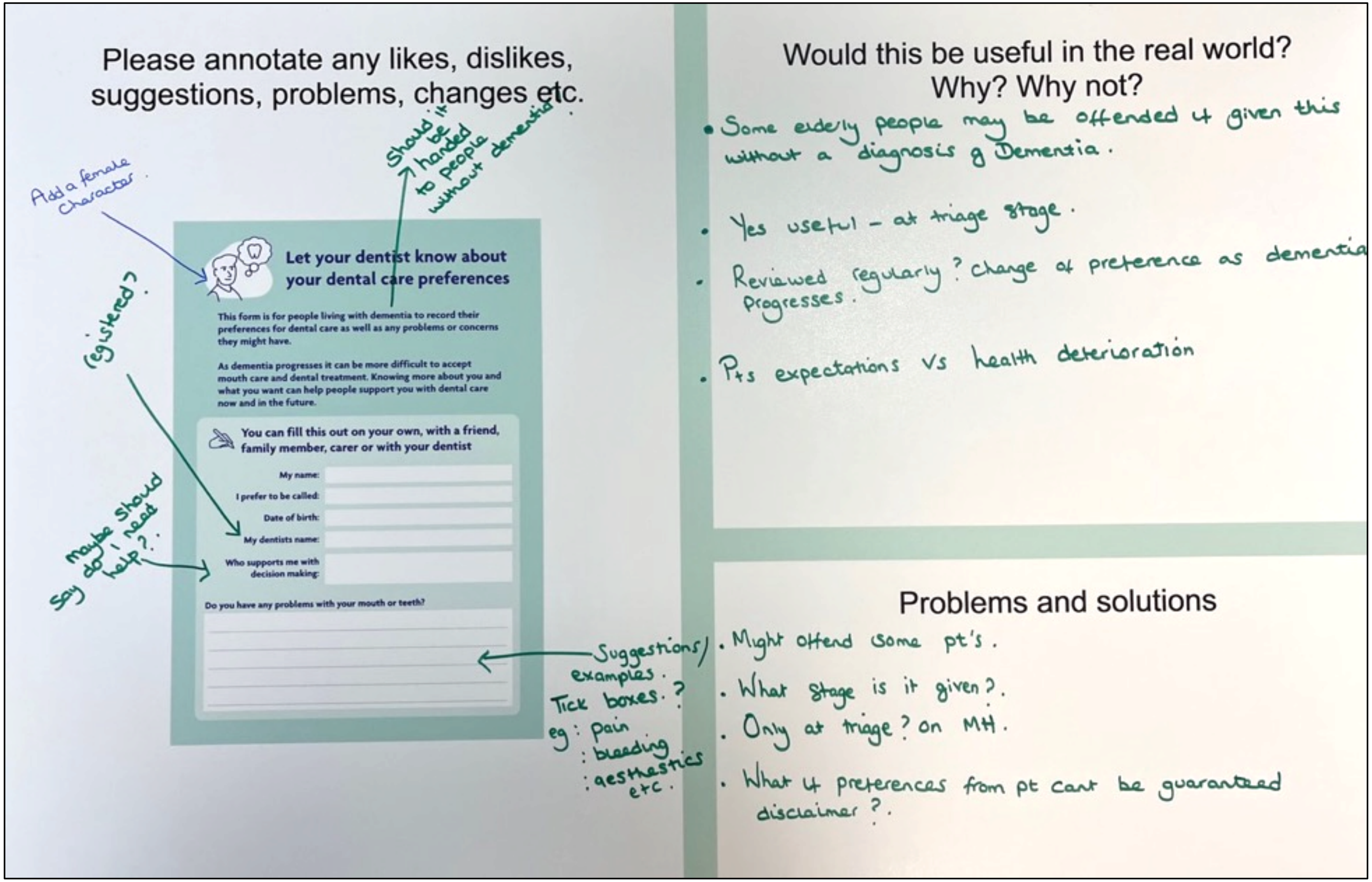
10.10 Second dental team feedback session: Develop

In a face-to-face interaction with a dental team, I shared a summary of the work's progress alongside a presentation of the session's objectives. A1-sized boards displaying either the front page, the back page, or both pages of Prototype 1.0 were produced. These boards contained prompt questions to guide the participants to consider aspects of usability and the prototype's content. These boards were given to each of three small groups which contained five, five and six dental team members. Participants were encouraged to discuss the concept and to write their thoughts, annotations, and answers to questions directly on the boards. Figure 10.16 shows one example of a completed annotated board from this workshop.

I rotated around the small groups to ask questions about their annotations and encourage them to share any thoughts and comments openly. I also actively encouraged each team member to offer their insights, especially non-clinical team members who I noted were speaking less during the small group discussions. Listening to discussions within each group allowed me to understand their thoughts and comments and use these to guide the next steps of the co-production process.

A crucial discussion point from the dental team workshops related to the fact that some people have dementia but may not have a formal diagnosis or that they may not wish to disclose this to a dentist. Dentists' experiences of managing this challenge are discussed in Chapter 7 (Category 1, 'Detective work') and the dental team's views aligned with the experiences described by the dentists who were interviewed in Project 2. A dementia-specific decision-support tool could only be used if patients or cares disclosed a diagnosis of dementia. The dental team felt this may be a barrier to using the prototype tool to support decision-making:

> *"You don't want to be guessing that somebody has dementia…like they might have mild cognitive impairment or be in denial of any changes. The last thing you want is to be asking 'do you have dementia then?'. This would totally ruin any rapport and support for someone who may be struggling before getting assessed or a diagnosis, you know?"*
>
> Adele (SDO)



Please annotate any likes, dislikes, suggestions, problems, changes etc.

Add a female character.

Should it be handed to people without dementia.

(registered?).

maybe should say do I need help?.

Let your dentist know about your dental care preferences

This form is for people living with dementia to record their preferences for dental care as well as any problems or concerns they might have.

As dementia progresses it can be more difficult to accept mouth care and dental treatment. Knowing more about you and what you want can help people support you with dental care now and in the future.

You can fill this out on your own, with a friend, family member, carer or with your dentist

My name:

I prefer to be called:

Date of birth:

My dentists name:

Who supports me with decision making:

Do you have any problems with your mouth or teeth?

Suggestions/ examples.
Tick boxes.?
eg: pain
: bleeding
: aesthestics
etc.

Would this be useful in the real world? Why? Why not?

- Some elderly people may be offended if given this without a diagnosis of Dementia.
- Yes useful – at triage stage.
- Reviewed regularly? change of preference as dementia progresses.
- Pts expectations vs health deterioration

Problems and solutions

- Might offend some pt's.
- What stage is it given?.
- Only at triage? on MH.
- What if preferences from pt cant be guaranteed disclaimer?.

Figure 10.16: Annotations made by the dental team regarding Prototype 1.0

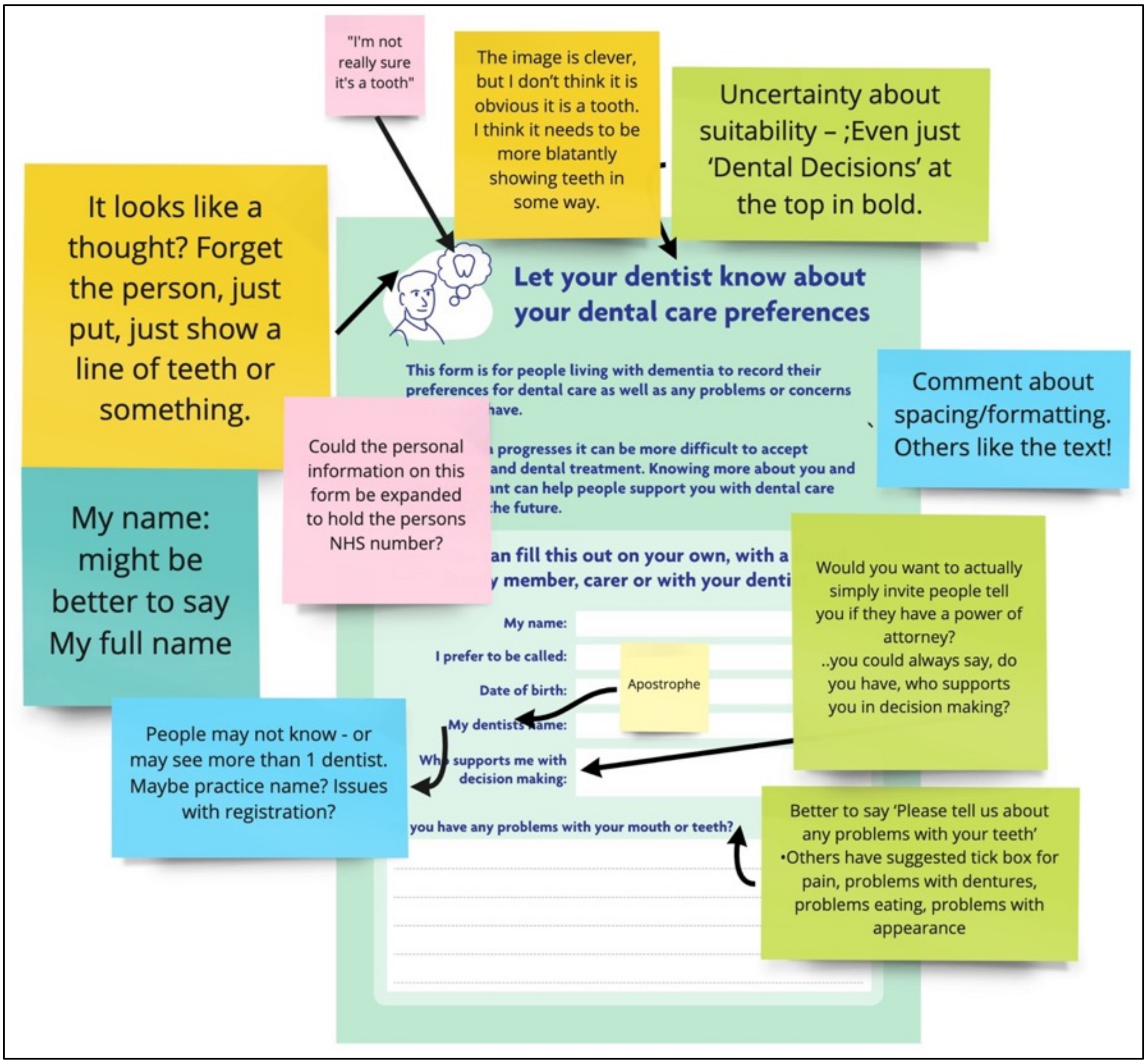
Specifically, they wondered if it was necessary to refer to dementia at all:

> *"Can you just take dementia out of it…like off the page? You've got a complex person needing some help with a decision so just give them this tool whether or not they've got dementia…that way they'd not get frustrated at a label or something they've not told you about?"*
>
> Adriana (Dental nurse)

I documented and reflected upon the dental team members' comments and their annotations (such as those shown in Figure 10.16) to guide the content of discussions in Workshop 4.

10.11 Research team activity after dental team feedback and interaction with PLwD

I reviewed the comments from PLwD and the dental team and prepared a summary of these as annotations on the latest prototype on the MIRO whiteboard (Figures 10.17 and 10.18). Before workshop four, an amended version of the prototype (version 2.0) was produced (Figure 10.19) based on the more objective comments shown in Figures 10.17 and 10.18. More subjective comments or those that needed more discussion and debate (such as the relevance of a 'thought bubble' or the need for both male and female character icons) were not implemented at this point so that the co-production group to explore the need for these changes collaboratively. I also arranged for CR to produce a non-dementia version of the document (Figure 10.20). This was based primarily on the dental team's concern about the reference to dementia limiting the usefulness of the tool for those who are yet to receive a formal diagnosis or those who may decide not to declare this when accessing dental care. Having two prototypes (Figures 10.19 and 10.20) meant that the initial version and a potential modification could be explored and discussed in Workshop 4.



"I'm not really sure it's a tooth"

The image is clever, but I don't think it is obvious it is a tooth. I think it needs to be more blatantly showing teeth in some way.

Uncertainty about suitability – ;Even just 'Dental Decisions' at the top in bold.

It looks like a thought? Forget the person, just put, just show a line of teeth or something.

Let your dentist know about your dental care preferences

This form is for people living with dementia to record their preferences for dental care as well as any problems or concerns have.

progresses it can be more difficult to accept and dental treatment. Knowing more about you and nt can help people support you with dental care he future.

Comment about spacing/formatting. Others like the text!

Could the personal information on this form be expanded to hold the persons NHS number?

My name: might be better to say My full name

an fill this out on your own, with a member, carer or with your denti

Would you want to actually simply invite people tell you if they have a power of attorney? ..you could always say, do you have, who supports you in decision making?

My name:
I prefer to be called:
Date of birth:
My dentists name:
Who supports me with decision making:

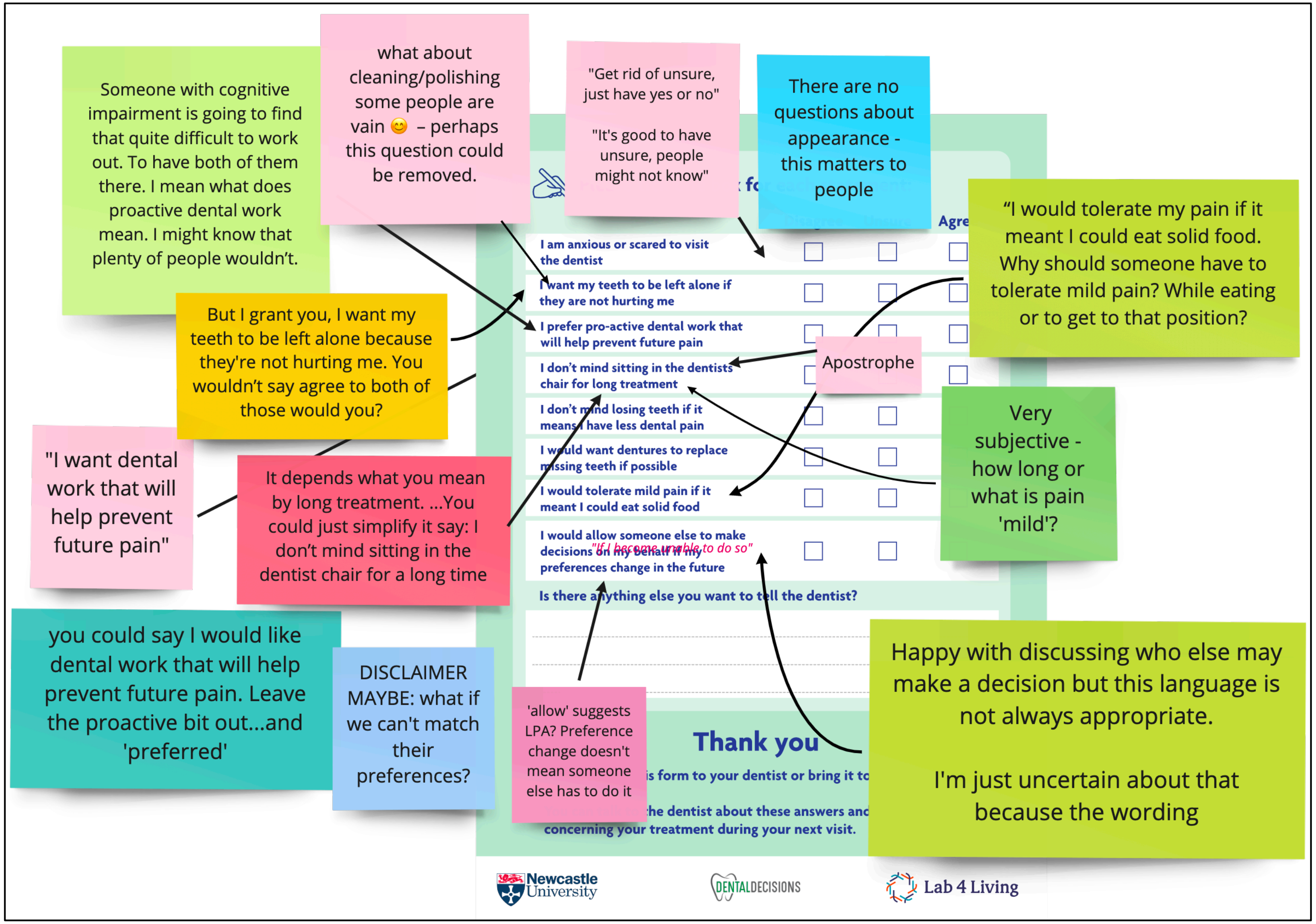
Apostrophe

People may not know - or may see more than 1 dentist. Maybe practice name? Issues with registration?

you have any problems with your mouth or teeth?

Better to say 'Please tell us about any problems with your teeth'
•Others have suggested tick box for pain, problems with dentures, problems eating, problems with appearance

Figure 10.17: Comments made by PLwD and the dental team on page 1 of the prototype



Someone with cognitive impairment is going to find that quite difficult to work out. To have both of them there. I mean what does proactive dental work mean. I might know that plenty of people wouldn't.

what about cleaning/polishing some people are vain 😊 – perhaps this question could be removed.

"Get rid of unsure, just have yes or no"

"It's good to have unsure, people might not know"

There are no questions about appearance - this matters to people

"I would tolerate my pain if it meant I could eat solid food. Why should someone have to tolerate mild pain? While eating or to get to that position?

But I grant you, I want my teeth to be left alone because they're not hurting me. You wouldn't say agree to both of those would you?

Apostrophe

"I want dental work that will help prevent future pain"

It depends what you mean by long treatment. ...You could just simplify it say: I don't mind sitting in the dentist chair for a long time

Very subjective - how long or what is pain 'mild'?

you could say I would like dental work that will help prevent future pain. Leave the proactive bit out...and 'preferred'

DISCLAIMER MAYBE: what if we can't match their preferences?

'allow' suggests LPA? Preference change doesn't mean someone else has to do it

Happy with discussing who else may make a decision but this language is not always appropriate.

I'm just uncertain about that because the wording

			Agre
I am anxious or scared to visit the dentist	☐	☐	☐
I want my teeth to be left alone if they are not hurting me	☐	☐	☐
I prefer pro-active dental work that will help prevent future pain	☐	☐	☐
I don't mind sitting in the dentists chair for long treatment	☐		☐
I don't mind losing teeth if it means I have less dental pain	☐	☐	
I would want dentures to replace missing teeth if possible	☐	☐	
I would tolerate mild pain if it meant I could eat solid food	☐	☐	
I would allow someone else to make decisions ~~on my behalf if my~~ *"If I become unable to do so"* preferences change in the future	☐	☐	

Is there anything else you want to tell the dentist?

Thank you

concerning your treatment during your next visit.

Figure 10.18: Comments made by PLwD and the dental team on page 2 of the prototype

Let your dentist know about your dental care preferences

This form is for people living with dementia to record their preferences for dental care as well as any problems or concerns they might have.

As dementia progresses it can be more difficult to accept mouth care and dental treatment. Knowing more about you and what you want can help people support you with dental care now and in the future.

You can fill this out on your own, with a friend, family member, carer or with your dentist

My name:

I prefer to be called:

Date of birth:

My dental practice or service:

Who supports me with decision making:

Does the person above has a Lasting Power of Attorney for health? Yes ☐ No ☐

Please tell us about any problems you have with your teeth or mouth:

Please tick one box for each statement:

	Disagree	Unsure	Agree
Visiting the dentist makes me scared or anxious	☐	☐	☐
It's important to me that my teeth look good	☐	☐	☐
I want my teeth to be left alone if they are not causing me pain	☐	☐	☐
I am happy to sit in the dental chair for as long as it takes to fix a broken tooth	☐	☐	☐
I don't mind having teeth removed if it means I have less pain	☐	☐	☐
I would want dentures to replace missing teeth if possible	☐	☐	☐
Being able to eat whatever I want is important to me	☐	☐	☐

Is there anything else you want the dentist to know?

Thank you

Please return this form to your dentist or bring it to your next visit.

You can talk to the dentist about these answers and anything else concerning your treatment during your next visit.

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Figure 10.19: Prototype 2.0, showing small changes from Prototype 1.0

Let your dentist know about your dental care preferences

It can be useful to think about what matters to you about dental care before your visit.

This form can be used to help you and your dentist talk about what treatment might be best for you.

You can fill this out on your own, with a friend, family member, carer or with your dentist

My name:

I prefer to be called:

Date of birth:

My dental practice or service:

Who supports me with decision making:

Does the person above has a Lasting Power of Attorney for health? Yes ☐ No ☐

Please tell us about any problems you have with your teeth or mouth:

Please tick one box for each statement:

	Disagree	Unsure	Agree
Visiting the dentist makes me scared or anxious	☐	☐	☐
It's important to me that my teeth look good	☐	☐	☐
I want my teeth to be left alone if they are not causing me pain	☐	☐	☐
I am happy to sit in the dental chair for as long as it takes to fix a broken tooth	☐	☐	☐
I don't mind having teeth removed if it means I have less pain	☐	☐	☐
I would want dentures to replace missing teeth if possible	☐	☐	☐
Being able to eat whatever I want is important to me	☐	☐	☐

Is there anything else you want the dentist to know?

Thank you

Please return this form to your dentist or bring it to your next visit.

You can talk to the dentist about these answers and anything else concerning your treatment during your next visit.

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Figure 10.20: A non-dementia version of Prototype 2.0

10.12 Workshop 4: Deliver

The focus of Workshop 4 was twofold: firstly, to further explore how the intervention may be used and secondly, what adaptations to the prototype are needed or appropriate based on how it may be used. Usability was therefore discussed with the co-production group first. The second half of the workshop explored specific refinements that might be made to the prototypes shown in Figures 10.19 and 10.20 to support their use in practice. The co-production group also had to consider whether a non-dementia version of the prototype (Figure 10.20) might be more appropriate or usable to address the issues discussed in Section 10.10.

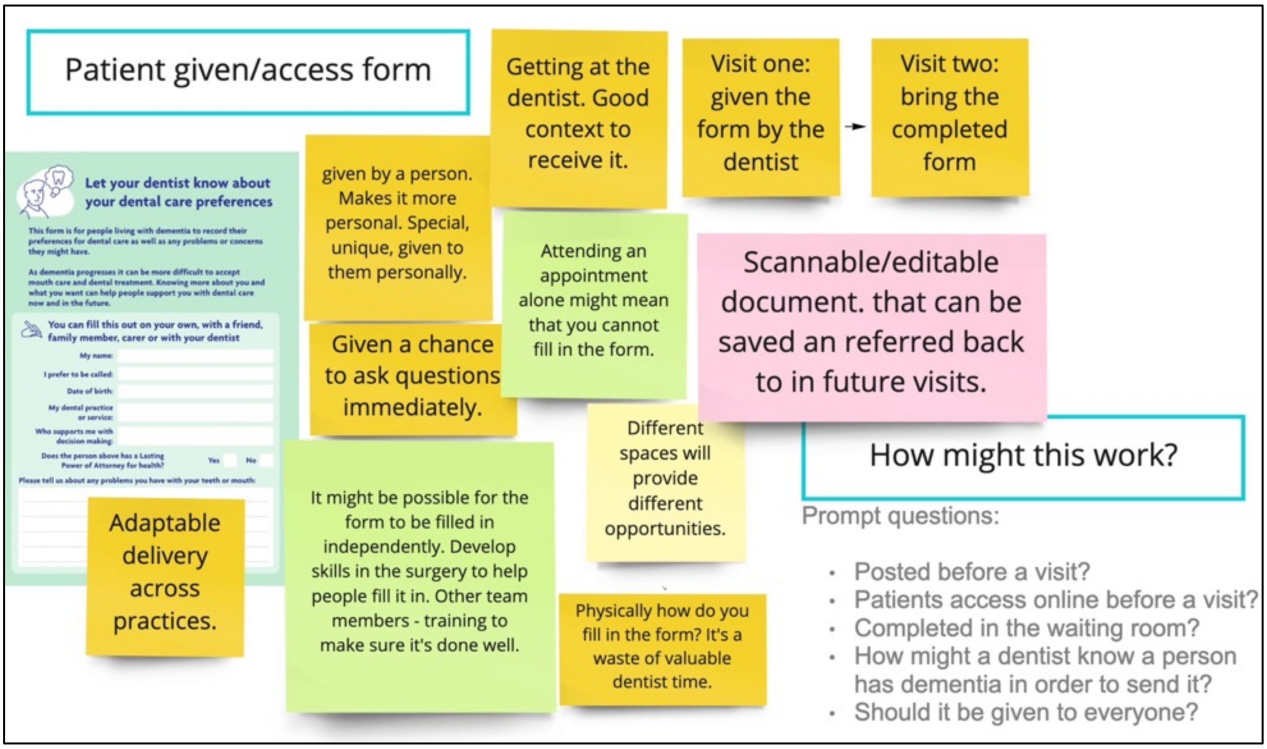
The prototypes presented were expected to have four key stages of use:

1. A patient is given the form or accesses this before a dental visit
2. A patient completes the form (with or without support)
3. The form is used in a dental visit to guide current dental care
4. A historical version of the form is used to guide decision-making at a later time point

In Workshop 4, the two breakout groups discussed each of the stages at which the tool could be used. I worked with the Lab4Living team to produce prompts that would guide discussions within these breakout groups. Figure 10.21 shows the comments made during one of the breakout groups when considering the tool's usability when it is given to or accessed by a person with dementia. The comments show how one group felt the concept should be paper-based and given at an initial dental visit. The other breakout group discussed the possibility of completing the form before a visit, having either been sent a copy by post or signposted to an online version:

> *"giving it to them makes it more personal. It makes it more personal, and I think they're more likely to engage in the process rather than asking them to download it online. Maybe you could send it out in advance and sort of say, 'We're going to discuss this with you at your visit'."*
>
> Adam (Out-of-hours emergency dentist)

> *"It might be that they receive it in person in context at the appointment, but then they have to take it home and fill it in separately. But they get a chance to ask questions about what it is…I guess it depends on what they're comfortable with… it can be filled out right now as you receive it, or it can be filled out at home later, and there's no sort of pressure to complete it now?"*
>
> Alyson (Dental policy-maker)



Patient given/access form

Let your dentist know about your dental care preferences

This form is for people living with dementia to record their preferences for dental care as well as any problems or concerns they might have.

As dementia progresses it can be more difficult to accept mouth care and dental treatment. Knowing more about you and what you want can help people support you with dental care now and in the future.

You can fill this out on your own, with a friend, family member, carer or with your dentist

My name:
I prefer to be called:
Date of birth:
My dental practice or service:
Who supports me with decision making:
Does the person above has a Lasting Power of Attorney for health? Yes ☐ No ☐
Please tell us about any problems you have with your teeth or mouth:

Adaptable delivery across practices.

given by a person. Makes it more personal. Special, unique, given to them personally.

Given a chance to ask questions immediately.

It might be possible for the form to be filled in independently. Develop skills in the surgery to help people fill it in. Other team members - training to make sure it's done well.

Getting at the dentist. Good context to receive it.

Attending an appointment alone might mean that you cannot fill in the form.

Different spaces will provide different opportunities.

Physically how do you fill in the form? It's a waste of valuable dentist time.

Visit one: given the form by the dentist → Visit two: bring the completed form

Scannable/editable document. that can be saved an referred back to in future visits.

How might this work?

Prompt questions:

- Posted before a visit?
- Patients access online before a visit?
- Completed in the waiting room?
- How might a dentist know a person has dementia in order to send it?
- Should it be given to everyone?

Figure 10.21: Comments about the usability of the dementia version of prototype 2.0

When the breakout groups returned to the main workshop space, the co-production group agreed that a paper-based or online approach could be suitable depending on the needs of different patients and dental services. When discussing the receipt or access and completion of either version of the form, a carer of a PLwD stated the form should act primarily as a conversation starter. The full co-production group endorsed this sentiment:

> *"In essence, it's to get people talking about what they want…people like me and my mam never thought about it…this way you can think about what you want and it's good that it's so broad because we never knew how her dementia would affect her and her teeth, so the simplicity of it*

> *all starts those conversations at home and with the dentist…it doesn't matter if you do it on a computer or at the clinic or both."*
>
> Rodney (Carer of PLwD)

For decision-making when a PLwD may have lost decisional capacity, a dentist summarised how their group viewed the intervention could function:

> *"It allows the dentist or the therapist or whoever's working with the patient to actually work with the caregiver, to work with the family member to say, 'Well, we had these discussions, and yes, it was some time ago, but these are their preferences, and we know that preferences may have changed over time.' And I think it is just that conversation starter - like [NAME] said – but with patients and later with family."*
>
> Nicola (CDO)

The group discussed how they felt a completed version of the prototype would be purely advisory to support consideration of a wide range of factors relevant to decision-making:

> *"[Our breakout room] spoke about the format being advisory, not rigid, and you know the historic preferences being the final piece of the jigsaw that's used in terms of making decisions and shared decisions."*
>
> CR (Group Facilitator)

> *"you can make generic kinds of decisions about what they think they would like and then apply it to the new situations. So, you then kind of refer back and say, 'Well, when we were talking about it generally you said you would like this, bearing in mind in this specific situation it would mean X, Y and Z, how do you feel about that? Would you like to go with what you said earlier, or do you want to find out more?' Yeah, it's a good conversation starter."*
>
> Carl (Carer of PLwD)

Despite the group's understanding of the prototype, it was noted that dentists might need to receive training specific to this concept to support its use:

> *"The dentists should know – they need to know – what principles guide decision-making discussions or what principles should…then they can understand the value of this form and the information it gives them. But if they don't get the basics, they won't know how to use it, so they need some training to cover the principles of it and the use of it then they should easily be able to use it day-to-day".*
>
> Denise (CDO)

> *"there is a need for the dental professionals to have some skills and capabilities around how to have those conversations or introduce those conversations…it needs to be clear to dentists that what is captured here is just the first part of an interactive process for a dialogue or a conversation."*
>
> Alyson (Dental policy-maker)

The need to train dentists had been proposed earlier in the process as a standalone idea (Idea C). This need was explored further in Workshop 3. Training specifically related to the prototype, however, is more specific and could support the use of this tool in practice. The co-production group detailed that a user guide and videos demonstrating the concept in use would be valuable in supporting an understanding of the Idea that had been developed.

Potential changes to the format and content of the form were discussed in the second half of Workshop 4. When discussing the benefit or necessity to mention dementia, the group collectively agreed that there was no need for the prototype to be specific to PLwD:

> *"it's so easy to assume that what we make has to be dementia specific, it's so easy to make that assumption, but we've talked before… about terminology that patients are familiar with or not*

> *for their diagnosis and I think yeah that’s really interesting. Logically, this should still work for people, the non-dementia version should still work for people with dementia, shouldn’t it.”*
>
> Louise (Academic)

There was general agreement that the tool would be most useful for PLwD but that it didn’t need to mention dementia in the introductory text. A query was raised about when it might be used for patients without dementia or those suspected of having cognitive impairments: when discussing this in depth, the group agreed that such an issue would likely need to be explored once the tool started to be used but that the lack of reference to dementia made it suitable to use with other patient groups and that there was little likelihood of harm from doing so.

As suggested by one carer of a PLwD, the group agreed that there would be merit in adding a version number and date to the form to detail when it was first completed:

> *“I would like somewhere on the form the date that I filled the form in. There’s no reference, and there’s no time reference for me as to when I did it. And that would make my little brain a little bit better if I can go back through time to such and such a date, that was the last time when I filled the form in.”*
>
> Carl (Carer of PLwD)

Most of the remaining changes discussed were related to spelling, grammar, and the phrasing of the introductory text. For example, one participant highlighted that one question on the form contradicted the focus on the individual:

> *“It makes no sense to ask, ‘Does the person above have a lasting power of attorney?’ Because all the rest of the form is about you. So why isn’t it, ‘Do you have a lasting power of attorney?’ So that kind of just grated on me that it suddenly changed from it being the person doing the form. I don’t know. I just didn’t like it.”*
>
> Philippa (dementia nurse)

The group discussions supported refinements to specific questions that were felt more aligned with the principles of ascertaining patients' values and preferences. The subjective proposals for changes to the form (detailed in Section 10.11) were discussed to agree on what changes were felt to be needed.

There was a debate about the need for free text boxes to allow people to expand on their preferences or thought processes. Whilst the group agreed there was merit in understanding peoples' views in more depth, there was also a concern expressed - by carers of PLwD in particular – that this would make the form more complex to complete. The simplicity of the form was seen as a strength by the carers of PLwD who may complete it with a PLwD:

> *"You have all this waffle on so many big forms…it just makes it much more complicated. This one's really nice because it's just very short, simple sentences."*
>
> Rodney (Carer of PLwD)

As the group had agreed it was beneficial as a conversation starter, the group agreed to include an additional *'I would like to discuss this more'* selection for each question presented. The group felt this change would allow the specific areas to be further explored in a dental visit. Building on a version of the prototype that did not refer to dementia directly, the co-production group present at Workshop 4 all supported and agreed upon specific refinements to implement to produce a final prototype. The specific changes were implemented, and the group agreed on the simple name of 'The Dental Decisions Tool' for the prototype. I present the final prototype, with these changes in place, in Chapter 11.

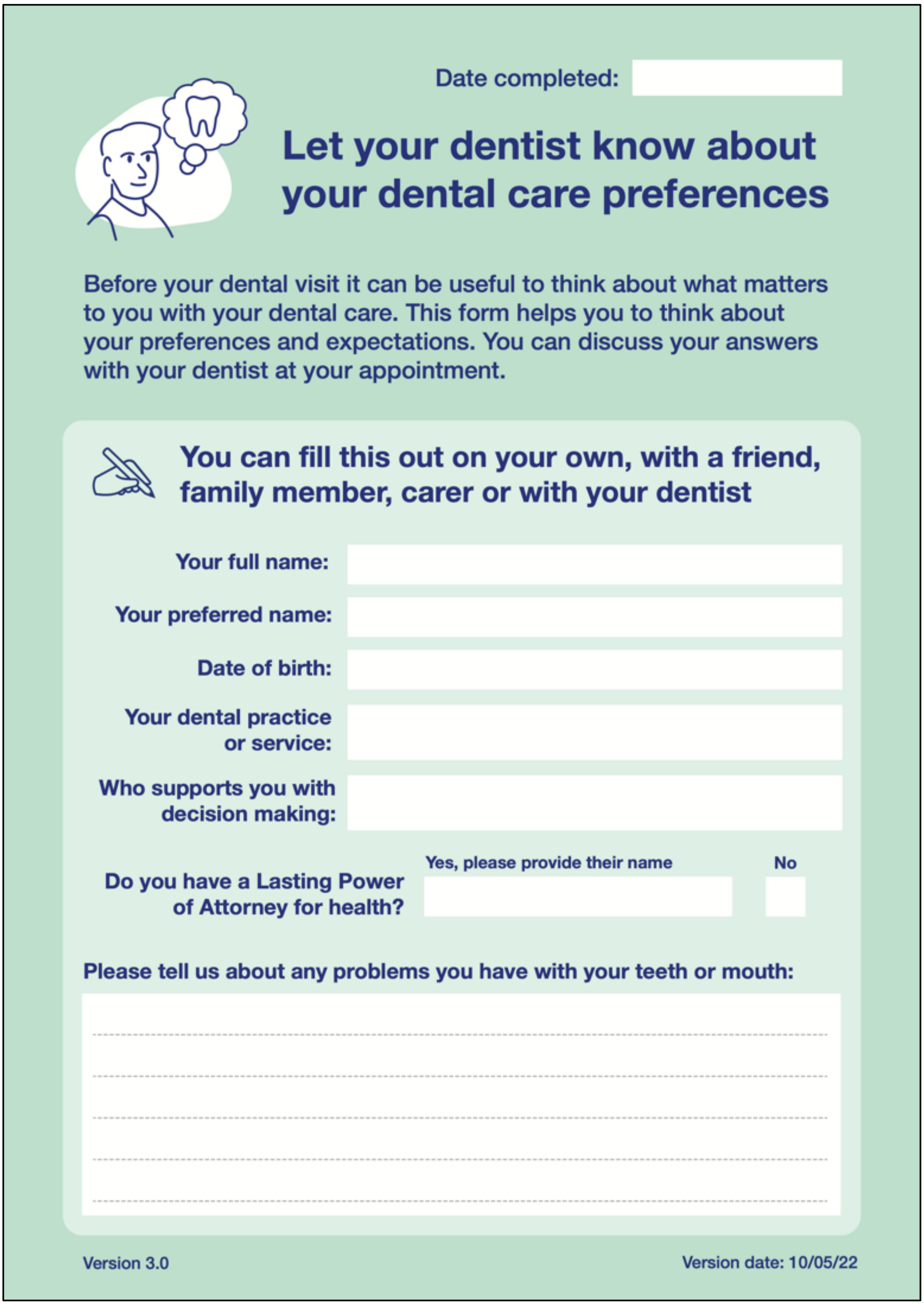
Chapter 11. The ‘Dental Decisions Tool’

Here I describe the final prototype of the Dental Decisions Tool that was produced through the previously described co-production process. I discuss the core functions of this tool and how elements of it aim to address some of the challenges that were identified in Projects 2 and 3 and further explored in the co-production process described in Chapter 10.

11.1 Introduction

The Dental Decisions Tool is presented in Figures 11.1 and 11.2 which show the two sides of the paper-based version of the tool. An online version is also available at www.dentaldecisions.uk where video demonstrations are also presented. The tool can be sent to or accessed by patients before their dental visit, allowing them to consider and record their preferences before a dental consultation. If a patient has not accessed the tool before attending a dental clinic, it can be completed whilst waiting for the dental visit or during a conversation with a dentist. The form functions as a conversation starter and a framework on which decisions can be discussed during a consultation. A secondary function of the Dental Decisions Tool is to support BIDM if a person loses decisional capacity in the future. If this occurs, dentists and those involved in BIDM can refer to the tool to consider a person's previous wishes and their applicability to a newly encountered situation.

The Dental Decisions Tool has been designed to be as accessible as possible to those with cognitive impairment and to adhere to design recommendations proposed by the Alzheimer’s Society (2021) and Dementia Voices (2013). Furthermore, the tool has been designed to comply with the requirement of the Care Act (2014, section 4.4), which states, *“Information…must be accessible to, and proportionate to the needs of, those for whom it is being provided”.* The involvement of stakeholders, including PLwD, supported the development of a tool that was suitable from the perspective of its users.



Date completed:

Let your dentist know about your dental care preferences

Before your dental visit it can be useful to think about what matters to you with your dental care. This form helps you to think about your preferences and expectations. You can discuss your answers with your dentist at your appointment.

You can fill this out on your own, with a friend, family member, carer or with your dentist

Your full name:

Your preferred name:

Date of birth:

Your dental practice or service:

Who supports you with decision making:

Do you have a Lasting Power of Attorney for health? Yes, please provide their name ☐ No

Please tell us about any problems you have with your teeth or mouth:

Version 3.0

Version date: 10/05/22

Figure 11.1: The front of V3.0 of the physical version of the Dental Decisions Tool

Please tick one box for each statement:

	Disagree	Agree	Unsure	I'd like to discuss with my dentist
It's important to me that my teeth look good	☐	☐	☐	☐
I want my teeth to be left alone if they are not causing me pain	☐	☐	☐	☐
I am happy to sit in the dental chair for as long as it takes to fix a broken tooth	☐	☐	☐	☐
Visiting the dentist makes me scared or anxious	☐	☐	☐	☐
I don't mind having teeth removed if it means I have less pain	☐	☐	☐	☐
I would want dentures to replace missing teeth if possible	☐	☐	☐	☐
Being able to eat whatever I want is important to me	☐	☐	☐	☐

Please use the space below to tell us more about your answers above or write any questions you have for the dentist:

Please return this form to your dentist or bring it to your next visit.

You can talk to the dentist about these answers and anything else concerning your treatment during your next visit.

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Figure 11.2: The back of V3.0 of the physical version of the Dental Decisions Tool

A series of videos are available online (www.dentaldecisions.uk) to describe the development and use of the tool. The website also invites further comments and feedback so that anyone accessing the website and seeing the concept can express an opinion about it or propose changes they believe to be necessary. Dentists may need specific training to support the tool's implementation into routine practice, which will be considered in future work (discussed in Chapter 13).

11.2 Relating the Dental Decisions Tool to findings of qualitative research.

A fundamental feature of version 3 (Figures 11.1 and 11.2) that is changed from earlier iterations of the prototype is that this revised version of the Dental Decisions Tool does not refer to dementia. The findings of Projects 1, 2 and 3 relate specifically to PLwD and the tool was designed for use with this group. The lack of reference to dementia allows the tool to potentially be used with other patient groups. The dementia-focused co-production process may mean that the tool is suitable for those yet to receive or disclose a dementia diagnosis but that it may be less appropriate for those without cognitive impairment. When evaluating the Dental Decisions Tool, it should be noted that factors of the tool specifically informed by data from Projects 2 and 3 may need to be reconsidered or modified if the tool was designed to be used generically across other patient groups. As the tool was the output of a comprehensive co-production process, and its aim is to support dental care decision-making with or for PLwD, it is worth circling back to explore the elements of the intervention that address the challenges and problems identified in Projects 1-3. Figure 11.3 shows the tool with labels that are referenced in the detailed description of the tool below.

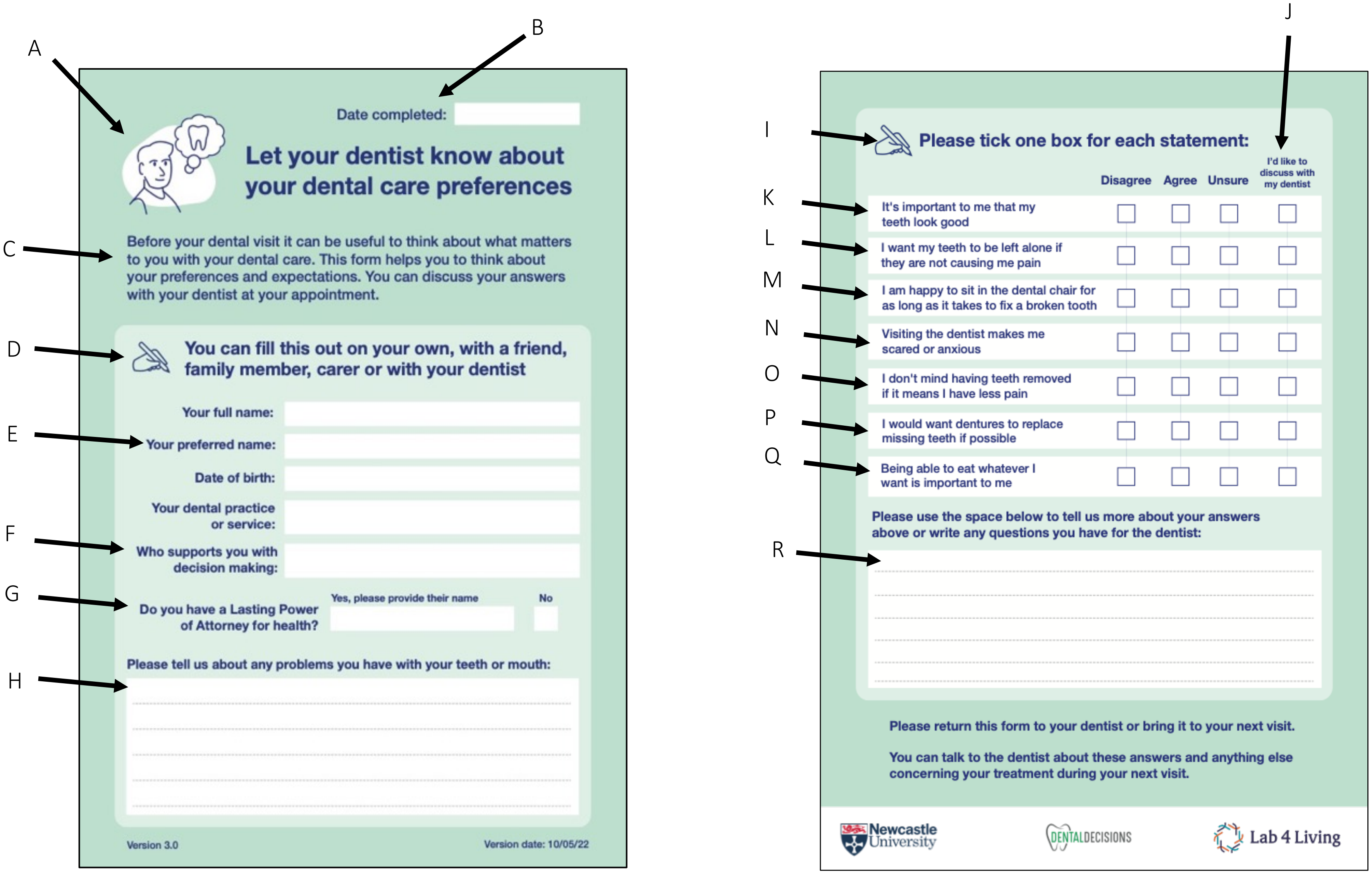
Label A shows a visual icon summarising the form's purpose in a non-text format. Such an approach complements the text-based content of the form and can support an understanding of the form by those with cognitive impairment (Dementia Voices, 2013). Label B shows where the date the tool is completed can be recorded. This is important if it is used to support future decision-making as the time at which historical views were expressed by a PLwD needs to be known. Having a date here allows the form to potentially be reviewed as a person's experience of living with dementia progresses over time. Dated versions of the form allow the most recent completed version of the tool to be used in decisions made with or for PLwD. Project 2 detailed how dentists describe focusing on historical preferences of PLwD

(Chapter 7, Category 1). Whilst the tool supports consideration of current preferences, including a date ensures that the time at which any preferences were expressed is considered.

Label C highlights a basic summary of the purpose of the Tool. This encourages people to actively consider their preferences and details how people can discuss their care options with dentists. Label D details that people can gain the support of those involved with their care, or dentists themselves, in completing the form. Even by simply receiving the tool, patients can be informed of their ability to make decisions about their care. Facilitating the expression of preferences should empower patients to engage in discussions with dentists and support dentists in facilitating patients' active and intentional involvement in dental care decisions. The tool asks for a person's preferred name and full name, shown by Label E. Whilst this appears to be a basic consideration, it ensures a person's preferred name is known and sets a foundation for person-centred care.

The components of the tool labelled F and G allow those who practically support people and those with a relevant LPA to be identified. By having this information recorded, a dentist may have to do less 'detective work' (Chapter 7, Category 1) when establishing how to proceed with BIDM.

It is important that people can directly express their oral health concerns (Label H). Typically, patients may not be asked about or be able to express concerns until they attend a dental visit. The tool allows patients’ specific concerns to be identified and considered. While pain management was described as a priority for PLwD and caregivers, other desired outcomes and expectations for care were detailed (Chapter 8, Category 5). Capturing other concerns, such as cosmetic or functional concerns, should ensure that discussions and decisions can address these. Similarly, dentists described a heavily biomedical approach to care (Chapter 7, Category 4). Patients may be tolerant or accepting of a dental status a dentist may see as problematic. Asking patients about their current dental problems allows these to be addressed. This should further support person-centred decisions about care.



Date completed:

Let your dentist know about your dental care preferences

Before your dental visit it can be useful to think about what matters to you with your dental care. This form helps you to think about your preferences and expectations. You can discuss your answers with your dentist at your appointment.

You can fill this out on your own, with a friend, family member, carer or with your dentist

Your full name:

Your preferred name:

Date of birth:

Your dental practice or service:

Who supports you with decision making:

Do you have a Lasting Power of Attorney for health? Yes, please provide their name ☐ No

Please tell us about any problems you have with your teeth or mouth:

Version 3.0 Version date: 10/05/22

Please tick one box for each statement:

	Disagree	Agree	Unsure	I'd like to discuss with my dentist
It's important to me that my teeth look good	☐	☐	☐	☐
I want my teeth to be left alone if they are not causing me pain	☐	☐	☐	☐
I am happy to sit in the dental chair for as long as it takes to fix a broken tooth	☐	☐	☐	☐
Visiting the dentist makes me scared or anxious	☐	☐	☐	☐
I don't mind having teeth removed if it means I have less pain	☐	☐	☐	☐
I would want dentures to replace missing teeth if possible	☐	☐	☐	☐
Being able to eat whatever I want is important to me	☐	☐	☐	☐

Please use the space below to tell us more about your answers above or write any questions you have for the dentist:

Please return this form to your dentist or bring it to your next visit.

You can talk to the dentist about these answers and anything else concerning your treatment during your next visit.

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Figure 11.3: Labels of specific aspects of the Dental Decisions Tool

Section I gathers more quantified basic information to form a baseline assessment of a person's preferences and values. This parallels the OHVS proposed by Edwards, Randall and McNeil (2021) yet it contains questions informed and refined by the co-production processes detailed in Chapter 10. The fourth box a person can tick (label J) allows patients to specify where they wish to have further discussions with dentists. Ongoing knowledge imbalances may remain, yet this may support dentists in knowing how to tailor discussions to focus on the areas where patients wish to seek further information. Labels K-Q show questions that allow insight into various factors about which preferences can vary significantly between individuals. Completing this should support individualised care delivery (Chapter 7, Category 2) and an understanding of patients as individuals (Chapter 8, Category 3). Specifically, labels M and N allow patients to express anxiety about dental care, for which they may seek pharmacological support to receive dental care (as discussed in Chapter 8, Category 5). Understanding whether patients are anxious about dental care should help dentists establish what support they may need to receive dental care. Label R shows where patients can detail any additional information that they feel is relevant. This should account for any preferences or considerations not captured by the questions labelled I-Q.

The questions labelled H, K-Q and R place a degree of responsibility on patients to provide information to dental teams. If patients provide information from ticking boxes or free comments, this can be discussed and explored in a consultation in a process aligned with SDM. The tool, therefore, supports sharing of responsibility and knowledge aligned with the core principles of SDM (Charles, Gafni and Whelan, 1997; Elwyn et al., 2012), as detailed in Figure 3.1. Chapter 7, Category 6 identified that some dentists might be under-confident about leaving dental problems untreated for PLwD. This aligns with the ethical tensions detailed in the only relevant research exploring decision-making in this context (Nordenram, Norberg and Bischofberger, 1994; Nordenram and Norberg, 1998). Such ethical tensions may be mitigated if a dentist has a clear record of patients' preferences to inform current and future care.

The information gathered on the second page of the tool, labelled K-Q, can also be revisited by dentists and anybody holding an LPA or supporting BIDM. One existing document that aims to support dentists in the care of PLwD states that: *"it may aid your decision-making if you are aware of previous treatment choices"* (Faculty of General Dental Practitioners, 2017, p. 53). The Dental Decisions Tool does not capture treatment-specific choices but does identify factors that may inform these (via questions labelled K-Q). Knowing these factors may support dentists with BIDM and working with family members, those with an LPA or other advocates. Chapter 7 Category 2 details how dentists focus on more historic treatment preferences, whilst Chapter 8 Category 5 shows how the views and preferences of PLwD may change over time. The tool supports the consideration of historical preferences, yet dentists may need training and support to consider whether these are relevant in BIDM, considering how each individual's views may change over the life course (Gibson et al., 2019).

By asking about an LPA and who may support patients less formally (Labels F and G), there is scope to engage with appropriate individuals, if needed, during future care. The factors explored in questions labelled K-Q may help to guide dentists in what treatment options they present and discuss with family members or other advocates, whether or not they hold an LPA.

11.3 Evaluation

The APEASE criteria (Michie, Atkins and West, 2014, pp. 23–24) were used to consider the suitability of emerging ideas for interventions, as described in Chapter 10. The same criteria can be used to evaluate the initial version of the Dental Decisions Tool. A discussion of the tool against each of the APEASE criteria is detailed below:

> **Affordability:** Implementing the Dental Decisions Tool in dental practices would not be expensive. Physical copies would need to be produced, which would come at a cost. In addition, more time may be spent completing the form or reviewing the form during a dental appointment, which may take more of the dentist's time. Arguably, this small amount of additional time is well spent if it improves patient involvement in decision-making as promoted in national guidance (National Institute for Health and Care Excellence, 2021).
>
> **Practicality:** The tool is feasible and practical to be completed either before a dental visit (online or on paper) or whilst waiting for a dental appointment. There is some dissonance between a paper-based tool and the widespread use of electronic records in primary care dental services. The availability of an online version of the form may overcome this challenge for dental practices using electronic records alone. When referring to the tool to support BIDM, it may be impractical to find older versions of the completed tool in services using

paper-based records. However, the potential value of the tool could mean the time spent retrieving earlier versions is well-spent.

Effectiveness: The tool cannot be stated to be effective without a formal study of its efficacy and effectiveness. Project 1 found that studies aiming to support advanced care planning may support the decision-making process with surrogate decision-makers. However, the Dental Decisions Tool is not a specific ACP intervention, nor is this its purpose. The effectiveness of the tool remains unknown at present.

Acceptability: The development of the tool actively involved stakeholders, including PLwD. An earlier version of the concept (Prototype 2.0) was shared with PLwD during the co-production process and received generally positive feedback. Those involved in producing the tool felt it would be acceptable, yet further testing would be needed to gain insight into the views of other individuals, specifically if it were to be used for patient groups other than PLwD. The tool's acceptability to dentists outside the co-production group has not been explored. Further investigation is needed to consider this acceptability and to explore barriers and facilitators to implementing the tool into routine practice. In addition, the acceptability of the tool in supporting BIDM needs to be explored from the perspectives of dentists and caregivers.

Side effects and safety: Completing the tool is expected to be a straightforward and non-invasive process for patients. People with dental anxiety may worry about certain aspects of dental care mentioned on the form, especially aspects that may not apply to their care. For example, the tool mentions teeth removal, which may be unnecessary for many patients. However, understanding patients' preferences regarding this option might inform their future care, so this low risk of minor distress is arguably justifiable. In contrast, patients may be less worried about dental care if they consider their preferences and feel able to discuss these with a dentist. Further evaluation of the tool in practice could allow further insight into any side effects or safety issues related to its use.

Equity: A core purpose of the tool is to promote discussions about peoples' values and preferences. This includes those who might not feel empowered to discuss their care with dentists. The tool aims to ensure that all patients can contribute to dental care decision-making, including contributing to future decisions that may be made on their behalf. The tool has been designed to be accessible to those with cognitive or visual impairments. A paper-based and online format should support the use of the tool by a greater range of individuals with specific needs.

Evaluating the Dental Decisions Tool against the APEASE criteria shows its numerous strengths, particularly its ability to support current decision-making with PLwD and BIDM if a person loses decisional capacity. Coulter et al. (2022, p. 3) detail the need for clinicians and patients to be able to access and use a range of decision-support tools to make SDM 'business as usual’. Hopefully, the Dental Decisions Tool can be one such tool. Further research is needed to understand how practical it may be to implement the tool into practice and how easy it may be for patients and dentists to use. Understanding these factors will be important to inform any iterative changes to the version of the tool presented.

11.4 Summary

The Dental Decisions Tool aims to tackle several of the challenges described in Projects 2 and 3. Specifically, it provides basic information to support decision-making processes and it allows PLwD and those involved in their care to consider and discuss their preferences before and during a dental appointment. This should support SDM as encouraged by national guidance and policy (King’s Fund Institute, 2010; Collings and Coulter, 2011; Department of Health, 2015, p. 4; National Institute for Health and Care Excellence, 2021) and professional standards for the dental team (General Dental Council, 2013, section 2.1-2.3). It also supports value-concordant BIDM when the PLwD can no longer make decisions about their dental care. In this situation, the tool should support surrogate decision-makers, LPAs and clinicians to make decisions informed by greater insight into a person's values and preferences. This also should support adherence to separate guidance and relevant legislation in devolved UK nations (Adults with Incapacity (Scotland) Act, 2000; Mental Capacity Act, 2005, Mental Capacity Act (NI), 2016).

Chapter 12. Reflecting on the co-production process

In this chapter, I reflect on the challenges I encountered leading the co-production process described in Chapters 9 and 10. For transparency and to support my iterative understanding and development, I kept a reflective log detailing decisions made alone or with the supervisory or collaborating team, the challenges I met, and the tensions I negotiated personally or with the various teams involved. Based on these logs, I reflect upon key challenges across four domains.

12.1 Multi-purpose co-production

The work presented had two purposes: the research objectives and my academic development as part of a doctoral studentship. I had initially anticipated – possibly naïvely - that these two purposes would be compatible and harmonious. On reflection, there was a degree of compatibility with these aims, but they were not consistently harmonious. In delivering a co-production process, patients, carers or dental teams - or a combination of these – should benefit from what is produced (Robert et al., 2015; Filipe, Renedo and Marston, 2017; Wolstenholme, Grindell and Dearden, 2017). In contrast, only I benefited from my academic development, at least in the shorter term. The 'benefit' here felt much more personal, even selfish. I accepted that my development had to be secondary to achieving the research aims detailed but hoped delivery of a suitable co-production process would allow me to develop as a researcher.

My prior experience with qualitative research highlighted how varied and debated the acceptance of qualitative research has been (Loder et al., 2016). Co-production is an even less well-trodden path, with more significant variability and flexibility. Therefore, even as I made positive progress with the co-production process, I became concerned that the work might be viewed as unscientific, poorly planned, or even chaotic by those less familiar with co-production. This concern arose primarily because of the need to defend the work presented in a doctoral thesis, meaning I had to consider both the project's progress and any potential perceptions of the suitability of its conduct.

When reflecting on my view of the project over time, I realised my concerns about the 'soundness' of the science were rooted in an incorrect assumption of what a 'suitable' process would entail. Reed

(2018) details how critical reflection on long-held beliefs is a crucial element of qualitative research; the need for this reflection logically extends to work such as co-production, which is based on a similar epistemological foundation. Reflecting on my assumptions was fundamental to allow me to appreciate the constructivist epistemological stance I strived to take and the need for such subjectivity to be embraced in a collaborative process. This reflection supported me in accepting and embracing the research format and its underlying principles. I realise now that my concerns about the academic nature of such iterative and participatory approaches arose because I retained aspects of a positivist mindset. Such a mindset may have led to a degree of closed-mindedness and may have counterintuitively compromised the project planning process.

In retrospect, I realise that my discomfort with co-production's messiness and flexibility was unwarranted. Reflection on the project process helped ensure that the impact of my concerns about rigour or academic development had a minimal impact on the project. As noted, the optimal conduct of the co-production process was my primary concern. However, I could not disregard my academic considerations. I considered and discussed these two purposes of the work with the Lab4Living and the supervisory teams. These discussions acted as checkpoints to ensure the aims of co-production and personal development were both met but without compromising one another. Specifically, the Lab4Living team and I held open and honest discussions in which I felt able to challenge this team's proposed approach to co-production. This team also pushed back and challenged my preconceptions and false assumptions and challenged me to remain open-minded when using this method, particularly as I had not used it previously.

This culture of honest and open discussion and reflection supported my academic development and the process of actively involving the co-production participants in the project. Reflective practice kept my focus on the primary consideration of a quality process but also allowed me to reflect on producing defensible and rigorous work. I noted, on reflection, that my role in any co-production work in the future is likely to be part of a team and would lack a formal educational component. This aside, any future co-production projects would benefit from a similar culture in which the nature and direction of co-production processes are continually challenged and questioned by the team delivering it. Such an approach should support a team to achieve a project’s aim whilst optimising its suitability and progress.

12.2 Flexibility and inflexibility

Co-production is inherently ‘messy’ (Facer, Enright, and Connected Communities Programme, 2016, p. 31) from both practical and ethical perspectives. Thomas-Hughes (2018) suggests this ‘mess’ has to be accepted when using co-production. However, it was hard to accept messiness when seeking the relevant approvals for the work presented. It is not always necessary to seek ethical approval for co-production. Those supporting the process can be seen as research team members, not individuals from whom data are collected, meaning ethical issues are potentially less significant (NIHR Applied Research Collaboration West, 2020, p. 6). Though it was theoretically unnecessary to seek ethical approval for this work, the supervisory team and I decided to seek approval for Project 4 at the same time as gaining approvals for Projects 2 and 3, particularly as the project involved PLwD and NHS staff.

The supervisory team and I had hoped that applying for formal ethical approval would identify and support the resolution of any significant ethical issues. Instead, gaining approvals was laborious and imparted a degree of rigidity to the project. For example, in seeking approvals, I was required to specify sample sizes for each aspect of the project and provide a detailed summary of participants and their roles at each stage. Considering these requirements, it was challenging to prepare a suitable application for a project using iterative and flexible approaches inherent to co-production. The funding application and research protocol allowed me to detail the need for flexibility in line with co-production methods, however, various other systems (such as the NIHR Central Portfolio Management System) required specific numbers and descriptors to be provided. I encountered such inflexibility in a range of situations, which reinforced my earlier perception feel the work may not be viewed as scientifically sound. Whilst I complied with relevant regulatory approvals that had been granted, it was frustrating to be held to the requirements of conventional quantitative studies based on statistics, power calculations and positivist epistemological stances.

The regulatory oversight meant that I felt only a limited ability to exercise flexibility where this could have been advantageous to the project. For example, there were instances where the planned stages of the project could have been expanded to allow more insight to be gained from the co-production group members. More interactions might have allowed co-production partners to take a more proactive role in determining how the project would progress and could have led to a more refined output. However, progress may have stalled without sticking to at least a rough project plan. Being too flexible, however, could have hindered the project's progress. Furthermore, it could have been seen as unethical to over-involve people, particularly if the level of involvement exceeded what participants had agreed to support. On reflection, a balance was struck by planning a set number of workshops without being overly prescriptive about their content. Sticking to the pre-specified plan did pose challenges. Engineering more flexibility into the project plan could have acted as a safety net, particularly if progress had been slower than anticipated. On reflection, building flexibility into the project design and subsequent approval could have been a more actively considered process.

Unfortunately, the inflexibility in gaining such approvals is a long-standing challenge (Goodyear-Smith, Jackson and Greenhalgh, 2015). My experience suggests there has been limited progress in supporting the facilitation of research that proactively involves non-academic contributors in producing new knowledge, processes, services, or interventions. The need to seek approval for future projects must be carefully considered. An overly-limited or rigid process could be potentially more ethically contentious than issues arising in co-production processes. For future work, I would consider the suitability of formal approvals on a project-by-project basis.

12.3 Data and knowledge

By undertaking the work presented in this thesis, I became increasingly immersed in the existing literature exploring healthcare decision-making, including that focused on supporting PLwD and exploring decisions in dental care. I had initially expected the knowledge or data generated from the literature review presented and Projects 1-3 would directly and linearly support the conduct of Project 4, as detailed in Figure 12.1. When undertaking the project, the processes involved and stages of work interacted in a way that contrasted with my initial expectations; the true nature of the interaction between the stages of each project is shown in Figure 12.2.

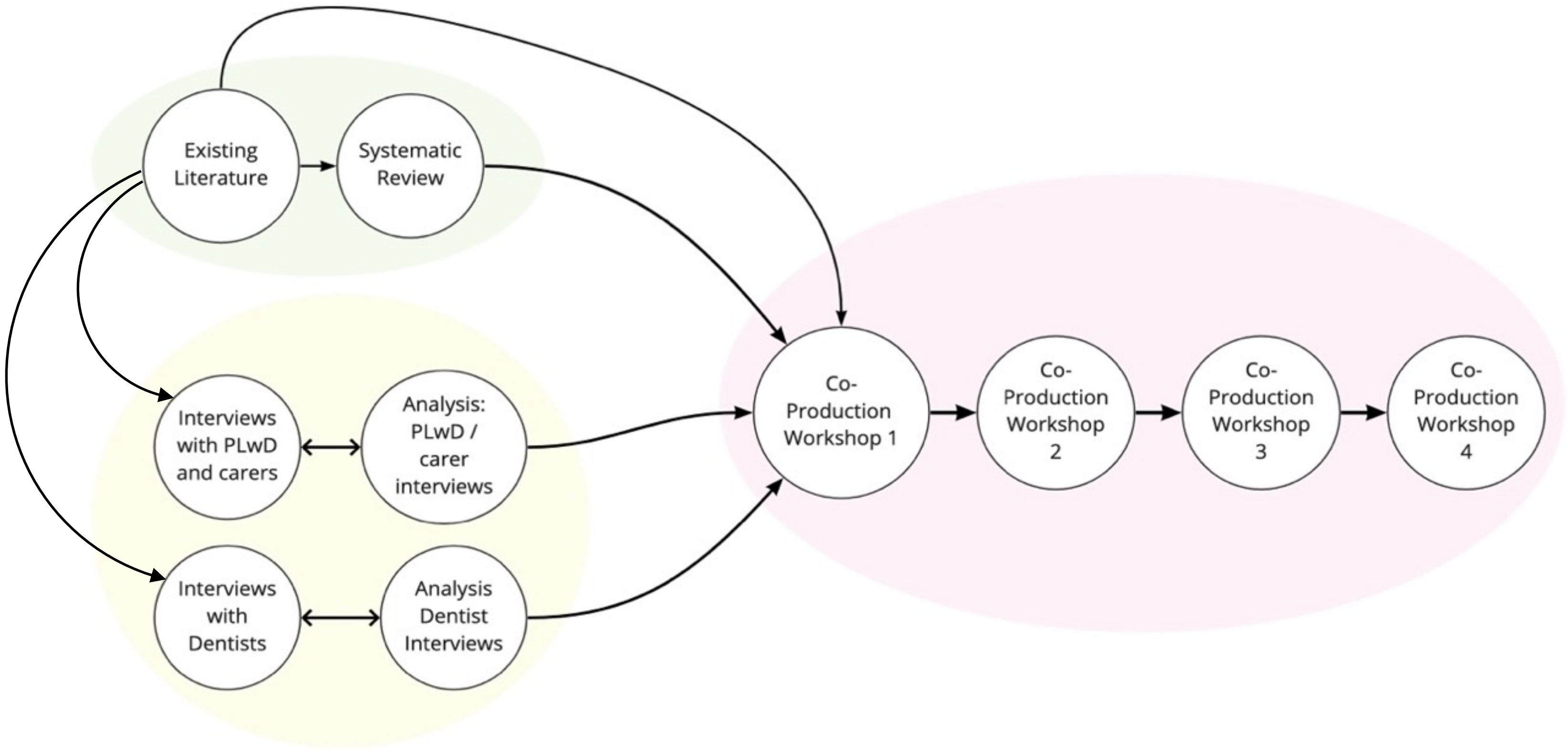

Figure 12.1: My expectation of how Projects 1, 2 and 3 would inform Project 4

The bi-directional arrows shown for Projects 2 and 3 reflect the iterative data generation and analysis process

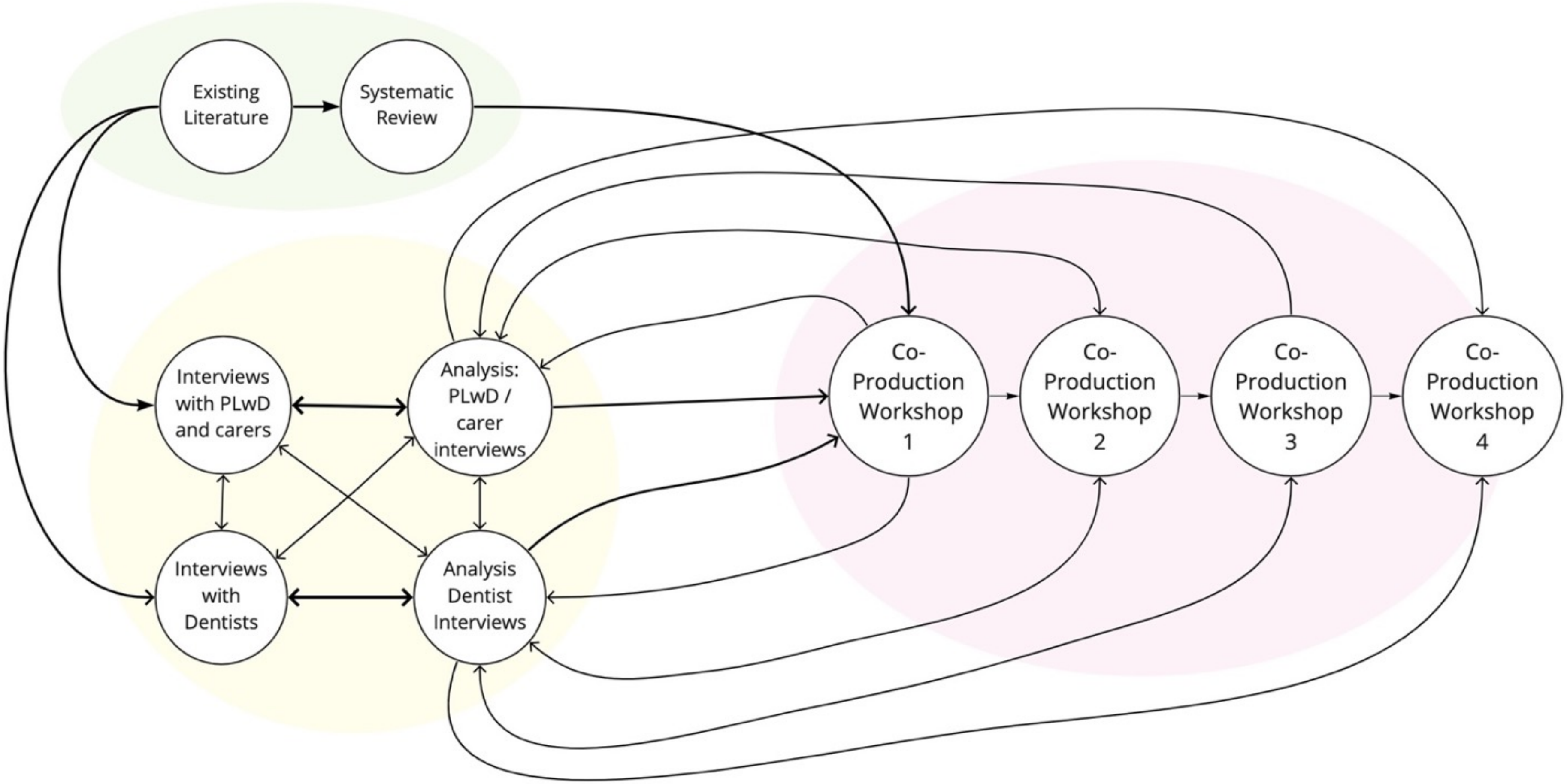

Figure 12.2: How Projects 1-4 actually influenced one another

To simplify the overall project progress, I could have decided to end my qualitative analyses before commencing Project 4. Indeed, it might have been more straightforward to present the final findings of Projects 2 and 3 in the first co-production workshop and refrain from any ongoing analysis. When planning Project 4, I initially thought my qualitative analyses were near completion. However, multiple stages of Project 4 led me to ask further probing questions about the data generated from Projects 2 and 3 and supported the iterative analysis of qualitative data. Therefore, the later stages of analysis from Projects 2 and 3 overlapped significantly with the planning and delivery of Project 4.

This overlap allowed me to consider more perspectives in writing the analysis and analyse the data in greater depth. In addition, I was able to be more reflexive in my analysis. The co-production workshops exposed me to multiple viewpoints and ideas that differed from mine. This exposure made me more aware of my preconceptions and biases and how these may have impacted data analysis. While such biases and preconceptions cannot be eliminated, it is essential to be aware of them. Such awareness is vital for reflexivity and qualitative analysis within GCT (Charmaz, 2006, p. 32, 2017). I hope that embracing a reflexive process strengthened the writing presented. Project 4 supported data analyses for Projects 2 and 3, but the reverse also occurred: revisiting qualitative data allowed this data and the findings of this work to feed into Project 4.

I found it difficult to ascertain how much knowledge or data to share with those involved in different aspects of the project. To share what I perceived as the 'right' amount of information would have meant I assumed what people needed to know or how they might interpret any data I had shared. Had I presented my findings or interpretation of the data from Projects 2 and 3 to the Lab4Living team, these could have been accepted and passed on to the co-production partners within the workshops, constraining the potential for open discussion and individual interpretation of the data generated. In contrast, providing a complete set of interview transcripts to the Lab4Living or co-production teams would have been excessive and cumbersome. I had to provide a degree of baseline knowledge for the Lab4Living team to support them in understanding what needed to be achieved during the co-production process. To do so, I sought their advice on how much of an understanding they felt they needed to facilitate the workshops. Following discussions with the Lab4Living and supervisory teams, I shared the project summary and a selection of salient quotes from multiple participants from both qualitative datasets with the Lab4Living team. CR used these to develop the storyboards shown in Chapter 10 (Figures 10.1-10.3). As per the ‘Discover’ stage of the double diamond model (Design Council, 2021), these storyboards allowed both the Lab4Living team and the workshop participants to interact with the data to gather their understanding of the challenges for which we aimed to co-produce a solution.

Whilst other individuals needed to form their own understanding of the specific problem we were seeking to address, it felt deceptive to withhold my analysis of Projects 2 and 3 from the co-production group. Therefore, as detailed in Chapter 10, I delivered a summary of the findings of Projects 2 and 3 at the end of the first co-production workshop to allow further the participants to build on their earlier knowledge. Having reflected on how these data were shared, it seems the discussions of the storyboards would have enhanced the co-production group's understanding of the later shared data. I felt comfortable with the volume and nature of data shared with this group and the different ways it was presented.

12.4 Power-sharing and pragmatism

'Sharing power' is a central principle of co-production (INVOLVE, 2018, p. 7), yet it was challenging to facilitate this in practice. Ideally, each aspect of a co-production process would be democratic, with participants sharing their views and agreeing on the project's direction and output. Aligning with reflections of other authors using similar methodologies (Miller et al., 2006; Madden et al., 2020), I felt there was only a limited extent to which this can occur in practice. The fact that someone – a research team or otherwise – must lead co-production distinguishes the individuals involved from one another. A difference in power or control over the process is inevitable from this distinction alone, even if the research team includes patients, members of the public and other stakeholders.

Whilst I did not doubt that sharing power is desirable, I questioned when this could feasibly be employed within this project. When reflecting on the extent to which power was shared with participants, I felt it was necessary to distinguish between the power-sharing outside of the planned co-production stages and directly within these interactions. Within the workshops, the Lab4Living team brought a wealth of experience to support the optimisation of participant involvement and ensure participants' voices were heard and their comments actively fed into the co-production process through various routes. Decision-making outside of the workshops was the most significant challenge I encountered. The Lab4Living team and I had to consider how to take the outputs of each workshop to subsequent stages of co-production and how to optimise the ongoing involvement of co-production partners. It was not feasible to involve each co-production partner in planning each session. Furthermore, I was learning how to deliver co-production as part of my doctoral fellowship, so I had to seek advice and input from experienced team members about how best to deliver and facilitate the workshops. Working equally with each participant here simply could not happen, yet we remained open to any ways the co-production partners might steer the project to a greater extent over time. Although I could justify each reason for excluding the co-production participants from certain strategic decisions about the workshops, I continued to wonder if we were falling short of an acceptable and appropriate process.

With the support of the Lab4Living team and having reflected on the direction the project was taking, I could rationalise making minor decisions about the project's direction, particularly in determining the workshop content. As a key example, the Lab4Living team and I grouped the proposed ideas from Workshop 2 into six key ideas (shown in Figures 10.5 and 10.6). Either individually or collectively, the co-production partners may have categorised these differently. To ease my discomfort with how much independence became nested in a collaborative process, I revisited transcripts of the workshops and the notes and comments I had received directly from group members or those added to the Miro whiteboard. I also ensured the Lab4Living team agreed with the grouping of ideas and the plan to share these during the following stages of the project. By doing so, I confirmed decisions were made, having revisited the opinions of contributors to ensure I was not contradicting these or deviating from their suggestions, viewpoints, or prior contributions. Reviewing these contributions mitigated the discomfort I felt about the nature of power-sharing, but only to a limited extent.

One significant major decision caused me substantial internal conflict. After three workshops, the components and format of the developing intervention became clearer. Nevertheless, there was no workable concept to discuss in the remaining stages of the project. To drive the project forwards and allow participants to comment on the proposed project output, I had to take a leap of faith to produce something to present as the project progressed. To do this, I revisited the existing literature and the outputs of Projects 1, 2 and 3. I used these combined sources to support a prototype based on aspects of the ideas discussed in earlier workshops (shown in Figure 10.13). I was not entirely comfortable with taking such a decision, despite how it felt necessary to do so. Specifically, this leap forwards felt unnatural and contradictory to the collaborative patient-informed process I strived to facilitate. Whilst I felt this was the right thing to do, and the co-production process informed it, I still felt uneasy about doing so. No matter how much I justified this decision to myself, I wondered whether I could have avoided having to do so. In addition, I was wary that the decision was a risk. In particular, I feel that such a risk had no place in externally-funded, co-produced work and I was also mindful that this risk could have alienated group members or led to a concept based purely on my perspectives.

I imagined I would have been more comfortable if at least some co-production group members had helped to directly produce the first prototype. Although I had initially produced the prototype outside of a workshop, it was not based on my ideas alone, and I did not blindly accept that this would be the project's output. Furthermore, I openly shared this prototype and its rationale with the co-production group during Workshop 4 to seek their comments. Thankfully these were mostly positive and supportive, allowing me to take the prototype to the dental team workshop and discussions with PLwD before Workshop 4. The receipt of positive feedback and constructive direction went some way to ease my discomfort about the decision to produce the first iteration of the prototype concept.

Reflections on this co-production process led me to question whether researcher-initiated co-production can ever be genuinely based on an authentic power-sharing dynamic Throughout the project, I strived to balance being democratic and pragmatic. I sought to achieve the project aim by actively involving a range of individuals and actively seeking their comments, ideas and feedback on data, concepts, and a prototype intervention. Potentially, attempts to amplify power-sharing outside of planned interactions might have distracted participants from what happened within the sessions. Before interacting with co-production partners, research teams would benefit from considering when and how power-sharing is possible. Had I thought about this challenge in advance of the project, I may have invited the group to support the project delivery to a greater extent if they were willing to do so. That said, this could only extend so far.

12.5 Conclusion

Some of the challenges and tensions I have discussed may be unique to this project. Some difficulties, such as balancing pragmatism and democracy, and working with numerous individuals and teams, will likely arise in many co-production projects. Reflecting on the process and decisions made, I believe compliance with co-production principles is aspirational but often impractical or unfeasible. This does not mean researchers should not try to align with these to the greatest extent possible. A reflective process was highly beneficial in navigating my attempts to adhere to these principles. In addition to my reflections, I sought to navigate the tensions I encountered by regularly revisiting what was said, written or documented in the co-production workshops. Revisiting comments and transcripts ensured that where I could not fully adhere to the co-production principles, I could at least consider the voice of the co-production participants. The reflective and iterative process adopted, despite my inexperience, scaffolded the resolution of such tensions in practically delivering the research presented.

Chapter 13. Conclusions and Recommendations

In this final chapter, I summarise how the aim and objectives of the thesis were met. The overall project aimed to develop an intervention to support PLwD, their carers, and dental teams to make collaborative decisions about dental treatment. The four related projects presented in this thesis led to the development of a new intervention, the Dental Decisions Tool, that can support decision-making with PLwD and other patient groups.

13.1 Conclusions

Project 1: In Project 1, I aimed to identify and explore any existing interventions that support healthcare decision-making with or for PLwD. The review, presented in Chapter 5, found no interventions in the dental setting, meaning no existing dental intervention could be adapted to support PLwD. The review found a patient-decision aid related to enteral feeding was effective in supporting caregivers with authority to make decisions for PLwD. The review also highlighted how some interventions regarding Advance Care Planning may improve decision-making processes when studied using specific measures. However, PLwD were rarely involved in the determination of how effective specific interventions were. None of the interventions were effective at improving the *quality* of decisions that were made with PLwD individually.

Project 2: In Project 2, I sought to explore and describe how dentists approach dental treatment decisions with or for PLwD. Chapter 7 presents and discusses six categories of data detailing different aspects of how dentists approached decision-making with or for PLwD. One of the more significant findings to emerge from this study is that dentists describe wishing to provide individualised care, but that risk assessments related to care planning and delivery were based heavily on biomedical factors and specific assumptions. Due to this biomedical focus and their perception that they should lead decision-making processes, dentists detailed an approach which may under-emphasise individuals' autonomy and that could fail to fully consider PLwD as individuals.

Project 3: In Project 3 I aimed to understand PLwD and carers' experiences regarding dental treatment decision-making. In Chapter 8 I present an exploration of these experiences over five categories of data. PLwD and carers detailed that they encountered multiple challenges in accessing dental care which may, in turn, complicate decision-making processes. In addition, PLwD generally wanted to remain actively involved in decisions about their care, and family members wanted to be consulted about decisions affecting their relatives. The accounts of PLwD and family members suggest that they often felt passive in dental treatment decision-making. Specific hopes for and expectations of treatment were described by PLwD and carers, yet these may not be achieved if dentists do not actively identify and discuss them.

Project 4: The insight gained from Projects 2 and 3 provided a new understanding of PLwD, carers and dentists' experiences that have not been otherwise explored in primary research. Using this new knowledge, Project 4 used co-production to develop a new intervention aiming to support people living with dementia, their carers, and dentists with dental treatment decision-making. A collaborative process of idea generation and exploration, as well as existing knowledge and concepts, informed the development of a prototype of the Dental Decisions Tool. This tool was then further refined with the input of the co-production group, PLwD and dental team members. The Dental Decisions Tool aims to facilitate the elicitation and documentation of PLwD's preferences to guide dental care decision-making processes for their current care and any future decisions made regarding their care. Consequently, the overall aim of the study was achieved at the conclusion of Project 4.

I also aimed to reflect on the challenges and processes involved in co-producing a new intervention with PLwD and other stakeholders. The complexities in a constructivist paradigm, the challenges of using an inherently flexible approach and the challenges in sharing power and knowledge during collaborative working are considered and discussed in depth in Chapter 12.

13.2 Strengths and limitations

I sought to engage with a diverse range of relevant individuals in Projects 2, 3 and 4, in the hope that the intervention is informed by relevant but diverse perspectives, opinions and experiences. On reflection, as detailed in Section 8.8., the diversity of participants was limited. A strength of the work is that I became extensively familiar with the existing literature and clinical guidelines to ensure the overall work program considered existing knowledge, whilst also generating new knowledge to address commonly encountered clinical challenges. When undertaking each piece of work, however, my role in the study’s delivery and the impact of this cannot be ignored. Significant subjectivity, grounded in interpretivism, is inherent to both qualitative methods using CGT and co-production. Whilst reflexive practice and iterative analysis processes aimed to account for and acknowledge the role of my existing knowledge and preconceptions, the mechanism for addressing the potential impact of subjectivity in co-production is less clear.

A further limitation relates to the context in which the Dental Decisions Tool was produced. All individuals supporting the co-production process and the qualitative studies were based in the UK and spoke fluent English. This may mean the tool supports care in the UK and within a publicly-funded healthcare system whilst being less suitable to use in other cultures, nations and healthcare services. The ability to speak English was an inclusion criterion for the PLwD supporting the co-production process. The lack of resources to support interpretation or translation meant this was a necessary criterion, yet those unable to speak English were therefore excluded. The suitability and acceptability of the Dental Decisions Tool to those unable to speak English or from other cultural groups, is not currently known. This would need to be explored in future work, especially as those from ‘non-western’ cultures may have different expectations and preferences regarding involving in healthcare decision-making (Obeidat, Homish and Lally, 2013).

13.3 Recommendations for clinical care

1. PLwD should be able to access proactive and preventative dental care to prevent oral and dental diseases and allow early management of any dental problems that arise. As population demographics change, general dental practitioners may need to be supported and remunerated to provide care for the growing number of PLwD so that specialist services can focus on those with more complex care requirements.

2. Dentists should actively seek their patient’s views, values and preferences regarding dental treatment. This could be through using the Dental Decisions Tool or through considered proactive discussions during dental appointments, that adhere to the principles of SDM.

3. When patients lack capacity to consent to specific treatments, dentists should seek to identify and understand their historical and current views for care, as much as is feasible, and use this information to inform best interests decision-making in line with legislation.

4. When proposing or discussing dental treatment or the possibility of deciding against providing active dental treatment, dentists should consider biological, social and psychological aspects of care provision in isolation and in combination. The short and long-term outcomes of treating or not treating dental diseases should be considered from these multiple perspectives.

5. Any new or updated clinical guidelines regarding dental care for PLwD should emphasise person-centred care and the need to establish what matters to patients as individuals, regardless of the stage of dementia. Revised guidance could support GDPs to care for a larger proportion of PLwD, as detailed in Recommendation 1 above.

6. Training for general and specialist dental teams on shared and best interest decision-making may support decision-making for various patient groups including those with cognitive impairments.

13.4 Recommendations for future research

1. Further assessment, refinement and testing of the Dental Decisions Tool is needed to explore its suitability, acceptability, and effectiveness in practice. Initially, this should involve user-testing with PLwD, family members and professional carers outside of a clinical setting. Efforts should be made to ensure such testing includes people from a range of socio-economic, and cultural backgrounds, and those with varying degrees of health literacy.

2. The Dental Decisions Tool should then be trialled in a clinical setting that provides care for PLwD living with mild and moderate dementia. An ethnographic method would allow the use of this tool by both dental staff and patients/carers to be understood and identify barriers to its use.

3. Following refinements to the Dental Decisions Tool guided by its user testing and an ethnographic study exploring its use, a feasibility study should be planned. This will determine

whether a larger-scale study of the effectiveness of the Dental Decisions Tool is viable and support the design of a larger study. If a more comprehensive study is feasible, a cluster randomised trial should then be designed. This should include measures of decision process and decision quality.

13.5 Thesis Summary

This thesis describes how I undertook a systematic review and two qualitative studies to support the co-production of the Dental Decisions Tool to support PLwD, those who support them, and dentists with dental care decision-making. The tool aims to support current dental care decision-making with PLwD as well as future best interest decisions that may become necessary for dental care as dementia progresses. The Dental Decisions Tool aims to address some of the challenges that were described in Chapters 7 and 8, to facilitate individualised care, to empower PLwD to contribute to decision-making and to support dentists to consider psychological and social factors when considering treatment decisions with or for PLwD.

Appendices

Appendix A: A summary of included studies in Project 1 (Systematic Review)

Study Country Study Design	Aim of study	Nature of Intervention	Participants	Outcome Measures	Key findings
Studies of Interventions to aid feeding decisions					
Hanson et al. (2011) USA Cluster RCT	To test whether a decision aid improves quality of SDM about feeding options in advanced dementia	A printed decision aid modified from that presented in Mitchell et al. (2001) with a more basic format that was easier to read (simplified language and reduced font size)	256 dyads of people with later dementia and their family/member or power of attorney (127 dyads in intervention, 129 dyads in control)	Knowledge, Expectation of benefit, Decisional Conflict at three months, Frequency of Discussions about options	The intervention improved knowledge scores and lowered decisional conflict after three months. Surrogates more often discussed feeding options with a health care provider. Specific results are shown in Table 5.2
Snyder et al. (2013) USA Controlled Before-after study of intervention with qualitative enquiry	To describe surrogates' perceptions of feeding options and assess if a decision aid alters their knowledge, decisional conflict, or expectation of benefit	As above: (Hanson et al., 2011)	255 surrogate decision-makers of nursing home residents with advanced dementia and feeding problems (126 intervention, 129 control)	Knowledge, decisional conflict, expectations of benefit, preferred approach, and certainty of preferences	Intervention surrogates had improved knowledge scores, decreased expectation of benefits from tube feeding and reduced decisional conflict. Specific results are shown in Table 5.2
Studies of Advanced Care Planning Interventions					
Ampe et al. (2017) Belgium Before and After study with control group	To evaluate the influence of 'We DECide' on the policy and practice of ACP in nursing home dementia care units and to study the perceived barriers and facilitators affecting the use of SDM.	WeDECide: An educational intervention designed to support nursing home staff in using SDM in relation to conversations about advanced care planning for PLwD	90 nursing home staff members in a range of roles from 18 different dementia care units. 21 conversations (11 in intervention group, 10 in the control group) were recorded (with residents and family members) for analysis	Degree to which ACP was discussed Degree of involvement of residents and families using OPTION-12. Perceived barriers and facilitators	'We DECide' positively influenced ACP policy, but routine practice was unaffected as ACP was not discussed more frequently. OPTION scores (measuring the extent of SDM with family members) did not differ between intervention and control groups

Brazil et al. (2018) UK Paired Cluster RCT	To evaluate the effectiveness of ACP with family carers in dementia care	Multiple components: an ACP facilitator, family education, family meetings, documentation of decisions, and orientation staff to the intervention	142 family members of residents with dementia (51 in intervention group, 91 in control group) for main analysis	Family carer uncertainty in decision making via Decisional Conflict	ACP reduced carer uncertainty in decision making. There was evidence of a reduction in total Decisional Conflict Scale score in the intervention group compared with the usual care group (−10.5, 95% confidence interval: −16.4 to −4.7; p<0.001)
Goossens et al.(2019) Belgium Cluster RCT	To assess the effects of the intervention on (1) the level of SDM in ACP in nursing homes, (2) the perceived importance, competence and frequency of staff members concerning SDM	WeDECide optimised: 2 workshops to assist patients in making choices about. A revision of the intervention detailed by Ampe et al. (2017)	311 staff members from 65 nursing home wards: 316 audio recordings included staff, patients and a family member	Level of SDM during ACP conversations between residents (OPTION-12 scale) families and staff members. Perceived competence in SDM, perceived importance and frequency of use of SDM	The level of SDM increased in the intervention group (p<0.001), which persisted at 6 months. Time spent on discussions did not increase. Staff participants felt more competent in SDM (p=0.01) and felt it was more important (p=0.031) though it was not used more frequently (P=0.201)
Hanson et al. (2017) USA Single-blind cluster RCT	To test if the Goals of Care (GOC) decision aid improves the quality of communication and palliative care for nursing home residents with advanced dementia	A 'Goals of Care' Video Decision aid and subsequent meetings between family caregivers and the wider care plan at the nursing home after 3 months	302 dyads: people with advanced dementia and their family decision-makers. (151 intervention, 151 in control group)	Quality of communication scores, concordance with clinicians on goals of care and degree of concordance of treatment with expressed preferences	The intervention group showed better communication at 3 months (6.0 vs 5.6 p=0.05). Goal concordance did not differ at 3 months. At 9 months or death, decision-makers in the intervention group felt there was greater concordance with physicians views than in the control group (88.4% vs 71.2%, p = 0.001)
Hanson et al. (2019) USA RCT	To test dementia-specific specialty palliative care triggered by hospitalisation.	Protocolized specialty palliative care consultation while hospitalised, plus 2-week post-discharge phone support by a palliative care nurse practitioner.	62 dyads of people living with late-stage dementia and family decision-makers (32 intervention, 30 control).	Secondary decision-related outcomes: Discussion of prognosis, goals of care, completion of Medical Orders for Scope of Treatment	Intervention families were more likely to discuss prognosis (90% vs 3%, p<0.001) and goals of care (90% vs 25%, p<0.001), and to have a Medical Order for Scope of Treatment at 60-day follow-up (79% vs 30%, p<0.001).

Whitlatch et al. (2019) USA RCT	To evaluate the effectiveness of the SHARE program, considering the immediate effects of SHARE on each member of the patient-carer dyad.	SHARE (Support, Health, Activities, Resources and Education): A psycho-educational program using counselling approaches to support people living with dementia and their family caregivers to consider future care preferences	128 patient/carer dyads (totalling 256 participants): 44 dyads in in control group, 84 dyads in intervention group)	Care preferences, service use, dyadic functioning, emotional disruption, positive and negative affect. Satisfaction with various aspects of the process.	Dyads in the intervention group constructed care plans and used services more frequently. Satisfaction was not improved except in relation to a counsellor from the perspective of PLwD. In the intervention group, dyadic functioning improved in only one dimension: decreased emotional disruption. There was no increase in care-related agreement or in either positive or negative interactions.

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Appendix B: Abstract of publication of systematic review

Received: 18 August 2020 | Revised: 27 October 2020 | Accepted: 5 November 2020

DOI: 10.1111/hex.13167

REVIEW ARTICLE

WILEY

Enhancing shared and surrogate decision making for people living with dementia: A systematic review of the effectiveness of interventions

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Funding information
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Abstract

Background: Dementia can have a profound impact on decision making. People living with dementia (PLwD) often need to make decisions about health care, and, as dementia progresses, decisions may need to be made on their behalf. Specific interventions may support this process.

Review Question: What interventions are effective in improving shared decision making or surrogate decision making on the health care of PLwD?

Methods: A narrative systematic review of existing literature was conducted. Seven databases, grey literature and key journals were searched. After exclusion by title, abstracts then full texts were reviewed collaboratively to manage any disagreements.

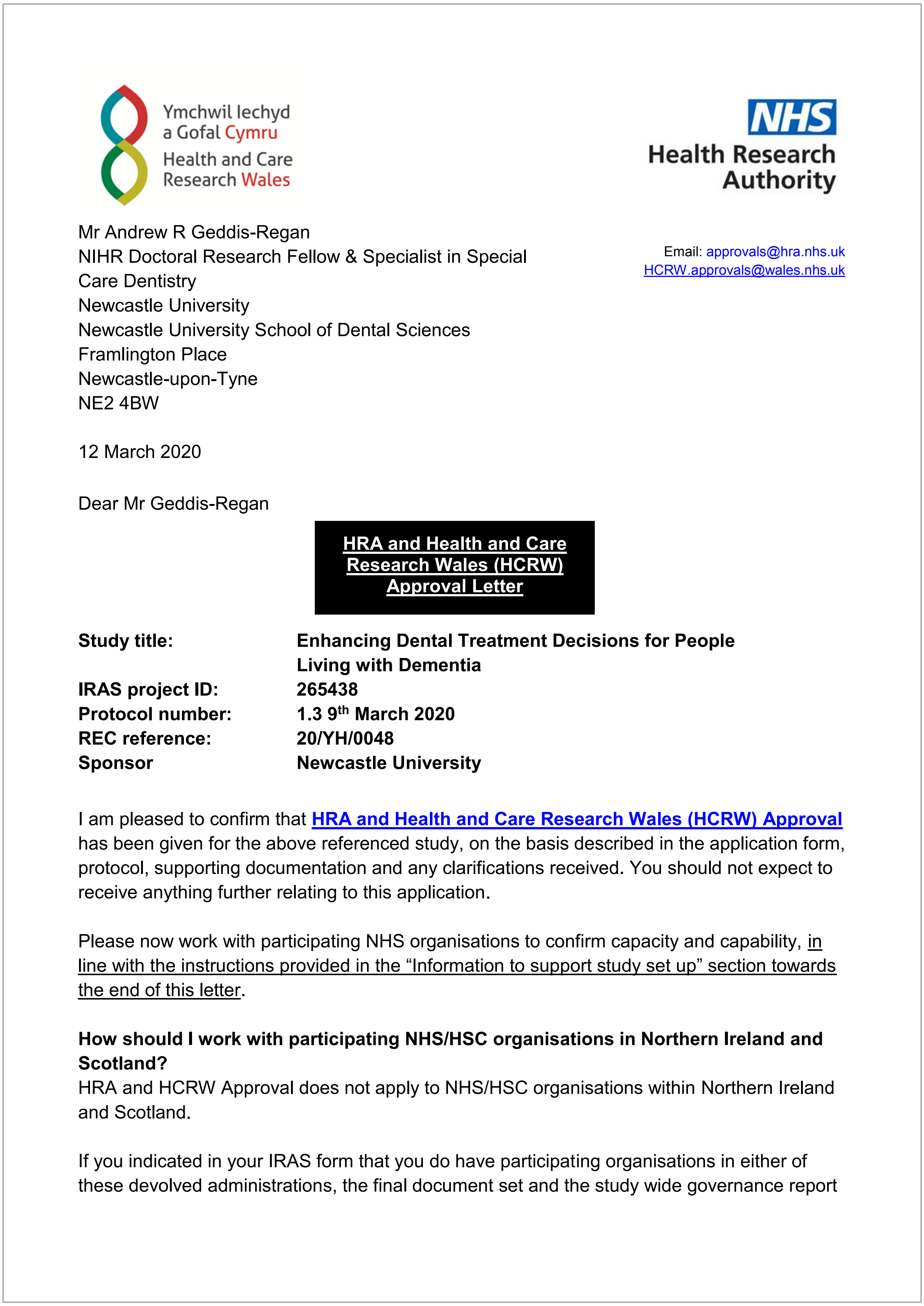
Results: Eight studies met the inclusion criteria. Two articles, including one RCT, evaluated decision aids regarding the use of enteral feeding in advanced dementia. Six further articles, including five RCTs, were found which evaluated the effectiveness of interventions supporting patients or carers with advance care planning.

Conclusion: Decision-making interventions typically consist of multiple components which aim to establish preferences for future health care. Advance care planning interventions supported aspects of the decision-making processes but their impact on decision quality was rarely evaluated. Interventions did not increase the concordance of decisions with a person's values. The decision-specific interventions are unlikely to produce benefit in other decision contexts.

Patient Involvement: Two caregivers, a public stakeholder group and a carer group were consulted in the design of the wider study to which this review relates. Six PLwD refined the research questions addressed in this paper.

KEYWORDS
cognitive impairment, decision making, dementia, proxy decision making, shared decision making

Appendix C: Health Research Authority approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mr Andrew R Geddis-Regan
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Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

12 March 2020

Dear Mr Geddis-Regan

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

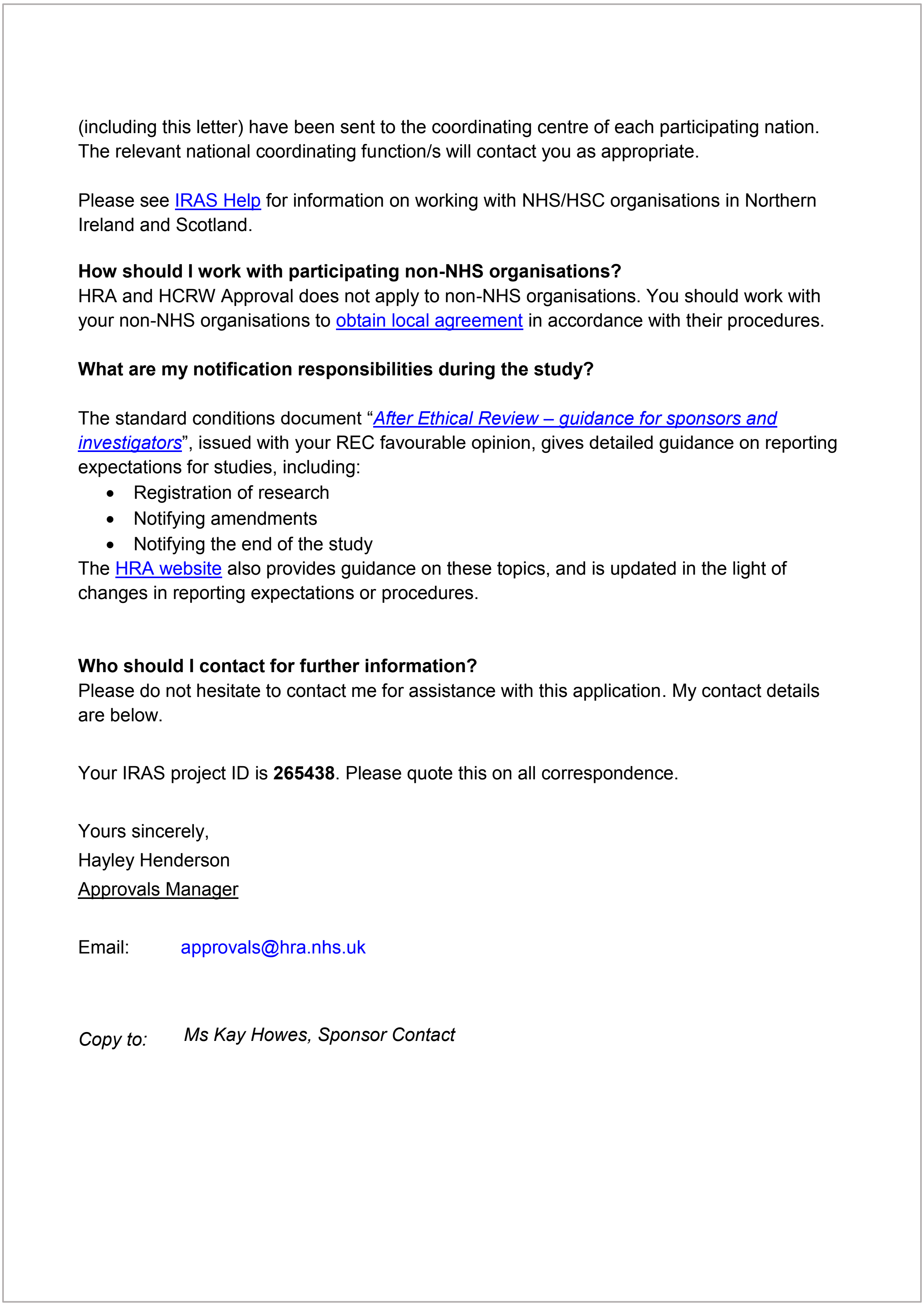
Study title:	**Enhancing Dental Treatment Decisions for People Living with Dementia**
IRAS project ID:	**265438**
Protocol number:	**1.3 9th March 2020**
REC reference:	**20/YH/0048**
Sponsor	**Newcastle University**

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

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

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

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report



(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

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

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

What are my notification responsibilities during the study?

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

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

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

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

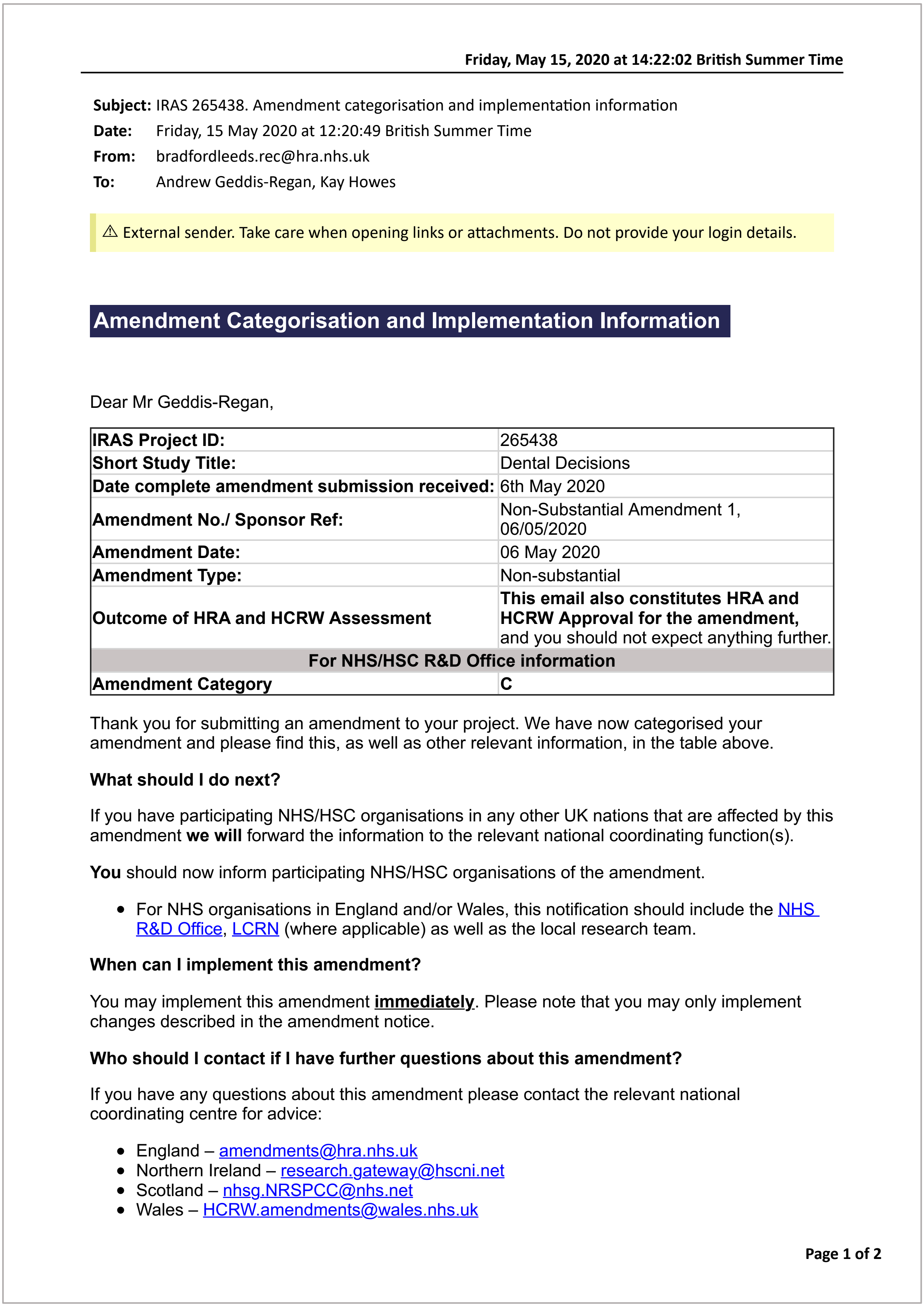
Your IRAS project ID is **265438**. Please quote this on all correspondence.

Yours sincerely,
Hayley Henderson
Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Ms Kay Howes, Sponsor Contact*

Appendix D: Health Research Authority approval of study amendment



Friday, May 15, 2020 at 14:22:02 British Summer Time

Subject: IRAS 265438. Amendment categorisation and implementation information
Date: Friday, 15 May 2020 at 12:20:49 British Summer Time
From: bradfordleeds.rec@hra.nhs.uk
To: Andrew Geddis-Regan, Kay Howes

⚠ External sender. Take care when opening links or attachments. Do not provide your login details.

Amendment Categorisation and Implementation Information

Dear Mr Geddis-Regan,

IRAS Project ID:	265438
Short Study Title:	Dental Decisions
Date complete amendment submission received:	6th May 2020
Amendment No./ Sponsor Ref:	Non-Substantial Amendment 1, 06/05/2020
Amendment Date:	06 May 2020
Amendment Type:	Non-substantial
Outcome of HRA and HCRW Assessment	**This email also constitutes HRA and HCRW Approval for the amendment,** and you should not expect anything further.
For NHS/HSC R&D Office information	
Amendment Category	**C**

Thank you for submitting an amendment to your project. We have now categorised your amendment and please find this, as well as other relevant information, in the table above.

What should I do next?

If you have participating NHS/HSC organisations in any other UK nations that are affected by this amendment **we will** forward the information to the relevant national coordinating function(s).

You should now inform participating NHS/HSC organisations of the amendment.

- For NHS organisations in England and/or Wales, this notification should include the NHS R&D Office, LCRN (where applicable) as well as the local research team.

When can I implement this amendment?

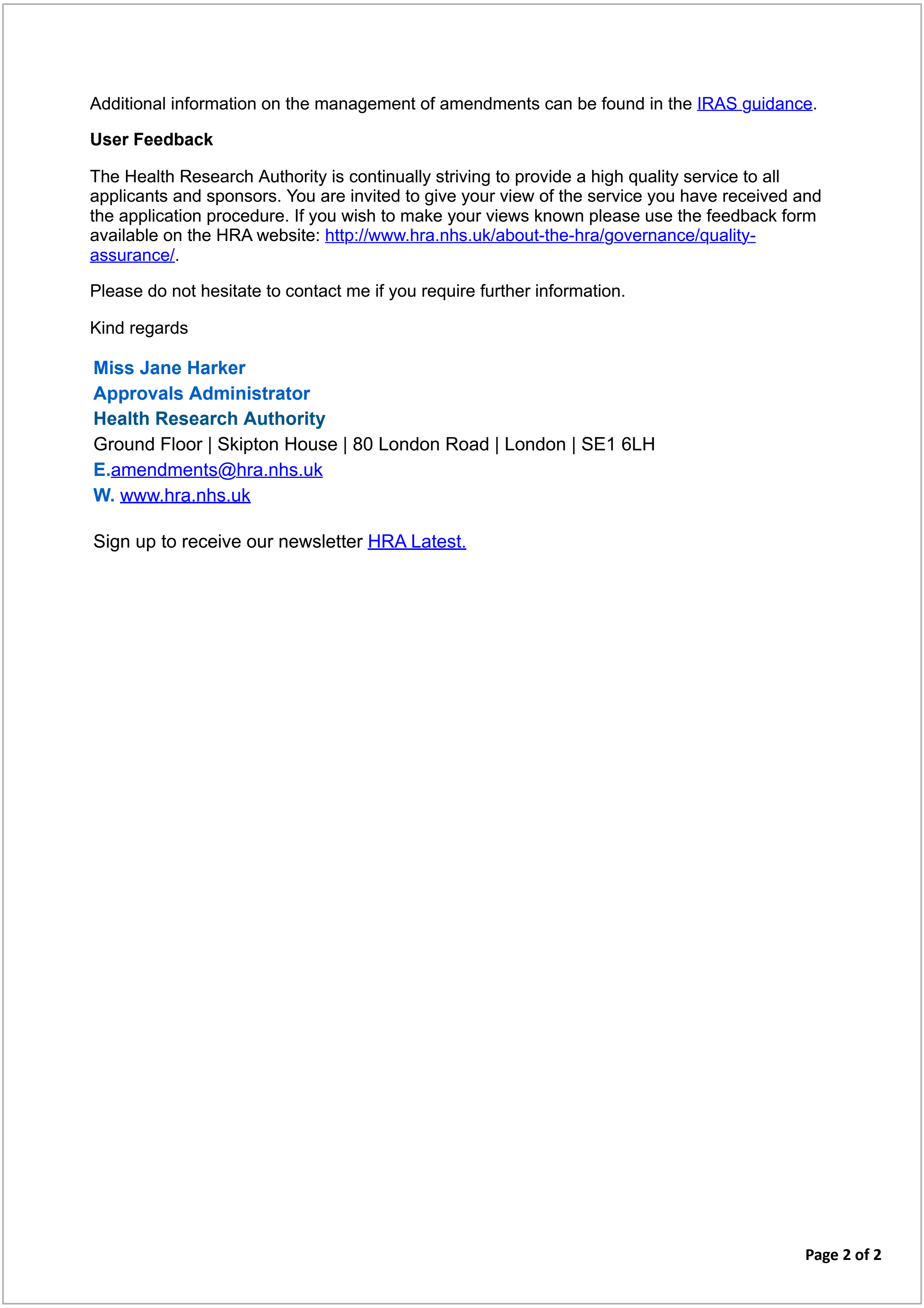
You may implement this amendment **immediately**. Please note that you may only implement changes described in the amendment notice.

Who should I contact if I have further questions about this amendment?

If you have any questions about this amendment please contact the relevant national coordinating centre for advice:

- England – amendments@hra.nhs.uk
- Northern Ireland – research.gateway@hscni.net
- Scotland – nhsg.NRSPCC@nhs.net
- Wales – HCRW.amendments@wales.nhs.uk

Page 1 of 2



Additional information on the management of amendments can be found in the IRAS guidance.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please do not hesitate to contact me if you require further information.

Kind regards

Miss Jane Harker
Approvals Administrator
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.amendments@hra.nhs.uk
W. www.hra.nhs.uk

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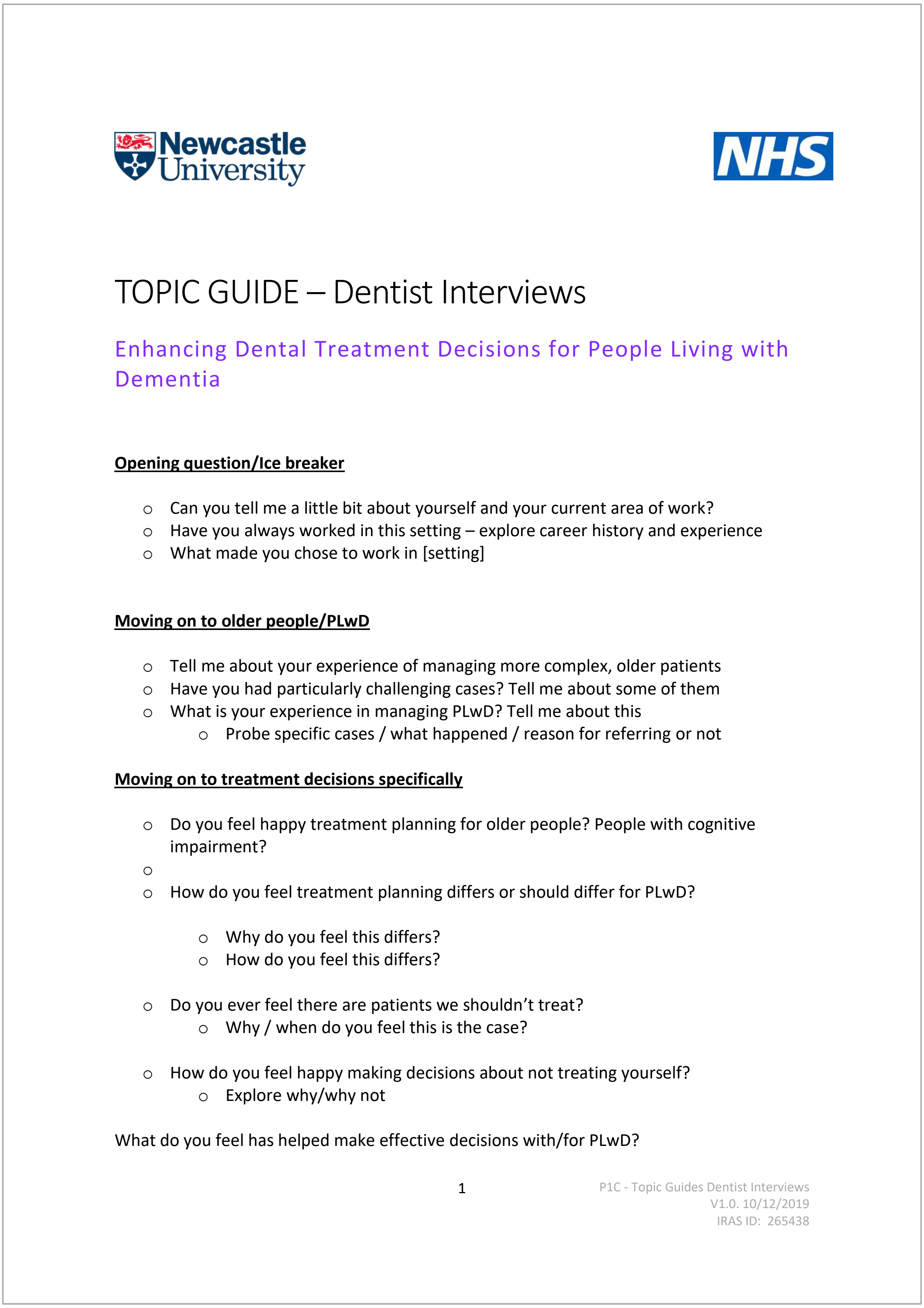
Appendix E: Topic guide used during interviews with dentists



TOPIC GUIDE – Dentist Interviews

Enhancing Dental Treatment Decisions for People Living with Dementia

Opening question/Ice breaker

- Can you tell me a little bit about yourself and your current area of work?
- Have you always worked in this setting – explore career history and experience
- What made you chose to work in [setting]

Moving on to older people/PLwD

- Tell me about your experience of managing more complex, older patients
- Have you had particularly challenging cases? Tell me about some of them
- What is your experience in managing PLwD? Tell me about this
    - Probe specific cases / what happened / reason for referring or not

Moving on to treatment decisions specifically

- Do you feel happy treatment planning for older people? People with cognitive impairment?
-
- How do you feel treatment planning differs or should differ for PLwD?
    - Why do you feel this differs?
    - How do you feel this differs?
- Do you ever feel there are patients we shouldn't treat?
    - Why / when do you feel this is the case?
- How do you feel happy making decisions about not treating yourself?
    - Explore why/why not

What do you feel has helped make effective decisions with/for PLwD?

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P1C - Topic Guides Dentist Interviews
V1.0. 10/12/2019
IRAS ID: 265438

[For General Dentists / more junior hospital or community dentists]

  - Where do you feel PLwD should be managed for dental care?
  - Why do you feel this is the case?

  - What factors do you feel should affect treatment setting?

  - What factors/situations make you feel you should refer a patient?
  - To where may you refer somebody?

[For Specialist/Consultant/Senior staff taking referrals]

  - Tell me about some of the patients who have been referred to you

  - What is your experience of receiving / acting on referrals?

  - How do you feel things have gone with patients referred to you have seen GDP/other staff member for patient/family and for GDP?

- As you have progressed with experience / time / career changes [depending on answers to initial questions and interviewee] how do you feel your approaches to PLwD and their treatment have changed?

<u>What concerns (if any, or attitudes) do you have regarding:</u>

  - Complex treatment regardless of a dementia diagnosis?

- AND/OR

  - Not treating people, or a less invasive treatment approach/watch and wait?

<u>Do you feel decision-making for treatment could be improved? How?</u>

- What barriers do you feel arise to decision-making?

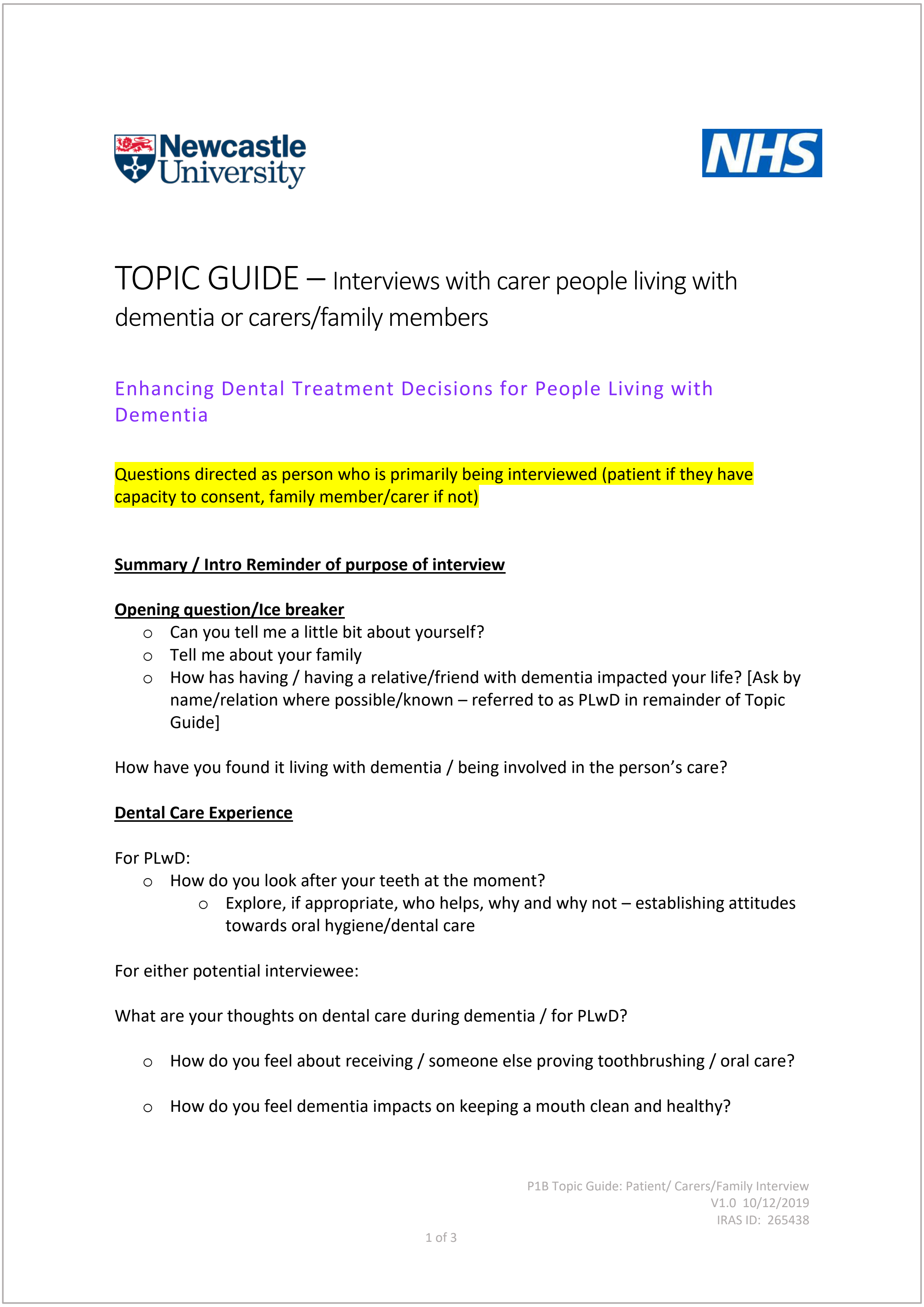
- What do you feel constitutes a ‘good’ decision for treatment?

- Do you feel this is your decision or the patient’s decision?   Why?

<u>How can you see dental treatment/needs for treatment changing with PLwD?</u>

<u>Is there anything else you’d like to discuss about dental treatment for PLwD?</u>

Appendix F: Topic guide used in interviews with people living with dementia and carers



TOPIC GUIDE – Interviews with carer people living with dementia or carers/family members

Enhancing Dental Treatment Decisions for People Living with Dementia

Questions directed as person who is primarily being interviewed (patient if they have capacity to consent, family member/carer if not)

Summary / Intro Reminder of purpose of interview

Opening question/Ice breaker

- Can you tell me a little bit about yourself?
- Tell me about your family
- How has having / having a relative/friend with dementia impacted your life? [Ask by name/relation where possible/known – referred to as PLwD in remainder of Topic Guide]

How have you found it living with dementia / being involved in the person's care?

Dental Care Experience

For PLwD:

- How do you look after your teeth at the moment?
    - Explore, if appropriate, who helps, why and why not – establishing attitudes towards oral hygiene/dental care

For either potential interviewee:

What are your thoughts on dental care during dementia / for PLwD?

- How do you feel about receiving / someone else proving toothbrushing / oral care?

- How do you feel dementia impacts on keeping a mouth clean and healthy?

- How have you / PLwD coped with having their teeth brushed
- Tell me about when you / PLwD needed a dental visit / treatment?
- What happened?
- How involved were you with the dental care planning? (As patient or any role)
- Do you think it went well? Why / why not?
- What was helpful / unhelpful?

Decisions in general

For PLwD:
How do you normally make important decisions?
What factors do you take into account with decisions?
What do you feel is a 'good' decision?
How do you approach decisions for health care compared with other decisions?
How do you approach decisions for dental care compared with other health decisions?
Who should decide on treatment? You, the dentist, or both?

Re-phrase: do you like to have a recommendation from the dentist or do you prefer to make your own choice from a list of options? Why?

For carers:
How involved in decision-making for [PLwD]? Why?
[If appropriate] How do you normally make important decisions for [PLwD]?
What factors do you take into account with these decisions?
What do you feel is a 'good' decision?
How do you approach decisions for their health care compared to other decisions?
How do you approach decisions for dental care compared to other health decisions?

Decisions for Dental Treatment

[If specific dental treatment process described]:

What options were given for management of the teeth / dental problem?

How was a decision made? [By patient, best interests, family supported]

- Did anybody / who helped you make this?

- Could anything have made the decision-making process easier?

- How does pain impacts on decisions made about dental care for PLWD?

  How important do you think it is for [PLwD] to keep teeth / to keep pain free / to have a functioning mouth / smile?

Appendix G: Abstract of presentation of Project 2 to IADR Conference 2021

Dentists’ accounts of planning care for people living with dementia

Geddis-Regan, A., Abley, C., Durham, J., Wassall, R., Exley, C.

Abstract ID: 3565281

Objective: People living with dementia (PLwD) are at significant risk of dental diseases which can cause pain, infections and reduced function. Each of these can impact quality of life. Dental care planning can be challenging for this group as a deterioration in cognitive function affects both consent for, and acceptance of, dental treatments as well as safety. This study aimed to explore the factors that dentists have to consider when planning dental care for PLwD.

Methods: Qualitative semi-structured interviews were undertaken with dentists in general practice, hospital or community settings. Dentists were recruited through incoming referrals and professional networks. Data collection and analysis followed the principles of Constructivist Grounded Theory. A purposive maximum variation approach to sampling was identify a range of dentists whose views may differ then to explore the developing concepts in more detail. Interviews were recorded, transcribed verbatim then analysed.

Results: A diverse group of 22 dentists were interviewed from across the UK. Four themes were identified that detailed factors that dentists incorporating into dental care planning; knowing the person and providing individualised care; piecing a puzzle together; anticipating decline and longer-term planning; balancing risks and benefits.

Dentists described trying to deliver individualised care whilst securing patients’ oral health over the short and longer term. Information to inform risk assessment was perceived to be frequently lacking. Where risks - medical, surgical or ethical- of care provision increased, dentists report balancing multiple factors to inform care planning. Whilst aiming to provide individualised care, dentists focused. Tensions arose when trying to facilitate safe care without putting people at risk. Participants explained how difficulties in care planning accumulated as dementia progressed.

Conclusion: Dentists reported facing multiple inter-related difficulties in planning dental care for PLwD. Some of these difficulties might be reduced with easier access to relevant medical and social information and earlier insight into the preferences of PLwD.

Appendix H: Abstract of presentation of Project 3 to IADH Conference 2022

00100050

“[The dentist] just kind of gets on and does it” Exploring the experiences of dental care decision making with or for people living with dementia

A. Geddis-Regan[1], R. Wassall[1], C. Abley[2], C. Exley[2]

[1]School of Dental Sciences, Newcastle University, Newcastle Upon Tyne, United Kingdom
[2]Population Health Sciences Institute, Newcastle University, Newcastle Upon Tyne, United Kingdom

AIM(S)

To explore the perspectives and experiences of people living with dementia (PLwD) and their family caregivers regarding dental care decision-making.

METHODS

Remotely conducted semi-structured one-to-one interviews were undertaken with PLwD or family caregivers. Participants were recruited through invitations in dental clinics, self-identification, and a research database. A maximum variation purpose sample was sought. Qualitative data collection and analysis occurred concurrently and a constructivist grounded theory approach was adopted. Data underwent initial open coding and then more focused coding. Iterative categorisation of data led to a theoretical understanding of dental care decision making with or for PLwD.

RESULTS

Interviews were completed with 8 PLwD and 17 family caregivers between April 2020 and March 2021. Three key categories were identified: 1) wanting to be understood, 2) wishing to be involved and 3) hopes and outcomes for care. PLwD and family members felt dentists often failed to understand dementia, its impact on each person and the support they may need with decision-making and accepting dental care. PLwD reported wanting to be actively involved in decisions about their care, and family members wanted to be consulted when decisions were being made on behalf of the PLwD they supported. Both PLwD and carers, however, felt they were insufficiently involved in decisions made about their care or the care of PLwD. Such under-involvement meant that the outcomes that PLwD or family members desired were not ascertained to inform decisions made about dental care.

CONCLUSIONS

The accounts of PLwD and family members suggest that they often have a passive role in decision-making. Whether or not PLwD can consent for their care, dental teams should actively seek to understand what matters to each PLwD. Seeking such insight can ensure dental care decision-making is aligned with patients' values and preferences regardless of their cognitive status.

Appendix I: Information leaflet given to co-production group members

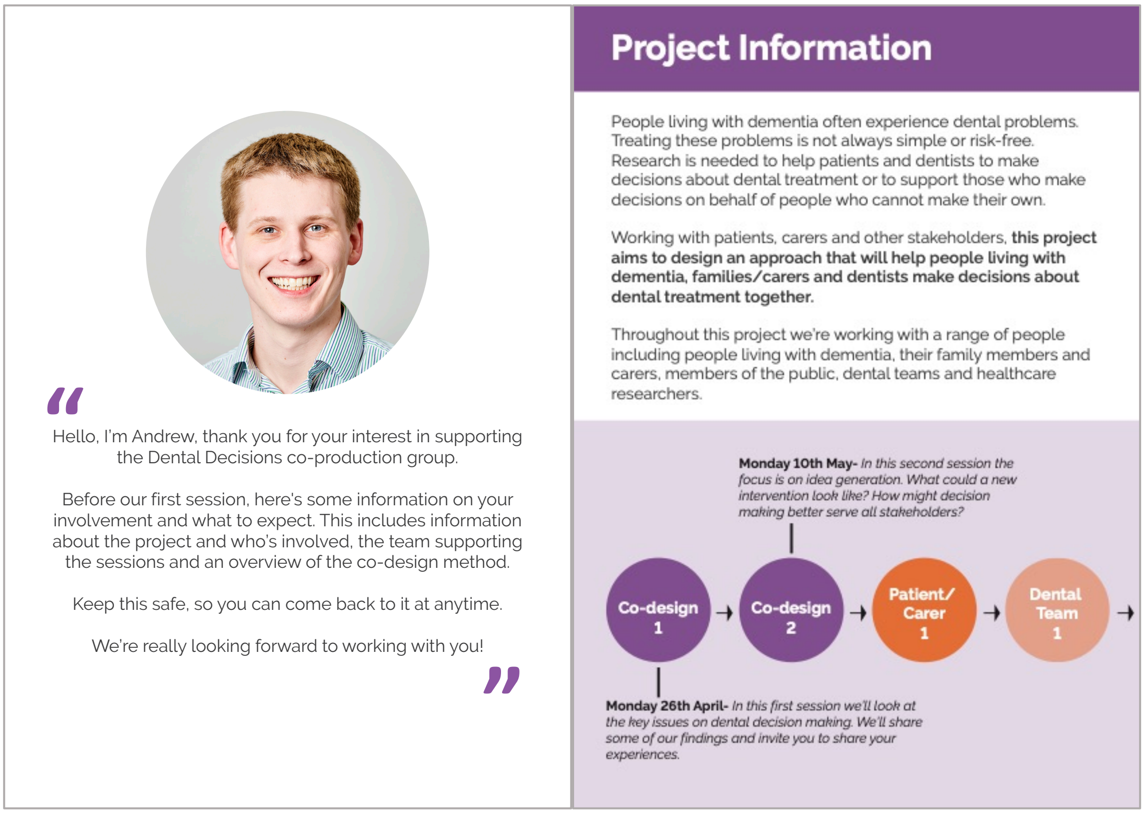
Newcastle University

Let's get started...

DENTALDECISIONS

www.dentaldecisions.uk

If you have any questions about the study or your involvement please contact: **dentaldecisions@ncl.ac.uk**



“

Hello, I'm Andrew, thank you for your interest in supporting the Dental Decisions co-production group.

Before our first session, here's some information on your involvement and what to expect. This includes information about the project and who's involved, the team supporting the sessions and an overview of the co-design method.

Keep this safe, so you can come back to it at anytime.

We're really looking forward to working with you!

”

Project Information

People living with dementia often experience dental problems. Treating these problems is not always simple or risk-free. Research is needed to help patients and dentists to make decisions about dental treatment or to support those who make decisions on behalf of people who cannot make their own.

Working with patients, carers and other stakeholders, **this project aims to design an approach that will help people living with dementia, families/carers and dentists make decisions about dental treatment together.**

Throughout this project we're working with a range of people including people living with dementia, their family members and carers, members of the public, dental teams and healthcare researchers.

Monday 10th May- *In this second session the focus is on idea generation. What could a new intervention look like? How might decision making better serve all stakeholders?*

Co-design 1 → Co-design 2 → Patient/ Carer 1 → Dental Team 1 →

Monday 26th April- *In this first session we'll look at the key issues on dental decision making. We'll share some of our findings and invite you to share your experiences.*

Your Involvement

This co-production stage builds on interviews with dentists, people living with dementia and carers that took place between March 2020 and March 2022. The diagram below illustrates the stages of the co-production. Each of the circles represents an interaction with a stakeholder group. The co-production group meetings (the purple circles) will be interspersed with sessions with patient/carer and dental team professionals.

We hope you can be involved in all four co-production meetings happening over the next 8 months. These meetings will take place over Zoom and a link will be emailed to you before each meeting. We'll be looking at lots of content on the screen: please let us know if we can help with technology to support your involvement.

Late November (Date TBC)- *In this final session we'll look at the prototypes that have been developed. Together we'll refine them so they can be tested in future research.*

Co-design 3 → **Patient/ Carer 2** → **Dental Team 2** → **Co-design 4**

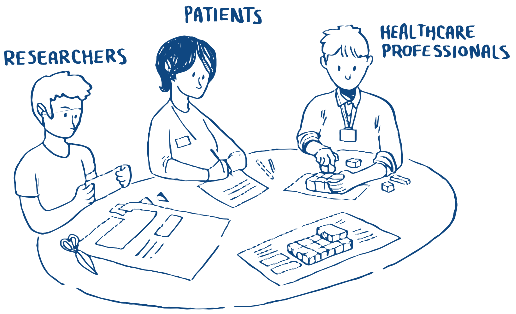
Early September (Date TBC)- *In this third session we'll develop the ideas we generated in session two, adding more depth and detail. We'll explore what patient and dentist groups have said about our work in the first two workshops*

Co-design

Co-design (or co-production) describes a design process used in research where designers and those with experience or knowledge of the thing to be designed, work together.

Co-design spans the whole design process from understanding experiences, deciding design priorities, proposing solutions, and developing the desired outcome. It doesn't dwell on the past, but looks to create new and better futures.

In co-design, designers, other researchers and co-design partners (you) share knowledge, skills and experiences. It is creative and uses a range of methods.



Lab4Living

Lab4Living is a collaborative community of researchers in design, healthcare and creative practices. Lab4Living's expertise is in designing things with end users like yourselves.

Becca, Joe and Chris from Lab4Living will be supporting these sessions. It's important to know that they're experts in co-design but not dental decision making.

LAB4LIVING - EXCELLENCE IN COLLABORATIVE DESIGN RESEARCH -

FUNDED BY
NIHR | National Institute for Health Research

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